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Regenerating Movements: Human Stem Cells and the Politics of Potentiality

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Regenerating Movements: Human Stem Cells and the Politics of Potentiality
Christopher B. Ganchoff
Abstract

This dissertation was a sociological analysis of Proposition 71, The California Stem Cell Research and Cures Act in 2004. Using the conceptual domains of biomedicalization and science & technology studies, my research examined the emergence of health social movements within the fields of regenerative medicine, as well as the debates around the reification of human biological objects. The narrative arc of this dissertation begins with the drafting of Prop 71, through the initial implementation of the California Institute for Regenerative Medicine, the organization created by Prop 71. This project was animated by two central research questions. First, what are the institutional contexts and processes through which regenerative medicine is becoming a legitimate form of medicine? In my dissertation, I approached this question by examining the lineages of regenerative medicine in the biomedical and biological sciences. Second, what are the on-going, enduring effects of the intersections between controversial sciences and forms of biological citizenship? I developed the concept of "biomedical counterpublics" as a lens to examine the forms of social organization in and around human stem cell research. I conducted participant observation of the Yes on 71 Northern California field campaign, as well as interviews with activists (both in support and in opposition to Prop 71), campaign staff, and bench researchers who worked on behalf of the campaign, and textual analyses of campaign documents. These data revealed the contours of collective identities formed around diseases or conditions that could be ameliorated by stem cell technology, as well as the institutional transformations that have brought biomedical scientists into varied relationships with different publics. This research does not critique regenerative medicine as a new form of instrumental rationality or technological domination or slippery slope. Rather, I argue stem cell research is taking shape both within existing institutional situations, both in terms of research agendas as well as other lines of work, and simultaneously producing new forms of affiliation and political representation.. In this sense, regenerative medicine marks sets of practices and institutions that are productive of new forms of attachment, as well as new modes of exclusion.

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Chapter I: Introduction to the Project

It was a beautiful fall day in southern California. People were gathering at an auditorium on the campus of the University of California, Irvine for a daylong conference on human stem cell research. Many of the individuals at the conference appeared to be in their fifties, thus even though it was at a university, the event had a different feel than most campus activities. The conference was set up to have morning sessions covering state of the art scientific approaches to stem cells, followed by afternoon sessions dealing with legal and ethical issues raised by this research, and concluding with a debate on Proposition 71, the California Stem Cell Research and Cures Initiative.

During the sessions, speakers addressed a variety of issues related to human stem cell research, and the auditorium remained about halfway filled, tapering off over the course of the day. The format was like most professional conferences: a group of speakers taking on a common issue or question each speaking for fifteen to twenty minutes, followed by questions from the audience. However, this protocol was occasionally broken. For example, one stem cell scientist referred to research on "metazoans," and did not explain this term. During a brief pause in his talk, an audience member shouted, "What is a metazoan?" The scientist paused, and answered that metazoan is a term for an organism made up of multiple kinds of cells.

I highlight this exchange at this particular conference in order to point out the deeply public nature of emerging controversies in the sciences within liberal democratic societies. A foundational right within societies of this type is the right to free speech and, more sanguinely, open discourse among citizens about matters of concern. Ostensibly, public speech in general, and this conference in particular, is organized around the transmission of information among a variety of actors. Of course this regulative ideal is always empirically enacted, thus reflecting and refracting hierarchies, inequalities, and exclusions already present within social structures. When public speech involves the dense, technical lexicons and discourses of the sciences, the built-in gradients of expertise become readily apparent, as exemplified by the use of the term metazoan by the scientist.

However, the real excitement was yet to come. The evening session is framed as a debate over Proposition 71. There are four participants: three Ph.D. biologists in support of Prop 71, one Ph.D. sociologist in opposition. The first presenter is Evan Snyder, a neurobiologist from the Burnham Research Institute in San Diego, California. He describes human stem cell research as a "paradigm shift," and as shifting the parameters of medical research: "If DNA was the exciting discovery in the first 50 years of the 20th century, this [stem cells] was the most exciting realization in the second half of the 20th century, and that we were going to combat disease not by stopping disease, but by recapitulating

development." He also describes his role as a neo-natologist, and the experience of having to make life or death decisions. He talks about his professional role as pediatrician, and asks the audience to consider the possibility of saving children's lives.

Diane Beeson, a sociologist from California State University East Bay, follows Snyder. She begins by saying that she thought she was being invited to a scientific conference, but that "it feels more like a political rally." She argues that the panel she is sitting on at that moment, "reflects some of the bias in the design of Prop 71's ICOC." She says that unlike the ICOC (Independent Citizens Oversight Committee, the governing body of the California Institute for Regenerative Medicine), this panel has "one truly independent citizen on it." After talking about the historical contexts of biotechnology, the moderator interrupts Beeson by saying that her time is up. Beeson continues on, and tries to make a few more points. After a few minutes, the moderator again tries to cut her off. Someone from the audience shouts that UCI does itself a disservice by not allowing equal time on perspectives. There is a palpable feeling of excitement. This panel is very different from the rest of the day, as voices are raised and challenges made. The moderator attempts to regain control, and allows Snyder to respond to Beeson.

Snyder begins by claiming that there are strict guidelines to prevent stem cell research from becoming ethically troubling, and makes a comparison to gene therapy. Beeson argues that unethical acts will

continue to occur without tighter guidelines, and Snyder replies that this will happen whether or not Prop 71 is in place. An audience member asks how much profit will come back to California taxpayers, and Shane Smith, the science director for the Yes on 71 campaign, says that the exact amount is unclear. Snyder jumps in and claims Harvard (his former employer) has a specific institutional set-up to deal with licenses and royalties. Beeson replies that the ICOC will have vested interests, and Snyder vehemently disagrees, claiming that Beeson is misinterpreting Prop 71. Smith attempts to explain what the ICOC's conflict of interest policy might look like, and claims that Beeson is inferring some kind of "nefarious intent" from Prop 71.

That action is fast and furious, quite unlike the slower pace of the rest of the day. Beeson replies to Smith that sex selection is now marketed for non-medical reasons, beyond any medical intentions. Snyder interrupts her, and says that this is irrelevant to Prop 71. Beeson, not backing down at all, retorts that there are strong market forces for human modifications, and that there is nothing in the text of the initiative that says techniques developed will be limited to therapeutics: "This is moving us toward a techno-eugenics driven by a market that is doing incredible damage in health care generally." Snyder replies the opposite is true; Prop 71 can stop the renegade scientists who might do ethically questionable work, and that Prop 71 will stop people from going offshore. Beeson, unconvinced of this position, says that she is concerned that Prop

71 promotes risky research that will be done without appropriate oversight and control: "I have seen overzealous scientists so eager to make reputations and names for themselves coax people into clinical trials prematurely." Snyder again insists that Prop 71 will prevent this from materializing.

After about thirty minutes of this sometimes-intense argumentation, the tone of the debate begins to drop. Beeson appeals to the audience, and claims that the public does not know how far along this science is, and what happens with Prop 71 has implications for the future of humanity, but the initiative keeps everything in secret. Smith replies that this is not true, and Snyder attempts to undermine her position by saying that if he were planning an oversight board he would have Beeson on it. Another neurobiologist, Hans Keirstead from UC Irvine, implores the audience: "Please don't be afraid of scientific improvements," he says asking for support on a controversial political project.

This dissertation project locates stem cell research, in all its formats (human and non-human, embryonic and adult, *in vitro* and *in vivo*) within the emerging fields of regenerative medicine. Regenerative medicine differs from older forms of medicine: curative medicine uses techniques such as surgery, chemo- or radiation therapies, prosthetics and organ transplantation, and/or pharmacological interventions to isolate and destroy the lesion or infection that is the underlying cause of the pathology, or to mechanically or molecularly replicate lost functionality. Regenerative medicine, in

contrast, constructs *replacement parts*, such as cells, tissues and organs, which substitute for the malfunctioning biological system. These replacement parts are formed from human (and non-human) biological precursors, for example embryonic stem cells, which can be created from a person's own somatic cells and a donor egg cell (through a process known as nuclear transfer or NT). They can also be amalgams of biological and mechanical parts. Thus cell therapies from NT result in cells that are created *in vitro*, but are genetically identical to those of the person needing cell replacement therapy.

The above example of the stem cell conference embodies three central social phenomena explored in this dissertation. First, Professor Beeson embodies the growing importance of health social movements in the organization and mobilization of lay expertise (Epstein 1995) within the fields of the biomedical sciences in the United States and elsewhere. Second, the discussion described emerging *political* opportunities for scientists as a result of structural transformations in the institutional activities of modern biosciences. Finally, struggles over representations of biomedical science by different actors in the public sphere are vivd. Before turning to these three phenomena, I situate this project within what I call the sociology of biomedicine.

The Sociology of Biomedicine

Broadly, the project locates itself within the *biomedicalization* tradition. First coined by sociologist Carroll Estes (Estes and Binney 1989), the term biomedicalization captured growing contemporary social problems regarding human aging, both in terms of the structuring of institutional responses (such as Medicare, Social Security, and other social policies), and creating ideologies that denigrate and marginalize the elderly as a

social group. Biomedical definitions of, and subsequent control over aging and age-related phenomena served to structure clinical practices, state policies, and public opinions about the elderly. Drawing from earlier work (Estes and Binney 1989; Estes 1980; Estes 1984), she argued that while biomedicine, "merits a respected place for its contributions…its extension to and control over all aspects of life diminish its own effectiveness and divert the field from the essential and critical work needed to understand the complex social and environmental factors that significantly shape, structure, and modify the basic processes of old age and aging on multiple levels" (Estes et al. 2001: 46). This project is deeply influenced by Estes's emphases on political economy and the roles of the state (and state-level actors) in the mechanisms of expanding the jurisdiction of biomedicine. These pioneering efforts helped pave the way for further refinements and updates of the concept of biomedicalization.

Adele Clarke and colleagues (2003) statement about the "new" biomedicalization was one such rhizome. Clarke and colleagues identified a series of changes, including theoretical, political economic, institutional and organizational, as well as practice- and identity-level transformations in the United States. This project is also deeply influenced by this approach, especially their attention to "technoscientific identities," and Chapters III and V utilize this concept to articulate the identity category of "stem cell activist."

Sharon Kaufman and colleagues (Kaufman, Shim and Russ 2004; Kaufman, Shim and Russ 2006; Shim, Russ and Kaufman 2006; Shim, Russ and Kaufman 2007) have also been developing a research program in biomedicalization. They have highlighted the emergence of a "new ethical field" taking shape as clinical interventions on the elderly

become routinized (Kaufman, Shim and Russ 2004). The authors approach this emerging field as a location of possibilities and dangers, as a generalized experiment upon the social body: "In this regard we are all the subjects of a medicoethical experiment taking place on a broadening social scale" (2004:737). I build from this claim in terms of looking at regenerative medicine as not simply a set of technical changes, but also transformations in what is and is not ethically acceptable to do to human beings.

Finally, Charis Thompson's description of what she calls the "biomedical mode of reproduction" (2005:247, see also Franklin and Lock 2003, Chpt. 1) has been deeply influential on the trajectory of this project. She characterizes this mode through a series of analyses regarding biomedical sciences and social institutions. Specifically, I build from her arguments that human embryos possess "promissory" value: their value lies in what they promise to deliver in the future, which is different for the different sets of actors involved (Thompson 2005:258). Thompson's framings of promissory value emerge out of the worlds of in vitro fertilization. In this project, I use her analytics to understand the forms of promissory value human embryos hold for human stem cell research.

Specifically, this project examines the three phenomena described above. In presenting each phenomenon, I next also introduce the relevant theoretical tools that I used in this project.

Health Social Movements and Stem Cell Activism

There has been a recent explosion in the literature covering the dynamics, organizational forms and implications of the activism found in and around the biomedical sciences (Barbot 2006; Barbot and Dodier 2002; Brouwer 2001; Brown et al. 2001b; Brown et al. 2004; Callon and Rabeharisoa 2003; 2004; Crossley 2003; Dumit 2006; Epstein 1996; Hess 2004; 2005; Klawiter 1999; Kroll-Smith and Floyd 1997; Morris and Balmer 2006; Mykytyn 2006; Rapp 2003; Rapp, Heath and Taussig 2001). It would be an impossible task to reduce the vast diversities of groups, ideologies, strategies, conflicts and affinities to even a loosely bounded set of concepts or theories that can account for the ranges of differences found in empirical cases. However two concepts, that of patient advocacy organizations and health social movements, have been put to productive use to explain activism in and around the contemporary institutional domains of biomedicine.

The concepts of patient advocacy organizations and health social movements (1990; Barbot 2006; Brown et al. 2004; Epstein 1996; Klawiter 1999) have become indispensable tools for understanding the social stratification of health and illness, and the attempts to ameliorate the problems caused by institutional inequalities found around the world. Their theoretical force is bolstered by connections with social movement theory, from which theorists who employ the concepts of patient advocacy organizations and health social movements draw resources. One of the critical junction points in organizations and movements, for both activists and theorists, is the front door. That is, the question is under what conditions do individuals join a movement or an organization that is pressing for social change? More specifically, what are the processes that push and pull individuals into becoming part of patient advocacy organizations or health social movements?

In one sense, patienthood can function as a collective identity, and foster social movement mobilization. Patienthood becomes a ground state or principle from which broader political or moral claims can be articulated, similar to what some have termed "biological citizenship" (Petryna 2002; Rose and Novas 2005). What is interesting in the case of patienthood is that it does not automatically produce something like a collective identity. While standardized diagnoses produce populations of people, individuals and groups within any focal population will have very different understandings and expectations about their diagnosis, available treatment modalities and potential outcomes. Rose and Novas (2005:441) refer to this diagnostic classification as simultaneously "dividing" or setting the parameters of who gets treatment or who does not, and "unifying" individuals under a diagnostic category in the face of other social differences. However, despite the power of unification that diagnostic procedures possess, a "politicized collective illness identity" (Brown et al. 2004:60) will not be isomorphic with the population that has the disease or condition. Thus, the collective identities that emerge in the fields of biomedicine are neither transparent nor automatic signifiers of the focal population that they represent. Collective identities must be constructed, and require organization and negotiation in order to remain salient.

This dissertation project examines the collective identity of "stem cell activist," in the context of California's Proposition 71, the California Stem Cell Research and Cures Initiative (henceforth Prop 71), which passed with 59% of the popular vote in the November 2004 general election. This collective identity was not constructed directly in opposition to a counter-identity framing, or economic injustice, or even state-sanctioned repression or violence. Rather, I highlight this collective identity's connections to a

controversial biomedical technology. These connections positioned stem cell activists in close contact with other groups of actors interested in that technology as well, including bench scientists, biotechnology advocates, university officials, policy makers and government regulators.

Scientists as Activists

Stem cell research has, over the last eight years, fractured older political frames, and helped produce new ways of imagining social relationships through what anthropologist Paul Rabinow (1992b) terms "biosociality." Rabinow defines biosociality as the relationships and identifications taking shape in the wake of the reformulation of the biological substrate of organic life, using techniques including recombinant DNA, gene therapies, nuclear transfer, and human stem cell research that materially combine, subtract and alter elements of molecules, cells and bodies. Nikolas Rose (2001)echoes this argument by claiming that it is biotechnology with its transformative techniques, not moral philosophy or bioethics, that is defining what it means to be a human being in the contemporary moment.

This emphasis on technique is important for my purposes, since it is bench scientists who are directly involved in producing such transformations. It has been insightful to follow scientists as they do the many kinds of work that they do. For example, much attention has been placed on the relationships that have been created between bench and bedside to borrow Ilana Lowy's (1996) title, and scholars are currently tracing the movements of objects and relations between the lab and the clinic.

What happens when bench researchers become involved in politics? First some clarifications. What do I mean by politics? I mean both the formal institutional politics of modern bureaucratic states (elections, policy-formation procedures, advisory committees) as well as the informal elements of what political sociologists refer to as "political culture." This itself is a fraught term, but here I use it as a placeholder for what we might call the politics of representation, that is, the forms of talk and interaction that serve as a foundation for institutionalized activity. I do not claim that either the formal or the informal is more important; rather the two domains interpenetrate and my analysis attempts to keep both strands in play.

How do bench researchers become involved in politics? Historically, scientists have become politically engaged in different ways. Many of the scientists I interviewed talked about their past and present activities around issues like the Vietnam war or pro-choice abortion movement. For this project, I am interested in the ways in which scientists engaged with political formations qua scientists. For example, several prominent biomedical researchers were part of the drafting process of the initiative. Many elite Californian researchers took public positions in support of Prop 71. They spoke at Yes on 71 rallies, they appeared on Yes on 71 television commercials, and/or they spoke favorably of Prop 71 at public and quasi-public events. Scientists were clearly central to the framing of Prop 71 as a therapeutic project. The framing processes used during the campaign depicted stem cell research as a legitimate scientific enterprise, supported by reputable individuals, with the potential to cure various debilitating conditions. The forms of proof used by scientists were important elements for their public speaking on behalf of the Yes on 71 campaign.

Although one could argue that the reason bench researchers became active in the Yes on 71 campaign was that they stood to gain materially from Prop 71, I think this is a partial and less than satisfactory answer. While it is true that they receive resources from the CIRM, scientists also have deep histories of activism. So rather than focusing on individual self-interest, it is important to think about scientists as constitutive of social movements, as well as working between movements. This project foregrounds the use of what I call "logics of representation" used by scientists in order to articulate the salience of regenerative medicine to different publics.

At the same time, I do not think that the researchers on the Prop 71 campaign trail should be regarded as presenting purely technical information, or acting solely as scientific advisors. Electoral politics require that explanations about stem cell research be made in public. During the campaign, scientists spoke compellingly about the possible therapeutic outcomes of human stem cell research. Stem cell research has profound potentialities. My analysis here seeks neither to ratify nor reject these potentialities but rather to think about the social positions from which regenerative medicine is being articulated and understood.

Regenerative Medicine and Logics of Representation.

Given the structural transformations that have occurred in processes of biomedicalization (Clarke et al. 2003), it is not surprising that scientists have found themselves in new situations, and have responded in terms of new political practices. As political actors, scientists are now (re)producing frames not only for understanding regenerative medicine per se, but also for understanding scientists' own positions within

this emerging social formation. That is, scientists involved with the Yes on 71 campaign articulated the benefits of human stem cell research as both a biomedical project and a social project.

One central aspect in constructing both the biomedical and social projects of regenerative medicine are the ideological struggles. Regenerative medicine necessarily involves techniques and practices that will challenge established frames of understanding and interpretation. For example, current human embryonic stem cell research requires the disaggregation of human blastocysts. For some groups of actors, this is tantamount to murder. For others, this is a question of obtaining research materials. While there are certainly many different groups with different positions vis-à-vis human stem cell research, at different moments groups will unite to form provisional coalitions. The "pro-cures" movement represents one of those coalitions. This movement, composed of patient activists and their families, representatives from patient advocacy organizations, legal and political professionals, biotechnology officials, scientists and clinicians, and politicians, publicly supports all forms of human stem cell research. Members have held conferences designed to share information, develop and debate strategies, and promote the scientific, clinical, and industrial aspects of human stem cells. In addition, these stem cell activists keep in contact with each other through email list serves and websites (web logs or "blogs"), and keep track of the various debates and conversations regarding human stem cell research and politics.

During my field work, what I refer to as "lay conferences" were important sites for stem cell activism. The vignette I opened this chapter with is emblematic of lay conferences. These conferences were designed to cover the different aspect so human

stem cell research, and while they were targeted at non-experts, the speakers included important actors from the scientific, legal, ethical, and commercial worlds of stem cell research. These conferences were important sites for the production of what I call "logics of representation," or systematic narrations and organized sets of metaphors designed to nautralize human stem cell research. These logics circulate through and animate the framing strategies that represent regenerative medicine, and are not confined to any one site. Like metaphors, it is important that they can be transposed and translated in different locations.

This project explores these three social phenomena (health social movements, forms of science activism, and logics of representation) in order to take on two nested research questions. *First, what are the institutional contexts and processes through which regenerative medicine is becoming a legitimate form of medicine?* Like earlier professional medicine, regenerative medicine is unfolding through its scientific methods and clinical effects, many of which are deeply upsetting and unsettling to multiple groups of actors, as well as implicating the political, economic and social work of different groups of actors around regenerative medicine. Proposition 71, the field campaign organized in support of the initiative, and the informal networks and small groups that worked tirelessly in support of it, are all critical actors, not only in the immediate tactics for electoral victory, but also in the medium- and long-term strategies for the emergence and coalescence of regenerative medicine.

Second, what are the on-going, enduring effects of the intersections between controversial sciences and forms of liberal government? Prop 71 was the first instance of basic science funding being installed within a state constitution ratified through the

techniques of direct democracy in the United States. It has subsequently lead to initiatives in other states, such as Missouri, which adopted some of the frames and rhetorics developed by the Yes on 71 campaign and their professional campaign managers and technicians. These forms of "traveling biomedical politics" are certainly important in provoking new political relationships and outcomes. This project focuses in particular on the production of "biomedical counterpublics," or the processes of assembling collective identities through public representations of technoscientific identities (Clarke et al. 2003:182-83). The on-going, enduring collective identity of "stem cell activist" has become both a central regulative principle for the organization of political subjectivity within liberal democratic social orders, but also a site of contestation and struggle between and among patient activists, and their elite and non-elite allies, supporters, and opponents.

Research Methods, Data Sources, and Data Analysis

This dissertation is a qualitative analysis that employs three methods of data collection, and grounded theory and situational analysis as modes of analysis (Clarke 2005; Glaser and Strauss 1967; Strauss and Corbin 1994). The methods employed on this project were useful for capturing data on what is by nature a decentralized, transitory event: a political campaign. Given the bounded geographical (Prop 71 was a California initiative) and temporal (there was a fixed terminus, namely election day) horizons, qualitative methods were best suited to capture multiple forms of data. In order to capture these multiple data sets, this project was organized around a social worlds and arenas perspective, which involved the production of maps of actors. For example, Table

1.1 describes a map of actors and their social worlds to a focal institution. The production of these analytical maps helped to focus data collection and sampling strategies.

In terms of collecting data, I sampled from both elite (e.g., bench scientists) and lay (e.g., patients and campaign volunteers) actors, and examined perspectives from a multitude of social positions. I interviewed a variety of stakeholders from different social worlds in order to examine heterogeneous perspectives on Prop 71. I refer to this approach as "studying up, across, and down;" I attempted to avoid privileging one perspective as the most accurate or valid perspective regarding Prop 71, and let respondents articulate what they saw as their connections, frictions, hopes, tensions, and/or concerns about the campaign. I have drawn this approach from feminist and science and technology studies approaches which have consistently argued for situated notions of knowledge production, as well as the dangers inherent in assuming a single, fixed perspective as an epistemic foundation (Clarke and Montini 1993; Clarke and Olesen 1999; Haraway 1991; Reinharz and Davidman 1992).

This project was based on a grounded theoretical approach to analyzing social processes as developed by Glaser and Strauss (1967), with a Straussian emphasis (1987). Grounded theory is an inductive, comparative mode of analysis that seeks to develop concepts through iterative interpretations of data. Data collection included participant observation within a variety of field sites, in-depth interviews with stakeholders, and textual analysis of documents produced by actors in the arena of Prop 71. I initially coded data from transcribed interviews and field notes, and specific codes were

elaborated by examining the dimensions of each code. These codes served to build a system of categories that became the foundation of analysis for this project.

Participant Observation

Given that the central analytical object of this work was an electoral campaign, I attended different events in California from June through November 2004 that were related to the campaign. I volunteered with the Yes on 71 campaign, and my initial action was to speak at a kick-off meeting for San Francisco Bay area volunteers at UC Berkeley. Subsequently, volunteers met with campaign staff and other volunteers from June through November in order to be activated for different purposes (tabling, letter-writing, etc.) These events included planning meetings, where various tactics to be used in San Francisco were discussed, as well as recent events and campaign gossip. Other events included tabling and handing out campaign literature. I also took part in a campaign conference call, at which time the northern and southern field offices explained strategies and took questions from volunteers. Field notes were taken during all these events, and used in the analyses that comprise this project.

In addition, a local chapter of the Stem Cell Action Network (SCAN), based out of an activist's home in Berkeley, held several meetings in order to activate volunteers in support of Prop 71. I attended two of these meetings. The SCAN meetings differed from the Yes on 71 meetings as they often involved criticism of the Yes on 71 campaign, including objections to the strict controls over communication and word choice that the Yes on 71 staff attempted to impose.

In October 2004, I attended three stem cell conferences (San Diego, San Francisco, and Irvine), two public debates on Prop 71 (Mountain View and Palo Alto), and two community discussion or "town hall" style meetings in Los Altos Hills. In addition, I partially transcribed two debates (in October and December 2004) over Prop 71 on San Francisco public radio station KQED. Field notes from these events served as data.

In early 2003, I enrolled in the UCSF Center for Bioentrepreneurship course "From Idea to IPO" designed to give bench and clinical scientists an introduction to the worlds of commercialization of scientific research. The course included sections on intellectual property (trademarks, trade secrets, and patents), material transfer agreements between actors, conflict of interest policies, and the ethics of science and business. Field notes were taken during this course, and served as data for this project.

In-depth Interviews

I interviewed a total of forty subjects for this project from a variety of social worlds (membership is described in Table 1.1). This was a convenience sample based on subject's public participation in Prop 71 events. Subjects were recruited either through direct conversations at events, or through email communication. Additional subjects were recruited through snowball sampling by asking respondents to identify other key stakeholders as possible subjects. These subjects were then recruited as above. The interview protocols were tailored for subjects from each specific social world.

Table 1.1: Interview subjects

Social World Membership	Number of Interviews Conducted
Patient Activists	17
Scientists (Ph.D.)	10
Opponents of Prop 71	4
Biotechnology Representatives	3
Professional Organizations	3
Science Movements	2
Governmental Officials	1

Textual Analysis

In order to construct a recent history of stem cell research, I reviewed 205 papers from natural science and biomedical journals using key words "hematopoietic stem cells," "neural stem cells," "teratocarcinoma research," and "human stem cell research." From this set of articles, I constructed a historical picture of the development of mammalian hematopoietic and neural stem cell research, as well as related and/or pre-existing fields of knowledge, such as radiobiology, hematology, immunology, bone marrow transplantation, oncology, neural grafting and neurobiology. In addition, I reviewed several reports from federal and state agencies covering human stem cell research, as well as campaign literature and DVDs produced by the Yes on 71 campaign.

Overview of the Chapters

This dissertation is structured around two central thematic actors: patient activists and bench scientists. I argue that both of these actors were necessary for the success of Prop 71. Without the deep active work of these two groups, Prop 71 would not have passed. Each chapter combines both conceptual work and empirical data to make a series of analytical arguments.

Chapter II provides the historical background for the project, offering an historical overview of mammalian stem cell research, focusing on *homo sapiens*, and concentrating on the hematopoietic and neural stem cell traditions. This chapter also looks at human embryo research from in vitro fertilization through human embryonic stem cell research, examining both the scientific work and policies of the United States government towards the derivation and use of human zygotes for research purposes. This chapter thus paints and analyzes the broad scientific and political milieux out of which Prop 71 emerged.

Chapter III frames health social movements and the currently increasing intersections between health social movements and controversial sciences. It examines the new and different forms of health social movements currently taking shape, and positions the "pro-cures" movement in support of human stem cell research within this analysis. This new movement developed recently to support human stem cell research, especially the embryonic variety. While it existed prior to Prop 71, the initiative provided a crucial material and symbolic boost to this movement.

Chapter IV examines the California research and policy context more closely, and lays out the history of Prop 71. It frames both the policy environments, and funding of biomedical research in the Golden State prior to Prop 71. I then offer a close analysis of

empirical data collected during the campaign to examine the representational practices of scientists and patient activists in support of Prop 71. These two sets of actors worked together on the campaign, often speaking and campaigning side-by-side on the podium. This chapter looks closely at ethnographic data collected during campaign, and details the unfolding of the Yes on 71 campaign and the rhetorical frames deployed during the spring and summer of 2004.

Chapter V analyzes the formation of a new collective identity, stem cell activist, during the Prop 71 campaign. I argue that this collective identity emerged from what I term "biomedical counterpublics." Drawing from political philosophy, I argue that stem cell activism is not simply a reflection of individual or group interests. Rather, I analyze stem cell activism at structural (the terrain of health social movements in the contemporary United States), organizational (a focal patient advocacy organization), and individual (stem cell activists) levels with data drawn from interviews and observations. I argue that this multi-level analysis reveals the different determinations and effects that produce a biomedical counterpublic, which does not reduce to a simple reflection model of social relations. That is, the collective identity of stem cell activist does not just reflect social structural positions, but is a site of political and representational struggles.

Chapter VI focuses on scientist activism. This chapter begins with brief histories of previous episodes of scientist activism, including atomic scientists during and after the construction of the atomic bombs, reproductive scientists and their efforts to secure the legitimacy of their research, and molecular biologists and their work to create new social policy to address recombinant DNA research. I then turn to an examination of scientists' participation in the Prop 71 campaign. I argue that it is critical to take into consideration

the political economic structure of biomedical research in the USA since WWII. In short, scientists have become increasingly dependent on what I term "speculative investments," or revenues devoted to biomedical research that are targeted at specific diseases or conditions. Speculative investments have become important for a variety of groups, including economic organizations (biotechnology companies, pharmaceutical and other multi-national corporations, and venture capital), philanthropic foundations, and patient advocacy organizations, all of who now fund biomedical research in university- and research center-based laboratories. Prop 71 represented yet another revenue stream, this one from the state of California, which joined other moneys funding targeted or "mission oriented" research. I argue that speculative investments have served to create new political opportunities for scientists to become active, and that scientists have mobilized in response to these changing structures.

Chapter VII summarizes the major findings of this dissertation, and integrates these findings within extant and on-going debates in sociological literatures. This chapter shows the advances that this projects contributes to scholarship in social movement research, as well as science, technology, and medicine studies. Gaps and lacunae in the arguments are reviewed, and possible future lines of research to both correct omissions and weak spots in my analyses, as well as new directions opened up as a result of the execution of this project are also put forward.

Chapter II: The History of Stem Cell Research in the USA (and elsewhere), 1945-2001

Human stem cell (hSC) research, as a field of biomedical research, has emerged since the 1990s from multiple disciplinary traditions. I refer to hSC research as a field since it is itself not yet a discipline nor is it departmentalized. Rather, it is composed of collections of researchers, tools, techniques and institutions from different knowledge-producing sectors of modern society organized differently in different locales. I argue this is a critical difference. That is, disciplines and departments have both flexibility and obduracy. An established discipline can ramify into sub-specialties, but yet not lose complete coherence as to become unrecognizable to either insiders or outsiders. As later Chapters in this dissertation will make clear, the alliances and networks among groups of people around biomedical questions and problems are dependent to some degree on the social organization of biomedical knowledge. That is, rather than a bright line between expert and lay person, current research has revealed the deep and important connections between the social worlds of expertise and lay knowledges, or what some call "partnership models" (Rabeharisoa 2003, see Chpt. III for more detail) spanning such worlds. For example, in Steve Epstein's work (Epstein 1995; 1996), it was consequential for AIDS treatment activists in the late 1980s/early 1990s that immunology, virology and molecular epidemiology were established, formalized disciplines of knowledge, with their own norms, practices and ideologies. This organization was consequential because it provided the activists with clear targets or objectives, such as learning complicated vocabularies or understanding different statistical theories, that they could identify and strategize around and within. As Epstein (1996) makes clear, these activists brought with

them histories of mobilization, and well-developed capacities of social capital, that facilitated their entree into biomedical research worlds.

Stem cell research is similar to these disciplines in that it is obviously composed of vocabularies tools, norms, and theories. In addition, many of the activists who support hSC research have longer histories of activism (including activism outside of biomedical domains, such as labor organizing or anti-war protests), as well as sophisticated levels of scientific knowledge, sometimes through painstakingly auto-didactic methods. However, unlike the disciplines mastered by AIDS treatment activists, stem cell research is a sprawling domain with fuzzy borders that expand and contract on a nearly daily basis.

As this chapter will make clear, since the beginning of the 1970s, human stem cell research has provoked some fundamental changes and discoveries regarding mammalian physiologies. While the consequences of these changes and discoveries for "curing"[1] remain unclear, multiple research fronts are rapidly expanding. To make matters more complicated, human stem cell research is cross-cut by several intense arenas of live, on-going controversies (see Chapter III). These controversies also overlap at crucial junction points. For example, in order to identify and characterize human stem cells, a necessary step in their transition from bench to bedside, their capacities must be demonstrated by *in vivo* and *in vitro* models. That is, stem cells must be examined and tested "in a dish," ideally to uncover fundamental properties that are unique to these cells (sometimes refered to as "stemness"). The same cells must then be also implanted within model organisms in order to demonstrate that they can survive and structurally and functionally replace or replicate the physiological processes of which they are a component. These

[1] I use scare quotes to indicate the "curing" is itself a contested and polyvalent term within and across social worlds and arenas. "Curing" itself, as a meaningful, consequential term is being reworked as an effect of the human stem cell debates.

are the standardized forms of proof for producing evidence of biological action in molecular and cellular biology. However hSCs in general, and human embryonic stem cells (hESCs) in particular, are difficult to culture for many reasons due to the propensity of these cells to change into committed progenitor cells. As I will show later in this chapter, the "transdifferentiation" debates (the ability of adult stem cells to cross lineage lines in a manner analogous to the pluripotency of embryonic stem cells) that flared up in the first years of the twenty-first century involved contestations over cell culturing techniques and methods of characterization. It is not only scientific objects, but also the norms and practices of data production that foment intense fights and struggles for credibility (Epstein 1995).

In order to meet this demanding *in vitro* and *in vivo* dual standard, stem cell researchers use many different reagents, materials, tools, techniques and instruments. They include using research materials from human beings at various stages of development. Obtaining these research materials is no easy task because the use of human cells, tissues, and organs in biomedical research is deeply controversial. In this chapter, my argument is that it is important to address technical controversies (such as the transdifferentiation debates, see below) that go far beyond the shrill rhetoric of debates about the status of the embryo. That is, as regenerative medicine unfolds, it has and will continue to move human cells, tissues, and organs across boundaries both *in vitro* and *in vivo*. This is already causing debates internal to technoscientific sub-specialties about what constitutes proof of a cellular process. However, such technical debates may also be significant for other groups of actors. For example, those opposed to the use of human embryos in research picked up on one aspect of the transdifferentiation debates as

providing evidence of the experimental success of human adult stem cells which could potentially eliminate the need for human embryonic cells..

Arguments around the use of embryonic and fetal cells and tissues is one subset of debates that constitute regenerative medicine today. There are many others, some of which are still coming into focus. This chapter will lay out the recent technoscientific histories of human stem cell research, with an eye towards their unsettling abilities. That is, human stem cell research is, like any living science, producing more questions than answers. I will begin with the hematopoietic, neural and developmental biological traditions of stem cell research. Here I argue that while these traditions are deeply experimental, major advances occurred due to their articulations with clinical research and treatment. These traditions experienced major growth periods in the 1970s, and again in the 1990s, through their incorporation of novel tools (such as recombinant DNA, monoclonal antibodies, and improved imaging technologies), as well as breakthroughs on the clinical side (improvements in various transplantation technologies and treatment regimes, and better characterized disease pathways).

Parallel to this bench-clinic traffic of objects, people and ideas, the 1970s and 80s witnessed the dramatic development of *in vitro* fertilization (IVF), culminating in the first human live birth in 1980. As one application of experimental embryology, IVF helped to reveal some important aspects of human development. At the same time, it created a new "population" in the United States (and in the UK to a lesser degree): surplus embryos. These surplus (or spare) embryos have become articulated with both the politics and science of hSC research. They are both potential research materials and/or potential people. As Monica Casper (1994) pointed out, these surplus embryos are overcoded:

they are, depending upon the perspective of one's social world, either persons (or quasi-persons, persons-in-the-making), therapeutic objects, or research materials. As many scholars have noted, IVF has, and continues to transform perspectives regarding parenthood, gender, reproduction, kinship and belonging. I will briefly review the development of IVF and its social consequences.

This 30-year period (1970-2000) also saw momentous technoscientific changes. However, these changes were not simply the result of better technologies, more robust theories, or more dynamic scientists. They were also the result of a series of changes in other domains of modernity, including cultural, political, and economic elements related to the sciences, including science policy. At the end of this chapter, I briefly review the federal policies of the United States government regarding the use of fetal and embryonic cells and tissues for research purposes. This will set the stage for the following chapter, which more closely profiles biomedical research in the state of California.

My undergirding assumption in this chapter is that technoscientific changes, such as the development of hSC research, are not only the result of improved science (an internalist view) nor merely a change in social context (an externalist view). Rather, I argue that it is important for analysts of the biomedical sciences to pay attention to the connections between and even interpenetrations of internal and external social worlds and arenas. This is critical because the development of the biomedical sciences in the United States at least since 1970 has been undergirded by flows of actors between the bench, the clinic, the state, and the corporation. Therefore, a more comprehensive picture of the emergence of hSC research must take into account the multiple links and articulations

between and among the social worlds both present and implicated in the broad project of regenerative medicine

Theoretical traditions in human stem cell research

The human hematopoietic system

The symbolisms of blood are perhaps the most enduring and malleable metaphors and myths that humankind has ever devised (Wailoo 1997). Blood, as well as the circulatory system and its major organ the heart, have continued to represent the nation, society, city, health, illness, death, and life itself. Stretching back much farther than either the cell or the embryo, blood is a primordial object of wonder and terror that still haunts and captivates both biomedical researchers and lay citizens in the hemato-political culture of modernity. It was within hematological debates that the concept of the "stem cell" was first articulated, and experimental hematological techniques were instrumental in revealing the human hematopoietic stem cell.

Investigation into bone marrow, which was initially considered to be the source of bone formation, as the "seed bed of the blood" is credited to Ernst Neumann (1823-1918) and Giulio Bizzozero (1849–1901), who separately identified the marrow as a crucial site in blood cell formation, or *hematopoesis* (Dreyfus 1957:40; Tavassoli 1980). Hematopoesis was to become a central concept as hematologists thought through the complicated processes of blood cell genesis. From the middle to the end of the nineteenth century, hematology focused on morphology, or the study of the form or structure of blood cells. One major set of debates at this time focused on the origin of the cells of the blood stream. In one sense, this debate positioned those who saw a single cell

as the ancestor to all the different varieties of blood cells (the "unitarists") opposed to the "dualists," who claimed that *lymphocytes*, or white blood cells (later identified as belonging to two principal classes, T-cells and B-cells) arose from tissues of the lymph system, and *myelocytes*, or cells that regulate immune responses to various invaders, among other phenomena, arising from the bone marrow (on blood cytology, seeAlberts et al. 1989). A major figure in this history is Paul Ehrlich (1854-1915), who played a considerable role in the emergence of hematology as a medical discipline. Ehrlich's contributions were wide ranging, from staining techniques to immunological assays. Importantly, he was also a high profile supporter of the dualist theory of blood cell formation. Wintrobe argues that clinicians were stronger supporters of the dualist position, because of their proximity to the various forms of diseases, such as leukemia (1985:33). Ehrlich, a clinician, had also developed a new staining technique that made it possible to see the wide variety of cells in the marrow and blood stream. Following Ehrlich, Swiss clinician Otto Naegeli (1871-1938) also argued vigorously for a distinction between the cellular precursors to *granulocytes,* a type of white blood cell, and lymphocytes (Lajtha 1980:85). However, dualists began to run into problems in the first half of the twentieth century, as morphologic description began to reveal more and different white blood cells that would not fit neatly into either category.

Lajtha (1980:83) marks Ehrlich's work as singular event in hematology: "The was perhaps the first attempt to describe the 'ancestral' cell, or to be more precise, *an* ancestral cell in the hematopoietic series. It was also the beginning of the concept of the *stem cell* - a cell type that can maintain its own numbers by cell division and yet can provide descendents which eventually 'mature' into the various blood cells." While

Lajtha's claim is overstated in the sense that the origin of blood cells (or any cell) has always been an open question for biology, it is useful here to see Ehrlich's work as a culmination rather than a source. To make sense in the exploding fields of late nineteenth century biology, Ehrlich's work depended upon a network of objects, actors, experiments, and institutions, as well as theoretical frameworks.

In another sense, debates about blood cell origins were inflected through positions that have recurred through the other fields of biology, such as cytology and embryology. Tavassoli (1980:70-71) points out that the debates between scientists studying blood cells during the height of the "morphologic era" were cross cut by differences between staining techniques, disciplinary orientation (embryologists vs. histologists), form of medical work (clinician v. bench researcher), as well as the type (frog v. chicken) and developmental stage (embryo v. adult) of the model organism. But, as others have pointed out (Lajtha 1980; Tavassoli 1980; Wintrobe 1985), the different perspectives in morphology could not explain certain questions, and it was not until the advent of the nuclear age that new positions vis-à-vis the stem cell could be imagined.

The nuclear blood stream

Wintrobe's (1985) history of hematology presents the great pioneers of blood research, and identifies Edwin Osgood (1899-1969) as the North American hematologist who first asked questions about the "ancestral cell of the blood, about stem cells" (Wintrobe:300). Osgood was a biochemist and a skilled mathematician, who innovatively applied mathematical models to understanding cell division. The mathematical modeling of blood cells was linked with available technologies; before the

development of radioisotopes, and later, antibody technology, cytology and hematology relied on tools and methods such as light microscopy and visual identification. Lajtha (1980:86) claims that Osgood was responsible for developing the concept of *asymmetric division* of the stem cell: following stem cell mitosis, one of the daughter cells possesses pluripotency, while the other develops into one form of blood cell. While Osgood may have been a founding father of mathematical modeling for blood cell populations, hematologists still had no *in vivo* models for blood stem cell dynamics. The development and use of radioisotopes in medicine post World War II addressed this lack.

The discovery of the effects of radiation on living tissues revealed changes occurring at the cellular, organ system, and whole body levels (e.g., see Chpt. 7 Thornburn 1972). The development of radionucleotides owes much to the creation and use of nuclear weapons in Japan in 1945, as well as subsequent tests by the United States in the Pacific, including on the Bikini atoll (1946) and the Marshall Islands (1954). For example, the development of radioactive iodine as a treatment for thyroid disorders is closely tied to physicist Enrico Fermi's work on nuclear fission (Chapman 1987). Following the Hiroshima and Nagasaki bombings, the United States formed the Atomic Bomb Casualty Commission (ABCC), which then conducted longitudinal studies of the effects of radiation exposure until 1975, when it was replaced by a private nonprofit research organization (Finch 1979:50). While it was initially thought that radiation exposure produced profound and lasting damage to tissues and cells, by the 1950's researchers were observing some surprising results in animals exposed to high doses of whole-body irradiation (Lajtha 1980:86). For example, in a 1956 paper in *Nature*, a team of researchers reported that adult mice, following exposure to x-ray radiation,

incorporated hematopoietic cells from donor mice that had been marked by a chromosomal alteration (Ford et al. 1956).

While this experiment was important in demonstrating that hematopoietic function can be restored by transplantation, it did not address the mechanisms by which cellular repopulation occurs: "To answer this, one had to learn which cell type can proliferate in the marrow and to discover to what extent it can proliferate" (Lajtha 1980:87). This direction was given support by the development of a new system of visualization also aided by nuclear science, *autoradiographic* studies. Autoradiography involves getting cultured bone marrows cells to take up DNA that has been tagged with a radioactive tracer, and then spread across a layer of photosensitive material. These experiments showed that certain morphologically identified blood cells were "transit populations;" that is, "their proliferation potential is limited to only a few cell divisions" (1980:88). However, transit populations are a middle step in the hematopoietic process; a precursor cell must still be lurking in the shadows.

Radiological techniques were opening up new vistas of biological research. In the search for the elusive precursor cell, one of the first major steps "backwards" in a sense was the identification of *colony forming cells* (CFCs or colony forming units, CFUs). In 1961, researchers in Toronto published an important paper regarding the existence of a stem-like cell that they referred to as a "colony-forming unit," or CFU (Till and McCulloch 1961). Replicating Ford's team's experiment, Till and McCulloch exposed groups of mice to high levels of radioactivity, destroying their bone marrow. These experimental mice were then injected with a bone marrow suspension from other mice, and after 10 to 11 days, they were killed and dissected. Their spleens revealed a curious

development; they were infiltrated with nodules that contained various colonies of different types of blood cells, at different stages of development (1961:215). The authors detected a relationship between the number of marrow cells injected into each mouse, and the number of colonies in the spleen of each mouse (1961:216). However, because of the uncertainty these researchers felt about their experiment, they were hesitant to refer to the bone marrow cells that produced splenic colonies as stem cells. Hence, they called them, more neutrally, CFUs (1961:217).

The discovery of CFUs lead to a flourishing of research on hematopoiesis, and the elucidation of a family of cell chemical signals know as *colony-stimulating factors* (CSFs), such as erythropoietin, which is responsible for the production of erythrocytes, or red blood cells (Alberts et al. 1989:980). The discovery of the interactions between CFUs and CSFs lead to articulation of a developmental pathway:

Pluripotent stem cell >> Multipotent progenitor cell >>

Committed progenitor cell >> Terminally differentiated cell

The interactions between each stage of cell development and CSFs will determine the morphology of the terminally differentiated cell (1989). At the beginning of the 1970s, many difficult questions remained. One major problem involved identifying the origins of myeloid and lymphoid cells, which seemed to arise from different lineages. Were myeloid and lymphoid precursors the same (or similar) stem cells, or were there different stem cells for each system? Different attempts at framing this question were proposed. For example, Metcalf and Moore, in their 1971 contribution to the "Frontiers of Biology" series called *Haemopoietic Cells*, refracted contemporary understandings of HSCs through the unitarist and dualist arguments that characterized late nineteenth century

hematological controversies. They pointed out that earlier hematologists debated between monophyletic (unitarist) understandings of stem cells, which posited one type of stem cell that gave rise to all the cells of the blood and immune systems, and polyphyletic (dualist and trialist) understandings, which posited two or three types of stem cells. Metcalf and Moore (1971), while nodding to the monophyletic theories as closer to the modern "scheme," argued that *both* paradigms were misguided. Interestingly, they claim that it has been "relatively simple experimental procedures" that have undermined these older competing paradigms. However, as this chapter argues, it is not only experimental data that moved human stem cells into their rarefied status. It is also their usefulness in other domains, such as clinical approaches to cancers of the blood that have made human stem cells important biomedical objects.

Lingering questions also remained about the cellular composition of CFU-S colonies. Namely, were they pure colonies of a single kind of cell, or were heterogeneous kinds of cells present? How could experimentalists get a handle on the heterogeneity of these colonies? This early line of research, which established the theoretical entity of the stem cell, was to open up a new series of research questions, experimental and clinical lines of investigation, including: what are the regulatory systems that ignite and/or inhibit assymetrical division? Where in the marrow does such division occur? Is there one kind HSC or several kinds? One source of tools for experimental hematology was emerging from the clinical study of bone marrow transplantation (BMT).

A short history of human bone marrow transplantation

Human BMT began to take shape in parallel with human HSC research (for historical reviews see Storb 2002; Bacigalupo 2004; Donnel and Blume 1999). Early transplantation of allogeneic (unrelated donor), syngeneic (from an identical twin sibling), and autologous (frozen marrow from the same patient) BMT had mixed clinical results, but fomented great excitement. This work was done in conjunction with research on overcoming immune rejection barriers, such as the elucidation of the human leukocyte antigen (HLA) system and methotrexate to combat *graft vs. host disease* (GVHD) (Storb 2002). However, the early excitement dissipated as clinical failures mounted, and BMT research moved away from humans and towards primate and canine research materials (Donnel and Blume 1999). Dogs in particular were useful model organisms, since their blood groupings had been studied for some time. Donna Haraway (2003) points out the importance of dogs for researchers interested in questions of behavioral genetics. At the same time as these behavioral studies were pursued, researchers were also very interested in canine blood groups. The extensive research on canine blood groupings in the first half of the twentieth century then facilitated the use of dogs as research materials in BMT experiments in the second half.

Human BMT initially seemed to hold great promise for many different problems. For example, transplanted marrow cells occasionally demonstrated an interesting phenomenon called *graft vs. tumor effect* (GVT). GVT effect occurred when HSCs from the donor engrafted in the recipient and produced new cancer-fighting cells of the human immune system (lymphocytes). The lymphocytes (derived from donor HSCs) would then recognize the recipient's cancer as foreign and attack the malignant tissues. However, a major drawback was that donor lymphocytes can also attack other host (non-cancerous)

cells and tissues, producing GVHD, a difficult condition that continues to plague transplant medicine. Experimental hematological discoveries have given clinical oncology a new arsenal of anti-cancer treatments called "non-myleoablative" or "reduced intensity" approaches that rely less on radiological and chemotherapeutic interventions, and more on the therapeutic effects of donor immune cells (Wynberg and Childs 2004). This therapeutic field is now in the process of formation.

Throughout the 1970s and 80s, a series of assays were developed to trace the differentiation of multipotent progenitor cells (MPCs) (for selected reviews see Lajtha 1980; Till and McCulloch 1980; Weissman 2000). Even as late as 1990, deep questions remained about how to properly characterize human HSCs (Visser and Van Bekkum 1990). Detailed characterization of all the MPCs was a critical and necessary step, especially if stem cells were to have a future in clinical medicine. The development of monoclonal antibodies (mAbs) was a major leap forward. While mAbs have not (yet) become the widespread anti-cancer therapy that some forecasted, they have become a standardized tool for bench work. An important discovery involving the use mAbs in the mid-1980s occurred at Stanford, as researchers were able to successfully characterize and isolate mouse HSCs (Spangrude 1988). Using mAbs, the Stanford team argued that mouse HSCs were a distinct population with unique cellular markers. The Stanford team included Irving Weissman, who has since played a major role in the stem cell politics of California and the nation. In the introduction to the article, Weissman is quoted as saying: "This is the end of the particular road that was the search for the stem cell" (Barnes 1988:241). While not all stem cell researchers shared Weissman's optimism (Lord and Dexter 1988), the Stanford team's characterization of the mature HSC through

the use of cell surface markers was to become one of the central mechanisms for purifying stem cell populations.

Weissman's team at Stanford was also able to successfully create a useful chimeric model organism, the SCID-hu (severe combined immuno-deficient) mouse (McCune et al. 1988). Chimeric organisms are creatures that possess two different genomes, either intra- or inter-species. The SCID-hu mouse is genetically altered to remove the murine immune system. Weissman's team implanted the glands of a human immune system (human fetal thymus gland and lymph node) and stimulated the mouse with human fetal liver cells (McCune 1996; McCune 1997). This chimera proved to be exceptionally useful in the study of AIDS, and also helped to characterize the human HSC (Baum et al. 1992).

The identification of a set of HSC-specific surface markers also indicated that stem cell division was regulated by complex cascades of signals in the form of molecules called cytokines or proteins that are secreted by cells in order to causes changes in the nucleus (Dexter and White 1990). The subsequent elaboration of these cell-signaling factors, and the understanding of the relationships between human stem cells and their "microenvironments" or "niches" consolidated a wing of experimental hematology around HSCs (for selected reviews see Fukushima and Ohkawa 1995; Greenberger 1991). The debates around stem cell niches were linked to other debates, including controversies around the regulation of cell division in the marrow. A 1990 paper in Nature indicated that a negative feedback loop might exist in mammalian bone marrow that regulates the "switching on and off" of HSCs by cytokines (Dexter and White 1990). Cytokines are thus deemed responsible for promoting transcription in the nucleus of the

target cell. In turn, the applications emerging out of experimental hematology helped to elaborate the fields of clinical oncology, as many cell-signaling molecules and pathways were initially thought to be promising anti-cancer therapies (like interleukin-3, see Lowy 1996). Experimental hematological approaches thus not only validated many beliefs about the bone marrow as the prime locus of blood cell reconstitution, but also served as the material foundations for techniques involving marrow and cell transplantation.

The transdifferentiation debates

The 1990s were a time of rapid expansion of HSC research. The complicated lineage pathways that constitute the taxonomy of human blood cells was further elaborated and refined, and methods for identifying the cells along the developmental pathway were developed, as well as the molecules responsible for signaling for changes in the cell (Berardi et al. 1995; Morrison and Weissman 1994). This continued refinement of cellular identities opened up new comparative perspectives about cells in other organ systems. For example, one team reported that under certain conditions, HSCs can become types of liver cells (Petersen et al. 1999). Over the next four years, more papers were published making similar claims about HSCs contributing to the production of neural, bone, skin and heart muscle cells through a process called transdifferentiation (for an overview see NIH report 2001). In this process, cells originated from one germ layer can be coaxed into cells from another germ layer. This "plasticity" of certain adult stem cells was called "transdifferentiation." Transdifferentiation had been known to occur under certain conditions since the 1970s, and had been studied through limb regeneration experiments in vertebrates (Tsonis 2000). These new findings were

remarkable, since they indicated that HSCs could cross lineage boundaries, which had previously been considered impossible (for selected reviews, see Beresford 1990; Eguchi and Kodama 1993).

To briefly explain, all the cells in an adult mammal have arisen from one totipotent cell, the zygote, which became a blastocyst after 10-14 days post-conception. Following uterine wall implantation, the blastocyst begins a process of folding, and segregates into three primordial germ layers (from NIH report 2001 p. 22): ectoderm (which produces skin and the cells of the nervous system among others), mesoderm (bone marrow, fat, and muscle cells) and endoderm (lung, liver, and pancreatic cells). A cell that arises from one germ layer was though to be set on a pathway that was fixed and immutable. For example, claims that HSCs (originating from the mesoderm) could be coaxed into producing neurons (ectoderm) would imply that the HSC was dedifferentiated "backwards" towards a primordial state, and "reprogrammed" to move down a new developmental pathway. Papers claimed that HSCs could turn into liver cells and neurons (from a vast literature, see reviews by Goodell 2003; Goodell et al. 2001; Lemischka 2002; Morrison 2001; Vieyra, Jackson and Goodell 2005; Wulf, Jackson and Goodell 2001).

HSCs arise from the mesoderm. Thusfor experimental results to claim that they could form cells from the other germ layers was greeted with intense skepticism. Almost immediately, papers were published refuting the claims (Anderson, Gage and Weissman 2001; Wagers et al. 2002). Several arguments were put forward attempting to explain transdifferentiation, including contaminated materials, cell fusion events (two mammalian cells will occasionally fuse into one cell under certain conditions), and

disagreements over protocols. In his recent review, Raff (2003:8-9) argues that these debates emerged because of improved techniques in stem cell research. First, given the advances documented above, researchers were able identify and transplant smaller numbers of cells into a number of heterotopic locations, for example, transfusing purified HSCs into cardiac muscle. This meant that scientists could both readily see the effects of the implanted cells, and thus know with a great deal of certainty that the effects were caused by the stem cells.

Second, advances in fluorescent labeling allowed scientists to accurately and clearly see small numbers of cells in situ. Tools developed over the second half of the twentieth century, such as tritiated thymidine ([^{3}H]-thymidine), bromodeoxyuridine (BrdU), and the green fluorescent protein (GFP) assay have given researchers unprecedented visual access to cells and cellular activity (discussed in greater detail below).

The apparent plasticity of HSCs was immediately seized upon by other groups. For example, groups opposed to the use of human embryos and fetuses in research pointed to the plasticity of HSCs as a scientific equivalent of the pluripotency of embryonic stem cells. This equivalency was then used as evidence that human *embryonic* stem cell (hESC) research was not necessary, and HSC (and all adult stem cell) research was morally preferable. Many scientists who were in favor of hESC research responded by "undoing" the embryonic/adult distinction. For example, at a stem cell conference I attended, a prominent stem cell researcher framed this distinction not as a dichotomy, but as a continuum from zygote to adult. He argued that scientists need to understand the properties and functions of cells from all the phases of human life, and

that these understandings will mutually reinforce each other. Moreover, they cannot replace each other.

At the present moment, there is no established agreement on whether or not transdifferentiation is actually occurring throughout the varied cellular environments of the human body. One of the areas of interest regarding this phenomenon is molecular and cellular responses to injury or trauma. While mammalian transdifferentiation is a very interesting physiological phenomenon, it remains a series of open questions and emergent research agendas.

The mammalian hematopoietic system was the first well characterized stem cell system, and remains a model for other physiological systems. Research in this area spawned multiple experimental and clinical discoveries that I have only touched upon in this section. Emerging hypotheses and experiments in HSC research are now beginning to re-imagine the causes and trajectories of many cancers of the blood. Buoyed by successes in HSC research, stem cell researchers began to push in other directions, most notably vis-à-vis the mammalian central nervous system. The elaboration of the human neural stem cell (hNSC) was a major breakthrough and, while it was initially modeled after the human HSC, it has subsequently moved in novel directions both experimentally and clinically. HNSC research shares with human HSC research a deep connection between the bench and the clinic. I next turn to human neural stem cell research, and its implications for human health and biosociality.

Neural stem cells

Over the 1990s, a "quiet revolution" (Kaplan 2001:617) happened in research on the development of the human brain. This revolution ushered (some would say resurrected like Star 1989) in a new word: *plasticity*. Of course this word is not absolutely new, as it has long been applied to various regenerative properties of human physiology, including the central nervous system. However, it was not until the end of the twentieth century that plasticity again began to be taken seriously for the sciences of the human brain after a century of localizationsim (Star 1989). Subsequently, it has opened up wide vistas of research, as well as potentialities for therapeutic application. By revolution I mean changes in both how the human central nervous system was imagined, and the tools and techniques developed to provide empirical results. At the heart of the conceptual and technical changes associated with plasticity in the late twentieth century was a special kind of cell: the human neural stem cell (hNSC).

Rhetorical flourishes like claims of revolution in science are usually overblown. That is, rather than sudden epistemological or disciplinary upheaval, these changes can often be traced back to earlier research, which prepared the way for more challenging claims. One usual move is to then re-evaluate the earlier claims as "prescient" statements that paved the way for current work. Thus historical analysis consolidates past work around the new "epistemic object" (Rheinberger 1997). Rather then claiming that the hNSC is absolutely new, I will argue that the capacities of hNSC were known at least since the mid-twentieth century (perhaps earlier). Specifically, this opens up questions for the analyst of emerging technosciences, focused around the status of novelty. By what warrant can something be claimed as novel or new? Is novelty secured by the

claims of scientists or journal articles? Or does it require legitimation from other sources?

This is a well-worn debate. Rather then resuscitation, perhaps we should let the patient die with dignity. Here, I take off from the work of many in current science & technology studies (Clarke 1995; Creager 1999; de Chadarevian 1998; Galison 1997; Geison and Creager 1999; Kohler 1993; Lederman and Burian 1993; Logan 2002; Myers 2001; Pickstone 1993; Rader 1998; Star 1995) who emphasize the importance of tracking the flows, intersections, and disruptions around *material cultures* rather than debate novelty. I am particularly interested in the processes that unfold theories through material cultures. Within social studies of science, it has been persuasively argued that both epistemic objects and the means to identify, visualize and classify these objects emerge simultaneously.

Analytically, focusing on material cultures raises interesting questions, as well as some potential dangers. I want to avoid the pitfalls of technological reductionism that could accompany attention to technical changes. This is not easy to do, especially in the deep technical realms of the experimental technosciences. For example, Ron McKay, a pioneer in neural stem cell research and director of the NINDS, retold the story of neural stem cell research and discovery at the dawn of the new millennium as the triumph of molecular biology and a new synthesis of lines of research: "If we are allowed to use the rate of progress in molecular genetics to calibrate our imagination, you might agree to the following: manipulating CNS [central nervous system] stem cells will contribute to our understanding of the cellular organization of the brain and provide a set of rules that link molecular biology and psychology. Happy New Millenium" (McKay 2000b:299-300).

McKay's narrative re-centers the logic of discovery on the technical bases of molecular biology, and the neural stem cell emerges as the lead actor on the stage in the reformation of the sciences of the brain. This reformation continues to be deeply consequential. Neural stem cell biology is in the process of reshaping domains of experimental neurobiology, clinical therapeutics and patient activism. The neural stem cell, like all of stem cell biology, recapitulates both the hope and the hype (McKay 2000a) that are endemic to regenerative medicine.

To be clear, I am not claiming that McKay's argument is wrong or misguided. Quite the contrary; it is a clear exposition of the emergence of neural stem cell biology told from the vantage point of one of the field's leaders in one of its most important journals. It is a true story. My argument is that McKay's linear narrative of the development of neural stem cell biology effaces the complex, and often contradictory, processes of the actual day-to-day scientific work itself. Rather than either claiming that McKay's arguments are true or false, or that they need to be improved or refuted, my intent is to move parallel to these discourses about the human neural stem cell. This is tricky ground to cover. That is, I will engage with the scientific literature about the hNSC, but remain agnostic about the ultimate status of this research. My own description of the science will appear to endorse realist assumptions about the science itself, as if summarizing a dense technical field in itself constitutes an endorsement. This is provisional and strategic. That is, I am interested in the parallel sets of interests that lie in the conditions of possibility for these discourses. These conditions are not lurking in the background, as some kind of "social context" that ultimately shapes or determines the content of the science. I am opposed to such forms of explanation. In other words, I

want to avoid the distinction between some form of purified scientific explanation, and some equally purified social explanation (Latour 1993). Instead I seek to reveal the social in the technoscientific – and vice versa.

Now that the hNSC is being experimentally validated, the narratives about neural regenerative medicine are shifting. The hNSC is now a central object around which institutional forms of knowledge production orbit, as McKay's article demonstrates. That is, the study of the hNSC is drawing attention and resources from universities and research centers, patient activists, and governmental agencies. To get to this point however, neurobiology had to "overcome itself." That is, the discipline had to get around its own internal blockages, namely the doctrine that no new neurons appear in adult mammals following birth. The question remains, how did neuroscientists overcome themselves and their disciplinary modes of thinking to embrace neural plasticity?

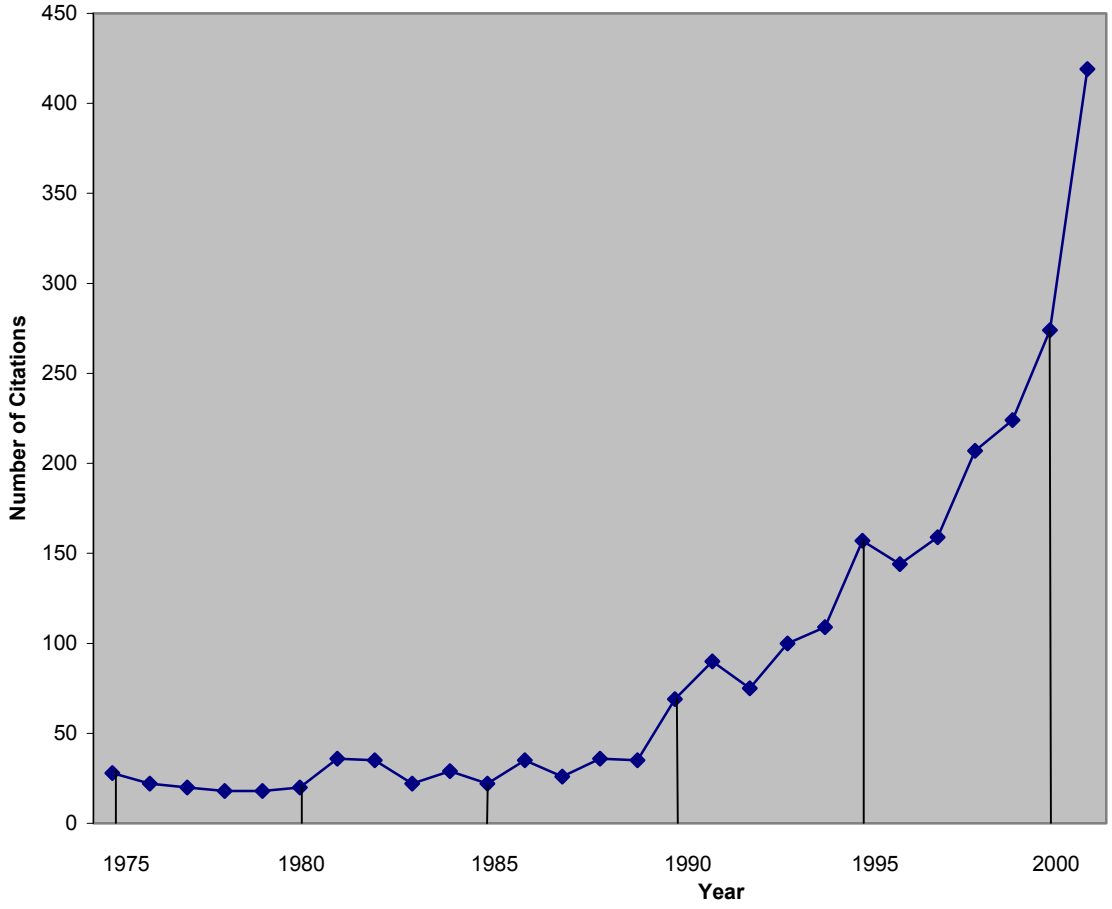
I do not think that Ron McKay would disagree with the above statements. His article serves several purposes: to help consolidate an emerging scientific field; to advance disciplinary and professional goals; to stage an appeal for material and symbolic resources; and, most importantly for this analysis, to position neural stem cell biology squarely within the discursive formation of curing. This is a critical move, and is now mandatory for controversial biomedicine (see Chapter III). The "discursive formation of curing" refers to claims and statements that articulate emergent experimental systems within the ongoing historical production of health and illness. What does this mean and why is it important? I will turn to these questions at the end of this chapter. First I will discuss neurobiology "overcoming itself."

From rigidity to plasticity

The transition from theories about the development of the central nervous system from being fundamentally rigid to being plastic did not happen all at once. Various investigators across the nineteenth and twentieth centuries found experimental evidence that vertebrate adult brains do possess some capacities for change over time. Thus this is not a scientific controversy over proof. Yet even as late as the mid-1980s, there was doubt about the plasticity of the vertebrate *adult* brain.

In order for plasticity to have conceptual coherence, there had to be at least one mechanism that explained how this plasticity worked, the conditions under which it occurs, and the cell(s) responsible for the observed changes. In developmental neurobiology, it was taken as given for most of the twentieth century that the development of new neurons (or neurogenesis) in the human central nervous system (CNS) stops following birth. By the twenty first century, this "dogma" had been shaken to the core (Gross 2000; Kempermann and Gage 1999). Models were borrowed from more well-characterized regenerative systems, namely the hematopoietic system. Chart 1 represents the English-language scientific literature on stem cells in the central nervous system. I conducted a PubMed search using MeSH database terms "Stem Cells" and "Central Nervous System" in a combination search (the limits were English language only and Entrez date range of 1975 to 2001) of PubMed on 9 May 2006, which revealed a total of 2429 citations. Then I conducted a focused date search for each year over the period of time 1975-2001 (Entrez dates, see Chart 2.1). This chart reveals a trend of increasing publications, beginning in 1990, with growing interest in explaining central nervous system plasticity in terms of the action of stem cells.

Chart 2.1: Neural Stem Cell Citations



The mammalian CNS is composed of two major types of cells: *neurons*, which transmit chemo-electrical signals across the different regions of the brain, spinal cord and body; and *glial cells*, which support neurons, but also do a host of different activities as well. Glial cells include oligodendricytes, which are responsible for secreting myelin, which provides an isulation for neurons in order for them to conduct an electrical signal (called an action potential) down the length of the neuron (the axon). Another type of glial cell is the astrocyte (of which there are two kinds), which are responsible for

secreting different biochemical to support the work of neural cells, and doing other kinds of work that are not completely understood.

Throughout the preceding century, glial cells played second fiddle to the importance of neurons in experimental neurobiology. More importantly, it was considered settled that there were no new neurons formed in the mammalian CNS shortly after birth. However, different experiments demonstrated that there is limited adult neurogenesis in some animals. In fact, as early as 1962, the question was posed in the scientific literature: "Are new neurons formed in the brains of adult mammals?" (Altman 1962:1127). What remains an intruiging historical question is, what took so long for this question to be asked?

As with all developmental biological questions formulated at the cellular level, there were a host of difficult problems in terms of identifying and tracking cellular activity over time. Following WWII, a newly developed technique of radiolabeling chromosomes using tritiated thymidine provided a visual opening into cellular processes, specifically cell division. Tritiated thymidine ([^{3}H]-thymidine) was developed in the early 1950s. Thymidine is a chemical precursor for thymine, which belongs to a class of molecules called pyrimidines. Pyrimidines are the central molecules that form deoxyribosenucleic acid (DNA). It was discovered that a pyrimidine molecule could be labeled with a radioactive isotope, and the radiolabeled molecule would be taken up by cells in a model organism (Reichard and Estborn 1951). In addition to pointing to the importance of pyrimidines, and thymine in particular, for deducing the structure of DNA, research began to focus on thymidine in particular as a tracking mechanism for cell division. It was demonstrated that [^{3}H]-thymidine was a particularly useful technique for

tracking cellular populations (Hughes et al. 1958; Taylor, Woods and Hughes 1957). When this technique was applied to mammalian neural cells, it was revealed that some cells do continue to divide in the adult mouse brain (Smart and Leblond 1961). Joseph Altman (1962) demonstrated a similar phenomenon in rats. Nearly twenty years following Altman's research, Michael Kaplan (1981) used electron microscopy to reveal the ultrastructure (detailed images of organelles only available with the electron microscope) of neural cells from adult rats marked with [^{3}H]-thymidine. This research should have pushed developmental neurobiology to reconsider its presuppositions of CNS rigidity. This did not happen.

Little interest was generated by either Altman's or Kaplan's research, and there was certainly no questioning of neural dogma in human neural development or response to injuries (Gross 2000:68). Attempts to repeat these studies in primates failed (Rakic 1985). Kaplan (2001) identifies Rakic as one of the major obstacles in overturning neural dogma. At the time of Kaplan's work, Kaplan had just finished his postdoc; Rakic, on the other hand, was a full professor at Yale Medical Center (2001:618). At a 1984 conference, Rakic argued that Kaplan's findings were spurious. In fact, Kaplan states that the most damaging claim to his research was Rakic's assertion at the conference that Kaplan's work would not meet Yale classification standards (2001:618). It was understood that while less developed animals may be able to regenerate damaged neural tissues, more complex mammals do not undergo such processes given that the neural circuitry is much more complex (Kempermann and Gage 1999:49). It took a serendipitous act to conclusively reveal that there is indeed neurogenesis in adult human brain.

In 1982, Howard Gratzner had published a paper in *Science* detailing his method for incorporating a marker into cellular DNA during its replication process. Gratzner (1982) discovered that bromodeoxyuridine (BrdU) will incorporate into cellular DNA during mitosis, and can be detected by the use of monoclonal antibodies, another useful technology then emerging in the biomedical sciences (Cambrosio and Keating 1995; Keating and Cambrosio 2003). BrdU was to become an important cellular tool for cell sorting techniques as well as imaging methods (Dolbeare 1995a; 1995b). It turned out that BrdU was also being used as an experimental way to track tumor growth in certain cancer patients (Kempermann and Gage 1999:50). A clinician from Sweden, Peter Eriksson was working on sabbatical with a team led by Fred Gage at the Salk Institute in San Diego, California. Eriksson learned about the BrdU trial while talking with a colleague who was a clinical oncologist. He realized that the administration of BrdU to the cancer provided the team with the experimental conditions for seeing whether the compound was incorporated within the brain (1999:50). Eriksson (1998) was able to obtain five samples of brain tissue from an area of the brain called the hippocampus from patients in the trial who had died. The team identified BrdU-positive cells in all five patients, and concluded that "cell genesis occurs in human brains and that the human brain retains the potential for self-renewal throughout life" (1998:1315). Thus, in a strange twist of fate, Eriksson "scooped" Michael Kaplan. As early as 1982, Kaplan garnered approval to administer [^{3}H]-thymidine to terminal cancer patients in order to counter Rakic's skepticism. However, Kaplan claims that neither the Dean of the School nor his department chair would support this apparently controversial experiment (see

Kaplan 2001:618, including the reprint of IRB approval for the experiment). Rakic (2002), meanwhile, changed his mind and grudgingly accepted adult neurogenesis.

These technical advances were also benefiting developmental neurobiologists who were interested in how the vertebrate CNS develops from the early embryo onwards. Researchers unfolding the processes of early neurogensis were confronted with a series of problems, such as how to identify progenitor cells, and how these cells change over time in response to internal (genetic) and external (micro-environmental) cues (for an early review, see Temple 1990). Being able to mark individual cells that gave rise to genetically identical daughter cells (clonal populations) gave researchers powerful tools to isolate and track cell populations over time both *in vitro* and *in vivo*. This work also began to cast doubt on the rigidity of the mammalian CNS.

Neural grafting

A second source of support for plasticity came from the tradition of neural grafting (also known as intracerebral transpantation, or transplanting neural tissue between brains). There is a long tradition in the biological sciences of neural grafting in a wide variety of model organisms (Das 1990; Fisher and Gage 1993; Gage and Fisher 1991). Das (1990) points out that since the nineteenth century, various types of tissues and cells have been grafted into vertebrate brains, including spinal cord tissues, fetal tissues and tumors. Researchers in this tradition have long noted cellular and histological anomalies following these different kinds of grafts.

While neural grafting is an older tradition within neurobiology, it was not until the 1980s that it was considered a possible tool for the treatment of human CNS disorders

(see Bjorklund 1991 for an editorial introduction to a special issue of Trends in Neuroscience devoted to this subject). Alongside recombinant DNA research, therapeutic approaches targeting genes (gene therapy) were emerging as means of treating human pathologies (Friedmann 1989). It was hypothesized that neural grafting could also be a useful technique for introducing genetically altered cells into the CNS (Gage, Kawaja and Fisher 1991).

Genetically altered neural cell grafting solves several problems. First, at that time, it was difficult to deliver pharmacological agents into the brain due to the the immunological priviledge the brain possesses (known as the "blood-brain barrier"). Second, even if an agent can be delivered into the brain, it is difficult to target the exact spot where the agent must be active. The human brain has different locations (cerebellum, hippocampus, and pituitary gland to name but a few), each of which are composed of different cell types. Third, the mammalian brain is regulated by intricate feedback and regulatory mechanisms. Neural cells secrete biochemicals at different rates at different times. For example, striatal neurons secrete dopamine in order to help coordinate motor functions in the body. These neurons are able to secrete dopamine at such precise moments that human movement can be elegant and complex. Striatal neurons are themselves regulated by other areas of the brain, resulting in dense, labyrinthine sets of neural circuitry. A pharmacological agent could not just be indiscirminantly "pumped in" to correct a deficit. Finally, the delivery systems themselves, whether a mechanical pump or drug-based agent, have their own problems, ranging from producing physiological sequelae to loss of therapeutic efficacy over time.[2]

[2] Gene therapy, which dates back to the early 1970s has its own genealogies which I will not explore here .

What gene therapy offered neural grafting was the opportunity to overcome many of these problems. As early as 1987, several diseases were identified as possible targets for genetically altered neural grafting, including Tay-Sachs disease and Parkinson's disease (Gage et al. 1987). The scientists were particularly excited about addressing Parkinson's disease (PD) for several reasons: the specific biochemical deficit, the loss of dopamine, had already been determined; an important human gene in the production of dopamine had been identified and cloned; the specific region of the brain where PD occurs had been identified; and the neural architecture of that region did not require complex re-wiring to occur in order to produce functional results (Gage et al. 1987:805). Further research demonstrated that cells could be genetically altered *ex vivo* or *in vivo*, and (re)integrated within the human CNS (Fisher and Ray 1994; Friedmann 1994). The altered cells would then (hypothetically) seamlessly integrate within extant neural architecture, and deliver the necessary biochemicals to ameliorate the pathology. These cells would be "biological minipumps" (Bjorklund 1991:320), mimicking the behaviors of the cells lost to disease. Unlike other vehicles for genetic therapies, grafting cells and tissues avoids the major problems of infectious agents, such as virus vectors. Using modified viruses to deliver genes to cells in the CNS was a Faustian bargain however; while the therapy may alter the cellular environment for the better, the virus vectors themselves could wreak havoc in the brain, which lacks the immunological defenses to control infection (Breakefield 1993). A second limitation for viral vectors in the CNS is that viruses only replicate in cells that are dividing, something that most neurons do not do after birth (Snyder 1994:746)

In order to make biological minipumps operate in an efficacious manner, there had to be detailed knowledge of the cellular processes that the minipumps were supposed to simulate. What this view of genetically altered neural grafting required was not only a better perspectives on the pathological conditions that necessitated minipump transplantation, but also a clear understanding of what kind of delivery system was best for what kind of disease state. What was needed was a cell that would facilitate this process. Gene therapy was again considered. For example, non-neural cells could be genetically altered so that they would behave like neural cells. This proposal has limitations, however, namely that non-neural cells have difficulty integrating into neural circuitry (Snyder and Wolfe 1996:127).

The human neural stem cell

The 1990s were a turning point, as the hNSC began to come into sharper focus as the candidate for the creation of new neural cells. One proposal was to model the study of the hNSC along the lines of blood cell differentiation, and thereby elaborate the processes of "neuropoesis" (Anderson 1989). This idea emerged from developmental neurobiological research on the mammalian neural crest. In mammals, the neural crest is an important phase in the development of the nervous system. In early development, a population of specialized cells migrates from a fold of embryonic tissue (known as the neural tube) into different regions of the developing organism to create the peripheral nervous system (Anderson 1989; Stemple and Anderson 1992). The experimental approach (*in vitro* and *in vivo*) to mammalian neural crest development marked a new intersection between embryology, molecular biology, and developmental neurobiology

(Anderson 1993; Fraser and Harland 2000; McKay 1989; McKay 2000b; Temple 1990). This intersection of disciplines, techniques, and research questions, beginning in the late 1980s and intensifying over the next 15 years, is the site where the hNSC was produced as an experimental object.

Is neuropoesis similar to hematopoesis? The first step in answering this question is defining a neural stem cell. Ronald McKay (1997:67) offered this definition: "To be considered a stem cell of the CNS, a cell must have the potential to differentiate into neurons, astrocytes, and oligodendricytes and to self-renew sufficiently to provide the numbers of cells in the brain. The term 'progenitor' refers to a cell with a more restricted potential than a stem cell. 'Precursor' is a less stringent term that refers to any cell that is earlier in a developmental pathway than another." Later, Fred Gage (2000:1433) defined the hNSC as follows: "The term 'neural stem cell' is used loosely to describe cells that (i) can generate neural tissue or are derived from the nervous system, (ii) have some capacity for self renewal, and (iii) can give rise to cells other than themselves through asymmetric cell division." Both of these definitions indicate some hesitancy in distinguishing the hNSC from other entities like progenitor and precursor cells. Some experimentalists described "stem-like" cells of the CNS (Gage, Ray and Fisher 1995; Snyder 1994).

In the adult mammalian brain, there is both neurogenesis and gliogenesis (formation of new glial cells). This occurs in two main areas; the hippocampus, and the subventricular zone (or SVZ, for a selection of reviews see for example Galli et al. 2003; Lie et al. 2004; Ming and Song 2005). The ventricles are holes or spaces within the adult brain filled with cerebrospinal fluid. The walls surrounding these cavities are lined with

cells that appear to be NSCs. Progenitor cells for neurons (neuroblasts) and glial cells (glioblasts) are formed in these areas and migrate to different areas of the brain (Alvarez-Buylla and Garcia-Verdugo 2002; Fisher 1997).

Developmental Biology - Teratocarcinoma research

Human stem cell research also emerged out of a series of research projects that spanned several disciplines which were examining a type of tumor called a *teratocarcinoma.* Teratocarcinomas are also known as "germ cell tumors," and are of interest to stem cell researchers because the embryonal carcinomal cells that produce these tumors display similarities to hESCs[3] (Kirchstein and Skirboll 2001:11). This work was first done in mice. In the early 1960s, research demonstrated that when teratocarinoma cells were injected into a mouse, tumors formed that were similar in organization to a developing murine embryo. These tumors were referred to as *embryoid bodies* (Kleinsmith and Pierce 1964). Teratocarcinomas are also known as "germ cell tumors," and are of interest to stem cell researchers because the embryonal carcinomal cells that produce these tumors display similarities to ESCs (Kirchstein and Skirboll 2001:11). Culturing the precursor cells to yield embryoid bodies proved to be difficult, however, until an experiment in 1981 cultivated pluripotent murine embryonic cells *in vitro*, with a normal (non-cancerous) set of chromosomes (Evans and Kaufman 1981). When these cells developed into embryoid bodies, they displayed characteristics similar to embryonal carcinomal cells (1981:155).

[3] Another line of human stem cell research comes out of work done on tumors that appear in the reproductive system called *teratomas* (which are similar to teratocarcinomas except that they are non-malignant). Teratomas have arosed interest in developmental biologists because they are comprised of a variety of cell and tissue types in different stages of development. This can include teeth and hair, and even rudimentary structures such as fingers .

Teratocarcinoma research was pivotal in providing an experimental medium that got around the technical difficulties associated with obtaining and culturing ESCs (for a review of this research, see Andrews 1998; Smith 2001a). This review of teratocarcinoma research is brief since I will now turn my attention to embryo research of which teratocarcinoma research is a part. Developmental biologists were to play important roles in isolating and characterizing the hESC. I will now turn in greater detail to this wing of biomedical research, and the science and politics of mammalian embryo research.

Embryo cultures: Research materials and controversial biomedical sciences

Research on the embryo has expanded over the course of the twentieth century, due to both technological improvements, as well as emerging cultural formations around assisted reproduction and regenerative medicine (Clarke 1998; Maienschein 2003). Embryologists, developmental biologists, clinicians and lay activists, biotechnology investors and government regulators strove to refine the process of *culturing the embryo*; in other words, fostering the experimental and social conditions of possibility of their work. The embryo was cultured *in vitro*, due in part to the advances in cell culturing techniques, as well as *in vivo*, as embryo researchers tied their enterprise to a variety of discourses, such as alleviating infertility and curing disease. I next briefly look at the material practices of twentieth century research on the mammalian embryo, and then turn to the moment in the early 1970s when the "social values" of the techniques and practices of *in vitro* fertilization became objects of different discourses (for example Edwards and Sharpe 1971; Etzioni 1968). I then examine how these "epistemic cultures" (Knorr-

Cetina 1999) attempted to manage the cultural politics of their work objects, and how the successes and failures of these biopolitical management strategies in the United States themselves cultured the conditions for contemporary biomedical situations, such as human embryonic stem cell (hESC) research. HESC research has a strong lineage stretching back through experimental embryology, which has been deeply committed to uncovering the minute details of the timeline of early embryological development.

Presenting the embryo

The emergence of the embryo as a target of biomedical intervention, and subsequent political concern, has been researched by a number of people (for a variety of perspectives see Alexandre 2001; Casper 1998; Clarke 1998; Edwards and Steptoe 1980; Hopwood 2000; Maienschein 1986; Mulkay 1997; Newman 1996; Pfeffer 1993; Pinto-Correia 1997). The closing decades of the nineteenth century, witnessed early attempts to fertilize and transfer mammalian embryos outside of the confines of the corporeal (Biggers 1984; Grobstein 1981). This "extracorporealization" of the embryo was to result in a series of political moves, including debates about infertility, sex selection, abortion and the status of the personhood of the embryo.

Walter Heape (1855-1928) is usually given credit as the first person to successfully transfer rabbit embryos between mothers, known as embryo transfer - ET (Biggers 1991; Clarke 1998). The rabbit was the model organism of choice, despite problems with cell culture media (Biggers 1987). Biggers argues that Heape was attempting to take on basic questions of heredity and the relative influence of sperm and egg on development (1991:177-8). Heape was also concerned with the commercial

development of these techniques, and their application to both industry as well as wider social relations (Clarke 1998:70). It is important to note here that ET was usually connected to some form of commercial development, and that this often involved support from a wide variety of sources. Heape's work initiated a "synthetic and intersectional tradition in reproductive physiology," (Clarke 1998:71) and opened up the field of ET for other researchers. One such stalwart was Gregory Pincus.

Pincus (1903-1967), working at both Cambridge and Harvard in the 1930s, faced some of the early obstacles to embryo research. As Clarke (1990a) points out, Pincus's research was considered controversial, and his career was damaged by negative portrayals of his work. Pincus ultimately left academia, and was supported by Margaret Sanger, Katherine McCormick, and others in the lay birth control movement to continue his work on a contraceptive pill (see Clarke 1998, esp. Chpt. 6). The links between research and activism were vibrant during the first half of the twentieth century.

Clarke argues for the development of a "quid pro quo" between birth control activists and maverick scientists involved with contraception from 1925 to 1945 (Clarke 1998:200). During that period, a very limited number of maverick reproductive scientists, mostly outside of the academy, began to do research on methods of contraception, and accepted funding from birth control/population movements. The quid pro quo emerged as a result of "changes within the lay, medical, and academic birth control movements between 1925 and 1945. The most pronounced shifts were from commitments to birth control as a means of enhancing reproductive and sexual autonomy for women to contraception with an economic ethic of childbearing - economic planning, eugenics and population control, often with racialized agendas" (1998:301). Parallel to

commercial interests in ET, social movements were also a vital part of early embryo politics. It is significant that by the 1920s, the reproductive sciences were already quite controversial (Clarke 1990a; Clarke 1998) – even among scientists.

Citing his enormous admiration for Pincus, Robert Edwards, also at Cambridge, began his work that was to produce IVF (Edwards and Steptoe 1980:43). In a 1971 paper in *Nature*, Edwards, Patrick Steptoe and Jean Purdy announced that they had successfully cultured human embryos to the blastocyst stage. The sources of gametes for Edwards' work are provocative. He obtained what he referred to as "superfluous ovarian tissue" from female patients who had surgery, facilitated by Dr. Molly Rose, the gynecologist who had delivered Edwards' own daughter; however there is no mention of whether the women consented to this "donation" (Edwards and Steptoe 1980:42-3). Edwards then fertilized the oocytes with his own semen; he notes that he consulted with his wife about this plan, and she approved (1980:52). That Edwards could perform this experiment, and write about it afterwards, marks a specific ethical moment. His team's work would eventually lead to the birth of Louise Brown, the first person born as a result of IVF technology. Brown, the world's first "test tube baby" was born in 1978 in England (Valone 1998). Since then, IVF (and fertility treatments in general) have become accepted reproductive practices, despite their status as demanding and expensive procedures and with low success rates and greater risks of disabled babies. This is due in part to understandings of "normal reproductive fitness" or standardized definitions and expectations of pregnancy for couples and individuals struggling to achieve pregnancy (for example Becker and Nachtigall 1992).

The technical background of IVF is important in understanding how the embryo was made visible to biomedical researchers and other invested groups and organizations. However, the controversies around IVF and other forms of assisted reproduction are very complicated stories. The development of IVF is inextricably linked to social and political forces, such as the development of state policy regarding assisted reproductive technologies, as well as judicial stances regarding the status of abortion, and social movements that take on the many sides of the abortion debates (for example see Blank 1984). The controversial success of IVF has only amplified the social attention paid to the embryo.

Embryos in/and culture

Defining the properties of culturing media was a crucial, albeit difficult part of the enterprise of embryo research, and continues to be important for human stem cell research. Rabbits were the model organisms of choice, and their ova were the material foundation of experimental embryology (Betteridge 1981; Biggers 1987). Both Heape and Pincus worked with rabbits, Pincus while he was working on his dissertation at Harvard, supervised by W.E. Castle (Biggers 1987; Clarke 1998). Rabbits were important model organisms at Strangeways Research Laboratory in the UK, helping to expand the "tissue culture point of view" that was emerging through the research of Honor Fell, John Hammond Jr. and Wesley Whitten (Biggers 1987; Squire 2000). Thus, advances in culture media were accompanied by a deepening knowledge of the mammalian reproductive system. Refinement of tools and techniques was imbricated within the production of knowledge, not outside of it (Clarke and Fujimura 1992). In

other words, theoretical questions needed novel tools, which in turn opened up new directions of research.

Rodents were also important model organisms. I have already discussed the importance of the SCID-hu mouse for hSC research. John Biggers and Anne McLaren did groundbreaking work in the late 1950s at the Royal Veterinary College in London using Whitten's medium (Biggers 1987:7). After Biggers moved to the Wistar Institute, one of his graduate students, Ralph Brinster, played a crucial role in defining the biochemical components and activity of rodent ovum culture (Hammer 1998). While many of these researchers and projects were dispersed around the globe, there emerged an "intensive mutuality of concerns" between researchers in biology, medicine and agricultural science (Clarke 1998:78). This mutuality of work led not only to the standardization of various culture media and techniques, but consolidated embryology into a commercial juggernaut: "Hammond and Pincus would surely have been gratified to know that one commercial company now completes 3000 transfers per year…They would have been pleased to see the transfer units attached to Universities, the financial support given to research by governments…They would equally have welcomed the way in which the technique has been extended to other species, to international trade, treatment of sterility, disease control and a myriad of research uses" (Betteridge 1981:10). Perhaps most importantly, this diverse group produced the embryo as an object of scientific inquiry and manipulation. However, despite Betteridge's glowing imagination, the extension of ET into humans proved to be fraught with difficulties.

Shortly after the publication of Edwards, Steptoe and Purdy's work in 1971, Edwards and David Sharpe, a North American legal scholar, published an article in

Nature entitled "Social Values and Research in Human Embryology" (1971). The authors made three important moves in this piece, the first being the articulation of IVF with the crusade to curing infertility, a problem short-circuiting "the most basic of human instincts," namely "the desire to have children" (1971:87). Second, the authors emphasize the discrepancy between emerging embryological techniques and current laws. This had the effect of making IVF seem novel, and outside of existing regulatory frames. Finally, the authors called for professional oversight of IVF, not state control: "The stress would be on individual and private action, inquiry and consultation, not on authority, control bureaucracy or 'laws with teeth'" (1971:90). The authors concluded by calling experimental embryologists into political activism.

Three years later, Edwards published a longer piece on the ethical and legal status of IVF (Edwards 1974). Using evidence from animal models that ET was safe, and the risks of insults to the embryo "very small," Edwards continued to argue that IVF would bolster the institutions of family and marriage (1974:9-10). He also took on his critics, namely ethicist Leon Kass (currently a key ethical figure for the Bush administration) , claiming that IVF is therapeutic despite the argument that it does not cure infertility in the strict sense. However, Edwards asserted that IVF would not lead to widespread human cloning: "Cloning depends on embryo transfer, but the converse is not true" (1974:13). Edwards concluded in a similar spirit to the 1971 *Nature* article, capitalizing on the turbulence and widespread calls for societal change that marked the earlier decade: "The increasing tempo of scientific advances is occurring at a time when earlier and accepted standards of society, and the value of many scientific and technological advances are being widely questioned" (1974:19). While he stressed transparency and public debate,

professional authority over the outcomes of regulation remained imperative. Articulating clinicians, researchers, patients, political authority and professional committees and organizations, Edwards both consolidated responsibility through individualized informed consent, and dispersed responsibility across a social terrain, including various organizations (e.g., Kennedy Institute, Hastings Center, etc.) and the mass media (1974:19). Thus, IVF, and the social institutions charged with its oversight, were simultaneously figured and fragmented as new spaces of imagination and targets for intervention.

The boundary work that Edwards and others interested in the implications of ET and IVF in humans attempted marked an important moment. While techniques of cloning and external fertilization had been imagined for some time, the mid twentieth century represents a watershed (Maienschein 2003; Shostak 2002). While developments in genetics, molecular biology and developmental reproduction were important, the appeal to technological innovation or experimental progress does not necessarily account for this transformation. It is important to pay attention to the wider contexts within which people like Edwards and colleagues labored and fought. As Mulkay points out, these experiments on embryos occurred at a time of multiple changes in the UK, includes shifts in policy on censorship, divorce and homosexuality (Mulkay 1997). 1967 was a particularly important year: the British Parliament passed the Abortion Act which liberalized access to abortion, and Edwards, Steptoe and Purdy fertilized human eggs outside the body (1997:8). Edwards's tireless enthusiasm interpellated the promises of scientific freedom from infertility with promises of social freedom from the straightjacket of a repressive past.

However, this liberalization of social policy was to provoke a backlash and, beginning in the 1970s and, eventually culminating in the rise of Prime Minister Margaret Thatcher, a new conservative social formation was to seize hold of the institutions of the state (on Thatcherism and articulation see especially Hall 1988; Hall and Jacques 1990). Edward Yoxen captured one articulation of this social formation with his concept of the "over-individualized notion of the embryo" (Yoxen 1990:175). This meant that one set of arguments about embryo research, namely those that focused on the personhood or identity of the embryo as paramount, came to dominate over other sets of arguments or positions. The over-individualized notion of the embryo was backed by an array of organizations that Yoxen refers to as the "moral Right," groups and individuals who were concerned with the state of British morals and values (1990:184). The moral Right, while not completely successful in their policy campaign, was thus nonetheless important in crystallizing a diverse set of positions into a political agenda with committed actors.

Technologies of the embryo

By the 1980s, a number of perspectives began to address the changing questions and problem spaces that were being produced by the new reproductive technologies of IVF, as well as other forms of assisted reproduction, genetic screening and surrogacy (including Clarke 1990a; Clarke 1995; Edwards et al. 1999; Franklin and Ragone 1998b; Ginsburg and Rapp 1995; McNeil, Varcoe and Yearly 1990; Rapp 1999; Strathern 1992; Van Dyke 1995). Many of these writers were/are interested in how culture was/is being reformulated by these new technologies: "It is this convergence of professional, technological, and commercial 'management' of conception, procreation, and pregnancy

that has been the subject of widespread public debate. In turn, the intensification of reproductive intervention has contributed to the increasing visibility of a significant site of late-twentieth-century cultural contestation, namely the foundational meanings connected to reproduction" (Franklin and Ragone 1998a:9). For my purposes, I am less interested in reproduction writ large than I am in the ways these interventions revealed the political technologies that make the embryo a social object.

For example, anthropologist Marilyn Strathern contextualized IVF as a part of "enterprise culture" (Strathern 1992). Enterprise culture represents a form of social life where notions of consumer choice are built-in to processes of object formation. They are assumed *a priori*. Thus, in the case of IVF, there emerges a "prescriptive fertility": if one *can* use IVF to get pregnant, one *should* utilize this technology (1992:36). Enterprise culture is the reformulation of previously obdurate processes and objects into projects and achievements (Franklin 1998:103). In her essay, "A partitioned process," Strathern discusses Parliamentary debates in the UK over the status of the embryo and embryonic development. She thinks about these debates over the complexity of development through changes in kinship formations as a result of IVF and new reproductive technologies. For Strathern, kinship is comprised of both biological and cultural elements and meanings, which are ceaselessly recombined and redeployed. This is due to a series of asymmetries between parents and children, as well as between parents. In other words, to recognize a child as a biological entity means that the child is a child of somebody: "For they [parents] exist only insofar as their children are *known* to exist, since persons are not presumed to be parents unless there is some way of knowing they have had children" (1992:148, original italics). Parents are thus *constructed* (Thompson

2005). However, they are constructed asymmetrically, as fatherhood is conferred after the mother/child bond is confirmed. Thus, while the mother is recognized in the process of birth, the father is constructed through the practices of (in this case middle class English) fatherhood (Strathern 1992:149). However, IVF and surrogacy relationships complicate these asymmetries. Surrogacy in particular splits open the natural and social aspects of motherhood by dispersing them across many people. Strathern argues that this fragmentation or devolution of motherhood can help us think about the embryo, which, like the "dispersible mother", has both natural and social futures: "In seeing how we are able to take that once complex person apart, we might better understand the imaginative procedures by which we put together its embryonic precursor" (1992:159).

In the United States, the articulations of embryo research were different from those in the UK. One of the major differences was played out in terms of abortion politics. Kristin Luker argues that abortion activism took a major turn following the *Roe v. Wade* decision (Luker 1984:137). Before the Supreme Court's decision, anti-abortion activists were generally male professionals; the post-1973 activist was quite different. They tended to be women who had gone through a pregnancy and, more importantly, "felt fewer constraints about expressing their concerns in vivid, public, and emotional ways" (1984:145). Also, most of the pro-life activists were "self-recruited" into the movement; that is, the individuals sought out information and groups on their own, rather than being recruited by friends, relatives, organizations or other formal and informal networks (1984:147-8). Thus the rapidly changing demographics of anti-abortion protestors following *Roe v. Wade* contributed to a massive change in the politics of abortion.

Shortly following the Supreme Court's ruling in 1973, the NIH placed a moratorium on embryo and fetal tissue research, and in July of 1974, Congress formed the National Commission for the Protection of Human Subjects (NC), with its initial task being recommendations for fetal research policy (Fletcher 2001; McCormick and Walters 1975). The NC was given only four months to produce a report, and its final product was an attempted compromise between the rapidly polarizing sides of the abortion debate. The major recommendations included the formation of an oversight body, the Ethics Advisory Board (EAB), and the extension of "societal protection" to the fetus (Fletcher 2001:28). The NIH imposed-moratorium was lifted in July of 1975. In 1978, following the birth of Louise Brown in England, the United States allowed federal funding for IVF research only if it was approved by the EAB (Thomson 1999). However, the EAB charter expired in 1980, and it was not renewed (Fletcher 2001:29).

Through the 1970s and 80s, a field of discourses about the embryo began to cohere and gain momentum in various locations around the globe. While I do not want to reduce the specificity of the local, this field was a complicated mix of "blurred genres;" in IVF newsletters, for example, "science, information and advertising all blend, almost beyond recognition" (Van Dyke 1995:77). This was especially profound in the early 1980s in the USA, with the need to naturalize the techniques of IVF in order to create a consumer base. According to Van Dyke, the blurring of genres in science reporting bolstered the "infertility myth:" "The creation of a (potential) market is evidently one of the prime results of this first round in the battle for signification" (Van Dyke 1995:84). A key weapon in this battle was the use of visualizing technologies to shift debates: "Technological instruments do not just affect the terms of debating; they actually change

the very perspective from which reproduction can be argued…New optical instruments and photographic techniques profoundly shape the narratives that constitute the public debate on new reproductive technologies, both in medical discourse, journalism and fiction. A combination of visuals and narrative appears to be a powerful agent in the construction of common sense – the appearance of IVF as a 'natural' commodity" (1995:121). In other words, IVF became successful through its appeal as a supplement to or bolster of the "natural" process of reproduction.

As embryos became natural commodities in Van Dyke's terms, they depended on flows of objects and actors in order to be reproducible. These flows are captured in Dion Farquhar's notion of "gamete traffic" (1999). Farquhar argues that the movement of embryonic precursors, namely semen and ova, both reiterates and challenges dominant versions of gender and sexuality. The need to extract, transport and preserve these bodily fluids as a part of IVF procedures creates many types of unique social arrangements, as well as unsettling others: "The now routine deracination and acoital extraction of gametes from their bodies of origin is both a technological and a social achievement bearing complex signifying effects for donors, recipients, and providers as well as the procreative process. Gamete traffic material incorporates new routes of relation and kinship as well as revolutionizes the significance of reproduction" (1999:23). Transport of gametes is relatively new: "The first successful long distance shipment of mammalian eggs, from Shrewsbury, Massachusetts to Cambridge, England, was accomplished in 1952" (Adams 1982:9). Thus the new routes that Farquhar elaborates have emerged only recently, and remain unstable connections across multiple social worlds.

The deterritorialization of embryos, gametes and other fluids and tissues has necessitated an infrastructure, material and symbolic, through which these objects can move. This infrastructure has benefited researchers, in that it standardizes and translates objects across different scales of time and space (Bowker and Star 1999). However, it also produces unintended consequences. Infrastructures are always vulnerable to sabotage, and require enormous maintenance. In addition, in order to be successful they must be expanded and elongated (Latour 1987). This includes the possibilities of new and unexpected alliances, as well as unforeseen problems for the management of biomedical supply lines.

Charis Thompson (2005: Chpt. 2) argues that feminist thought on IVF can be divided into two phases: Phase I (1984 to 1991), during which time many feminist theorists rejected IVF as a patriarchal and/or dominating; and Phase II (1991-2000), which was not a wholesale rejection of IVF, but rather a different perspective, influenced by poststructuralist, STS, and anthropological sensibilities. During Phase II, some feminist theorizing around IVF rejected binary thinking, or positioning IVF as completely consolidated in mutually opposing categories. In this rich body of work, some of which I reviewed above, Thompson points out that IVF and other assisted reproductive technologies have complicated entanglements with women and other actors. She argues that IVF is better conceptualized as a process, "whereby the ontology of naturalization and the politics of stratification occur" (2005:147). In other words, through the social processes of IVF, ontological categories, such as "person" or "parent" are co-produced along with the stratified or unequal outcomes of IVF. While Thompson does show the inequalities in IVF, she argues that these outcomes are not determined by the technology

itself, a primary Phase I critique. Rather, she argues that a woman going through IVF "renders" herself within the diagnostic procedures and clinical practices that comprise treatment: "She is locally and temporally drawn out into a series of bodily functions and parts, working in a way that forges a functional zone of compatibility with the means of medical intervention" (2005:203). It is this "functional zone of compatibility" that Thompson is interested in exploring. It is a provisional and changing assemblage of tools, drugs, institutions, clinicians, patients and families that is simultaneously fraught with great hope and danger. She refers to the processes that bring these different kinds of things together as "ontological choreography" (2005:203-04).

Thompson concludes her stunning work by elaborating what she calls the "biomedical mode of reproduction" (2005:247, see also Franklin and Lock 2003, Chpt. 1). This mode is characterized by transformations in the economy, the relationships between science and society, and notions of identity and kinship (2005:249). In terms of the economy, there are five significant aspects. First, embryos are *both* sacred and profane: they exist as both persons and commodities (2005:250). Second, within IVF clinics, individuals are alienated not from their abstract labor, but from their body parts (2005:255) Third, embryos possess "promissory" value: their value lies in what they promise to deliver in the future, which is different for the different sets of actors involved (2005:258). Fourth, there is a shift from efficiency to success in terms of clinical outcomes (2005:260). Finally, there are dilemmas with the category of "waste;" advances in biomedicine are causing objects formerly considered to be left over after procedures or "waste" to have subsequent value, such as hESCs derived from "surplus" IVF embryos (2005:263-4).

Human embryos and stem cells in a field of biotechnology

The embryo exists as an overdetermined entity: it is at once an organic thing, comprised of cells and cellular processes, but it is also dependent on multiple technical and moral interventions: "At once potential research material (scientific object), quasicitizen (it has legal rights), and potential person (human subject), the embryo has a cyborg liminality in its contested location between science and nature" (Franklin 1995:337, see also Franklin and Lock 2003, Chpt. 1). This has become clearer as IVF has been recently drawn into the maelstrom of ESC politics.

Historically, successful birth rates from IVF have been relatively low, and a recent study revealed that over 400,000 embryos are now frozen in IVF clinics across the country (Hoffman et al. 2003). For some, this has reopened questions regarding the necessity of IVF as a reproductive technology; for others, this has provided fodder for thinking about "spare" or "surplus" embryos as potentially available materials for ESC research. Determining the moral status of the embryo has become something of a cottage industry. While there are clear historical differences between the major religious systems in the world (Dunstan and Seller 1988), the harsh trill of "life begins at conception" has become a dominant frame for sorting out the collection of messy, ambivalent and contingent moments that comprise human life. This has to do with the moral politics of Yoxen's (1990) over-individualized embryo, as well as a certain kind of genetic reductionism that equates the human genome with "life itself."

The special properties associated with embryos and embryonic cells were noted by Edwards year twenty years earlier, as he drew on the imagery of *Brave New World* to

imagine a futuristic form of cell therapy: "Rows and rows of stem cells, deep frozen, waiting to fight our cancers, to restore our paling blood or repair our fading brains…Abnormal embryos, spare embryos, frozen embryos, research embryos-all these provide essential material for studies on early human life, studies of profound value for future men and women" (Edwards 1989:81-2). By the 1990s, biomedical researchers were realizing these potentialities of ESCs (Diukman and Golbus 1992; Hollands 1991).

In conclusion, I want to point out two strategies for management of the embryo employed by the opponents and supporters, and their constituencies, of embryo research. First, is the set of practices involved in the *fragmentation of the embryo*. One strand of feminist criticism of IVF and the new reproductive technologies focused on how the embryo/fetus became an object at the expense of the mother; she became a passive carrier, and her agency was erased (Casper 1998). Today, the embryo itself is experiencing a similar fate. Embryonic development is being scrutinized, broken down into many overlapping and cascading sequences at genetic and molecular levels. For example, debates emerged around the concept of the *pre-embryo*, or the form of life that exists prior to uterine implantation (Mulkay 1994; Trounson 1990). This opened up a series of questions that are not necessarily in the form of "when does life begin," but rather what exactly *is* life? This is not a new question, but it has taken on different valences in contemporary ESC debates. For example, if there is no clear embryonic origin, such as conception or syngamy (the unification of gamete chromosomes), what is the status of the gamete, or the conditions under which gametes are formed? Does semen have politics? This fragmentation, in turn, has provoked a multiplicity of positions, which utilize different discursive elements, some old and some new, to carve out political

space in a biotechnological field (Ong and Collier 2005; Rabinow 1992b; Rapp 1999; Rose 2001). Thus, actors use fragmentation for various purposes and goals within ESC research, while in turn, fragmentation produces new actors, unforeseen by the many protagonists involved.

The second strategy involves what I call the *logistics of biological objects*. This encompasses not only the movement of embryos and embryonic precursors, but also the cultivation of affinities and networks that facilitate movement. However, I do not want to stress only the instrumental aspect of strategy of these "biologistics." While it is true that actors do things in order to accomplish explicit political ends, these strategies also produce unintended consequences (on hybrid technoscientific affinities, see Haraway 1997). For example, there are "embryo adoption" programs, predominantly run by Christian organizations, which have developed working relationships with infertility clinics and reproductive medicine organizations, not only to determine availability of embryos, but also to reduce the number of frozen embryos, now burdensome for many clinics. Moving these delicate objects requires help not only from clinics, but also from transportation companies and interstate commerce regulators. Institutions are pulled into biologistic networks from many directions and with quite different goals and results.

These management strategies are but two possibilities in a growing field of biotechnology. These strategies are always inflected through material and symbolic cultures, and thus produce alliances that may seem scandalous or odd. Thus they are not quite strategies, in that they always exceed organized agencies. Mapping these quasi-strategies as they work through social space involves actors of many sorts, as well as

multiple origin stories. While it may not be possible (or desirable) to locate a beginning of these embryonic politics, it is clear that they are showing no signs of disappearance.

The politics of human research materials

By the mid-1990s, the epistemological and material conditions were thus fertile for the scientific discovery and articulation of the human embryonic stem cell. In a landmark study in 1994, a research team in Singapore obtained 21 "spare" embryos donated from IVF clinics, and maintained the "stem cell-like morphology" of selected cells for two passages, or the separation of cellular colonies into separate culture media (Bongso et al. 1994:2110). While the team claimed that this was the first example of developing "non-committed" cells from the inner cell mass of human embryos, they were also quick to articulate the ethical concerns raised by their work:

> Since the primitive streak starts forming at around day 14 of gestation it has been argued that life begins only then, and as such the ethical guidelines in Singapore allow experimentation and manipulation of human embryos up to day 14. The culture of embryonic cells after the 14th day should not face ethical problems since the organization of the embryo is lost in the process of cell culture, *and the ICM [inner cell mass] or ES-like cells are just a monolayer of cells with no potential of becoming a human.* (Bongso et al. 1994:2116, emphasis added).

The invocation of an ethical system based on reference to the nation, as opposed to a unversalist invocation of "humanity" or "personhood" in which the research took place is a crucial rhetorical device that changed the face of biomedical research at the end of the twentieth century. The flippancy with which the Singapore team disregarded their own

bioethical implicatedness in the process of culturing "just a monolayer of cells" may be perhaps the first volley fired in a conflict that was to eventual draw the most powerful governments, institutions, and scientific, religious, and lay actors in the world into a profound debate about science, life, and the basis of personhood.

In November 1998, researchers at the University of Wisconsin led by James Thomson, published a report in *Science* that became a focal point in ESC development. In that paper, Thomson's team received an undisclosed number of "fresh or frozen cleavage stage embryos, produced by in vitro fertilization (IVF) for clinical purposes…after informed consent and after institutional review board approval" (Thomson et al. 1998:1145). The team was able to culture five ESC lines from five different embryos, each with normal chromosomal structures: H1, H13, H14 had XY (male) karyotypes; H7 and H9 had XX (female) karyotypes. Line H9 was described as surviving the longest, 32 passages over 8 months (1998:1145).

The Wisconsin team ended their report by detailing the potential benefits of basic research understandings of ESC developmental dynamics, as well as listing the potential therapeutic interventions that could be produced (1998:1146-7). Unlike the Singapore team 4 years earlier, Thomson and his colleagues downplayed the ethical difficulties involved in their research, limiting comment to one statement about the "ethical and practical reasons" for conducting human and non–human primate ESC experimentation (1998:1145). The Wisconsin team then highlighted the benefits that could be gained, such as preventing infertility, birth defects, Parkinson's disease and diabetes mellitus, promoting advances in cell transplantation, and preventing immune rejection (1998:1146-7).

Running nearly concurrently with the Wisconsin team was another group of researchers working on human embryonic germ cells (hEGCs) under the direction of John Gearhart at Johns Hopkins University. While similar to ESCs, ESGs do have different properties. I do not pursue EGCs in this project (for a review see Thomson and Odorico 2000), since human germ cell research has had a quite different trajectory from that of human stem cell research.

The 1998 announcements of Thomson's and Gearhart's teams' discoveries were both landmark moments for biomedical research. The narrative of ESC discovery that I have laid out thus far is centered on the scientific discoveries that made ESC research for neurodegenerative disease possible. However, that is only part of the larger picture of ESC research in the United States. The 1998 papers themselves sparked off a firestorm of controversy, including reports by the NIH (National Institutes of Health 1999) and the American Association for the Advancement of Science (Chapman, Frankel and Garfinkle 1999), that eventually culminated in address to the nation by the President of the United States, George W. Bush in 2001. This conflagration was over a relatively new object, embryonic stem cells as research materials, but its roots reach deep into the history of North American cultural politics.

The social context of this research is comprised of many different and contradictory elements that congealed following the Supreme Court's 1973 decision to legalize abortion in *Roe v. Wade*. The scientific work of ESC research has occurred, and is continuing on, within several overlapping social worlds, such as social movements of life, health, illness and disease, the state, universities, bioethics committees and biotechnology industries, each of which is undergoing transformations as well. In order

to address some of these transformations, I want to briefly look at the embryonic/fetal tissue debates, as well as issues of intellectual property, as these have become important themes in the debates over ESC research.

The Reagan years were especially lean for biomedical scientists who were seeking access to fetal tissue. By 1985, Congress had terminated federal support for nearly all fetal research (2001:29). However, sentiment appeared to be turning towards the end of the 1980s, in large part due to the advances being made in neural grafting. Then NIH Director James Wyngaarden and Assistant Secretary of Health and Human Services (HHS) Robert Windom convened a panel to assess the usage of fetal tissue from abortion for research on PD (Culliton 1988). Despite the panel's recommendation that the use of fetal tissue was sound, HHS Secretary Louis Sullivan continued the moratorium on support for fetal tissue research (Sanders, Giudice and Raffin 1993).

At this time, research teams in Sweden, Mexico and the United States, among others, were examining the potential of implanting fetal tissue directly into the brains of individuals with PD. PD had already been identified as a good target for neural grafting techniques in rats, including cross-species transplants of human neurons in rat brains (Gash, Sladek and Sladek 1980; Stenevi, Bjorklund and Svendgaard 1976). This lead to human clinical trials around the world, using human fetal tissue in subjects with PD, including Sweden, Mexico, and the United States. By 1997, over 200 patients had received fetal tissue grafts, with mixed results. In early 2001, the results of a fourty-patient trial involving human embryonic dopamine-producing neurons were released in *The New England Journal of Medicine*. The same day, *The New York Times* released an article covering the trial. While scientists were largely supportive of the research, the

clinical outcomes were mixed, and *The Times* report cast a pall over the research. The opening line read: "A carefully controlled study that tried to treat Parkinson's disease by implanting cells from aborted fetuses into patients' brains not only failed to show an overall benefit but also revealed a disastrous side effect, scientists report." While *Nature* offered a different perspective, the uncertainty around the outcomes did not secure an unambiguous platform from which to argue for support of fetal or embryonic tissue transplantation.

By the beginning of the 1990s, scientific research and rhetoric were beginning to sway even former staunch enemies of fetal tissue research. In 1992, for example, conservative Republican Senator Strom Thurmond (R-SC) pleaded with the Senate to overturn the ban on behalf of his daughter, who suffers from diabetes (Sanders, Giudice and Raffin 1993:402). The election of the Clinton administration further changed the policy terrain; one of Clinton's first executive orders was to overturn the moratorium (1993). The Clinton administration also convened the Human Embryo Research Panel (HERP) in 1993; while this was not the first group that attempted to adjudicate the ethical concerns of new biomedical technologies with public policy, it did represent a closer relationship between state power and the governance of life in the US conflict (Green 2001:25). By September 1994, HERP completed its report that laid out both acceptable and unacceptable instances of human embryonic research, as well as a liminal category of research that "warranted further review" (2001:Appendix B). HERP's recommendations were to allow some latitude in research on embryos, as well as ESCs, in the context of fertility and IVF investigations. Three months later, the NIH voted to accept HERP's recommendations, but in a startling move, President Clinton rejected the panel's advice

and shut down any NIH funding "'used to support the creation of human embryos for research purposes'" (2001:104). However, attention to human embryonic research was only beginning to heat up.

The National Bioethics Advisory Committee (NBAC) was formed by executive order in October, 1995 (Clinton 1995). Its first meeting in the fall of 1996 came on the heels of the cloning of Dolly the sheep by a team from the Roslin Institute in Scotland (Green 2001:110). Dolly was an instant media darling, a familiar face for a very unfamiliar process: somatic cell nuclear transfer (SCNT). SCNT was soon replaced by the shorthand "cloning," and the ethics and policy debates flared up once again. The NBAC produced a report on the status of cloning in June 1997, which was greeted with mixed appraisals (for examples see Brower 1997; Childress 1997; Green 2001:Chpt. 6; Wolf 1997). The dust had hardly settled on the report when Thomson's announcement came out in November 1998 of his team's success in culturing ESCs. Clinton then instructed NBAC to develop recommendations regarding ESC policy, and the NIH began to review existing laws and the scope of regulatory coverage of ESCs (Green 2001:136). In April 1999, the AAAS and the Institute for Civil Society (ICS) convened a group which published a report in November 1999 that called for, among other recommendations, public funding of ESCs research, but not their purposeful derivation (Chapman, Frankel and Garfinkle 1999:viii). In September 1999 NBAC released their report, but diverged from the AAAS report in recommending NIH funding for *both* use and derivation of ESCs (Green 2001:158).

Interestingly, policy makers and advisory committees were not the only ones involved in the ethical tangles of hESC and embryo research. Scientists and the scientific

communities involved with hESC research themselves became involved early on in the ethical debates over their work. For example, in April 1999, Thomson weighed in on the debate in a commentary in *Nature Biotechnology* (1999). Drawing upon the history of IVF research, as well as the fluid nature of federal funding of embryonic research, Thomson pointed out that ESC research will happen outside of NIH funded projects regardless of federal policy positions since it could be privately funded. Further, this research would not be covered by federal ethical guidelines, which only cover federally-funded research. He concluded his article with the claim: "It is in the public interest that the ban on NIH support of human embryo research be removed, and that the guidelines suggested by the NIH Human Embryo Research Panel be adopted by both the public and private sector" (1999:312). In August of the same year, *Nature Neuroscience* published an editorial that called for continued basic research on hESCs for neurodegeneration, as well as careful ethical consideration of the implications of possibly creating a "chimeric mind," or a brain that has neurons from different sources, including humans and/or animals (1999:684). However, any clear answers from the NIH would have to wait for the outcome of the 2000 Presidential election.

The Republican candidate for President, George W. Bush, narrowly won a deeply contested election, and appointed former Wisconsin governor and pro-life supporter Tommy Thompson as head of the Department of Health and Human Services. In August 2001, after much deliberating by the Bush administration, the President addressed the nation and declared that the NIH would fund stem cell research using only a set number of immortalized stem cell lines already in existence. However, there were casualties even before Bush's announcement: in July of 2001, a top stem cell researcher at the University

of California, San Francisco announced his intention to move to Cambridge (UK) to continue his research there, due to the lack of public support in the U.S. (Abate 2001). NBAC's charter expired in October, 2001. The President's Council of Bioethics, which continues to review the ethical and social implications of cloning and ESC research, then replaced NBAC as the nation's highest bioethics advisory committee.

President Bush's decision to allow the NIH to fund limited hESC research produced mixed responses. There were different responses from the social worlds involved in the human stem cell research arena, and there were no simple oppositions, such as scientists vs. pro-life activists. For example, while some stem cell researchers hailed the President's decision, others were unhappy, and found the outcomes logically incoherent and/or bureaucratically inefficient. My intention here is neither to endorse nor critique the Administration's policy. Whatever their ultimate intensions, the new NIH policies gave stem cell researchers the rhetorical resources to justify seeking funding from outside the NIH umbrella. This is very significant, given the dominance of the NIH in funding basic and applied biomedical research since the end of WWII (discussed in greater detail in Chpt. VI). Bench researchers and their colleagues in university and research center administration petitioned other organizations to help champion the cause of human stem cell research. This included philanthropic foundations, industry, patient advocacy organizations, health social movements, and other non-federal levels of government, namely governors and state legislatures (Chpts. III and IV).

Conclusions

This chapter has covered much ground, including the experimental, clinical, and socio-political aspects of human stem cell research in the United States from 1945-2001. One goal was to point out the convergences of all these domains, and the key events that have shaped human stem cell research during the twentieth century that led up to the events that are the focus of this dissertation project. This chapter therefore introduced three central themes that will be in the next chapters investigated empirically:

1. *Why did Proposition 71 appear when it did (November 2004 general election in California)?* Given the historical and institutional difficulties of creating policy that addresses human embryo research, the United States federal government has either limited funding for the research, and/or maintained a laissez-faire attitude towards privately-funded human stem cell research. As I detail in Chapter IV, California has received (and continues to receive) the largest share of NIH research dollars of any state. This has contributed to the build-up of a massive biomedical research infrastructure. In addition, California has the highest level of venture capital funding of biomedical research. Thus, California dominates *both* the public and private financing fields. This chapter revealed how hSC research came to be poised at the edges of multiple research fronts through a series of remarkable experimental and clinical discoveries. Given the build-up of capital, research infrastructure, and the technical potentialities of human stem cell research and, as I detail in Chapter IV, a friendly political environment in the state capitol and the popular use of the initiative process in California, the conditions were ripe for something like Prop 71 to appear in that state.

2. *The rhetorical power of the discourses of curing.* As I have argued, hSC research is not just an experimental field. Human hematopoietic, neural and embryonic stem cell research emerged in close association with valued clinical lines of research. At various times this has provoked arguments around the possibilities of cures for various diseases, conditions, and disorders. Bone marrow and HSC transplants, non-myeloablative therapies for cancers of the blood, neural grafting, and fetal tissue transplants have all been advanced by research into the basic biology of hSCs, and have, to varying degrees, demonstrated levels of clinical efficacy against some conditions. As a therapeutic tool, hSCs have become invested with heavy curative potentialities. These potentialities are discursive in the Foucauldian (1972) sense. That is, the discourses of "curing" are in the form of statements about formalized objects within institutionalized contexts. The discourses of curing are generative of a variety of positions, including oppositional stances to hSC research.
3. *Emerging biosocialities around hSC research.* As a consequence of the bench-clinic traffic in hSCs, and the discourses of curing, many other groups of actors are becoming entangled within debates around hSC research. One important group is patient activists. I examine patient activism around human stem cell research in greater detail in Chapters. III and V. Rabinow's (Rabinow 1992b) concept of biosociality is helpful in understanding the depth and breadth of activism in support of hSC research. Briefly, biosociality stands for the emerging relationships between groups of actors around biological sites of difference and similarity, such as genes and/or diseases. Biosocial relationships are not just

> interest groups lobbying for more research funding, but deeper forms of affinity and belonging around processes of collective identity construction. Importantly, this "stem cell activism" is in support of a highly controversial technology. Rabinow's (1992b) initial formulation of biosociality black-boxed other groups of actors interests; for example, in the fields of hESC research, scientists, their institutions, and their financial backers all benefit from stem cell activists doing certain political work that they cannot, or will not do.

These three themes will be unfolded through the rest of this dissertation in my empirical investigation of Prop 71. Human stem cell research remains an expanding set of questions, problems, and situations, and this dissertation does not attempt to address all of them. Rather, I focus on one particular institutionalization of this aspect of regenerative medicine - human stem cell research in the state of California, and the development of Prop 71.

Chapter III: Health Social Movements and Scientific Controversies

This chapter operates at a wide angle, and is comprised of two central elements. First is an historical overview of social movements that intersect, overlap or are intertwined with questions around health, illness, life and death. This is certainly a huge field, and my goal in this chapter is to organize these movements into broad categories in order to compare and analyze similarities and differences among them. This analysis will serve as the foundation for the following chapter on stem cell activism by patient activists in the Prop 71 campaign.

Second, this chapter explicates the intersections of health social movements and scientific controversies. Health social movements are critical actors within and around biomedical scientific controversies. Drawing from Chapter II, this chapter analyzes stem cell activism in relation to recent controversies in the practices and policies of biotechnology and biomedicine. Using a social worlds framework, this chapter argues that contemporary debates on human stem cell research can be understood as emerging in some part from older controversies over technical interventions into biological life.

The chapters following this one will focus on one empirical political event, the Prop 71 campaign, and the complex social processes that both animated social action and produced emergent forms of social organization. The central form that this project is interested in is the "pro-cures" movement, or the collections of actors supporting human stem cell research in scientific, political, economic and civic social worlds. This chapter, in a sense then, describes the historic roots and engagements of this emergent movement.

What is a Health Social Movement?

In recent years, scholars from a variety of backgrounds have become interested in contemporary questions surrounding health social movements (HSMs). This is exemplified in special issues devoted to the subject in *Annals of the American Academy of Political and Social Science* (2002), *Sociology of Health & Illness* (2004), *Science as Culture* (2004), and *Social Science & Medicine* (2006), as well as numerous articles and monographs. The intersections of social movement research, science, technology and medicine studies (ST&Ms) and medical sociology are proving to be rich sites of inquiry into contemporary questions of the social organization of health, illness and biomedicine per se.

A recent attempt to summarize the field of HSMs was organized by Phil Brown and colleagues (2004). They define HSMs as, "collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organizations, supporters, networks of co-operation and media. HSMs' challenges are to political power, professional authority and personal and collective identity" (2004:52). They offer a typology of HSMs including "health access movements" addressing broad inequities in access and distribution of health care (see also Hoffman 2003). Second are "embodied health movements," or movements focused on living with specific diseases that engage dominant biomedical institutions in different ways across a variety of sites. These types of movements will be elaborated in further detail below. Finally there are "constituency-based health movements," which focus on health disparities that burden particular social groups, such as women or people of color.

The authors emphasize that these categories are ideal types, and that they frequently overlap in actual practice (Brown et al. 2004:52-3).

Brown and colleagues focus on the second category, embodied health movements, which are delimited by three main characteristics. First, they are centered on the body, or the embodiment process in relation to health and illness (Brown et al. 2004:55-6). That is, embodied health movements are fundamentally *corporeal*. They are animated by fluctuations or perturbations to the body, which are interpreted and acted upon by subjects. This process of interpretation is not done solely in the mind of the subject, but happens between persons and is a deeply social process of meaning-making. Thus there is a circuit of connections between body-self-others. Key others include family, peers who share the disease or condition, health professionals who diagnose, treat and manage the disease or condition, and researchers seeking cures, among others. Shared interpretations and joint action (Blumer 1969) can arise from these corporeal groundings.

The second characteristic is that embodied health movements confront expert knowledge in a variety of sites (Brown et al. 2004:56). Some see biomedical personnel as repressive agents of social control. This is especially true in mental health and disability movements, as we will see. Some conditions have difficulty gaining legitimacy (Clarke and James 2003; Dumit 2006). This blockage has been endemic vis-à-vis environmental illnesses, and in forcing activists to use different strategies to gain recognition. Additionally, activists in embodied health movements, even those with recognized illnesses or conditions, must remain vigilant in terms of public visibility of their positions. This includes testifying in public venues, sometimes in opposition to biomedical experts (Dresser 2001).

Finally, embodied health movements, while sometimes challenging scientific expertise, must also work with scientists (Brown et al. 2004:57). Steve Epstein's trail-blazing work on AIDS activism (1995; 1997; 1996) has shown how AIDS activists helped reshape aspects of clinical biomedicine through their "intrusions" into domains of expertise that had previously been off-limits to patients and their advocates. I will go into more detail about the emerging models of collaboration below.

Embodied health movements are certainly important in the current debates over stem cell research. Many such movements have solidified into formal organizations called patient advocacy organizations (PAGs). But PAGs certainly do not exhaust the range of forms of HSMs, though they do represent the formalized pole of patient activism. There exist myriad informal groups, gatherings and "crowds" of sufferers who do important political work (Canetti 1984; Oliver 1989). This project focuses on PAGs, and their contemporary positions in and around biomedical politics. Their inclusion within the Yes on 71 campaign was instrumental in the success of the campaign (as I make clear in Chapter IV).

For this Chapter, I define HSMs at their most general level as *social movements engaged with questions and problems around health and illness, the body and its habitats, life and death*. HSMs have three central criteria:

1. *They are more or less biosocial.* Biosociality, coined by anthropologist Paul Rabinow (1992b), encompasses new forms of association and affinity among patients, sufferers and their allies through biomedical techniques and concepts. For example, individuals and families with a genetic disease will be distributed across social categories, such as race, class, gender, etc. These individuals and

families, while different in many ways, come to see themselves as related through the possession of a genetic disease. These relationships are made possible by scientific means (the identification of a genetic locus), but they are not simply an endorsement of "more research, please." Biosociality, as elaborated below, comprises multiple "entanglements" (Callon and Rabeharisoa 2003) among people and objects.

2. *They are more or less mobile.* HSMs travel between the zones of modern life, such as the public and private, state and civil society, and the market and gift-exchange. Drawing of the work of Arjun Appadurai (1996; 2000), they operate on the different "scapes" that comprise the networked, deterritorialized world. Mobility is critical in the worlds of biomedicine. Patient activists need to quickly and smoothly move from bench to clinic to biobank to corporate boardroom to public protest. They need to be active across the social worlds and arenas.
3. *They have different "forms of involvement" (Barbot 2006) which produce different public identities.* In other words, HSMs are heterogeneous, and it is important to keep the kind of HSM in the foreground. That is, it is consequential if a HSM is organized around a genetic disease or an infectious disease in terms of the "forms of involvement" that will be produced, cultivated and/or contested over time. "Forms of involvement" is Barbot's term for capturing the ways that "active" patients are produced, and subsequently develop public identities across social spaces.

In order to examine these three criteria more thoroughly, I next review the major historical categories of HSMs. As with any typology, some individual entities do not fit comfortably within their assigned slots. One example of this is what David Hess (2005) terms technology- and product-oriented movements (TPMs). TPMs span civil society and the market by coalescing around "new or alternative forms of material culture" (2005: 517). One example of a TPM that overlaps with HSMs is the complementary and alternative medicine movement (CAM).[4] Hess (2002a) argues that the term CAM encompasses a wide variety of treatments and techniques that range in their integration with allopathic forms of treatment. Hess demonstrates how this integration changes the very nature of the object. For example, different CAM therapies for cancer have been integrated in multiple ways into traditional cancer treatment protocols (Hess 1997; 2002b). However, attempted integrations produced "object conflicts" or fights over dosage requirements for supplements or delivery systems for example, which in effect transformed the object per se (Hess 2005:524-5). This reveals the importance of issues of technical objects to HSMs, as well as the shifting bases of support for a technology (2005:530). These two points are critical for understanding the emerging activism around human stem cell research.

Not all TPMs are HSMs, and not all HSMs are TPMs. Stem cell activism is a HSM that is *also* a TPM. The enterprise of stem cell science is controversial due to the research materials needed for the bench research. In that sense it is a different kind of object controversy than that surrounding CAM therapies. In contrast, stem cell research

[4] Another important HSM that is close to the TPM pole is the anti-aging movement . This movement is a cluster of therapies, treatments, technologies and practitioners with some overlap with CAM fields. This cluster includes a variety of older "low-tech" objects such as tinctures or herbal supplements, as well as "high-tech" practices such as cloning and cell therapies. Like CAM, each technology is associated with different practitioners who attempt to attract followers and cultivate patients.

has no immediate product. The fights are actually over what the object will be. I conclude this section by looking at the implications of stem cell activism for what the technology may look like in the future.

Traditions of health activism in the USA (and elsewhere)

Historical movements of popular health

In the United States following the revolution of 1776, and on into the nineteenth century, medicine underwent massive changes. Not only were there transformations in the epistemological basis of medical treatment, such as the emergence of new therapeutics, but also an emerging embodiment of the "doctor-patient relationship," as each subject position began to be consolidated through the other (Rosenberg 1979:4). While professional allopathic or "Western" medicine was consolidating in the closing years of the 1900s, especially in the Europe and United States, lay medicine and popular health movements remained important participants/actors in defining the parameters of health and illness, as well as in treatment. As physicians developed their political clout through establishing state licensure for legal medical practice, popular practitioners and healers responded by crafting movements of popular health: "Conducted as part of a movement, lay medical practice may become an organized and self-conscious alternative to the dominant profession" (Starr 1982:48). Another alternative is cooptation within a profession, a path that has concerned women's health movement scholars and activists to the present day (Marieskind 1980:33). Popular health movements were crucial actors in the formation of modern biomedicine.

One such movement was founded by Samuel Thomson (Starr 1982). Thomsonian medicine, which combined elements of alchemy, herbal therapy and contemporary medical science, was as much ideology as therapy: "The genius of the Thomsonian system was to express a protest against the dominant order in its therapeutic as well as its political ideas" (Starr 1982:52-4). Following Thomson's death in 1843, the movement largely dissolved.

Popular movements like Thomsonianism, some of which continue to exist in different permutations today, are central in providing relief to those unable to gain access to professional allopathic medicine or who seek alternatives to it. Susan Cayleff (1987:12-3), in her study of hydropathy, argues that the success of Thomsonian medicine was its ideology of autonomous and self-directed care. She found popular health movements that followed Thomsonianism, such as eclecticism, homeopathy and hydropathy, shared this approach, as well as a distrust of doctors and an emphasis on hygiene, diet and environmental factors such as sunlight and air quality (1987:13). Hydropathy, or the "water-cure movement," involved cleaning and washing with water and soap, bathing and dipping in baths of various temperatures, focused cleansing of different body parts (eyes, mouth, and genitalia), as well as exercise and diet regimes (1987:35-8). In addition, the hydropathy movement shared ideologies and personnel with adjacent movements such as the temperance and dress reform movements (1987:139).

Women, excluded from professional medicine in the early part of the nineteenth century, were crucial participants in many popular health movements then and later (Weisman 1998). Women organizers were central in providing information about reproduction and pregnancy, as well as discourse about contraception and family

planning (1998:46). The women's health movement (WHM) of the second wave of feminism traces its roots to some of these earlier educational efforts.

During the late nineteenth century, schools of various types of medicine were established; some were only for women or "Negros." Some were primarily allopathic, while others were not. A key turning point for allopathic medicine's attempted displacement of other forms of healing was the Carnegie Report of 1910 (Starr 1982). This report, an early philanthropic intervention in the development of American medicine, recommended fiscal support for a handful of allopathic medical institutions to promote improvements in the teaching of medicine (especially the creation of full-time faculty), and linked allopathic medicine with the emerging life sciences and research programs. The Carnegie Report, along with later Rockefeller involvement in the development of modern medicine more fully established, legitimated and institutionalized allopathic medicine qua medicine. The very term "medicine" was increasingly naturalized as meaning allopathic approaches as formally instituted in American and Western European locations. Its imbrication with the life sciences was actively promoted (Brown 1981).

Largely as a result of this set of changes, most women's and Negro medical colleges closed, as did most other institutions training for non-allopathic approaches to healing. Key to my argument here, other approaches to healing, non-white male physicians and healers, and serious questioning of allopathic medicine were all increasingly marginalized, often as quackery (Starr 1982). A very active committee of the AMA was established and well funded to address what they saw as quackery and anti-alternative medicine activities have continued ever since in various guises by the AMA.

Organized social movements from those margins would hereafter be requisite for any and all serious challenges to the hegemony of Western allopathic medicine in the United States, and increasingly globally across the twentieth century.

Women's health movements

The history of the WHMs is deep and diverse (Friedman 1994; Marieskind 1980; Morgen 2002), and it maybe more accurate to refer to this constellation of women's actions as a *megamovement* (Weisman 1998:37). While there have been various manifestations since the nineteenth century, here I will focus on the post-1960s activism in the United States. During this time, women's health activism was spurred on by "spillover" (Meyer and Whittier 1994) from other movements, such as the civil rights, anti-war, and various nationalist movements (Marieskind 1980:289). The WHM emerged across the U.S. in different ways, such as self-help groups, informal contraception classes and workshops, and the traditions of female midwifery (1980:292). What also became important was political analysis and critique of the practices of medicine generally, and specifically the doctor/patient relationship in terms of gender (Eagan 1994:22). Women's health activists demonstrated the women were, and in some ways continue to be, treated differently than men in clinical situations. These critiques also made clear the importance of political organization in order to dislodge or change structural arrangements.

WHM scholars also pointed out that the systemic, formal delivery of health care relied deeply on informal networks of care in the family, entailed by perceptions and beliefs of women's roles as caregivers in the family (Olesen 1997). Given this context, Weisman argues that the WHM used two main strategies to leverage enhanced control

over their own health care (Weisman 1998:73). The first was a strategy of education through groups and publications (such as the iconic text *Our Bodies, Ourselves*), often at a local, grassroots level, but now increasingly globally. The second encompassed the formation of women-centered local organizations and institutions focused on the specificities of women's politics and health care at that time, from women's health clinics to shelters for battered women and their children to anti-rape organizing.

The 1973 *Roe v. Wade* decision that legalized abortion was a galvanizing moment for the WHM. While informal, underground abortions had been provided for some time, *Roe v. Wade* provided a boost for women's health organizing (Morgen 2002). However, some have felt that the WHM has become too closely welded to a "reproductive focus," and that this narrowing of political focus may have detrimental effects upon the movement as a whole (Marieskind 1980:306). Theoretical work in the WHM has opened up to questions regarding differences between races and sexualities, as well as challenges posed by science and technology (Clarke and Olesen 1999). Most recently, for example, Donna Dickenson (2001) explores the valences of embryonic stem cells (ESCs) in terms of the reproductive labor involved in creating them. She argues that the raging ethical controversy is over the value of the embryo per se, and not over the female gametes, tissues, reproductive system, or body, is a sign that female reproduction is taken as a given, natural state of affairs. To counteract this effacement of women, she proposes a new definition of property, through which women regain control over the usages of their cells and tissues (2001:214). Dickenson's paper, among others, is an indication that the legacies of the WHM remain vibrant in informing feminist criticism of new sciences and technologies.

Disease-focused movements

Overall, disease-focused HSMs constitute heterogeneous fields of social action that differ along conceptual axes, such as types of diagnosis or condition, characteristics of afflicted populations, degrees of medicalization, and geographies of activism. These movements focus attention on mental, infectious, environmental and genetic illnesses, as well as the processes by which various corporeal symptomologies become, or fail to become, classified as medical problems. There are hundreds of these groups, ranging from older, well established organizations with bureaucratic forms of management, to newer, smaller, "virtual" organizations which may be web-based, or smaller, informal groupings of actors. One disease that does not fit completely into these categories is cancer. That is, cancer is segmented by type or site/organ, therapeutic options, and notions of causation (environmental, genetic, or some combination). I examine cancer controversies more closely at the end of this section as they are particularly pertinent to stem cell work.

Mental health movements

Social scientists have long been interested in the social organization of mental illness (Estroff 1985; Foucault 1988; Goffman 1961). Patients suffering from a variety of mental illnesses have faced a series of challenges, including stigmatization and delegitimation due to the priority given to cognitive activities in Western epistemologies and practices. However, the United States also has a long history of mental health activism, stretching back to the 19th century, through the work of Elizabeth Packard and

Clifford Beers, two ex-patients who organized against involuntary hospitalization (Cook and Jonikas 2002). While some argue that patient activism has historically worked (and should continue to do so) with mental health professionals (Foulks 2000), others foreground the importance of "liberation groups," many of which started in the early 1970s: the Insane Liberation Front in Portland, Oregon (founded in 1970), the Mental Patients' Liberation Project in New York City, the Mental Patient's Liberation Front in Boston (both founded in 1971), and the Network Against Psychiatric Assault in San Francisco (founded in 1972) (Chamberlin 1990:323). These HSMs drew inspiration from the broader anti-psychiatry movement, which began as a critique of professional psychiatric care. At the same time, a less radical movement of practitioners and family members were pushing instead for community-based mental health services, a movement which had two basic missions: improving the mental health of the entire population, and developing alternatives to institutionalization (Hodge 287-8). Space prevents a more detailed examination of the relationships among these mental health movements.

In the 1980s and after, a new set of concepts became important for mental health activists. These include "survivor," "consumer," and "self-help." "Survivor" means someone who is recovering from an acute episode of mental illness, not necessarily an individual cured from a disease (Cook and Jonikas 2002:310-11). While space limits full discussion of the significance of this terminology, it marks several important changes. First, changes in psychopharmacology have produced therapies that reduce symptoms without the more extreme side-effects of earlier anti-psychotic medication. Second, as Cook and Jonikas (2002:311) argue, since many patients with mental illnesses were institutionalized against their will, they are "latecomers" to political activism. Finally,

the emergence and proliferation of self-help groups in the 1980s and 90s provided fertile ground for mental health activists (Borkman 1990). In 1987, the Surgeon General's Office sponsored the Workshop on Self-Help and Public Health, which focused on a wide range of self-help groups in mental and physical health, lead to the subsequent organization of the National Council on Self-Help and Public Health (1990:325). This National Council legitimated self-help activists, and supported the formation of self-help groups (1990:326). Self-help is now a wide field of activity, ranging from informal circles of friends (Gold 1994) to large federated organizations such as the Self Help Alliance (Borkman 1990).

Recent work by Nick Crossley (1998; 1999; 2003; 2006) has devoted attention to the histories and structures of mental health mobilizations in the United Kingdom, attempting to theoretically systematize these different levels of movements. Crossley (2006) argues that this mobilization can be thought of as emerging from "fields of contention." Drawing from both Pierre Bourdieu and Norbert Elias, Crossley makes several claims. First, these fields contain different social movement organizations (SMOs) and actors. Second, these SMOs and actors interact with each other in a "relatively autonomous" fashion. In other words, these different actors begin to share common understandings and practices (what Bourdieu refers to as *doxa*) primarily pertinent to the actors themselves. Third, this shared set of understandings and practices serve to both exclude outsiders, and to create space for insiders to develop new positions within the field. Fourth, this development is not static; rather fields are "mobile and fluid" (2006:553). Finally, this fluidity and mobility means that a focal field is impacted by other fields. Crossley asserts that from within the mental health field, four

"trajectories," or themes emerged following the 1960s: anti-psychiatry, survivorship, civil rights and paternalistic trajectories. Crossley's work is important in revealing the dynamics by which different social movements in the mental health field produce effects that are not reducible to major institutions or actors, but rather emerge over time from the sets of interactions among quite heterogeneous groups and actors.

Infectious disease movements

Infectious diseases have long been sites of action inside medicine that resembled social movements, such as battles against cholera, tuberculosis and venereal disease. While diseases such as diphtheria and polio have faded from public attention in developed countries, others, namely HIV/AIDS and other sexually transmitted diseases, as well as weaponized infectious diseases now have the spotlight. HIV/AIDS activism is today considered by many to be one of the central HSMs in the recent history of medical activism in the United States and elsewhere. Some even consider HIV/AIDS activists to be "the first modern disease activists" (Dresser 2001: 165). As the earlier history provided above demonstrates, this claim is certainly overstated. However, Steve Epstein (1995:411-13) points out some critical cultural elements constitutive of the AIDS epidemic. Due to the "failure" of biomedicine to develop a timely vaccine or other barrier to HIV transmission, he claims that a space was opened up for lay groups to become involved in science in the making. Drawing from new social movement theorizing, Epstein argues that this involvement was bolstered by activist's self-reflexive understandings of their own identity statuses (most of the activists were HIV-positive or recent seroconverters), which then became fundamental aspects of the movement.

The complicated positioning of HIV-positive identity in the 1980's, along with the self-reflexivity of the activists, contributed to HIV/AIDS activism turning towards biomedicine in its search for help with this disease. Epstein (1995:419-21) identifies four central tactics that the activists engaged in in order to get a seat at the AIDS treatment policy table: learning the languages of biomedicine; presenting themselves as representatives; knitting together methodological and moral arguments; and finally, taking stances within extant medical and scientific debates. He argues that the activists were successful in part through their tenacity and organization, but also due to accepting portions of the larger rules by which knowledge is produced: "For the most part, activist have been more interested in participating in science – or asserting the simultaneous importance of values *other than* the pursuit of science – than they have been in transforming the practices by which science constitutes knowledge" (1995:427). This position has allowed the activists to frame the AIDS epidemic in new ways, utilizing both scientific and lay discourses. For example, should clinical trials reflect the "messy" nature of social existence, or should they strive for a "clean" design that reduces the heterogeneity of modern life (1995:422)?

Janine Barbot and Nicolas Dodier (Barbot 2006; Barbot and Dodier 2002) have recently explored similar terrain regarding AIDS activism in France. Barbot (2006:547) demonstrates that as patients have become activists, they have developed multiple models of activism. She compares earlier ("first generation") and later ("second generation") AIDS associations in France, and identifies criteria that distinguish the kinds of "active patients" that make up each group. These generations are organized around "the different positions with regard to their public identity" (2006:547). The first generation is

characterized by a "form of involvement" (2006:540) that mediated between HIV-positive individuals and other institutions. This first form of involvement was animated by a distinction between "ill" and "not ill" individuals in terms of their serostatus (2006:542). First generation AIDS organizations (represented in France by the group AIDES) mediated between these categories, providing both lay and scientific perspectives in publications, for example.

Barbot's research found that the advent of diagnostic and therapeutic changes helped to usher in a second generation of AIDS organizations. These changes not only erased the distinction between "ill" and "not ill" individuals, but helped to proliferate different models of patient activism (2006:548), such the "empowered patient" (represented by the group ACT UP-Paris), the "science-wise patient" (represented by ACTIONS TRAITEMENTS), and the "experimenter" (represented by POSITIFS). The "empowered patient" is characterized by a critique of professional medicine as unresponsive to the concerns of marginalized populations. Barbot (2006:543) asserts that ACT UP-Paris imported their activist template from ACT UP-New York. ACT UP-Paris attempted to leverage state action through a "detailed critique" of information; ACT UP-Paris documented data from clinical trials conducted around the world, for example, to get the French government to simultaneously open up broader access to experimental treatments, and protect patients from "the deleterious effects of market forces" (2006:543). The "experimenter" shares with the empowered patient a critique of medicine, but focuses on a different terrain. The experimenter crosses the boundaries between and among allopathic "official" medicine and a range of "alternative" treatments

(2006:545), all the while cobbling together techniques from all these different worlds to produce new forms of knowledge about HIV.

Both the empowered patient and the experimenter represent second generation AIDS activism in France. While first generation activism, such as AIDES, modeled the "patient as *manager of his illness*" (2006:547, original emphasis), second generation activism created public identities that were intertwined with clinical and experimental research and institutions. Barbot's work opens up a set of questions about changes in patient activism over time and space. That is, rather than a singular patient activist either opposing or working with biomedical authorities, Barbot asks us to think about how patient activism takes different forms at different time across a series of social spaces that are themselves changing.

Genetic disease movements

Genetic diseases, such as Alzheimer's, Parkinson's and Huntington's diseases, ALS (amyotrophic lateral sclerosis or Lou Gerhig's disease in the USA), MS (multiple sclerosis), and an expanding variety of rarer conditions that become symptomatic at different points in the life course (neo-natal, adolescence, or early- and late-onset) have also become more visible over the course of the 20th century. Many commentators attribute this to the rise of *genetic medicine*, or the diagnostic, clinical and/or experimental tools and techniques that operate at the level of the molecule (Kay 1996). This has also lead to a flowering of research into *biosociality* (Rabinow 1992b). Similar to Barbot and Dodier's AIDS sufferers, families and groups relating to genetic diseases form associations that have different stances towards *all* aspects of the research

enterprise; experimental work, clinical trials, intellectual property and the social organization of health care. Rabinow's (Rabinow 1992b) concept of "biosociality" attempts to capture these complicated and contradictory forms of health activism.

Two important long-term engagements in mapping biosocialities have been undertaken by social science research teams in France and the United States. The French team has produced a series of papers around an organization called the Association Française Contra les Myopathies (AFM), which is a set of conditions known in the United States as muscular dystrophy (Callon and Rabeharisoa 2003; Callon and Rabeharisoa 2004; Rabeharisoa 2003). They are interested in what they call *research in the wild*; scientific practices done by lay people outside of formal scientific institutions. What they have produced is a remarkable research project that looks at the "forms of agency" that individuals engage in over the unstable and changing course of health activism.

Rabeharisoa's (2003:2128-29) initial typology of patient advocacy groups revealed three models. The first is the *auxiliary model*, which is organized around the mutual recognition of suffering, and the "questions of relations between patients and professionals". There are two responses these organizations engage in: "delegation," or letting scientific review boards or advisory groups take charge over the processes of knowledge production, and/or "becoming lay-experts," acquiring the professional expertise to evaluate scientific work. However, this model of group runs the risk of polarization and replication of lay/expert divides, or becoming the "emotional support" of patients, while experts take care of the "hard science." The second model is the *emancipatory model*. This model is derived from self-help traditions, often completely

rejects professional expertise and institutions, and attempts to produce collective identities around illness experiences (2003:2129). This model is useful for generating new identities and organizations, but runs the same risks as the auxiliary model.

Finally, there is the *partnership model*. Groups using this model, like the AFM, differ from those in an emancipatory model in that they do not reject "science" in favor of "experience," but articulate both personal suffering and scientific technique. For example, a group of parents with children who suffered from spinal muscular atrophy (SMA) wanted to encourage research on this condition. The parents used "proto-instruments" to capture data, such as taking home movies and photographs of their children (Callon and Rabeharisoa 2003:197), and eventually wrote a report that helped to establish clinical profiles of SMA. This helped to identify the gene responsible for SMA. Parents became well-versed in SMA genetics, and worked with scientists on the development of research questions, a critical stage in the social life of experiments (Rabeharisoa 2003:2133). This example reveals how the AFM differs from the auxiliary model as well. Activists are not just emotional supporters or care givers, but active participants in the processes of knowledge production. Moreover, this relationality is not unidirectional. AFM activists also appeal to "healthy" people, to see themselves as aligned with this research: "By showing that a defect is in fact a small genetic accident, the AFM demonstrates that we are all just one or two genes away from being MD [muscular dystrophy] patients" (Callon and Rabeharisoa 2003:200). Thus it is only an "accident" that keeps all of us from being patient activists. This is a powerful rhetorical frame.

Rabeharisoa and Callon's arguments also move beyond typologies of organization. Drawing from actor-network theory, they point out how objects and practices themselves are nonhuman actors in the partnership model: "Genes are not content just to make particular and general interests compatible; they also produce solidarity and compassion…The circulating gene entangles patients and researchers as it goes along" (2003:200-1). Objects and practices are not only sites for biosocial struggles; they themselves are responsible for bringing actors together as a collective forms itself.

A team of anthropologists in the U.S. has conducted a series of extended and multi-sited ethnographic projects tracing the contours of *genetic citizenship* and *mediated kinship* across different patient activist locations (e.g., Heath 1998; Rapp 2000; Rapp 2003; Rapp and Ginsburg 2001; Rapp, Heath and Taussig 2001; Taussig, Rapp and Heath 2003). Researching a variety of diseases and conditions, including Marfan's syndrome, achondroplasia (a form of dwarfism), and Down's syndrome among others, this team has produced a dense set of concepts through which biosocialities can be understood. They have highlighted the importance of kinship structures, as patients and families come to see each other as related in new ways through disease categories. Biosocial kinship networks are constituted in differently: they share *collective identities* and also have *corporeal components*, as individuals feel affinity through appearance or phenotypical traits associated with the disease or condition. The team has uncovered what they refer to as "knowledge coalitions" (Rapp, Heath and Taussig 2001:401) of patients, families and researchers similar to the partnership model framed in France. These coalitions extend all the way to specifying the nomenclature of diseases. The authors point out how terms

that translate as fatal are contested by researchers themselves as potentially unsettling to the families.

The U.S. researchers also attend to the intersections between knowledge coalitions and the increasing public attention and awareness of genetic disorders and "disability narratives" that foster "public intimacy," noting the presence of patients and their families in many aspects of civil society (Rapp and Ginsburg 2001:537). "Public intimacy" is a direct result of the disability movements I will turn to next. Understood both through knowledge coalitions and a civil rights frame, individuals with genetic diseases have become indelible elements in the public conversations over our shared "genetic futures." However, this can lead to *biotechnological individualism*, or the desire to perfect oneself through choosing genetic improvement techniques (Taussig, Rapp and Heath 2003:60). Biotechnological individualism obscures the historically stratified effects of this desire. Worse, it could lead to *flexible eugenics*, as those with non-normative corporealities are seen as willfully neglectful (2003:60-1). That is, if the technology exists to "improve" oneself, why would an individual refuse to take it (for a different perspective on this choice, see Agar 2004)?

Such questions opens up a host of difficult positions that actors are in the process of sorting out. Flexible eugenics constantly lurk in the background. Knowledge coalitions are constantly confronted with problems of medical techniques that have been standardized for "normal" bodies. Individual who do not fit standardized classifications face challenges, even within knowledge coalitions. In other words, flexible eugenics is not the conscious, directed effort of the state to eliminate or control "undesirable" populations. Rather, flexible eugenics may be outcomes of biotechnological

individualism and emergent norms of new(er) medical practices as they become established and routinized. For example, Karlberg (200) found that pregnant women discussed pursuing prenatal testing, which certainly can be read as eugenic as part of their responsibility for familial health and well-being.

Environmental illness movements

Environmental illnesses also represent an expanding class of diseases and HSMs (Hess 2004). While their ontological status remains murky, these diseases have benefited greatly from intense patient activism across social worlds. Environmental illnesses and related disorders have had different activist histories from infectious or genetic diseases. That is, the construction of *lay expertise* has been deeply contentious, perhaps more so than vis-à-vis infectious or genetic diseases because of the contested nature of environmental illnesses. The work of Phil Brown and his colleagues has focused on these conflicts over credibility (Brown 1987; Brown 1992; Brown et al. 2001a; Brown et al. 2001b; Brown et al. 2004). Brown has developed the notion of *popular epidemiology* to explain the processes by which lay victims of toxic waste induced illnesses organized to produce knowledge to support their claims (Brown 1987; Brown 1992). He defines popular epidemiology as, "the process by which laypersons gather scientific data and other information, and also direct and marshal the knowledge and resources of experts in order to understand the epidemiology of disease…Further, it involves social movements, utilizes political and juridical approaches to remedies, and challenges basic assumptions of traditional epidemiology, risk assessment, and public health regulation" (Brown 1992:269). Brown also lays out the elements of popular organizing, including both

internal dynamics (as actors speak to each other and begin to develop a collective identity), and external dynamics (working with institutions and agencies to forward their goals, and working against other institutions and agencies that challenge lay claims) (1992:269-272) These processes generate knowledge; but more importantly, Brown claims, these dynamics contribute to "good science" in that lay involvement can help point out blind spots or problems in scientific research, and uncover hidden data institutional scientists may have missed (1992:277). Thus, popular epidemiology serves to frame different aspects of movement activity.

Current work is in the process of elaborating the terrains of conflicts over *contested illnesses,* processes by which a disease is transformed from, "a personal trouble into a social problem" (Brown et al. 2001b; Kroll-Smith, Brown and Gunter 2000; Zavestoski et al. 2002). Contested illnesses arise out of challenges to a *dominant epidemiological paradigm* (DEP) by popular epidemiology. The DEP is rooted in the social constructions of knowledge at both the level of institutional and professional domains, and the social processes of diagnosis and interpretations of illness (Zavestoski et al. 2002). Unlike the partnership model of the French AFM, activists with contested illnesses have had to develop "practical epistemologies" to legitimate their conditions; practical epistemology, "joins the world of personal and biographical experiences to forms of instrumental rationality" (Kroll-Smith and Floyd 1997:38-9). However, these relationships unfold outside biomedical institutions, and often in contentious positions to biomedical expertise. Kroll-Smith and Floyd claim that multiple chemical sensitivity (MCS, one kind of environmental illness) "is a dispute over what will count as rational explanations of the relationship of the human body to local environments" (1997:43).

This may help explain the differences among the several types of activism. Infectious or genetic disease activists develop relationships with experts precisely because the terms of the debate occur *inside* the body, while environmental illnesses have to do with the *boundary between the insides and outsides of bodies*. While both are complex domains, the latter is much more *indeterminate* than the former.

Disability movements

The concept of "disability movements" challenges the formulation that links social movements and embodied categories. This is due to the heterogeneous natures of *disability*, which open up a set of questions about the status of ability.[5] Disability is a difficult identity category for some authors. For example, Barnartt and Scotch (2001:xvii-iii) argue that the category of disability varies widely across a host of dimensions, including visibility, stability, severity, prognosis, as well as aspects of socialization, among others. The authors do locate similarities as well, such as linguistic marking as different, experiences of discrimination, and histories of collective action (2001:xviii-xix). Disability movements have also differed geographically and nationally. For example, Gleeson points out that in the United States, disabled movements have been more of a "militant rights-based course," while their counterpart in the United Kingdom have focused more on changing social policy from a charity-based organizational field (on the UK context, see Bury 2004; Gleeson 1999:42-3).

For Barnartt and Scotch (2001:31-2), a central variable in the study of "disability protests" in the United States is *collective consciousness*, or what they term "disability

[5] This subsection is not intended to cover to flourishing body of literature known as *disability studies*. From a wide selection see .

consciousness". While disability movements have existed for some time, it was the waves of social movements in the 1960s that marked a significant change (2001:17). The authors split disability movements into two main types: impairment-specific and cross-disability movements. They also claim that both types of movements exhibit characteristics of both old and new social movements (2001:32-3). The old social movement component is the extension of the civil rights frame to people with disabilities. This frame extension technique is one of the most common. Many movements, often from very divergent ideological positions, engage in this process. Here, disability protestors focused on two central domains: *accessibility* in a range of arenas and *equal opportunity* in different aspects of social life (2001:38). In contrast, the new social movement component centered around debates in "independent living" (2001:42-4).

Barnartt and Scotch (2001:57) argue that disability consciousness was a necessary but not sufficient condition to incite the protests that arose in the 1970s. They (2001:57-8) add common spaces, networks of communication, and availability of resources as critical dimensions. From these dimensions, I want to highlight the broadening and deepening of activist networks during the 1970s. This was a general trend in North American social movements during this period. For example, Theda Skocpol (2003:179, 199, 204) asserts the importance of several changes, including the breaking down of older forms of exclusion, new opportunities within political institutions, and the development of new techniques and forms of organizing, like direct mail appeals and use of media outlets that dramatically resculpted the social movement landscape after the 1960s.

Disability activists were certainly beneficiaries of such transformations. As Renee Anspach points out: "Until the 1960s there were simply no alternatives to the

ideology of rehabilitation. And without an ideology or set of constituent ideas, a social movement is impossible. The social movements of the sixties provided the disabled and 'mentally ill' with just that ideology" (Anspach 1979:771). Anspach described the emerging disability movement as taking a new and overtly politicized form. This form was different from both the voluntary organization and the self-help group (1979:765). Drawing from Joseph Gusfield's (1986) typology of social movements in *Symbolic Crusade,* Anspach adds a forth type of movement organized around the pole of identity. She calls these types of movements *identity politics*: "Among its goals are forging an image or conception of self and propagating this self to attentive publics" (Anspach 1979:766). Building from Fred Davis's (1972) work on responses to stigma, Anspach identifies an additional response – political activism (Anspach 1979:769-70). An individual's decision to become an activist, as opposed to normalization or retreatism, is predicated on the severity of the disability, and the kinds of relationships the individual has with others, including family, friends and agents of social control (1979:770-71). Anspach focuses on two stratagems of disabled identity politics – *repudiation* and *self-elevation* (1979:772). Repudiation is the demedicalizing of a disability. Rather than seeing a disability as an individual corporeal and moral failing, disabled activists highlight the "societal etiology" of stigma (1979:772). Self-elevation follows from repudiation. Since it is social arrangements that produce stigma, not an individual, the disabled activist becomes a heroic agent struggling against oppressive institutions: "Madness emerges not as affliction, but as creative rebellion, and the disabled emerge not as passive victims, but as prophets, visionaries and revolutionaries" (1979:773). Anspach

concludes that actions and ideologies of the disabled create the conditions for new identities that undermine the norm of ability.

Recent works have expanded Anspach's groundbreaking article on disability activism. As Joseph Shapiro succinctly puts it: "People with disabilities are demanding rights, not medical cures" (1993:14). This has produced numerous successful movements and protests. For example, student protests at Gallaudet University, a university that primarily serves deaf students, were successful in replacing a newly-selected hearing president with a deaf president (1993:74-104). In 1991, President George H.W. Bush signed the Americans with Disabilities Act (ADA), a major policy milestone (for a full discussion of the ADA in historical perspective, see Scotch 2001). It was propelled by a "hidden army" of supporters in government who had family members or close friends who had a disability (1993:117-18). This hidden army metaphor is important; as we will see, the Yes on 71 campaign relied on its own hidden armies to do political work that the formal campaign either could not or would not conduct.

Environmental movements

Connected varyingly to HSMs are environmental movements. While environmental movements certainly focus on protecting vanishing habitats or endangered species, a major wing of these movements has become focused around the concepts of environmental racism (ER) and environmental justice (EJ) that are linked to the geographic and population-based distribution of environmental health risks (Sutton 2004). ER is the deliberate dumping of waste materials or toxic substances, or the siting of toxic industries, such as waste incinerators, in communities of color, many of which

also tend to be low income. ER can be deliberate, as companies wantonly or surreptiously dump wastes in these communities. It can also be due to a lack of political power. That is, marginalized communities often lack the political clout, or access to influential political insiders, to prevent the siting or dumping of hazardous materials and industries in their "back yards." Commentators are also broadening the historical and geographical parameters of EJ movements, including struggles in the global South that link with activist around the globe (from a growing literature, see Bullard 2000; Cole and Foster 2000; Moore, Kosek and Pandian 2003; Pellow 2004; Pellow and Brulle 2005; Pinderhughes 1996; Szasz and Meuser 1997).

EJ movements arose due to ER. Numerous studies have demonstrated unsettling connections between hazardous waste sites, race and class. One origin story locates the birth of the EJ movement in the United States in 1982, with community protests over the illegal dumping of soil that had been contaminated with a carcinogenic agent, polychlorinated biphenyl (PCB), in a rural, predominantly African American county in North Carolina. The United Church of Christ led the protests, and in 1987, released a report showing that race is the strongest variable in determining the location of hazardous waste in residential communities (Pinderhughes 1996:236-40).

EJ movements foreground the detrimental effects waste and pollution have on low income communities of color. These effects are often compounded by structural deficits in health care access and delivery within these communities. EJ movements are close in form to movements that take on environmental illnesses. Both tend to not be involved in partnership models, and are driven by community members who become champions. Some EJ movements are supported by local politicians and state environmental

protection agencies; however, these political actors are also sometimes complicit in the ER (Pellow 2004:82-3). Pellow argues that it is therefore better to conceive of ER as involving "multiple stakeholders" who take different positions, rather than as a simple "good community v. bad company" dichotomy (Pellow 2004:89). Focal communities are themselves often internally divided and riven with conflicts. EJ research has thus revealed complex tangles of social relations that do not line up neatly across class, race or other social variables.

Health Social Movements and Human Stem Cell Research

As is clear from this review, HSMs are a heterogeneous collection of formal and informal actors, organizations, networks, and technologies. There are no sharp breaks between different HSMs. There is constant spillover and traffic of personnel, discourses and tactics among movement categories. Sufferers may be part of one, or several, or none of these categories at different times. At the current moment, the partnership model described by Callon and Rabeharisoa is an exemplar of the interactions between lay and expert actors. However, it is important to stress that this model is a result of a history of extended struggles between actors (see, e.g., Epstein 1996). Partnerships are neither isomorphic nor stable across space and time.

There are also tensions. For example, many disability rights activists critiqued notions of a "cure" as inherently discriminatory. This site of difference has reappeared over concerns of "flexible eugenics" in genetic screening and therapeutic development, and has created a deep abyss in relations between disabled activists and researchers, for example, seriously problematizing possibilities of partnership. There are varied

relationships between different groups of patient activists and biomedical institutions. A larger, more difficult question, concerns why these differentials exist.

While there is no single answer, several processes are important to highlight. I would argue that while social movement scholars disagree over what precise conditions must be met in order for a social movement to mobilize, grow and attempt to be successful, there is general agreement on several key elements: a relative openness in the structures of authority or governance ("political opportunity structures"); some degree of shared perceptions or community organizing ("cognitive liberation"); the production of shared relations or affinities ("politicized collective identities"); and, successful rhetorical engagements with different audiences and publics ("framing"). These concepts have been immensely helpful in understanding social movements (from a vast literature, see Gamson 1990; Klandermans 1984; Laraña, Gusfield and Johnston 1994; McAdam 1999; McAdam, Tarrow and Tilly 2001; McCarthy and Zald 1977; Melucci, Keane and Mier 1989; Oberschall 1973; Snow et al. 1986; Stryker, Owens and White 2000; Tarrow 1998; Zald and Garner 1987). This body of work serves as the foundation for HSM theorization, and has lead me to highlight three processes that I would argue stratify HSMs in the United States at the present moment.

First is the changing structures, expectations and experiences of patienthood in the United States. The experience of being a patient is clearly stratified by other social categories, and inflected by other social dynamics. In other words, while technologies of diagnosis have become standardized, the experience of diagnosis is inflected through the social categories (such as race, gender, and/or class) that individuals inhabit. Patients are now routinely told to be vigilant managers of their own health and health care.

Pharmaceutical companies advertise directly to consumers, and urge patients to "talk with their doctors," and actively engage in their own diagnosis. This broad set of imperatives for active health management can work well with the requirements of HSMs. That is, by activating patients vis-à-vis their health, these changes help push patients towards HSMs which amplify the politicized aspects of contemporary health care. One outcome of this push is that "astroturf" movements, supposed patients' movements actually organized by private interests (e.g. scientists, corporations) to serve as window dressing and/or political foot soldiers, have begun to proliferate. As one result, any analysis that focuses solely on HSM form may overlook important differences across movements. As much of the work presented in this section makes clear, there are multiple models of patient activism. Many different styles of engagement emerge from specific historical interactions, but are becoming increasingly more mobile across the globe.

The second process includes historical interactions between patients and bench researchers. Genetic diseases are of a relatively recent specification; the structure and function of DNA itself was not understood until mid-twentieth century. Only in the last five years has gene therapy become a realistic prospect, though beset by clinical and regulatory problems. Despite its eventual efficacy, the relative newness of genetic therapies affords a degree of "interpretive openness." That is, its newness mitigates to some degree against potentially damaging frames. As a counter example, disabled activists have a long history of opposing not only medical institutions and personnel, but also struggling against the discourses of curing. If "cure" is framed as equivalent to eugenics, then patients will be less likely to form partnership models. Historically, disabled individuals were targeted by eugenic practices in many countries, including the

United States. In contrast, for many genetic disease activists, "cure" is often framed as an end to suffering, or an amelioration of pain. This very different framing is critical; it motivates family members to devote large amounts of resources towards learning complex technical languages and becoming part of the massive bureaucracies that comprise modern biomedicine. Steve Epstein (1996) has pointed out how the effects of this motivation replicate lay/expert divides already in existence. While the partnership model accounts for this divide in some cases, the discourses of curing certainly structure patient and researcher interactions.

Finally, there is the concept of collective identity. All of the movements described above rely, more or less, on some form of politicized collective illness identity. The experience of being ill, or having a disability, is an event that shatters a person's biography, and contributes to the rewriting of a life. However, these identities are far from universal, and are tied often tautly to their conditions of production. While the standardization of medical care affords degrees of commensurability between persons and locations (Espeland and Stevens 1998), it is the processes of relationality that condition the trajectories of patient identities. That is, a person with ALS in France might go through similar diagnostic and therapeutic process if they were in Japan or Brazil (again recognizing the stratification of health care within and between nations). However, the forms of patient activism that appear are asymmetrical with this relatively standardized map.

The structures of patienthood, patient/expert interactions, and the production of collective identities are three central processes or sets of conditions that are productive of and account for the vast diversity of HSMs that traverse contemporary society. In the

next chapters, the project examines these processes in greater detail through the case study of Proposition 71. The political event of Prop 71 compressed the processes that produce HSMs in a brief period of time. This time compression intensified the controversies that surround human stem cell research. Scientific controversies are important moments revealing the contests over credibility, power and resources within and among the sciences in a public manner. They require that actors stake a position and defend it in front of multiple audiences. This has been shown to be consequential for thinking about the scientific outcomes of controversies in terms of who wins and who loses (Clarke 1990a; Garrety 1998; Jasper 1988; Nelkin 1992). Here, I want to extend the thinking about scientific controversies through the frame of HSMs.

Controversial Sciences and Health Social Movements

From even a cursory glance at the literature in social studies of the sciences, it is apparent that sciences have always been controversial. This makes sense, as many scientific projects ask audiences to suspend their beliefs or assumptions about how the world works, and offer instead theories that challenge or undermine these beliefs and assumptions. This has been especially true in the emergence of human biomedicine as a scientific enterprise. The scientific study of the body and its systems and properties has produced intense opposition at different times. Some human organ systems and properties have been more difficult to study than others. One exemplar case is human reproduction. This has contributed to the development of model organisms that stand in as proxies for human physiology.

Among the first science studies scholars to enter controversy studies, Dorothy Nelkin (1971; 1983; 1984; 1992) examined the multiple forms and venues of scientific controversies. Nelkin argues that controversy is far from singular, and developed a typology of scientific controversies. First, some controversies are about the *implications* of a line of research (Nelkin 1995:447). This is clearly seen in the hESC and cloning debates of the early 21st century. This can be measured by the use of concepts such as the "slippery slope" and the "Brave New World" metaphors that regularly appear in editorials and reports regarding these technologies. The implications are often presented in stark terms: reproduction becomes dominated by technical interventions, and human life is turned into a giant genetic experiment that stratifies the world in fascist ways.

The second type of controversy involves clashes between *environmental values* and *commercial interests* (1995:448). For example, this might involve debates between environmental activists, as well as those affected by accidents or purposeful dumping, and business interests and their political allies. The controversies may center on disaster sites, such as Woburn, Massachusetts or Love Canal, New York.

The third type is similar to the second, but focuses on controversies around *risk* (1995:448). This is exemplified in debates around genetic screening for various diseases and conditions that have no immediate cure, or dangerous or experimental treatment protocols, or the use of genetically modified organisms in commercial food production. Unlike the second form, these controversies have no specific sites, but often involve many different venues, such as laboratories, agricultural fields, clinics, factories and shopping markets often distributed widely.

The final type of scientific controversy is enacted through the discourses of *rights* (1995:449). This usually appears when individual rights are framed as in conflict with the group or rights of the community. Examples of this include debates over fluoridation of municipal water supplies, or demands by patient activists to have access to novel therapeutics. Nelkin also points to other foci of controversy, such as debates over justice and equity in terms of science funding, fights over ownership claims to technoscientific objects, and debates over scientific fraud and research misconduct (1995:449-50).

Nelkin's typology was particularly important in that it moved analyses away from a now dated "science vs. society" lens that misses the complex social dynamics of a specific debate. This perspective assumes that opposition to scientific projects, regardless of whether that opposition is democratic or not, is ultimately animated by fear, anger or anxiety over the contents of a particular science – that it is somehow inherently "anti-science." This model often symbolically pits rational "scientists" against irrational "citizens" in shrill conflicts over "values" or "outcomes." This clumsy distinction mirrors "strain hypotheses" in social movement theories, or the arguments that social changes produce psychological dissonances that are expressed as irrational outbursts of protest (for a good summary of strain models, see McAdam 1999).

Just as social movement theorizing moved away from the rational/irrational dichotomy, the analyses of scientific controversies began to incorporate different social institutions and actors in their frames. For example, James Jasper (1988) introduced the concept of the *political life cycle of controversial technologies*. Jasper begins by comparing a *strong media model* against a *basic-values approach* (1988:358-59). The strong media model claims that news reporting and media representations "channel"

public beliefs about technology, such as nuclear power. These beliefs are channel-able because they are generally not connected to other political beliefs. The strong model is distinguished from the weak model, which claims that media only "sets the agenda" of public debate, and has little effect after that (1988:359). In contrast, the basic-values approach connects public beliefs about an issue with the fundamental values of a group.

Jasper argues that while there are strengths to each model, they can both be consolidated into a political context that includes the availability of spokespeople for each side, public representations of the debate (in news reports for example), organizations involved in the debate, and public discourse that "encourages a member of the public to take a position on an issue" (1988:360). Jasper then temporalizes controversies over technology into a set of stages: *prepolitical*, or the time prior to a controversy; *political*, constituted by active mobilization around the controversy; and *postpolitical*, or after the controversy has died (1988:360). Jasper develops this model from a cross-national analysis of nuclear energy development. He concludes that it is political struggles, not media-fueled irrationality that account for this staged model (1988:374).

In *Disciplining Reproduction*, Adele Clarke (1998) identifies two central conditions that made the reproductive sciences so controversial. The first is the centrality of sex and reproduction to many people. Reproduction is "simultaneously very private and highly public" (1998:235). Second, reproductive scientists had to "sell" their research to a variety of audiences and publics via "marketing strategies" essential to drawing fiscal and other support and resources to the emerging discipline. However, an unintended consequence was to make reproductive sciences into public phenomena

(1998:235). The rhetorics and representations were widely available to supporters, opponents, interested observers and bystanders. The marketing strategies reproductive and other scientists engaged in, while necessary for their survival, were thus one cause of a decline in the autonomy of science over the 20th century (1998:236). That is, the sciences have experienced a decline in their ability to justify their claims to social importance through internal or self-referential logics. A claim that the scientific study of object X is good or important or necessary "in itself," or that the production of scientific knowledge about object X is always good or important or necessary, has lost credibility. This is not to say that the sciences have lost all credibility. The sciences remain central institutions in modern society. But they are increasingly confronted *in their own terms* and *on their own turf* by groups of actors such as funding sources, corporations, governments and activated publics - HSMs. The effects of these confrontations on the practices of science remain open questions.

Clarke (1998:238) made clear that controversy is not solely negative for the sciences; in fact, the same controversies that draw opponents to abortion, animal experimentation, nuclear weapons development and testing, and human stem cell research also draw new social worlds of support. She identifies four realms of controversy that reproductive scientists had to manage in order to be successful: their association with sex and reproduction; their association with controversial social movements like eugenics and birth control; the association of their science with dubious therapies and quacks; and, their association with possibly dystopian futures (Clarke 1998:237-254). Clarke's analysis shows that in the case of the reproductive sciences, and

in the sciences in general, there is no one controversy that plagues a discipline. Rather, there are multiple concerns and disputes with shifting alliances and interlocutors.

Scholars have investigated controversies in other sciences as well. Karin Garrety (1997; 1998) used a social worlds approach to parse the controversies around cholesterol, diet and heart disease. Garrety (1997:740) claims that concerns over levels of dietary fat were first raised by "interventionist scientists," and allies in the food production industries who hoped to capitalize on their findings regarding fat levels in food. The American Heart Association (AHA), itself an important entrepreneurial "boundary organization" (Garrety 1998; Guston 2001) between scientific, medical, business, and patient social worlds, was initially skeptical of claims promoting lower levels of intake of fat, but eventually endorsed such claims in 1964. While the AHA and medical researchers struggled over competing claims, trade organizations pushed forward with several simultaneous "strategies" to secure their positions, including lobbying for favorable federal legislation, producing new "diet" forms of their usual commodities, and undermining claims of their opponents by emphasizing the uncertainties or incompleteness of any scientific claim (Garrety 1997:746-47).

Garrety concludes that while the scientific facts about dietary fats levels remained uncertain, consequential policy changes occurred as a result of the efforts of a variety of social worlds using legitimate forms of political legitimation and domination to secure their positions (1997:756). This concern with forms of power and negotiations is central to social worlds analyses of technoscientific forms of work and practices (among others, see Casper and Berg 1995; Clarke 1990b; Clarke and Fujimura 1992; Clarke and Montini 1993; Fujimura 1996; Star 1995; Star and Griesemer 1989).

Applying Controversy Models to Biotechnology.

While Jasper's argument suffers from the problems that plague all staged models, he foregrounds political struggle in understanding scientific controversy. This foregrounding of politics has informed subsequent analyses of the sciences and, of import for this project, research into the field of *biotechnology*. Biotechnology is an expansive concept, and can do more or less analytical work. Schurman and Kelso (2003:2) define the term narrowly to mean the use of recombinant DNA technologies in "food, feed and raw materials." Brodwin (2000:2) extends this definition to include "the background practices and treatment rituals in which a given device acquires its meanings." My use of the word encompasses both the technologies and the contexts of their use. Specifically, I am interested in how biotechnologies operate within cultural formations to bring actors together in terms of biosociality.

Some have argued for a distinction between "old" and "new" biotechnologies, since the origins of the word itself stretch back to the early twentieth century. Robert Bud (1993; 1998) argues that what differentiates the two forms of biotech is the emergence of the discipline of molecular biology. Consolidated between 1953 (Francis Crick and James Watson's announcement about the biochemical structure of DNA) and 1973 (Stanley Cohen and Herbert Boyer's transfection of DNA across different viral vectors), molecular biology was to become the intellectual spine of the biotech industry that has blossomed since (Bud 1998:10). The controversies involving the new biotech were to define the parameters of human stem cell research (for a closer look at human stem cell research and biotech see Chapters II and VI).

We can now bring Clarke's analysis of controversy together with elements of my categorization of HSMs to bear on human stem cell research. Building upon Clarke's formulation of realms of controversies, I have framed five realms of controversy in the arena of human stem cell research:

1) Material culture: What are appropriate research materials for human stem cell research?
2) Scientific funding and oversight: Who should pay for human stem cell research, and who should monitor these investments?
3) Translational research: What kind of science is human stem cell research? Who is it "for?"
4) Ownership and property: Who owns the objects used and produced by human stem cell research?
5) Justice: Who should benefit from stem cell research? Who should bear the costs? How should the distribution of costs and benefits be decided?

Each of these questions is a public question. Each domain emerged at some point during the Prop 71 campaign. As Clarke makes clear, scientists who work in controversial fields must engage in marketing strategies to consolidate their positions qua researchers. As we shall see next, each of these questions animates different strategies that stem cell researchers used in different venues.

1) What are the appropriate research materials for human stem cell research?

This is the most public of the debates. The status of gametes, zygotes and embryos is usually the most talked about and controversial area of human stem cell research. For space purposes, I am not going to cover the twists and turns of these debates that are seemingly endless (Bonnicksen 2002; Green 2001; Holland, Lebacqz and Zoloth 2001; Maienschein 2003).

Stem cell researchers were, and continue to be, deeply aware of these debates; that awareness helped motivate them to make public appearances regarding human stem cell research on the Prop 71 campaign trail. A simple counter-factual example would posit that these researchers have no awareness of these debates, that they are only concerned with "technical" matters, not "politics." This is not unreasonable, as one of the major pro-human stem research claims is that "politics" blocks the "research." However, if scientists were unaware of these debates, for whatever reason, the problem would be to explain scientists' deep involvement in the Prop 71 campaign (Chapter VI explores these questions in greater detail). Yet these scientists were not just advisors or talking heads, despite the fact that much marketing research argues that professionals are bad for campaigns. A better representation is the "common person" who will be somehow affected by the political decision. But the scientists were very visible and present during the Prop 71 campaign.

Scientists and their advocates are aware that the status of gametes, zygotes and embryos is controversial. One problem is that no other research material can stand in for human tissue *at a certain point* in the research process. That is, non-human tissues and cells are routinely used, and model systems are foundational for many experiments within

the biomedical sciences. These model systems have become standardized in the processes of developing human therapies which are extremely costly, time-consuming, and risky for researchers and human subjects. For bench researchers, what is so critically important about human stem cell technologies is that they can recapitulate human biological processes and functions over time *in vitro*, and nothing else can do this. For all stem cell researchers, this is the key point. If human biological processes, such as disease pathology, can be modeled in vitro, *with human cells*, many experiments can be done on these cells that cannot be done on living human beings. This kind of research helps to modulate the rate-limiting step in drug development: clinical trials.

The controversies over research materials for human stem cell research do not fit Jasper's stage model of life cycles of controversial technologies. That is, the research materials themselves have never been prepolitical. They have always been controversial, albeit in different forms, contents, and contexts. Nor do they show any signs of entering a postpolitical phase. However, Jasper's conclusion is on target. In order to understand these controversies, it is less helpful to look at either underlying values (is the blastocyst a full human being or not?) or a strong media model (are beliefs being channeled one way or another?). Following Jasper, I argue it is more helpful to look at the political conflicts over research materials. This leads us to an examination of HSMs and the social organization of political conflict.

2) Who should pay for human stem cell research, and who should monitor and evaluate these investments?

Despite the intriguing "promise" of human stem cell research, many people and organizations remain deeply categorically opposed to this research. This opposition varies from calls for more "oversight" and "accountability," to complete bans on the research, along with criminal penalties for those who engage in segments of this research. Historically, in the United States, the federal government, through the complex of NIH centers, has funded some proportion of basic and applied biomedical research. As Chapter II made clear, NIH funding for human stem cell research has been "restricted" by "politics." I use scare quotes here to foreground what I term the entitlement discourse that animates the rhetorics of pro-science movements. That is, the term restriction implies that the research would otherwise be completely deserving of an endless supply of resources, if not for "irrational" or "non-scientific" demands of other groups. In other words, human stem cell research in itself is deserving of funding per se because scientists believe it is worthy.

The struggles over NIH funding for this research have raised questions regarding the financing of biomedical research more broadly. One of the major struggles emerged around President Bush's August 2001 announcement that no human embryonic stem cell research with unapproved cell lines could occur in facilities, or with equipment and materials, that *had been paid for* by past NIH grants. This is a critical point, as the federal government has paid for much of the construction and on-going maintenance of the infrastructure of the United States biomedical sciences. In other words, stem cell researchers were free to develop and use non-NIH approved hESC lines; they just could

not do so in their already-existing federally-funded labs. It was this aspect that was most troubling to both scientists and their allies in research administration. A violation of the executive order could cost an institution all of their NIH funding. This was (and continues to be) a major problem for stem cell researchers.

In order to secure non-NIH funding (both public and private) for human stem cell research (specifically hESC research), scientists and their allies have mobilized on multiple fronts. One strategy includes working with allies in state government to both pass "stem cell research friendly" laws, and to open up state coffers to fund the construction of new labs and buildings and the creation of new (non-NIH registry) hESC lines. In the case of California, the initiative process proved to be a helpful, and ultimately successful, institutional vehicle to move this process forward. Other states have taken on this project in different ways. For example, as Prop 71 was starting, the New Jersey legislature approved state funding for hESC research, and the construction of new facilities to do this research. Other states are also pursuing funding.

A second front was to seek non-governmental funding sources. This included venture capital financial organizations, wealthy individuals, philanthropic organizations and PAGs. This has been a mixed bag of support, but critical for "seed" money to start the capital-intensive work of building construction. This strategy is not new.

A third front was to begin to position human stem cell research in a different institutional position than other biomedical research. This included the coalescing of "stem cell biology" as a quasi-discipline (see Chapters II and VI). It also includes the formation of new oversight mechansims, such as special Institutional Review Boards (IRBs) in major universities. This was eventually codified in a National Academy of

Sciences report on human stem cell research. One of the conclusion called for the formation of Embryonic Stem Cell Research Oversight (ESCRO) committees *in addition to* regular IRB oversight.

All three of these fronts require coordination with HSMs and their social worlds. Activists involved with HSMs operate in a variety of ways, including lobbying state governments for resources for medical research, working to get research-friendly laws passed, testifying at public hearings, and organizing groups and publics to be visible and active across pertinent social worlds and arenas. This has led to new coalitions of researchers, activists, business actors, politicians and governmental actors pushing together for support of controversial sciences.

3) What kind of science is human stem cell research?

In order to push forward on these fronts, stem cell researchers had to sell human stem cell research as a legitimate science benefiting the public good. In order to do so, they had to describe exactly what they were doing, what they wanted to do in the future, and what kind of outcomes could be expected from the research. In many ways, this was not a difficult task. Decades of cell and molecular biology showed what was theoretically possible with human stem cells. What was more difficult for the stem cell scientists to avoid was what I will call the *trap of translational research*.

What do I mean by the trap of translational research? As Clarke (1995; 1998) made clear, the sciences have been losing autonomy in society, albeit unevenly. One built-in benefit of pursuing biomedical research is that the knowledge is, to some degree, to be directed towards the understanding and improvement of human health. I am not

arguing this is its ultimate goal or function. As I hope I have made clear, biomedical research has multiple goals and functions. However, it is easier, for example, for biomedical researchers to articulate some "social benefit" of their bench work than it is for physicists who work on nuclear weapons or chemists who develop pesticides or defoliants. In other words, a cell biologist using hESCs to help develop a cure for Type I diabetes has a built-in rhetorical weapon, in that to oppose the cell biologist's argument, one would risk being perceived as opposed to curing Type I diabetes. Some groups have recognized this difficulty and preface their arguments by saying they "support human stem cell research, but…" Other groups simply ignore this dilemma and attempt to reframe the debate around the status of the zygote as human, for example.

HSMs play a key part in this set of conflicts. They push for research that is going to cure specific diseases or conditions. However, they are not parochial. HSMs are able to work with each other in larger coalitions to support biomedical research *generally*. This is critical given that human stem cell research, for example, is deeply controversial. Activist participation in this research is neither window dressing nor merely a helpful supplement. It has become *a necessary part of the public form of biotechnology*. That is, as part of biotechnology, human stem cell research is always already an applied form of work. This too has deep historical roots. As Lily Kay put it: "From its inception, the rationale for the technology-based program of molecular biology, and for its residual eugenic goals, was its future social returns; not so much immediate commercial applications (though such activities were applauded), but a long-term promise of generating *social technologies*" (1998:22, original emphasis). By social technologies, Kay means the practices and techniques of molecular biology. These include cementing a

"cultural hegemony" articulating funders (such as the Rockefeller Foundation), intellectual institutions, and industrial and academic elites from the 1930s to the 1960s. Social technologies may not always be applied research, but they are always "mission oriented" (1998:24). By cultivating what Warren Weaver of the Rockefeller Foundation called in the 1930s a new "Science of Man" during this time, this cultural hegemony unwittingly ensured "long-term market value" for molecular biological approaches (1998:34). Kay's argument can be nicely fitted within Clarke's framework for analyzing controversy. That is, hegemony is never total; it is always shifting and must be constantly reproduced. Clarke's concept of management strategies represents attempts and appeals negotiated multiply over time as needed to ensure the market value of biotechnology. These management strategies, as mission oriented, are able to accommodate supportive HSMs.

As noted, appealing to the social benefit of biomedical research is not a new phenomenon. Nor am I claiming that biomedical researchers are being disingenuous or lying about their motives. But biomedical research in general, and human stem cell research in particular, can easily make strong claims about the social utility of their experimental work building on a century or more of such claims. However, these claims "cut both ways" (Clarke 1998:238). By associating their bench research with a defined end, researchers risk losing autonomy over their own work. That is, the freedom to explore open-ended questions, or follow interesting data that do not fit an interpretive frame, is restricted in certain ways when research is targeted towards specific end points. I am not claiming that there is some form of "pure research" in which scientists have "absolute freedom" to follow any and every interesting anomaly. Even pure (as opposed

to applied) research is bracketed by parameters, such as what reagents are easily available, or what funding streams are at hand. This complicated issue is parsed in Chapter VI.

Significantly, these controversies have certainly not slowed the human stem cell research enterprise. The research is going forward, around the globe, and very little can slow it down, not even outright fraud and deception. Like any emerging highly valued science, human stem cell research is producing a large amount of interesting objects and entanglements. One of the dominant social fields that structures how objects are ordered, moved around and consumed is *property*.

4) Who owns the objects used and produced by human stem cell research?

In order for human stem cell research to move from bench to bedside, not only must difficult technical questions about stem cells and their properties be understood, but also questions about who owns these objects and processes must be decided, however temporarily. This latter set of questions falls under the broad heading of *intellectual property* (or IP). Increasingly, the rationalities and logics of IP have come to bear directly on experimental questions as well (see Chapter II). Some see this as business as usual. That is, some sciences have always been closely tied with industry, and biotech in particular, whether of the old or new variety, has long been tied with commercial concerns and motivations. Others are alarmed by these ties, and have dire forecasts for the future of democratic forms of science because of them. The exact future picture remains unclear.

My intent here is not to determine whether or not patenting has had net benefits or drawbacks for these different industries. That is not a sociological question. Instead, my interest is in the effects patenting has had on biomedical bench research in particular. Here the paradoxes of IP become acute. The patenting of objects has had different consequences for different industries. On the one hand, ownership of property is a fundamental condition for modern economic freedom. This is what under girds the logic of patents. A patent only gives the patent-holder the right to restrict others from encroaching on some protected idea or object. In this sense it is a "negative freedom;" patents do not give license to the patent-holder to do anything at all with the patented material. Patents "fence off" a small piece of the world and provide strong ownership claims to the holder of the patent. Simply being a patent-holder does not guarantee any income. The patented material has to do something, or work with other objects or processes in order to do something. An automobile is a good example. It is a composite of patented objects that work together. Many different actors receive revenues (known as *royalties*) from these different patents through allowing other actors to use the patented object in an agreed-upon way, formalized through a contract (known as a *license*). Licensing out a patented process, such as an air conditioning system for an automobile, provides the patent-holder with a royalty stream. Ownership of this patent provides freedom for the patent-holder to enter into agreements with any and all auto manufacturer who wants to produce cars with that form of air conditioner. The only limitation is the kind of license that is issued. One kind of license is called an *exclusive* license. This means that the patent-holder enters into a contractual agreement with only one (or several) defined partners to use the patented object. A second kind is called a *non-*

exclusive license. This means that the patented object can be licensed to anybody and everybody (for a more detailed look at patenting in biomedical research, see Chapter II).

On the other hand, the ownership of property can lead to intractable situations. In bench research, experimental systems are now extremely complicated production assemblies. Because of their ability to reveal novel aspects of the world, experimental systems are very good for creating potentially patentable objects at the molecular level. That is, by being able to represent and intervene (Hacking 1983) at a level that is invisible, experimental systems are very good at producing novel objects.

Contemporary experimental systems are extended complexes of interrelated subsystems. These subsystems often include vast amounts of bench space; many kinds of complicated, expensive pieces of hardware such as real time polymerase chain reaction machines (rtPCR), microarrays, fluorescence-activated cell sorters (FACS), and ultracentrifuges to name but a few; proprietary computer software packages; reagents, vectors and transgenic model organisms, which necessitate vivariums and breeding colonies; and finally, specialized personnel, from PIs to graduate students to technicians, to move the experiment forward. Except for the personnel, *all* of these objects are patented. For many of these objects, there is not a problem as an institution can purchase an object, such as a freezer, and then use the object to produce new objects without the owner of the freezer objecting. That is the easy case.

The more difficult case involves patented objects that are necessary for the experimental system to work but that come with strings attached. This is often the case with reagents like molecules and molecular complexes such as probes or monoclonal antibodies. For example, lab X discovers a very useful probe for identifying a gene of

interest. The personnel of lab X patent the probe (usually under the name of the PI, but also with institutional representatives). Lab Y, which does similar research, wants to use the probe. They contact lab X, and the two institutions come to an agreement to share the reagent, known as a *material transfer agreement* (MTA). This agreement stipulates who gets what, when, at what cost and under what specific conditions, including licensing agreements should the probe lead to the discovery of a subsequent diagnostic or therapeutic object. In human stem cell research, these agreements to not end the controversies. They are themselves key elements at stake in the debates.

Experimental systems now involve multiple layers of licensed objects, which sometimes lead into problems called *anticommons* or *patent thickets* (for more on these terms see Chapter II). One argument might be that the freedom that patenting provides may turn into its opposite – paralysis. This has lead to recent intensification of concerns with patenting in academic biomedical science.

5) Who should benefit from stem cell research? Who should bear the costs? How should the distribution of costs and benefits be decided?

As Lily Kay (1998) pointed out, a group of elite actors in the middle of the twentieth century ensured the hegemonic status of biotechnology by "writing in" the long-term market value of molecular biology through a strategy of representations and interventions (Kay 1998:24, borrowing from Hacking). Human stem cell research is the latest such "product line" that actors seek to capitalize. Kay's analyses focus on the producers of biotechnology. Here I expand upon her claims to include consumers/users.

In addition to writing in market value, actors also wrote in long-term moral value as well. While this has been a feature of biomedical research for some time (see Chapter II), its appearance in the worlds of human stem cell research is uneven. For example, a glance at the scientific literature reveals that while the Singapore team's 1994 report briefly talks about the ethical difficulties of deriving hESCs from IVF embryos, it makes no mention of possible cures from this type of therapy (Bongso et al. 1994). Four years later, the research teams at Johns Hopkins (Shamblott et al. 1998) and University of Wisconsin (Thomson et al. 1998) both referred to the therapeutic potential of hESCs. Thomson's group was especially clear in listing the benefits that could be gained from this line of research, such as preventing infertility, birth defects, Parkinson's disease and diabetes mellitus, as well as promoting advances in cell transplantation and preventing immune rejection (1998:1146-47). This listing of potential therapeutic benefits is now a standard feature of most scientific papers on hESC research, appearing in specialized scientific journals. While such papers are generally not read in other social worlds outside of research communities, this claims-making rhetoric has become pro-forma justificatory writing due to the ethical challenges to such research.

As I have argued, a crucial aspect of biomedical research is its built-in moral rhetorics. Rather than hand-waving about benefiting humans in general, human stem cell research can and now does discuss in precise detail the specific benefits anticipated for defined populations. Human biotechnology and biomedical research have produced some remarkable tools for treating different diseases and conditions. However, the cost

of creating these tools, from "idea to IPO"[6] as in one entrepreneurial-inflected description, is immense.

Some critics of human stem cell research in the United States argue that because of such costs, the kinds of therapies that arise from this research will only be available to the wealthy. Given the structure of American health care, that is not an unreasonable claim. Individuals and groups in the Yes on 71 campaign attempted to deal with this issue with mixed success (see chapter IV). However, guaranteeing universal access to potential stem cell therapies for at least the citizens of the state of California provoked challenges, and remains an open question.

Scaling-up science is expensive and, as the previous section claimed, is moved forward through intellectual property agreements. These agreements only cover ownership; they have no purchase over the research and development that must occur to produce a therapy. Since the federal funding of human embryo research has been so conflictual, actors have sought resources elsewhere. State-level governments have been one recent target for human stem cell research funding (see Chapter II).

Individuals on the Yes on 71 campaign attempted to allay financial concerns by arguing that stem-cell derived therapeutics would lower the health care cost burden on the state of California (see Chapter IV). Whether or not this claim will bear fruit remains an open question. What is important is the confluence of discourses. Human stem cell research is simultaneously an economic development and moral project (discussed in greater depth in Chpt. VII).

[6] "Idea to IPO" is the title of a course at the University of California, San Francisco. See http://www.ucsf.edu/cbe/ideatoipo1.htm

Conclusions

This chapter synthesized contemporary theoretical approaches to health social movements. From this synthesis, I highlighted three social processes that animate HSMs in the United States (and elsewhere)[7]: the structures of patienthood, patient/expert interactions, and the production of collective identities. These processes of course extend beyond HSMs, and produce effects in other social worlds. These processes (and their effects) are knowledge naturalized and go unnoticed. However, there are moments when they are foregrounded as sites of contestation. I have considered some such moments through the lens of scientific controversies.

Human stem cell research is controversial in multiple ways. These different arenas of controversy are current events; they are on-going live debates that involve different actors across the worlds of biomedical science, law, politics, and economics and HSMs (to describe the worlds at the most general level). Indeed these worlds themselves are segmented into sub-worlds, such as the endlessly ramifying disciplines of biology (Clarke 1990b; Hughes 1984; Strauss 1978; 1984). A central point here is that the controversies over human stem cell research, while publicly represented as problems or barriers to bioscience, are at the same time quite productive of the emerging assemblage of regenerative medicine.

In the following three chapters, I focus on Proposition 71 and the activism of patients and scientists in support of this initiative as an empirical example of the increasing importance of HSMs to controversial basic science research. By 2005 pro-

[7] The immediate focus of this project is the United States. For this review of HSMs, I have also considered work from Western European countries as well. This leaves a serious gap in thinking about HSMs from other places not within this tight orbit. Unfortunately due to time constraints, my focus is extremely narrow. Further research will explore HSMs in "out of the way places" .

human stem cell research activists had coalesced around the symbolism and rhetorics of a "pro-cures" movement. I discuss the effects of this movement in Chapter VII. Next, I turn to the genesis and development of Proposition 71.

Chpt. IV California and the Politics of Hope: A Sociohistory of Proposition 71

Human stem cell research expanded in the United States over the latter half of the 20th century due to a variety of reasons and sponsors. In Chapter II, I foregrounded three elements in this expansion: bench research on human embryos, the development of assisted reproductive technologies (ARTs), and the resulting changes in federal research policies covering these domains of scientific work. *In vitro* fertilization and other ARTs certainly reformulated public ideas about human reproduction capacities; they also helped forge new relationships among groups of actors in the United States who were all interested in seeing this research succeed despite a lack of support from the federal government. Given the need for gametes and zygotes, bench researchers and their institutional allies worked with philanthropic organizations and social movements to gain support to help procure these research materials. However, such processes are never unidirectional or linear; organizational links are tenuous and must be maintained and supported. Rather than simply tapping into existing funds of "resources," we need to understand that embryo researchers themselves played an active role in constituting different publics as potential beneficiaries of ARTs.

I concluded Chapter II by looking at US federal stem cell policy up to the Bush administration's August 2001 announcement on limitations on NIH funding for hESC research. As has been demonstrated, biomedical research in the United States has historically been deeply dependent on the federal government for support. However, both prior to and following the August 2001 announcement, actors in different states initiated political projects designed to make those states friendlier to human stem cell research. In California over the last five years several bills have become laws, but no

state funds were dedicated to stem cell research. By 2003, stem cell researchers and their supporters began to organize to construct some kind of funding mechanism for human stem cell research. Later that year, a now-epic dinner occurred in the Los Angeles area that set in motion what was to become Proposition 71. This dinner included bench scientists, patient activists and state lawmakers.

In this chapter, I will lay out the California stem cell policy context that paved the way for the emergence of Proposition 71. First, I will look at the context of scientific research and development (R&D) in California over the last decades of the 20th century. This context is important, as it reveals some transformations in scientific funding, primarily the growing importance of biomedical and biotechnological research. This changing constellation of scientific R&D has been complemented by a relatively permissive policy context. However, despite state policy supportive of human stem cell research, securing funds proved to be difficult. This difficulty was to lead to the use of the initiative process as a solution.

I then turn to the genesis and unfolding of the Yes on 71 campaign, and focus on the production of campaign rhetorics in different public settings. The Yes on 71 campaign, through working with professional political advisors, deployed a series of arguments in order to gain public support. In addition, bench researchers played critical roles for the success of Prop 71. I argue that we can understand their participation in this campaign not as a case of scientists becoming political, as they have always been political actors. Rather, I claim that scientists (and other groups of actors) relied on distinctive *logics of representation* developed within the social worlds of biomedical research. These logics both explain (what is a stem cell?) and promote (we should do

human stem cell research) a branch of technoscience, and can be easily transposed across social worlds. A key representational element within logics of representation is the *metaphor*. A metaphor is an object, image, or statement that stands in for a second object, image, or statement. Metaphors bring different objects into relations of equivalency for the purposes of making an argument. The use of metaphors in scientific discourses has been of interest for some time. Scholars have looked at metaphors in the life sciences, including molecular genetics (Allchin 2005; Avise 2001; Knudsen 2005; Nelkin 1994; Nelkin 2001; Ratto 2006), behavioral genetics (Nordgren 2003), reproductive biology (Martin 1991), neuroscience (Cela-Conde and Marty 1997), ecology (Allchin 2005; Cuddington 2001; Mittman 1988), biodiversity (Valiverronen 1998), and biosecurity and biotechnology (Cook, Pieri and Robbins 2004; Larson, Nerlich and Wallis 2005; Liakopoulos 2002) among others (Brown 2003; Chew and Laubichler 2003; Lenoir 2002). This chapter closely examines both the metaphors deployed by scientists, as well as the public contexts of their deployment.

The use of metaphors by scientists has attracted considerable attention. For example, Nelkin (1994) argues that even as late as the 1970s, scientists actively restricted access to their work by media representatives and deliberately used dense technical language to prevent publication. However, human genetic research has since become "coffee table science" (Nelkin 1994:27), meaning that genetics, and the objects and representations of this science have garnered broad public interest. She claims that scientists do still get unhappy with certain media depictions of them and their work, but in general they have become more accepting, and more savvy at working with various media (1994:30).

The strength of Nelkin's argument lies in the polyvalent nature of metaphors. Metaphors in science are extremely powerful for researchers in helping them generate new ideas and research questions. Chew and Laubichler (2003) point out the importance of literary metaphors, such as information, signaling or editing, for molecular biology. While metaphors certainly possess epistemic utility (Knorr-Cetina 1981), they produce different effects, both between disciplines, as well as between competing theories within (sub-) disciplines. Metaphors can help move certain arguments forward, sometimes with mixed results. For example, in population ecology, the metaphor of the "balance of nature" became closely tied to a notion of mathematical equilibrium found in natural systems, such as predator-prey interactions, developed as ecology flourished in the mid-20th century (Cuddington 2001). However the balance of nature metaphor also served to steer nascent mathematical approaches in a certain direction, and Cuddington (2001:477) concludes that equilibrium theory may have been slowed down by the force of this metaphor. Chew and Laubichler (2003) share this concern. In their article, they are concerned that the metaphor of "natural enemies" is misleading, or at best, contributes nothing new to ecological theory (2003:53). They argue that "enemy" is a normative term, and can pose problems for theory construction similar to Cuddington's conclusions.

Metaphors do other kinds of work as well. Maasen and Weingart (1995; 2000) have developed a branch of the sociology of knowledge that emphasizes the roles and functions of metaphors as "circulation units" (Maasen and Weingart 1995:16) and how metaphors follow a "career" (1995:18) through and across expert and lay social contexts. The authors propose that analysts should follow the movements, linkages and changes that metaphors produce in different social situations. The authors also argue for a broader

selectionist approach to the study of metaphors as circulation units, asking, why certain metaphors survive and flourish while others disappear?

Some contemporary work takes up this direction of research. For example, Ratto (2006:33-4) argues that metaphors operate as boundary objects (Star and Griesemer 1989). That is, metaphors produce and maintain coherent meanings across different groups of actors. Ratto refers to these linguistic objects as *splicing metaphors*: "Rather than sitting at the heart of struggles over meanings, the diversity of meanings and associations connected to these terms are accepted and not necessarily debated…The metaphor of splicing thus emphasizes the interfiliated nature of large-scale scientific projects, made up of various scientific, public, and private interests" (Ratto 2006:34-5). In other words, splicing metaphors are able to span boundaries and organizations because of shared assumptions and concerns that animate the metaphor. Ratto (2006:35) also emphasizes the processual aspects of splicing. Splicing metaphors have both a *temporal openess* that creates an "historical strand" describing both past activities and future possibilities, and an *interpretive openness*, that allows actors to use the multiple and shifting meanings of splicing metaphors to construct alternative articulations.

Splicing metaphors therefore do the work of what Nelkin earlier called "promotional metaphors" (Christidou, Dimopoulos and Koulaidis 2004; Nelkin 1994). *These metaphors not only help to explain complicated scientific objects or processes, they also promote the research* (or, representation is intervention Hacking 1983). This can lead to "overblown expectations" (Nelkin 1994) for different groups of actors and publics. In contrast, attention to splicing metaphors can reveal how these expectations are cultivated, and the attempts to manage their circulation and mitigate possible

unintended consequences. Lay conferences during the Prop 71 campaign are an instructive site to examine these dynamics.

This chapter should be understood through an analysis of the unfolding of the relationships among actors, logics, rhetorics, and metaphors during the Prop 71 campaign. To make this argument, I detail the construction of Prop 71 and its subsequent passage in November 2004, and examine how these logics crystallized during the writing and debate over the proposition. It is the truncated time of the event that helped foreground these logics, which have since been taken up by many other social worlds.

The California Context of Biomedical Research

I next briefly frame scientific research and development (R&D) in California. I argue that there has been a transformation in the overall profile of scientific R&D, which was always central to California, from a predominantly public phenomena to predominantly private one. Concomitant with this transformation was the rise of biomedical research. While never reaching the stellar heights of defense or aerospace R&D in terms of overall expenditures, biomedical and biotechnological R&D have become central locations for the accumulation of knowledge, forms of work, resources and capital.

Biomedical research and biotechnology are conducted primarily in academia and industry. By the 1980s, many institutional linkages were being formed between these domains. By 2000, it no longer makes sense to view these as separated worlds. Rather, biomedical research in academia and industry now forms a dense network of linkages of varying historical durations. Through these points of contact shuttle many different kinds

of things; knowledge, research materials, capital and people. While many people have studied policy changes or political economic explanations of the causes and effects of these tangled networks, I will focus on one group of actors: bench researchers. In Chapter VI, I go more in depth into empirical evidence about bench researchers and their social worlds. Here I want to uncover the changing political economic contexts within which they work and move.

Following WWII, the federal government of the United States made a major commitment to support scientific R&D and, despite some fluctuations, has increased its support since the 1950s. Table 4.1 shows the source of R&D funds, and the sector that received those funds, from 1960 to 2003.

Table 4.1: Amount of R&D in the United States by Source and Performing Economic Sector (in billions of 2000 dollars). See Appendix A for sources.

	Source of Funds		Performing Sector		
FY	Federal government (%)	Industry (%)	Federal government (%)	Industry (%)	Academia (%)
2003	81.8 (30)	176.0 (64)	22.0 (8)	192.5 (70)	37.9 (14)
2001	71.1 (26)	184.0 (68)	20.0 (7)	197.3 (73)	32.9 (12)
1999	68.5 (27)	168.3 (67)	18.2 (7)	186.2 (73)	28.8 (12)
1997	67.7 (41)	142.8 (64)	17.6 (8)	162.9 (73)	26.1 (12)
1990	75.5 (41)	102.0 (55)	19.2 (10)	131.6 (71)	20.8 (11)
1980	55.5 (47)	57.2 (49)	14.5 (12)	80.0 (68)	11.9 (10)
1970	54.4 (57)	38.0 (40)	15.1 (16)	63.9 (67)	8.8 (9)

Table 4.1 shows two important transformations in the structure of R&D in the United States over the latter half of the 20th century. First, by the mid-1970s, R&D was equally funded by public and private sources. By the 1980s, industry had taken the lead, and now funds over 60 % of all R&D. Second has been the rise of academia (universities and colleges) as a location of R&D. Together, industry and academia perform nearly 85% of all R&D in the United States.

Post-WWII, California became a leader among the other states in terms of the amount of scientific R&D that occurred within its borders. Over the latter half of the 20th century, California's R&D base expanded dramatically. In 1975, total state R&D expenditures, in all research contexts, were $7 billion; by 1995, this figure had grown to $41 billion (Cohen 1999:2). This growth was due to the commitment of the federal government to support R&D. This growth was largely underwritten by two federal agencies; the Department of Defense and the National Aeronautics and Space Administration, and was driven by Cold War budgetary priorities (Cohen 1999:2-3). Table 4.2 represents the total federal R&D obligations[8] in California (see Appendix A). The table contains data from the top four agencies in terms of their obligations in California: Department of Defense (DOD); Department of Energy (DOE); Health and Human Services (HHS); and the National Aeronautics and Space Administration (NASA).

Table 4.2: Total Federal Obligations in California by Government Agency (in thousands of 2003 dollars). See Appendix A for sources.

		Agency			
FY	**Total**	**DOD**	**DOE**	**HHS**	**NASA**
2003	17,410,257	9,075,031	1,318,637	3,522,297	2,620,887
2001	13,157,170	6,054,436	1,353,171	2,335,958	2,617,120
1999	17,160,135	10,176,324	1,239,263	1,900,941	3,112,679
1997	15,790,924	9,396,135	1,186,008	1,600,011	2,983,453
1990	22,911,553	16,385,432	1,426,489	1,384,503	3,045,703

All figures calculated in thousands of 2003 dollars, using the U.S. Department of Labor's Consumer Price Index calculator to correct for inflation (http://data.bls.gov/cgi-bin/cpicalc.pl). For each year, one dollar was entered into the year under consideration and converted into 2003 dollars. This dollar amount was then multiplied into reported figures for each year. For example, $1 in 1993 = $1.27 in 2003.

These data show an oscillating pattern in total funding from the federal government to California. However, within this overall picture there has been an historical increase in

[8] Obligations were used instead of expenditures because obligations include future expenditures on on-going projects.

HHS funding, which includes the NIH. Overall, despite cutbacks in defense funding, California continues to lead the nation in scientific R&D. A 2002 National Science Foundation (NSF 03-303 *InfoBrief*: Table 1) report showed that California dominated R&D in the United States, with over $55 billion in total R&D (including industries, universities, and federal agencies and research centers). Michigan was second with nearly $19 billion in total R&D.

Following the restructuring of the federal budget in the early 1990s after the demise of the Soviet Union, overall federal government support of R&D began to decrease, while industry-supported R&D exploded (1999 CREST Report:16). Thus, while total R&D expenditures have increased, the locations of research have changed. From 1985 to 1997, federal government support for R&D decreased by 36%, largely reflecting the restructuring of the military budget (1999 CREST Report:16).

In contrast to defense- and aerospace-based R&D, biomedical research supported by the NIH has steadily increased. This is due to the political work of many individuals committed to doubling the NIH budget. Table 4.3 shows the historical increase in biomedical-related funding from the Department of Health and Human Services.

Table 4.3: Department of Health and Human Services Obligations, United States Total and Amount and Percentage to California (in thousands of 2003 dollars). See Appendix A for sources.

FY	Total HHS Obligations	Amount to California	% of Total
2003	24,815,130 c	3,416,628 c	14
2001	21,341,936 c	2,335,958 c	11
1999	16,551,325 c	1,849,097 c	11
1998	14,663,528 c	1,682,737 c	11
1995	13,173,534 c	1,501,171 c	11
1994	12,895,740 c	1,415,839 c	11

State-level funding for scientific R&D complements moneys from the federal government. Data on the state level are difficult to determine; a 1999 study sponsored by

the California Council on Science and Technology (CCST) found that for three fiscal years, California essentially spent the same amount on scientific R&D (corrected for inflation) over those three years (1999 CREST report:18). Table 4.4 displays these figures. Over 50% of state funding amounts was direct funding to the University of California system (1999 CREST:18). The CREST report points out that 80% of this funding "support[s] early stage R&D outlays…Rather than concentrating activity in areas that have proved fruitful in the past or which otherwise offer exceptional promise presently, funds appear to be distributed more or less evenly to different political constituencies. There is insufficient strategy or structure behind this research effort" (1999 CREST:18). Given California's budgetary problems over the last five years, it is safe to assume that state-level funding for R&D has remained at similar levels.

Table 4.4: State of California funding for R&D. Source: 1999 CREST Report "California Science and Technology Indicators."

FY	Total Amount*
1996-97	271,405,508
1995-96	271,505,907

These figures on public funding show that biomedical research has become increasingly important to the state of California. Scientific R&D occurs primarily in two domains: industry and academia. Table 4.5 indicates an overall shift in funding of industrial R&D that is now dominated by non-federal sources of funding.

Table 4.5: Funding Mix for R&D. See Appendix A for sources.

FY	Total Amount*	% Industry Financed	% Federal Financed
2000	45,769	90.76	9.24
1997	36,392	82.43	17.57
1991	26,812	58.12	41.88
1981	20,346	38.83	61.17

* in millions of 2000 dollars

Regardless of amount of federal funding, scientific R&D conducted within industrial contexts is now primarily funded by industry itself. Another way of looking at the effects of this shift is in patent rates. Table 4.6 shows an increase in the percentage of California's share of patents awarded in chemical and biological research.

Table 4.6: Patents issued in chemical/biological fields

Year	All Chemical/Biological	% of CA's Share
1995	2,267	12.45
1991	1,677	9.75
1985	1,246	8.9
1980	1,086	8.31
1976	1,192	7.42

By the mid-1990's, California had nearly 13% of all patents issued on chemical and biological patents. Related to the growth of industry-based R&D is an increase in available private financing, namely venture capital (VC). Emerging from its status as a relative financial backwater, VC has now become an indispensable source for early-stage financing for a select group of industries. In the United States, nearly 50% of all VC funding goes to software, information and communications industries; the next highest sector is healthcare, which receives 15% of all VC funding (Horvath 1999:1). From 1995 to 2001, over 66% of VC funding for biotechnology went to three regional areas: Boston, MA; San Francisco, CA; and San Diego, CA. California alone accounted for 47% of all biotech VC funding during that time, or just over $4.5 billion dollars (Cortright and Mayer 2002:22)

While VC support of early-stage biotech R&D is no guarantee of success, the combination of institutions such as financial organizations, professional services (such as law firms with expertise in the life sciences and pharma, or marketing organizations), universities, private and public research centers, biotech and pharma companies, and supportive local governments has lead to the creation of biotech clusters that represent a

disproportionate amount of biotech activity in the United States. The top four clusters in terms of percentage of biotech companies are: San Francisco, CA; Boston, MA; New York/northern New Jersey region; San Diego, CA (Cortright and Mayer 2002:29).

Table 4.7: Regional distribution of biotech start-ups. Source: 2002 Brookings Center Report "Signs of Life."

Region	Number of biotech companies founded 1980-2001	% of total
San Francisco	152	14
Boston	141	13
NY/NJ	127	12

Nearly a quarter of all biotechnology companies were located in California by 2001.

In terms of academic R&D, it has been historically supported by the federal government. Table 4.8 displays the sources for all R&D in academia from 1980 to 2003. Industry and state and local governments have played a relatively small role.

Table 4.8: Amount and source of academic R&D expenditures. See Appendix A for sources.

		Source of Funds			
FY	Total Academic R&D Expenditures*	Federal (%)	State & Local (%)	Industry (%)	Institutional (%)
2003	40,077	24,734 (62)	2653 (7)	2162 (5)	7683 (20)
2001	32,797	19,223 (59)	2321 (7)	2220 (7)	6607 (20)
1999	27,530	16,101 (58)	2021 (7)	2033 (7)	5380 (20)
1997	24,370	14,314 (59)	1909 (8)	1737 (7)	4698 (19)
1990	16,286	9638 (59)	1324 (8)	1127 (7)	3006 (18)
1980	6063	4098 (68)	491 (8)	236 (4)	835 (14)

* in millions of 2003 dollars

Table 8 shows the importance of institutionally-based funding streams for academic based R&D. These funds, largely coming from state and local government support of academic institutions goes to both organized research expenditures, and unreimbursed indirect costs and related sponsored research (NSB 2006 report Chpt. 5 pg. 16). What academic R&D has been spent on has been slightly changing. Table 4.9 compares life sciences (agricultural sciences, biological sciences, medical sciences and other), physical sciences (astronomy, chemistry, physics and other), computer science, and social sciences

(economics, political science, sociology and other). This table shows gains for the life sciences, losses for the physical and social sciences, with computer science remaining even.

Table 4.9: Distribution of academic R&D by field. See Appendix A for sources.

FY	All Fields*	Life (%)	Physical (%)	Computer (%)	Social (%)
2003	40,077	23,764 (59)	3273 (8)	1304 (3)	1661 (4)
2001	32,797	19,216 (59)	2804 (9)	956 (3)	1442 (4)
1999	27,530	15,630 (57)	2605 (9)	861 (3)	1252 (5)
1997	24,370	13,591 (56)	2371 (10)	710 (3)	1125 (5)
1990	16,286	8725 (54)	1807 (11)	515 (3)	703 (4)

* in millions of 2003 dollars

These data are meant to outline the economic context of biomedical research. Overall, a tremendous amount of both public and private resources are being committed to biotechnological and biomedical research. The funding of scientific R&D is indelibly connected with political institutions. That is, California has received such a disproportionate share of federal dollars for military research, for example, because many major defense contractors and manufacturers are located in the state. This in turn is due to a hospitable climate to do defense-related R&D. A central element in this hospitable environment is state-level political support. I will now turn to recent California policy on human stem cell research.

Dolly comes to the Golden State.

Following the announcement of Dolly's cloning, the California legislature went into action. In 1997, Senate Bill (SB) 1344, sponsored by State Senator Patrick Johnston (D – Stockton), prohibited both the cloning of a human being ("reproductive cloning"), and the buying and selling of gametes, zygotes or embryos for this purpose, and placed financial penalties of, "$1,000,000 on a corporation, firm, clinic, hospital, laboratory, or research facility and $250,000 on an individual, or twice the amount of pecuniary gain

from the violation, if greater, to be paid into the General Fund." (SB 1344 analysis) SB 1344 passed unanimously in the Senate and with a wide majority in the Assembly (CA Cloning report). Yet SB 1344 was not a permanent ban; it was allowed to sunset in 2003. Johnston also authored Senate Concurrent Resolution 39 (SCR 39), which called for the creation on an advisory group to address the implications of human cloning and review the existing public policy. SCR 39 passed through the legislature, and formed the advisory group that became known as the California Advisory Committee on Human Cloning (CACHC).

The twelve person CACHC began meeting in May, 1999, and held five public meetings across the state before issuing its final report, entitled *Cloning Californians?*, in January 2002. The report contained five major conclusions: one, reproductive cloning should be banned, for a variety of reasons; two, non-reproductive cloning ("therapeutic cloning") should be allowed, but regulated by the stage of embryonic development, procurement of informed consent from individuals donating cells for experimental purposes, and permission from an approved Institutional Review Board (IRB); three, attention needs to be paid to both federal and state policy on human cloning, in order to adjust California's policy appropriately; four, given the rapid changes in the science of human cloning, California policy makers need to be careful in how they define the terms that they use, and should create a state agency to specifically oversee human cloning research; and five, California should institute a permanent cloning advisory committee in order to advise the state government on changes in the science, politics and ethics.

The state legislature gradually began to act on some of these recommendations. In April 2002, the Assembly and Senate passed Senate Concurrent Resolution 55 (SCR

55). This authorized the formation of an advisory panel on human stem cell research. However, while SCR 55 passed, the panel itself was never formed, and no actions ever occurred with respect to SCR 55. In August 2002, the Assembly and Senate passed SB 1230, and then Governor Gray Davis signed the bill into law in September. SB 1230 made permanent the ban on human reproductive cloning established by SB 1344, as well as establishing a committee that addressed point five in the CACHC report. The same month, Davis signed into law SB 253, which allowed, "the derivation and use of human embryonic stem cells, human embryonic germ cells, and human adult stem cells from any source, including somatic cell nuclear transplantation," following IRB approval and appropriate informed consent. SB 253 also banned the sale or purchase of embryonic or cadaveric fetal tissues, but did allow their donation for research. The same year, the Senate Health and Human Services Committee killed SB 1557, sponsored by Senator Jim Battin (R – Riverside). SB 1557 would have banned both reproductive and non-reproductive cloning in California.

In 2003, there was a flurry of activity around stem cells and cloning issues in the state legislature. In February 2003, Sen. Battin again attempted to ban all forms of NT and cloning with SB 133, which, like SB 1557, failed to get out of committee. Also in February, Sen. Deborah Ortiz (D – Sacramento) attempted to get funds for the creation of state research facilities (SB 765), but the bill failed to get the needed majority votes. A similar end killed SB 778, which would have created the "Biomedical Research and Development Fund," funded through the sale of state bonds, and designed to, "award grants and make loans to public or private research companies, universities, institutes, and organizations for biomedical research and development, including, but not limited to,

research in the fields of cell differentiation, nuclear reprogramming, tissue formation and regeneration, stem cell biology, developmental biology, regenerative medicine, and related fields." SB 778 was held up in committee, which set the stage for an alternative source of funding. Both SBs 765 and 778 were victims of the state's budget crisis as California's worsening financial situation prevented either bill from moving forward.

Sen. Ortiz did have some successes in 2003. She sponsored SB 771, which directed the State Department of Health Services to develop and maintain a registry of donated embryos from individuals and couples undergoing fertility or other medical treatments. In September 2003, Gov. Davis signed SB 771 into law. Ortiz also sponsored SB 322. This bill called for the creation of a set guidelines for conducting hESC research in California. These guidelines were to be developed by a committee of thirteen members: seven biomedical researchers; two medical ethicists; two experts in the legal issues of stem cell and IVF research; and two people who represent religious organizations. The committee, called the Human Stem Cell Research Advisory Committee (HSCRAC), was never formed. The reasons for this are unclear. But in 2004, Governor Arnold Schwartzenegger, elected in a special recall vote in September 2003, attempted to repeal SB 322. This process was initiated in the state Assembly; Assemblywoman Sharon Runner (R – Antelope Valley) and Assemblyman Dennis Mountjoy (R – Monrovia) sponsored Assembly Bill (AB) 3012, which would have repealed the HSCRAC. AB 3012 was introduced in February 2004, and stalled in committee. There was opposition to this bill; the president of the California Healthcare Institute (CHI, a lobby organization for biomedical research in California), Dr. David Gollaher, wrote Assemblywoman Runner opposing the bill. Gov. Schwartzenegger

eventually was to change his mind about the repeal campaign, and AB 3012 died in committee.

As is clear from the above description of recent cloning and stem cell legislation, California can be considered a "stem-cell friendly" state. One of the major champions of this research is State Senator Deborah Ortiz, a Democrat whose district covers the Sacramento area in Northern California. Ortiz was elected to the California state Senate in November 1998 after beginning her political career as an Assemblywoman. Ortiz became interested in health issues following the diagnosis of breast cancer in her mother. Following the diagnosis, Ortiz began to push for legislation to increase funding for "gender-based cancers" but was unhappy with the therapeutic choices available, according to one of her former aides (personal interview). This unhappiness led her to an interest in hESC research as a therapeutic option.

While Ortiz was successful in getting legislation passed which made California stem cell-friendly, the major stumbling block remained - money. After it became clear that the state legislature, while not creating policy to block stem cell research, was not going to allocate resources directly to the science like the New Jersey legislature had done, in December 2002, she met with a group and began to discuss the strategy of funding stem cell research by initiative. The defeat of SB 778 signaled that the state legislature, while supportive of hESC research, would be unwilling to commit revenue to the research, largely because of the state's turbulent financial climate at that time. California stem cell advocates, it seemed, needed a different political vehicle to allocate money for the research.

The Emergence of Proposition 71

CuresNow and elite health activism

President Bush's August 2001 address interestingly affected a small group of Hollywood movie producers. Most notably were Janet and Jerry Zucker, and Lucy Fisher and Doug Wick. Together, these two families, both with children with Type I diabetes, along with many allies in Hollywood, formed CuresNow, a lobbying organization initially directed at politicians in the federal government. CuresNow lobbied representatives and senators to oppose legislation that would criminalize nuclear transfer, such as that sponsored by Senator Sam Brownback (R – Kansas). CuresNow relied upon the elite status of its organizers in order to secure meetings and events with major political leaders. One former employee of CuresNow described the organization as critical for getting support from Republican party politicians for hESC and NT research.

> I think CuresNow really gets a lot of credit for being one of the first national in scope stem cell advocacy groups that engaged high-profile Republicans like Orrin Hatch, Nancy Reagan, Arlen Spector on this issue, and really got them to see this for what it is, as an issue that shouldn't be partitioned by partisan lines because diseases don't see partisan lines, and help these folks understand the science…And really for a lot of different high-profile Republicans—senators and congress people—getting them to separate stem cell research from the abortion issue, which I think you and I can agree really has nothing to do with embryonic stem cell research, but is unfortunately linked. So at this time of great partisanship, they were really a voice of reason, and I think helped bring the Republicans in support of this issue.
>
> -Interview 7/6/05

These high-profile, wealthy Hollywood producers hosted events to raise awareness and broaden the network of supporters throughout 2001 and 2002. This included exclusive dinners with bench researchers and soon-to-be Governor Arnold Schwartzenegger and his wife Maria Shriver. They hired another Hollywood producer, Lauren Weissman, to become executive director. Weissman is the sister of Stanford researcher Irving Weissman, an elite scientist and major proponent of hESC and NT research.

In March 2003, a now-legendary meeting took place in the Zuckers' home in Southern California. The attendees included the Zuckers', Wick and Fisher, Sherry Lansing (former director of Paramount Studios, and later ICOC board member), State Sen. Deborah Ortiz, Irving Weissman (scientist from Stanford) and Lauren Weissman (a producer and Irving's sister), Lawrence Goldstein (scientist from UCSD), Peter Van Etten (former president and CEO of the Juvenile Diabetes Research Foundation [JDRF]), as well as "various A-list Hollywood liberals" (Kapp 2005). This meeting launched the Prop 71 campaign.

Peter Van Etten was familiar with another wealthy Californian parent with a child with Type I diabetes: Robert Klein. Klein had been a member of JDRF's international board, and was a member of the Board of Directors as of 2006. Klein, a graduate of Stanford law school in 1975, had started a financial organization that brokered real estate deals, Klein Financial Corporation, and was also active with the state government on bonds for low-income housing. Klein was to eventually become the leader of the Yes on 71 campaign, as well as Chairman of the Independent Citizen's Oversight Committee (ICOC), the governing body of the California Institute for Regenerative Medicine (CIRM).

Klein was absent from the March 2003 meeting in the Zuckers' home, but was brought into the fold by Van Etten. Klein became a key supporter, and canvassed various groups and individuals about the feasibility of a state bond initiative for stem cell research. By summer 2003, Klein had become convinced of the viability of an initiative to fund human stem cell research, and began to aggressively organize supporters to get the proposal on the 2004 ballot.

The California initiative process

The initiative process is part of a larger palette of techniques that citizens use to alter the composition of government or to change laws and constitutions known as *direct democracy*. Direct democracy in the United States has been of interest to political theorists for some time, although space prevents me from a thorough examination of the debates surrounding this field (for more detail see Bowler, Donovan and Tolbert 1998; Broder 2000; Cronin 1989; Ellis 2002; Hahn and Kamieniecki 1987; Sabato, Ernst and Larson 2001). California has become a leader, for better or worse, in direct democratic techniques. Prop 71 is only one example in a long history of initiatives that date back to the Progressive era (Ross 2000; Schrag 1998). Following Hiram Johnson's 1910 election as governor, the state constitution was changed to allow the techniques of direct democracy – initiatives, referendums and recalls – to combat perceived problems of graft and corporate influence of government (Schrag 1998; Starr 1985).

Once a potential proposition is drafted, it must follow a series of steps in order to qualify for the California ballot. It is first submitted to the Attorney General's office, which approves the title and summary of the initiative that appear on the signature petition sheets (Ross 2000:112). After that approval, the proposition has 150 days to gather the needed amount of signatures. Since Prop 71 was a constitutional amendment, it had to reach a signature threshold of 8% of all votes cast for governor in the most recent previous election (2000:112). The wording of a proposition is critical. In the case of Prop 71, it was challenged both before and after the election. Prior to the election, supporters of Prop 71 attempted to block language used by the opponents. The named

petitioners who brought the lawsuit were Paul Berg, Robert Klein, and Larry Goldstein. Klein had become the leader of the Yes on 71 campaign; Berg is a Nobel laureate biochemist from Stanford; Goldstein is a molecular biologist from UCSD, and one of the science advisors on the drafting of Prop 71. The lawsuit was directed at the Secretary of State of California, Kevin Shelley (as is required by law). On August 4, a hearing was conducted in the Sacramento Superior Court, with the Hon. Gail Ohanesian presiding. The lawyers from each side went through each disagreement, and changed the wording. Afterwards, both sides claimed victory. Following the November 2004 election, Prop 71 has been tied up by multiple lawsuits that have prevented the sale of the state bonds in order to fund the CIRM.

Given the importance of language, lawyers are now mandatory from the very early drafting phases on through the election (Broder 2000:71). This was not a hindrance for drafters and supporters of Prop 71 given their access to resources. While attempts were made to make the proposition "lawsuit-proof," it was inevitable that the proposition, if passed, would be challenged in court, as are most controversial propositions in California. Given the complexity of the initiative, its numerous levels of changes and additions to state bureaucracy, the open-ended aspects of the sections detailing intellectual property and oversight regulations, and the novel organizational form of the CIRM and ICOC, Prop 71 presented many opportunities for targeting by oppositional lawsuits.

Drafting and signature gathering phase

Following the March 2003 meeting, Sen. Ortiz became less involved with the formal campaign. The Yes on 71 campaign began to take shape in the summer of 2003, as political professionals were hired to sculpt the campaign image, and a legal team assembled around Klein to draft the proposition. Irving Weissman and Larry Goldstein were scientific consultants during the drafting process. The proto-campaign hired a skeleton staff to help with running the operation, and coalesced as a non-profit that became known as Californians for Stem Cell Research and Cures (*The San Diego Union Tribune* 2/07/04). This staff was eventually to become core staff for the Yes on 71 campaign, as well as the CIRM.

Drafting an initiative that would cover not only hESC and NT research, but governance structure, relationship to other state agencies, potential intellectual property agreements as well, was to prove a Herculean task. The core group from the March 2003 meeting tapped into expertise of various kinds, both from professional political organizations to personal contacts from social networks. The informal work done by two groups in particular was critical: patient activists and bench researchers. Each group is talked about in more detail in separate chapters (patient activists in Chapter V and bench researchers in Chapter VI). During the rest of 2003, CSCRC spent time building a coalition that included both of these groups. This coalition-building activity was facilitated by both groups' prior experience in political institutions. California scientists involved with the Yes on 71 campaign were by then no strangers to politics. Many of them had testified in governmental venues regarding human stem cell research, at both the state and federal levels. One scientist from a major research institution described being recruited to attend a PAG fundraising event in order to speak with senators who

were present. Scientists were involved in the Yes on 71 campaign in various ways, including: drafting the initiative and providing scientific advice during the drafting process; speaking with politicians about the importance of Prop 71 for scientific research; appearing at campaign fundraisers in order to give research updates, and/or provide visions of the future; and appear at public debates or conferences about human stem cell research.

Californians for Stem Cell Research and Cures (CSCRC) next major task was to gather enough signatures to qualify for the November 2004 ballot. CSCRC hired paid signature gatherers, as is now the norm for California. However, the organization also began a "grassroots" campaign mobilization at this phase, and tapped into patient activists to set up signature gathering stations across the state in public locations. Given state laws for ballot qualification, CSCRC needed just under 600,000 signatures in order to qualify as both a statutory and constitutional amendment. The signature drive netted around 1.1 million signatures. This fact was noted during the campaign as evidence of Californian's support for hESC research.

"Signature gathering" has become its own industry. The most popular technique is the "table method," which has been credited to a car salesman named Edward Koupal in the 1960s (Broder 2000:54). The table method involves setting up a table in a high-traffic area, such as a supermarket entrance or sporting event. There are usually two volunteers involved, one of whom stands away from the table and asks passer-bys if they are registered to vote in the state that the initiative is being considered. If the answer is "no," the conversation ends. If the answer is "yes," the passer-by is directed to the table, where the second volunteer awaits, with pens and petitions. The second volunteer usually

gives a one or two sentence description of the initiative, generally with the disclaimer, "This is just to get it on the ballot" in order to appeal to moderates who may be slightly opposed to the content of the initiative, but still value the direct democratic process. Koupal set the threshold at 80 signatures an hour; if the table does not average this rate, it is moved someplace else (2000:54-5). The key to the table method is efficiency. Volunteers are instructed not to debate the issues, or attempt to talk people into signing the petition. That simply takes up too much time. Like all political technologies, the table method is itself a site of struggle. For example, Molly McCann, a 17-year old Missouri resident, was unhappy after she was canvassed by a signature gatherer for a 2006 state initiative in Missouri that would endorse human stem cell research, similar to Prop 71. McCann set up a "counter-table" next to the signature gatherers and handed out information that attempted to dissuade people from signing the petitions (Brinkler 2006).

Most signature-gatherers attempt to be as efficient as possible because they are paid per signature, sometimes as much as $2.50 per signature (Broder 2000:63). Signature-gatherers are usually coordinated by a local or regional crew chief, who contracts with the signature-gathering company to do the actually work (2000:59). The crew chiefs may contract with several different companies, but some companies demand exclusivity (2000:59). The Yes on 71 campaign utilized these companies, in addition to using patient activists, who were actively recruited for the campaign. The successful enrollment of patient activists into one campaign helped to achieve immediate organizational needs, as well as producing the collective identity of stem cell activist (see Chapter V). Signature gathering, while considered to be merely an instrumental aspect of

political organizing, has other consequences. Before following events on the campaign trail, I next present a brief description of the proposition itself.

The California Stem Cell Research and Cures Initiative

Prop 71 was both a constitutional and statutory change. Its main thrust was to direct the state to sell three billion dollars worth of state general obligation bonds in order to pay for the implementation and on-going costs of overseeing and awarding grants for stem cell research. Specifically, Prop 71 established the California Institute for Regenerative Medicine (CIRM), to oversee the above activities. The CIRM would be directed by a 29-member board of directors, called the Independent Citizens Oversight Committee (ICOC). Prop 71 specified the eligibility criteria for ICOC members, who were subsequently appointed by state government officials. The ICOC is directed by a Chair and Vice Chair; candidates for these positions were nominated, and voted upon by the ICOC at the first meeting in January 2005.

Prop 71 is divided into eight sections. Section 1 is the Title: "California Stem Cell Research and Cures Act." Section 2 is the Findings and Declarations. In this section, the text describes the genesis of Prop 71:

> Recently medical science has discovered a new way to attack chronic diseases and injuries. The cure and treatment of these diseases can potentially be accomplished through the use of new regenerative medical therapies including a special type of human cells, called stem cells. These life-saving medical breakthroughs can only happen if adequate funding is made available to advance stem cell research, develop therapies, and conduct clinical trials.
>
> About half of California's families have a child or adult who has suffered or will suffer from a serious, often critical or terminal medical condition that could potentially be treated or cured with stem cell therapies. In these cases of chronic illness or when patients face a medical crisis, the healthcare system may simply not be able to meet the needs of patients or control spiraling costs unless therapy focus switches away from maintenance and toward prevention and cures.

> Unfortunately, the federal government is not providing adequate funding necessary for the urgent research and facilities needed to develop stem cell therapies to treat and cure diseases and serious injuries. This critical funding gap currently prevents the rapid advancement of research that could benefit millions of Californians.
>
> The California Stem Cell Research and Cures Act will close this funding gap by establishing an Institute which will issue bonds to support stem cell research, emphasizing pluripotent stem cell and progenitor cell research and other vital medical technologies, for the development of life-saving regenerative medical treatments and cures.

This introduction to Prop 71 constructs a narrative arc that presents human stem cell research as a life-saving medical technology ultimately dependent on funding. Even though many people could benefit from this technology, the federal government is not being forthcoming with resources. Therefore, Prop 71 "close[s] the funding gap" created by federal policies. The power of this section lies in its form. While one can certainly argue with the content (for example, will human stem cell research actually deliver on its promises? At what costs?), the rhetorical form is presents a possible solution to common problems (human stem cell research saving lives), a barrier to the solution (the federal government), and finally, a strategy for overcoming the barrier (a state-funded research institute). By focusing on the federal government, this carefully crafted statement avoided mention of other potential barriers, such as organizations in California opposed to human stem cell research or the technical and ethical complexities of aspects of the research (such as nuclear transfer experiments), and instead capitalized on California's voting demography, which tends to vote for the Democrat party. This rhetorical move focuses attention on a single enemy - the current Bush Administration - in order to consolidate popular support. To ensure this consolidation, human stem cell research is continually framed as "life-saving," making it difficult to argue against this position. As I will make clear below, I call this form of writing *logics of representation*, draws from

public representations of regenerative medicine in order to provisionally unify the publics and groups of actors necessary for the success of the enterprise.

Section 3 is the Purpose and Intent. This section lays out the outcomes that Prop 71 intends to produce, including:

> - Maximize the use of research funds by giving priority to stem cell research that has the greatest potential for therapies and cures, specifically focused on pluripotent stem cell and progenitor cell research among other vital research opportunities that cannot, or are unlikely to receive timely or sufficient federal funding, unencumbered by limitations that would impede the research. Research shall be subject to accepted patient disclosure and patient consent standards.
>
> - Assure that the research is conducted safely and ethically by including provisions to require compliance with standards based on national models that protect patient safety, patient rights and patient privacy.
>
> - Prohibit the use of bond proceeds of this initiative for funding for human reproductive cloning.
>
> - Improve the California healthcare system and reduce the long-term healthcare cost burden on California through the development of therapies that treat diseases and injuries with the ultimate goal to cure them.
>
> - Benefit the California economy by creating projects, jobs, and therapies that will generate millions of dollars in new tax revenues in our state.
>
> - Advance the biotech industry in California to world leadership, as an economic engine for California's future.

These statements act to formally delineate the scope of the potential research, "*pluripotent stem cell* and *progenitor cell* research among other *vital research opportunities* that cannot, or are unlikely to receive timely or sufficient federal funding" (emphasis added), without using contested words such as "embryo" or "cloning." "Pluripotent stem cells" and "progenitor cells" are both subsequently defined in the proposition without reference to developmental stages at all. For example, "pluripotent stem cells" are defined by the cells' inherent characteristics, and their creation through IVF. There is no mention of the developmental stage during which pluripotent stem cells are present. The only use of the word "cloning" is to indicate prohibition of human

reproductive forms. Finally, several claims present possible financial or commercial benefits to the citizens of California.

These first three sections can be considered the *logic* of the proposition. The Yes on 71 campaign was tightly focused on this rhetorical form and use of terms, and continually re-invoked this logic in heterogeneous public venues. This logic minimized the various complexities of human stem cell research. In turn, helped draw potential votes, as well as providing a set of "talking points" for campaign staff and volunteers. Both Yes on 71 staff and supportive stem cell scientists repeated these talking points in public settings. In addition, this logic provided the parameters for identity work. That is, patient activists could use these relatively general claims about "saving lives" or "benefiting the economy" in multiple ways. These claims are general enough to intersect with patient biographies, yet specific enough to be understandable as offering tangible benefits.

Section 4 lays out the changes to the California state Constitution initiated by the passage of Prop 71. Specifically, this is Article XXXV, amending the California state Constitution to establish the CIRM, prohibited funding for human reproductive cloning, blocked future changes to the funding mechanism by either the Governor or the Legislature, established stem cell research as a right, ensconced tax-exempt and taxable bonds as the source of funding, and exempted the Institute and its employees from civil service. Section 5 added Chapter 3 to Part 5 of Division 106 of the Health and Safety Code of California (for more detail on Chapter 3, see below). Section 6 amends Section 20069 of the Government Code to exempt "the California Institute for Regenerative Medicine and the officers and employees of its governing body" from state service.

Section 7 is entitled Severability, which protects other elements of the law if any part of it is declared "invalid or unconstitutional." Section 8 is entitled Amendments, and insulates the CIRM from the state government, requiring a supermajority vote (70% of both the Assembly and Senate) after three years of operation in order to change any statutory elements of the law. The constitutional changes can only be changed by subsequent constitutional amendments.

Chapter 3 is entitled the "California Stem Cell Research and Cures Bond Act." It contains three Articles, the major content of the proposition. Article 1 specified the implementation and creation of the ICOC (subsections 125290.10 - .15), the make-up of the ICOC (subsection 125290.20), establishing a quorum as necessary for board action ("quorum" being defined as at least 65% of eligible voting members being present, 125290.25), mechanisms for reporting and auditing the CIRM, public meeting, public record keeping and conflict of interest parameters (125290.30), medical and scientific accountability standards (125290.35), specification of ICOC functions (125290.40) and ICOC personnel and operations (125290.45), composition of scientific and medical "working groups" (WGs -125290.50), and the composition and roles of each specific WG – the Scientific and Medical Accountability Standards WG ("Standards WG," 125290.55), the Scientific and Medical Research Funding WG ("Funding WG," 125290.60), and the Scientific and Medical Facilities WG ("Facilities WG," 125290.65), and finally the scope and rules for the allocation of bond sale-derived funding (125290.70).

Article 2 (125291.10 - .85), entitled the California Stem Cell Research and Cures Bond Act, stipulates the rules and procedures for selling the bonds, and the methods the CIRM will follow for procuring the revenue created by the bond sales.

Article 3 (125292.10) is a series of definitions, including the following:

> "Adult Stem Cell" means an undifferentiated cell found in a differentiated tissue in an adult organism that can renew itself and may (with certain limitations) differentiate to yield all the specialized cell types of the tissue from which it originated.
>
> "Human Reproductive Cloning" means the practice of creating or attempting to create a human being by transferring the nucleus from a human cell into an egg cell from which the nucleus has been removed for the purpose of implanting the resulting product in a uterus to initiate a pregnancy.
>
> "Pluripotent Cells" means cells that are capable of self-renewal, and have broad potential to differentiate into multiple adult cell types. Pluripotent stem cells may be derived from somatic cell nuclear transfer or from surplus products of in vitro fertilization treatments when such products are donated under appropriate informed consent procedures. These excess cells from in vitro fertilization treatments would otherwise be intended to be discarded if not utilized for medical research.
>
> "Progenitor Cells" means multipotent or precursor cells that are partially differentiated but retain the ability to divide and give rise to differentiated cells.
>
> "Stem Cells" mean non-specialized cells that have the capacity to divide in culture and to differentiate into more mature cells with specialized functions.

Section 4 can be considered the *mechanics* of Proposition 71. It specifies exactly what will happen if it passes, and the limitations on the institutional processes of the CIRM, as well as the CIRM's relationships to other state agencies and institutions. The Yes on 71 campaign spent the majority of their effort directing attention to the logics of Prop 71, rather than the mechanics. That is, supporters of Prop 71 emphasized the necessity of the initiative to mitigate deficiencies in the advancement of biomedical science. Conversely, the opposition to the Yes on 71 campaign countered this strategy by pointing to possible problems in the mechanics. This included drawing public attention to "conflicts of interest" and "oversight and accountability problems" produced by the governance structures of the CIRM, and the relationships of the CIRM to the state legislature, for example. I will now turn to how the logics of Prop 71 were represented and contested over the months prior to the election.

Stem Cells on the Campaign Trail: June – August 2004

Following qualification for the ballot, the Yes on 71 campaign formally began. The structure of the Yes on 71 campaign bifurcated into northern and southern California field offices. The northern branch was the office of Klein Financial Corporation. For the rest of this section, I am going to focus on activity in Northern California[9].

David Broder argues that once all the signatures have been gathered and verified, a new group of political professionals takes over: the campaign managers (Broder 2000:72). An important decision at this point is how the campaign will be represented from now on as an official entity. The Yes on 71 campaign relied on professional political organizations in order to refine and disseminate its message. Given the geographic size of California, television commercials have become mandatory tools for statewide campaigns. The Yes on 71 campaign released a series of TV commercials imaging scientists and patient activists. These commercials featured bench scientists, celebrities and patients urging voters to vote yes on Prop 71.

In no way can the Yes on 71 campaign be considered a grassroots operation. As we have seen, its genesis was from an elite group of business people, scientists and politicians. This core group needed to develop an organizational structure. Fortunately, they had one already in existence in close proximity: the networks of patient activists across California and the nation that supported hESC research.

One of the first major events was a stem cell activist conference at the University of California, Berkeley (UCB) on June 5-6 2004. The conference was sponsored by the Stem Cell Action Network (SCAN), which is an organization of stem cell activists across

[9] Fieldwork was conducted at sites in Southern and Northern California. However, the majority of fieldwork and interviewing was conducted in Northern California. This was an artifact of the convenience sampling strategy of this project.

the United States. This conference brought together patient activists, biomedical scientists, corporate leaders, and CSCRC staff, and it was at this conference that Prop 71 was revealed to many northern California stem cell activists.

Opposition to Prop 71

While this project focuses primarily on the supporters of Prop 71, I next briefly describe the opposition to Prop 71. In terms of material resources, the opponents of Prop 71 were outspent by the proponents by 56:1. This vast disparity limited opponents in their strategies (see Table 4.10).

Table 4.10: Total campaign expenditures[10]

No on 71	$624,973.31
Yes on 71	$34,856,299.97

One of the major organizations the opposed Prop 71 was called "Doctors, Patients & Taxpayers for Fiscal Responsibility" (DPTFR). This organization, an umbrella group headed by Dr. Vincent Fortanasce, a clinical neurology professor at the University of Southern California, had a website but little presence in northern California.

Three other organizations, the Center for Genetics and Society (CGS), the Pro-Choice Alliance Against Proposition 71 (PCAP), and the California Nurses Association (CNA) were the most visible in northern California during the summer and fall campaign. CGS and CNA existed prior to the Prop 71 debates, and PCAP arose as a result of concerns with the proposed governance and oversight of the proposed stem cell institute (the CIRM), the amount of public money devoted to basic research rather than other

[10] Last checked 27 February 2006. Source: CA Secretary of State website (http://www.sos.ca.gov/)

public health needs, and the problems associated with the procurement of raw materials such as gametes, zygotes and embryos. CGS and CAN shared in these concerns.

The No on 71 campaign attempted to recruit academics, but did not have much success. While the Yes on 71 campaign had a virtual monopoly on natural/physical scientists and clinicians in California, the No on 71 had difficulty attracting any academic or professional-level support. For example, members of the CGS held a meeting during the 2004 conference of the American Sociological Association (ASA) in San Francisco, California. In addition, the CGS held other meetings at U.C. Berkeley to discuss Prop 71 and other issues. However, these meetings failed to generate direct political activity for the No on 71 coalition. One member of the No on 71 coalition claimed that bench researchers had been pressured not to speak out in opposition to Prop 71.

September 2004: It sounds good, but how much will it cost?

One of the major challenges confronting the CSCRC was the price tag of Prop 71 for the taxpayers of California. While Prop 71 authorized sale of $3 billion in bonds, the interest on those bonds pushed the total cost, given fluctuating interest rates, closer to $6 billion. One group of opponents to Prop 71 consisted of fiscal conservatives, who argued that this was a bad way to fund science. State Senator Tom McClintock (R – Thousand Oaks) was a visible leader of this wing. On August 23, the *Los Angeles Times* published a piece by calling into question the possible economic benefits of Prop 71.

In order to ground their economic arguments, the CSCRC paid for an analysis of Prop 71, authored by Dr. Laurence Baker, an Associate Professor in the Department of Health Research and Policy at Stanford University, and Bruce Deal from the Menlo Park

based company Analysis Group, Inc. The team developed their analysis by looking at four areas that would generate financial benefits for the state: income and sales tax revenues from new jobs created by Prop 71-funded research; income and sales tax revenues from expansion of the biotechnology sector; reductions in health care costs to the state from stem cell derived therapeutic advances (on six targeted conditions – stroke, heart attacks, insulin dependent diabetes, Parkinson's disease, spinal cord injuries, and Alzheimer's disease), and; royalty payments to the state from entities that developed profitable application from Prop 71-funded research (Baker and Deal 2004:5-9). From these four areas, the team modeled different outcomes of the passage of Prop 71 for the California economy.

The report was released on September 14, and painted an extremely rosy picture of the fiscal outcomes from the passage of Prop 71. Baker and Deal amortized the cost of the principle and interest of Prop 71 over a 35 year period, which given a set of assumptions about bond interest rates, would cost the state $5.355 billion over that time period (2004:25). The team then used three scenarios to model their projections. The first scenario was "Limited Therapeutic Success" which was a 1% reduction in health care spending as a result of therapeutics developed from Prop 71-funded research, which came to a savings of $9.2 billion. They also assumed a 2.5% increase in the overall size life sciences industry, and royalty revenues at 2%. Using their four areas, they forecasted at $6.426 billion. Deducting cost ($5.355 billion), the net benefit for California would be $1.071 billion (2004:10).

The second scenario was "Increased Therapeutic Success." Here, they assumed a 2% reduction in health care spending, a 5% increase in the overall size life sciences

industry, and royalty revenues at 4%. Following the same calculations as scenario one, the net benefit for California would be $7.257 billion (2004:11).

The third scenario was "Expanded Therapeutic Success." Baker and Deal enlarged their assumptions further, assuming a 10% reduction in health care spending, but kept the overall size life sciences industry at 5% and royalty revenues at 4%. Again, following the same calculations as scenario one, the net benefit for California would be $34.806 billion (2004:12). While the authors stressed the uncertainties associated with modeling a complex and controversial science, they considered their assumptions of possible benefits "modest" (2004:84).

The economics of Prop 71 soon became one of the major issues of both the Yes and No campaigns. An October 15 article in the *San Francisco Chronicle* claimed that "cracks were forming" among the progressive base of support for Prop 71 (Hall 2004). The CNA came out against Prop 71, and the San Mateo County Medical Association reversed its earlier support. The day after the Baker and Deal report was released, Sen. Ortiz held a hearing in San Diego on Prop 71. The hearing featured testimony from patient activists, scientists, governmental staff, and other supporters and opponents of Prop 71. Laurence Baker was on hand, and spoke about costs and benefits of Prop 71. Stem cell scientists Evan Snyder, Hans Keirstead and Larry Goldstein testified as well. In her opening remarks, Sen. Ortiz claimed that she had, "passed the first law in the nation to guarantee stem cell research, and out of that we set the model for other states to follow" (2004:3). She also pointed out that, "in 2003, I introduced legislation to provide bond financing for stem cell research. That became the basis for what is now Proposition 71" (2004:3).

Following Sen. Ortiz's introduction, two patient activists spoke in support of Prop 71, followed by testimony from two stem cell researchers. The first scientist was Dr. Evan Snyder from the Burnham Institute in San Diego. He begins by stating he is a pediatrician, so he is, "used to explaining very complex things to kids and their parents." He explains stem cell biology as an "ice cream store," with stem cells serving as vanilla ice cream which can become many types of flavors: "The beauty of stem cell biology is that this [plasticity] is what you need to restore the nervous system, for example. This is what the stem cell does naturally. This is your ice cream store. This particular taste here is the neural stem cell sitting up there, giving rise to all the rich flavors of the nervous system that then need to talk to each other" (2004:14). He concludes by referring to the economic analysis just released: "Even a one percent impact entirely pays the bill. I guarantee you, the scientists here, we will be able to do this" (2004:22). It is interesting that Snyder, who over the course of the campaign season, tended to emphasize the uncertain and open-ended nature of basic science, would conclude with a guarantee.

Following Snyder was Dr. Hans Keistead, from the University of California Irvine's (UCI) Reeve-Irvine Research Center. He began his talk by referring to the novel importance of human stem cell research: "This is really exemplary of something that happens every few hundred years. Maybe every one hundred years we have one major milestone in medical research; the advent of penicillin, things like that. This is one such thing" (2004:23). Both Snyder and Keirstead showed digital images of model organisms following treatment with hESCs. Time was running short, so Sen. Ortiz asked them both about the impact of federal restrictions on NIH funding, as well as the utility of the cell lines on the NIH registry. Snyder emphasized the speed with which the field was

moving, and that the cell lines on the registry are "flawed," meaning that the cells had come from infertility clinics, and couples who he asserted already had some kind of "genetic predisposition" to infertility. What is more, these cell lines, "certainly don't represent a range of disease accessibility. They do not represent a range of ethnics, a range of races" (2004:36). Keirstead seconded this position: "As Evan mentioned, and I won't run over again, the ethnic diversities simply aren't there. These are wealthy, white infertile stem cells, to put it bluntly" (2004:37-8). Numerous other references to the needed "diversities" of stem cell lines appeared during the Prop 71 campaign.

These references to cellular racial diversity are nothing new. As Hannah Landecker (2000:69) states: "Immortality, the uncanny double, and the cultural, scientific and individual effects of ideas of biological race have existed in an intricate reciprocity with the matter and practice of the science of tissue culture in this history" (see also Wailoo 1997; 2003). Tracing the intersections of race and cell cultures historically, Landecker (2000) argues that geneticist Stanley Gartler made a mistake in 1967 when he explained the contamination of cell cultures with cells from a cell line called HeLa (derived from the name of the donor, an African-American woman named Henrietta Lacks) by using racial distinctions. Gartler argued, based on the frequency of an enzymatic marker (G6PD) that the contaminating cells were of "Negro" ancestry (2000:61-2). Landecker argues that his description of cellular contamination in racial terms was mistaken because he could have shown the contamination was present without referring to racial difference (2000:62). That is, there were better explanations (frequencies of allelic distribution) than the one Gartler made public (racial difference).

This mistake was consequential, however, for the rhetorical connections that linked populations of cells *in vitro* with populations of persons in the world (2000:64).

In the example above, the two scientists reverse the mistake of Gartler, and apply an *identity politics* rhetoric to cells. That is, rather than linking cellular characteristics (frequencies of G6PD allele) to racial designations ("Negro" and "Caucasian") through tropes of contamination and miscegenation, Snyder and Keirstead assume that their audience understands the importance of and need for something called "diversity." That is, diversity is held up as a public good in its own right, or an end that at least deserves consideration in different contexts, from hiring practices to student profiles at public schools, for example. In other words, it is rhetorically easier for Snyder and Keirstead to point out the possible racial homogeneities of existing cell lines (the importance of which is predicated by tacit assumptions of *inequality*) than it is to explain how various human diseases may or may not map on top of groups called "races," or, what amounts to the same thing, avoiding a complicated (and controversial) discussion of things like genes, diseases, races and populations.

In this case, following Landecker and others, "diversity" operates like "contamination" in the public representations of biotechnology. That is, when scientists talk about diversity and cell lines, they really mean genetic diversity in terms of allelic frequencies that are significant for certain diseases or conditions. The frequencies of alleles for different diseases can be aggregated into *populations* – these populations are then mapped on to groups called *races*. Human stem cells in this case could be very *helpful tools* for tracking the development of diseases over the course of cellular development.

In his argument about the enduring legacies of race as a classificatory system, Ian Hacking (2005:105)makes a distinction between human characteristics as either *statistically significant* ("the distribution [of the characteristic under examination] in one population is significantly different from that in a comparable population"), *statistically meaningful* ("there is some understanding, in terms of causes, of why the difference is significant"), and *statistically useful* ("[the characteristic] can be used as an indicator of something of interest in some immediate practical concern"). He compares the examples of BiDil (a heart disease medication that is marketed towards African-Americans) and the matching of human leukocyte antigen (HLA) markers that serve to classify tissue for transplantation. In the case of BiDil, he argues, the medication may in fact work for a population of individuals (it is statistically significant), and provide relief for those suffering from heart disease (it is statistically useful). However, it is far from clear that the useful and significant aspects of BiDil are based on racial differences (it is not statistically meaningful). Hacking (2005:107-8) argues that BiDil's effectiveness could be due to "social factors," such as diet, rather than biological ones. Therefore, the racial differences that predicate BiDil's prescription and usage are not statistically meaningful.

In order to have donor tissue that matches the recipient's immune system, and avoids rejection, there must be a match for at least six HLA markers in order for tissue to engraft without serious complications. This realization has lead to the flowering of race- and ethnicity-based tissue drives, for such objects as bone marrow and stem cells. Like BiDil, HLA typing is both statistically significant and statistically useful; unlike BiDil, HLA typing is also statistically meaningful. That is, tissue rejection is due to a complex of physiological reactions mediated by cell-surface receptors classified by the HLA

system. This differs from BiDil, in that (at present) it is far from clear what the exact causes BiDil targets or ameliorates are.

Hacking's point in making the distinctions between the ways in which human differences are understood is in the service of his larger argument involving debates about the concept of "natural kinds" For space reasons, I will not go into those debates. That race for Hacking may be a significant, meaningful and useful characteristic in terms of certain biological processes (and not others) does not, however, argue against Landecker's point that scientific representations of difference will always borrow from the existing repertoires of tropes regarding human differences. In the case of the public hearing described above, the scientists stressed the need for diverse cell lines, and made their appeal to diversity along racial and class lines. That is they used examples of race and class ("wealthy, white infertile stem cells") and concepts from political worlds ("diversity") to not only equate stem cells with populations of humans, but to make a political argument for the desirability of increased numbers of disease cell lines.

Scientists were important political actors for the Yes on 71 campaign. They did not operate as concerned individuals however, as some self-described their campaign activities. Rather, they worked as a coordinated group to explain human stem cell research as a public good. Here, I am less interested in explaining scientist's political action as emerging either because of self-interest (they stood to directly gain from Prop 71's passage) or because they were the pawns of larger, more powerful interests. Instead, I am interested in how the public descriptions and explanations of human stem cell research served to knit together a variety of individual and group interests. Why are these public descriptions and explanations of human stem cell research so important? How did

they work? I will argue that these discourses are important sociologically because they deployed *logics of representation* that were consequential for the passage of Prop 71. I will now turn to a closer look at these logics.

October 2004: Science and politics on the campaign trail

The weeks before the November vote were filled with frenetic activity. While the internal polling done by the CRCSC staff was showing that they were ahead in the polls, their lead was not huge, and could be eroded if something dramatic occurred. This primarily concerned Governor Arnold Schwartzenegger who, by mid-October, had still not taken a public stand on Prop 71. Both sides lobbied his office, but no information had emerged regarding his position. The state Republican party had already come out against Prop 71, as had several prominent Republican politicians. However, other notable Republicans, such as former First Lady Nancy Reagan and former Secretary of State George Schultz, had spoken in support of hESC research. As October rolled around, it was unclear what the actor-turned-governor was going to do.

October was also a busy time for public activities concerning Prop 71. For this section, I will divide the events I attended into three categories: 1. Lay conferences; 2. campaign debates, and; 3. community meetings. The first category, lay conferences, refers to conferences that focused on the different aspects of human stem cell research. These events were framed as presentations that were open to all people, regardless of their state of knowledge about stem cell research. Their pedagogical function was

foregrounded, and their form was identical. They started with an overview of the state of human stem cell research, then turned to ethical debates in the research, before concluding with policy options. The second category, campaign debates, were formal debates between the Yes and No positions. The final category, community meetings, were debates, but not by official members of campaign staff.

The two campaigns engaged in a series of state-wide debates leading up to the election. I do not have quantitative data on how many of these debates were conducted; however, I will present qualitative data on a small set of these events. I attended three such debates in northern California (October 4 at Foothill College in Los Altos Hills, October 18 at Stanford University in Palo Alto, and October 28 at the Commonwealth Club in San Francisco). On October 7, San Francisco public radio station KQED hosted an on-air debate between the two campaigns. In addition, there were other venues, including "community discussions" put on by local organizations. For example, the town of Los Altos Hills put on two forums (October 17 and 24) about Prop 71 and stem cell research in general. In addition, there were a series of lay conferences held during the summer of 2004 that discussed Prop 71 and stem cell research. I will define and discuss the significance of these lay conferences in Chapter 5. I attended three of these conferences (October 2 at the Salk Institute in San Diego, October 12 in San Francisco, and October 20 at the University of California, Irvine).

What is significant about this sample of Prop 71-related events? First, they are all ostensively public events. That is, they were open to all (some of the lay conferences charged a registration fee), and advertised as public forums for talking about and understanding human stem cell research. Second, they took a variety of forms, ranging

from larger gatherings that were professionally run and managed to very informal "neighborhood chats." This does not take into account the many other layers of discussion about Prop 71 and human stem cell research that ribboned through the state that year. In other words, Prop 71 was discussed on a variety of levels quite deeply throughout the summer and fall of 2004. Finally, these events addressed many issues, and involved different actors. That is, they brought together elite biomedical researchers, bioethicists, social scientists and economists, lawyers and venture capitalists, politicians and government employees, patient advocates and their families and supporters, and different publics.

My argument is that these public events were critical junction points for the formation of *biomedical counterpublics* (see Chapter V). In other words, the collective public events regarding Proposition 71 and human stem cell research are important sites for the provisional unification of different social worlds. The social worlds of biomedical research, governmental regulation, and patient activism to name a few a brought into physical proximity, and the discourses and concerns of each social world are represented there to the others. If successful, this provisional unification can serve as the foundation for more extensive health social movement elaboration, organization and mobilization. However, many difficulties may arise during the processes of representation that may slow down or arrest attempts to consolidate support. I next present the observational data from these events, and conclude with the victory of Prop 71 in November, 2004.

Logics of representation

I attended three lay conferences for this project. I define lay conferences as public meetings that cover an issue(s) or topic(s) from a variety of perspectives ranging from expert to lay positions. They differ from scientific conferences, which are generally organized around a discipline, sub-discipline, or field of study. In addition, scientific conferences are designed for scientific audiences and tend to center around issues and debates within the scientific field per se. Specialized languages are used to analyze topics of concern.

In terms of human stem cell research, scientists are also important actors at lay conferences. They are considered the experts on what is actually happening, since they are the ones doing the work at lay conferences, as opposed to scientific conferences, focus tends to be on issues and debates about science-and-society. They are designed to present a variety of perspectives, and thus specific technical languages are "translated" into commonly shared idioms in lay languages and examples. One important concept for this representational process of translation is the *metaphor*.

Scientists use metaphors in many different situations, both inside and outside of their formal scientific practices. Here is an example from a lay conference from my fieldnotes:

> The stem cell researcher begins his talk by identifying himself as a doctor, which, he says, means that he puts the well being of the patient first. He also mentions that he owns a company, and with a slight grin says, "that might make me biased." He always has what looks to be a smirk, so it is hard to tell what this comment means. He argues that transdifferentiation or dedifferentiation does not happen, and that while plasticity does happen, it is very complicated and most people get it wrong. He also argues that since humans have mitochondrial and nuclear DNA, SCNT produces chimeras, not clones. The results of animal reproductive cloning are generally bad; the success rate is extremely low. He argues that there are different types of NT, and that the Weldon/Brownback bills do not take this into account. He mentions Prop 71 at this point as a possible solution. Some of the problems it will overcome have to do with the Bush administration's restriction on new ESC lines. He argues that no current lines have any kind of genetic diseases. Having such lines would be a great help in studying the developmental biology of some diseases through ESC models. He claims that NT

> produces "embryoid" blastocysts that are not quite embryos, and that there is confusion about just what to call these entities. He says: "If you don't ban IVF, then you shouldn't ban NT." He then goes on to draw the historical comparison with recombinant DNA: this technology had a contentious history, but scientists got together, worked on it, and it turned out to be safe. He gives the Lysenko affair as a counter narrative to the rDNA story. In response to the Lysenko affair, he says: "Where did the science go forward? Where were scientists trained? And where were the medical and commercial benefits?" By this he is referring to the West generally, and the United States specifically. He concludes with a view of moral responsibility: those who ban research that could save lives are responsible for the death and /or suffering of the victims of the lethal disease.
>
> - Field notes 10/2/04

This is a dense and complex set of representations. This chunk of discourse contains multiple metaphors, allegories and claims to expertise. There is a moral argument: I am a doctor, which means my prime concern is to heal the patient. There is a political argument: Prop 71 is useful because it will help scientists develop more cell lines. There is an historical argument: the Lysenko affair and Asilomar offer two competing versions of what could happen to stem cell research in the United States.

The metaphors used here are helpful to scientists for making a case for stem cell research, namely to help ameliorate physiological problems. Attention to individual metaphors and their polyvalent meanings is an important area of inquiry. I argue that it is also important to examines metaphors within their contexts of use, such as lay conferences.

Lay conferences were framed through the discourses of human stem cell research as somehow associated with human health. How human stem cell research is actually associated with human health, and with what consequences, remained an open question. The mere existence of lay conferences contributed to the "frame amplification" (Snow et al. 1986) that linked human stem cell research and possible human health presents and futures.

The structural format of these conferences is important. In a one day event, perspectives from the bench, the courtroom, the ethics seminar and the political assembly were spliced together. This does not, of course, make lay conferences metaphorical. The important point here is that the proximity of different discourses – different ways of talking about human stem cell research – facilitated the traffic of splicing metaphors, and more importantly, aided the processes of "splicing" and "interfiliation" (Ratto 2006) of social worlds necessary for complex scientific enterprises.

Many splicing metaphors in Ratto's terms (2006) were used at these lay conferences. Here is a sampling of those used by scientists during the three conferences I attended. Stem cell scientists characterized human cells as being either "sick" or "healthy" in terms of a disease, such as ALS. Human stem cells were described as "raw material" or "blank slates" as well as being "social creatures" (meaning that hESCs tend to agglomerate together in tissue culture). Human ESCs in particular were portrayed as "fragile" and "prone to various problems." The hESC lines on the NIH registry were depicted as "old biology," in that they were not well characterized and not "diverse" enough, referring to the racial make-up of donors. Various tools and techniques were discussed, such as tissue culture, which was compared to a "carpet." Human ESCs were considered helpful for drug development, but pharmaceutical manufacturers were facing several "bottlenecks," which are impeding progress of the science, such as "making organs in a dish," or tissue engineering. However, hESCs still presented many challenges, because "they are being asked to do something that is difficult for them to do," namely differentiate into specialized daughter cells without becoming tumor-like tissue.

Scientists used these metaphors at lay conferences to accomplish multiple goals. First, they were used to explain objects of biomedical interest at several levels, including cellular biology (what is a human cell?), as well as stem cell biology and regenerative medicine in specific (what is a human *stem* cell? How is a stem cell a different kind of cell?). At the same time, these scientists were talking about pathology (what makes a cell sick?) and therapeutic possibilities (how can we make a cell healthy again?). Finally, these metaphors explain how human stem cells can be turned into curative realities (how are drugs created? How would a stem-cell based therapeutic be mass produced?).

In his paper, Ratto (2006) looked at how single metaphors do the work of "leveraging" scientific claims for large-scale scientific organizational needs. Here, rather than focusing on singular metaphors, I want to emphasize the ways in which numerous, different metaphors work together to produce an overall coherent framing of a biomedical enterprise. That is, the multiple metaphors used at lay conferences worked together to construct distinctive *logics of representation*. These logics of representation are both internal to regenerative medicine per se; they are necessary in order for regenerative medicine to move forward as an enterprise in wider domains. Given the myriad controversies that lace the fields of regenerative medicine, logics of representation are critical political technologies for organizing and deploying splicing metaphors. These logics circulate through and animate the framing strategies that represent regenerative medicine, and are not confined to any one site. Like metaphors, it is important that they can be transposed and translated in different locations.

I next focus on three logics of representation at work during the Prop 71 campaign:

1. Human stem cells as *productive entities*. This logic is connected to the pluripotent aspect of stem cells - their ability to differentiated into different kinds of human cells.
2. Stem cell biology as *stretching from bench to bedside*. This logic is connected to the concept of translational medicine (an attempt to integrate researchers into both experimental and clinical worlds of biomedicine). In terms of formal training, M.D./Ph.D. programs would be considered creating translational researchers..
3. Regenerative medicine as *a new kind of biomedicine*. This logic is connected to the wider institutional bases of contemporary biomedicine.

1.) Pluripotentcy: representations of production

The public events I attended prior to the November 2004 presented as given that human stem cells (of all varieties) are a different kind of human cell due to the special qualities of pluripotentcy and immortality (see Chapter II for an explication of these terms). From molecular biological perspectives, these qualities serve technical purposes: they allow systematic classification and identification of stem cells as unique biological entities in the world. From lay perspectives, however, these qualities have different meanings above and beyond structures of technical classification. They indicate that stem cells, at a base level, are something new and possibly important in the treatment of illnesses.

For example, at the conference at the Salk Institute (October 2, 2004), the day's first scientific speaker, a well-respected stem cell researcher, began his Power Point presentation by offering a "foundation and framework" of stem cell biology that he hoped would serve to frame discussions about the science for the remainder of the day. He

started by stating that cells in the human body are "specialized like small businesses." They each do something important and, while self-contained entities, they are also connected to each other in myriad ways. Human diseases are caused by breakdowns in these small businesses, and face different fates. One is that the cells simply die. Other cells remain alive, but are damaged in various ways, compromising their functionality. He then talked about the status of knowledge about different human diseases which currently face several "bottlenecks." These include a lack of sources for human cells and tissues, the difficult and often unsuccessful nature of human clinical trials, incomplete or mistaken views of disease causation, and individual and group differences in terms of responses to therapeutic interventions. He then turned to human stem cells. He described these cells as being able to divide into more stem cells, as well as being able to take on special roles. Stem cells, he claimed, could be the "raw material" for different cell therapies.

At the San Francisco conference (October 12), the initial scientist to speak is also a well-respected bench researcher. He also starts with Power Point slides, and begins by pointing out that human stem cells have two important capabilities: the capacity for self-renewal and "inducible fates" – or that they can be turned into different kinds of cells. He then describes two different types of human stem cells, adult and embryonic. He mentions that these two stem cell types are not identical, and that hASCs lack some of the capabilities of hESCs. He also expresses dissatisfaction with the term "therapeutic cloning," and says that the better term is "SCNT," since there is no process of fertilization, and no mixing of maternal and paternal DNA. He mentions several "promises" of this research, including improvements in understanding of early human

development (with benefits for infertility and preventing birth defects), processes of cell division (with benefits for cancer research), and cell-based therapies (including treatments for Parkinson's disease, spinal cord injuries and osteoporosis).

Staff members from the Yes on 71 campaign repeated these statements about the productive potentials of human stem cell research. At the campaign debate at Stanford University (October 18), Marcus, a Yes on 71 staff member, began his position statement with the claim that stem cells are "undifferentiated cells in the human body that are capable of regenerating and also differentiating into any kind of part of the body that makes up the body." At the debate at Foothill College (October 4), another Yes on 71 staffer, Edgar, referred to the work of a stem cell researcher on spinal cord injuries. Edgar stated that this scientist "has been able to prove within rat models that if you inject ESC into the spine of a rat that has suffered a severe injury, that within 90 days those formerly crippled rats are running around their cages. The videos are there to prove it." The reference to videos is especially interesting. Edgar is referring to digital movies, made by researchers and their teams, depicting model organisms before and after treatments, usually involving human stem cells. These videos were shown at all the lay conferences I attended.

Human stem cells were continually presented as possessing special qualities. While there remains uncertainty and debate *within* scientific communities over the nature and scope of these qualities, stem cells' public lives were deeply infused with metaphors of controlled production and pluripotentcy. Stem cells could become "any kind of part of the body." Opponents of Prop 71 never attempted to undermine this logic of representation. For example, at a community meeting in Northern California, an

opponent of Prop 71 described undifferentiated hESCs as, "not having their job description yet," and that they can be "given a job description," or differentiated into different cells types through experimental interventions. Of course, she remarked, the major problem is that these differentiated hESCs are never pure cultures, and have spontaneously formed tumors, so hASCs are a better choice *for technical reasons*[11]. Interestingly, even though she is opposed to hESC research, she borrows from the logic of representation in order to make her argument for hASC research. Prop 71 opponents also tapped into this logic by downplaying their opposition to "stem cell research" in general, which they often publicly stated their support for, and focusing their critiques on the "bad public policy" of Prop 71, or the potential effects of the initiative, such as harm to women who would donate gametes for research. In short, Yes on 71 supporters could also deploy this logic of representation without contestation.

2.) Clinicality: stem cells and human health.

Given that human stem cells could be differentiated into other types of cells, it becomes a very short metaphorical step from the bench to the clinic. At the public events leading up to the election, scientists continually presented their research *in terms of the benefits it offers in addressing specific diseases*, and not as general advances in molecular or cellular biology. This framing helped lay publics to make the connections between bench science and clinical research quite directly. I refer to this framing as *clinicality*: the purposes and functions of work in one domain (bench science) are made recognizable

[11] The difficulty for this position is that getting hASCs to become another cell type (de-differentiation and trans-differentiation) is, at the current moment, an intense scientific debate, not a settled consensus or agreement.

through elucidating their applications in a second domain (clinical settings). Bench research (among other work) is explained and legitimized by the therapeutic objects that may appear as a result of that prior work. For example, at the September 15, 2004 public hearing about Prop 71, Dr. Evan Snyder, testifying as a scientist about stem cell biology, and about Prop 71 as a "win-win situation," stated: "From a scientist's point of view, obviously, we want to cure. We want to decrease the health care burdens." Snyder, trained as an M.D./Ph.D in neuroscience at Penn and Harvard, and a firm believer in translational medicine, most likely means "scientists (who are also clinicians)…want to cure" (2004:22). He is referring to the desire to cure diseases and/or improve patients' conditions that helps to animate clinical practices. Snyder's ability as a spokesperson to move between experimental and clinical worlds of discourses amplifies the clinicality of human stem cell research.[12]

Clinicality was represented in several ways. First, stem cells could be differentiated into specific kinds of daughter cells that could then be transplanted into patients with diseases or conditions that involve damage to one type of cell. A common example was Parkinson's disease (PD), which is caused by the death of striatal neurons in the human brain (see Chapter II). One common set of steps laid out clinically was that a cell could be taken from an individual with PD, and the nucleus of this cell be taken out and placed in an enucleated oocyte to begin the process of SCNT. ESCs could be harvested from the blastocyst that formed from this SCNT that could then be differentiated into striatal neurons for transplant. Second, human stem cells could be used as clinical research tools, either to track the development of diseases over time *in*

[12] M.D./Ph.D.s are especially important "carriers" of clinicality. Two leading M.D./Ph.D.s on the Yes on 71 campaign were Snyder (Ph.D. in neuroscience) and Irving Weissman (developmental biology).

vitro, and/or serve as high-throughput screening assays for various molecules and compounds.

Yes on 71 staff helped circulate this logic of representation. At the Foothill college debate (October 4, 2004), Edgar began by claiming that, "stem cell research has the opportunity to impact over 70 chronic diseases and conditions that are currently effecting over 128 million Americans." He then went on to state that, "over half of California families are afflicted by just 5 of over 70 diseases impacted [by stem cell research]: Parkinson's Alzheimer's, diabetes, cancer and heart disease. Prop 71 offers these and future generations the hope of a cure." As I will argue in Chapter V, these appeals to "hope" are always interpreted and framed by individuals against a larger background of expectations and negotiations. "Hope" is never mechanically or unreflectively embraced by actors. In this case, hope is an important rhetorical device for expanding clinicality. The rhetoric of hope provides a lens for imagining the connections between the experimental sciences and clinical applications, even when this link is tenuous and/or distant in time. For example, Marcus argued that in human stem cell research, "there are no promises, no guarantees in this work, but that doesn't mean we shouldn't do it." Here, hope operates as a rhetorical counterweight to the uncertainty of biomedical research.

3.) Development: novelty and speculation

Before and during the Prop 71 campaign, human stem cell research and regenerative medicine were often portrayed as an "uncharted frontier" or conversely, as a "brave new world" (on the potency of these metaphors in the USA, seeNye 1994; 2003) Actors from different social worlds often repeated the notion that regenerative medicine

represented a break with past forms of treatment. For example, at the Stanford debate (October 18, 2004), Marcus stated: "This [regenerative medicine] is a paradigm shift for medicine…regenerative medicine is a new concept. Traditionally, our medical model treats disease symptoms, perhaps the disease itself, but it's really ultimately a maintenance strategy for chronic disease." He then went on to talk about diabetes as an example of a disease that could change from advances in regenerative medicine. He made the distinction between taking insulin (old medicine) and creating new islet cells (new, regenerative medicine). At a subsequent lay conference at a major California university, a stem cell scientist described stem cell research as a "paradigm shift," that is shifting the parameters of medical research: "If DNA was the exciting discovery in the first 50 years of the 20th century, this [stem cells] was the most exciting realization in the second half of the 20th century, and that we were going to combat disease not by stopping disease, but by recapitulating development." While transplantation of engineered tissues and cells would carry with it a different set of complications, likely requiring a level of maintenance similar to insulin injections and blood sugar monitoring, regenerative medicine is presented as a better alternative or major advance over the current standard of care for diabetes.

Opponents of Prop 71 also spoke about the changes being wrought to medicine, albeit in pessimistic tones. For example, one outspoken critic of Prop 71 referred to the "biotech agenda" that is slouching towards Gomorrah. The biotech agenda is a product of both the rapid technological advances appearing in biomedical research, and the concomitant deformations these advances are making on our collective morality:

> And we lost the sort of Judeo-Christian ethic where we now look to science and technology to solve problems. So whether you ascribe to any kind of theological or

> religious answer – before perhaps fifty years ago people sort of defaulted to a religious ethic. It doesn't mean that everybody went to church on Sunday morning, it doesn't mean that everybody was of the same flavor of religion but there was a sense that society would listen to moral religious leaders. We'd sort of get our bearings. And we've gone away from that.
>
> -Interview 7/12/05

Here, the Prop 71 critic is articulating a dissatisfaction similar to Eric Cohen's (2006) lament for capitalism in his editorial entitled *Biotechnology and the Spirit of Capitalism*. Cohen is a fellow at the Ethics and Public Policy Center in Washington, DC (a conservative think tank) and leading conservative critic of biotechnology. Although Cohen's (2006:22) interpretation of Weber's work (from which he draws his title) is muddled[13], he is clear about the outcomes: "And this, I think, is what we should most fear about biotechnology's transformation of modern capitalism: that in the desire for worldly salvation – salvation of the flesh – we will profane the sacred, with the modern marketplace greasing the skids. We will come to believe that bio-capitalism can sell us everything that we desire, and thus come to accept that everything is for sale." Much like the Prop 71 opponent sees biotechnology leading to the loss of a "Judeo-Christian ethic," Cohen sees biotechnology hijacking capitalism in order to commodify bodies and embryos. Rather than seeing experimental advances in "recapitulating development," No on 71 organizers shared a belief that these experiments would lead to human cloning and exploitation. This anxiety or uneasiness about biotechnology is shared by many

[13] Cohen misinterprets Protestantism (as Weber talked about the religion) as a "God-seeking enterprise." Calvinism in particular posited that individuals were either saved or damned at birth (doctrine of predestination), and that there could be no intercession by Jesus or the Holy Spirit (which is characteristic of Roman Catholicism). In other words, Calvinists were not seeking God, but were rather looking for signs of salvation. In addition, Weber stressed that the early Protestant leaders were not supporters of capitalism, and the "spirit of capitalism" emerged as an unintended outcome of Protestant "this-worldly asceticism." Cohen turns Weber's argument upside-down when he states: "Through Protestantism, commerce was made a realm of 'grace'" It is more correct to say that the modern idea of the vocation or work ethic is a secularized relic of Luther's conception of the calling. To quote Weber: "The Puritan wanted to work in a calling; we are forced to do so" Thus Cohen profoundly misunderstands Weber's attempt to uncover the elective affinities between religious and economic forms of social organization.

individuals across many different social worlds. The paradox of this response is that it is symptomatic of the changes being wrought by biotechnology.

In this sense, both supporters and opponents of Prop 71 agree that regenerative medicine and biotechnology are new social forms, or are at least connected to novel effects in existing institutions. During the campaign, Yes on 71 staff and supporters continually reiterated the prognostications of the Baker/Deal report, and referred to Prop 71 as a net economic gain for the state. Opponents' moral framing of Prop 71 as leading to dystopian futures drew upon the logic of representation that Prop 71 in particular, and biotechnology in general, was a mode of development that could not be stopped.

I have referred to the three rhetorical ensembles of pluripotentcy, clinicality, and development as logics of representation. While they are similar to collective action frames, I distinguish them from this concept for several reasons. First, they exist prior to the construction of a particular frame. Second, they emerge from sources outside of the focal movement itself. Third, they are shared and reproduced by the social worlds engaged in both episodes of controversy and in moments of relative agreement, and are "owned" by no exclusive group or position. In other words, they constitute the ground upon which both agreement and conflict are enacted, contested and temporarily settled. Finally, they are enduring, and their efficacy is not diminished by individual political battles. Logics of representation do change, but their transformations are not caused by political fights, such as campaigns or elections. Rather, I am arguing the reverse; political events crystallize logics of representation into recognizable social forms.

While my criteria may sound similar to the definition of collective action frames and framing processes, I want to highlight the ways that logics of representation allow for

social movement participation that are oblique to shared cognitive or signifactory processes. For example, Benford and Snow (1992:136-7) define framing as "an active processual phenomenon that implies agency and contention at the level of reality construction…It entails agency in the sense that what is evolving is the work of SMOs or movement activists." The authors define collective action frames as "action-oriented sets of beliefs and meanings that inspire and legitimate the activities and campaigns of a social movement organization" (1992:137-38). These definitions of framing help us to understand how the Yes on 71 campaign elicited support from a variety of civil society organizations, such as patient advocacy groups. But it does not adequately reveal the dynamics of participation by scientists in the campaign. That is, when scientists presented their data, explained their tools and techniques, and drew conclusions about human stem cell research to different publics, they were not doing so solely as movement activists. On the one hand, they were relatively immune from the turbulent worlds of electoral politics. In other words, if Prop 71 were to fail, it would not mean the absolute end of human stem cell research or their own scientific careers. On the other hand, this is not to say that the scientists who were actively involved with the Yes on 71 campaign were disinterested experts or impartial advisors. As I have shown, the opposite is true: bench researchers were deeply involved in the politics of human stem cell research before Prop 71, as well as being intimately involved at every stage of the initiative's lifespan from proposition development to law.

I am arguing that logics of representation provide an analytic tool to examine how different social worlds may provisionally overlap rhetorically during delimited events. In other words, these logics do not spontaneously bring individuals and groups together.

They must be actively brought together. Here, the importance of the political event becomes apparent. Precisely because of the relatively short time span of an initiative campaign, the logics of representation of human stem cell research rapidly germinated and flowered.

Conclusions

On November 2, 2004, Proposition 71 became California law by garnering 59% of the popular vote. Its victory has subsequently become a milestone in the human stem cell struggles in the United States. In this chapter, I placed Prop 71 into an economic context in terms of the increased amount of biomedical funding that has been directed towards California, as well as the policy context, which has also been supportive of human stem cell research. These two factors, along with the historical use of the citizen initiative process in the state of California to advance controversial political projects were conducive for moving forward the human stem cell research enterprise.

Animating these conditions was a group of actors who organized and financed the early stages of what was to become Prop 71. Here, I focused upon the public face of Prop 71 and human stem cell research. This included scientists, as the producers of knowledge, at the heart of the Yes on 71 campaign. However, scientists were never subsumed completely within the Yes on 71 organization. While they were key actors in all stages of the proposition, and spoke publicly in support of it, I argue that they should not be considered "social movement entrepreneurs" (Johnston and Noakes 2005), or as acting solely on behalf of a social movement. Rather, they worked along side the Yes on 71 campaign, advancing the movement through participation, at the same time as

maintaining a complicated distance from the formal politics of the campaign. This distance was filled by logics of representation while scientists appeared as the legitimate producers of knowledge about human stem cell research. Through the logics of representation described in this chapter, stem cell scientists were able to *simultaneously* make scientific and political claims.

This is a complicated position, because I am arguing that neither the scientific nor the political aspects of the claims made on behalf of Prop 71 reduce to each other. That is, the stem cell scientists were neither disguising a political agenda behind technical discourse, nor were they simple stating facts as disinterested advisors for a political organization. Instead, the stem cell researchers working on behalf of Prop 71 were deploying logics of representation that have become a central plank in the public struggles over controversial sciences. Representation is intervention (Hacking 1983), or as they say in Chicago elections, "vote early and often."

As I argued in the previous chapter, drawing from the work of Adele Clarke (1998:236), the biomedical sciences have had to engage in a series of marketing strategies that, while requisite for their survival, were also one cause of the general decline in the autonomy of science over the 20th century. Stem cell scientists' participation along side other Yes on 71 campaigners was one way that scientists have responded to the changing economic, political, and academic contexts in which they find themselves (I explicate this position in greater detail in Chapter VI.) That is, much like the patient activists described in Chapter V, stem cell researchers are not simply opportunistic entrepreneurs, but rather engaged with and responding to complex

institutional transformations. Thus, like patient activists, they have multiple interests and commitments at stake.

Chapter V: From Sickness to Politics: The Making of Stem Cell Activists

This chapter is an analysis of a kind of activism during the Prop 71 campaign that I am calling *stem cell activism*. I define stem cell activism as the forms and practices of political work in support or opposition to human stem cell research (hESC research and NT in particular). These forms of activism are in part legacies of several older social movements, such as the varieties of patient activism like HIV/AIDS and disability movements, as well as specific therapeutic-based movements like the use of fetal tissue as a possible therapeutic agent for neurodegenerative disease. As I will highlight, stem cell activism both has continuities with older social movements, as well as important differences.

I anchor my analyses of stem cell activism during the Prop 71 campaign in social movement theory, a wide and deep theoretical and substantive domain (this is elaborated in Chapter III). In order to focus my analyses, I concentrate on the formation of *political identities*. I will argue that in order to answer the question 'Through what processes and mechanisms are individuals mobilized to take part in HSM activities?', attention must be paid to the functions and effects of political identities in fomenting and sustaining political activity. This is salient in modern, liberal democracies, and prominent in political claims within the United States in particular. That is, the United States has a history of social action that has come to be known as *identity politics*. The term identity politics has many meanings, and it is not my intention to catalog these debates (for recent

reviews of this vast field, see Guttman 2003; Kenny 2004; Lloyd 2005). For example, one set of meanings positions identity politics as "balkanizing," leading to social relationships based on pure exteriority. In other words, some ultimate principle, such as phenotype or group experience, is hypostasized as the transcendental point from which a focal identity emerges. Any individual who does not possess this principle is categorically excluded from the very possibility of constructing an identity under within the recognized category. I reject this model as too simplistic – political identities are never formed around unitary principles or poles. In pluralistic societies, political identities are always *overdetermined* – that is, the results of processes of identity construction (an "identity") cannot be reduced to a single pathway or vector (for a good analysis of this term, see Swanson 2005, pp. 95-97). However, overdetermination does not mean that political identities are arbitrary or purely imaginary. On the contrary, these identities can only be understood in relation to existing social conditions, and are always deeply material.

Social movement scholars have long been interested in such questions. A major concept that has emerged from this literature is *collective identity*. Polletta and Jasper (2001:285) define a collective identity as, "an individual's cognitive, moral and emotional connection with a broader community, category, practice or institution. It is a perception of a shared status or relation, which may be imagined rather than experienced directly, and it is distinct from personal identities, although it may form part of a personal identity." This is a good definition to start with, and I use the concept of collective identity in order to uncover the social relationships that make talk about political identities possible. In other words, I am less concerned with the question "What is an

identity?" in an ontological sense, and more interested in "Under what conditions is something called an 'identity' possible, how does it emerge, and what work does it do?" Here, it becomes important to think about the social processes that evoke and produce identities in specific situations – the most proximate being health social movements (HSMs). In the words of Barbot and Dodier (2002), this section is an elaboration of the "pragmatics of information gathering" that predicate the construction of collective identities.

Why is it helpful to analyze stem cell activism on behalf of the Yes on 71 campaign through the concept of collective identity? In this chapter, I operate under the following three central assumptions:

1. Having a particular disease or condition has become a locus of social organization. This is captured by concepts like biosociality (Rabinow 1992b) and technoscientific identities (Clarke et al. 2003). For stem cell activists in support of Prop 71, becoming active meant not only understanding one's disease or condition, but also understanding that disease or condition in relation to other diseases or conditions that could be ameliorated by stem cell research. This has been explicated in Chapter III.
2. The extant structures of stem cell politics implicates patients as public actors. As Chapter II pointed out, debates over human embryonic stem cell research stretch back to the 1970s, and operate at different institutional levels, including the national- and state-level bureaucracies, as well as civil society (especially in HSMs). This distributed set of struggles and sites of contestation have created a

fertile but tangled field of organizational forms and types of social action. These conditions produce and constrain the situations (Clarke 2005) that stem cell activists find themselves caught within.

3. The question of interests in on the table. Individuals, groups or classes do not possess "objective interests" as has been claimed by certain theoretical perspectives, and was also reiterated during the 2004 Prop 71 campaign. One could argue that the Yes on 71 activists had an "interest" in seeing 71 pass – the development of possible cures. Yet the activists understood they would likely not be direct beneficiaries of any therapeutics that might come out of the CIRM. Interests, rather than being static and given, are processual and emergent.

Individual patient activists come to see themselves as beneficiaries of stem cell research because, on one level, they have been told that the research is promising. However, becoming a stem cell activist is not simply taking scientific or medical pronouncements at face value. In other words, stem cell research is not an "objective" interest that is immediately recognizable to a specific subject. Rather, becoming a stem cell activist means synchronizing the beliefs and practices of patient advocacy with the discourses of stem cell research. This synchrony is done by an individual actor, but it is always a collective project.

One of the major difficulties confronting this project is categorizing actors as stem cell activists per se. That is, what constitutes this as an extant identity category? For example, different categories of embodiment are classified via phenotypical elements that serve as a simple proxy for inclusion or exclusion in a specific category. What is difficult

in thinking about the category of stem cell activist through the frame of identity is that the individuals within this category are deeply heterogeneous across different variables, such as class, race, gender, education, nature and extent of illness or condition, etc. I argue that rather than sharing any unified ideologies or values commonly associated with conventional identity politics categories, a stem cell activist identity must be constructed by working through the difficulties of supporting a novel and controversial technology-in-the-making. In other words, there is no stem cell activist *subculture* organized around "living with" Parkinson's disease or Type I diabetes for example, but rather diverse and heterogeneous *practices* that individuals and groups provisionally share.[14] In order to bound these practices analytically, I develop the concept of *biomedical counterpublics* to capture the arrays of practices that activists develop and deploy to support controversial biomedical research.[15] Biomedical counterpublics can be thought of the identities, as well as the social spaces and technologies of public representation that are necessary to produce legitimate and enduring claims across social worlds. These forms of involvement (Barbot 2006) with biomedical institutions are important to think about, not only for substantive questions regarding the social organization of stem cell activism, but also for thinking about HSMs in general.

In order to foreground questions of "politicized collective illness identities" (Brown et al. 2004), I will begin by outlining the structures of public stem cell activism in the United States under the subsection entitled, "Stem cell activism as a public issue."

[14] This issue has been raised in the investigations of other diffuse or distributed networks of actors, such as drug users. For a good review of the strengths and weaknesses of subcultural models of social groups, see Moore .

[15] It is critical to observe that stem cell activists also engage in and benefit from hegemonic relations, thus calling into question the "counter-" aspect of their publicity. I thank Charis Thompson for pointing this out.

This is a synchronic analysis in that I present a static picture of the organizational forms of this kind of activism. I will start from the top down, and look at the public forms of stem cell activism – that is, stem cell activism in civil society. This will include an emphasis on coalitions. The coalition form is important for biomedical politics in terms of constructing collective identities, as I will make clear. This chapter complements Chapter II, which examined stem cell activism within the state. This division of state/civil society does not imply a relationship of pure difference between the state and civil society. HSMs in general, and stem cell activism in particular, operates across this distinction, and facilitates movement by actors into state bureaucracies, as well as the dispersion of bureaucratic logics and rhetorics into the variegated worlds of civil society. HSMs and stem cell activists are crucial actors for in the flows of knowledge that interlace the worlds of biomedicine. Second, I will present interview data on how on small sample of patient activists became enrolled in the Prop 71 campaign. These individuals became stem cell activists through several different pathways, but given the public nature of stem cell controversies, they also share important commonalities.

Stem cell activism as a public issue

"Stem cell activism," or the forms and practices of political work in support or opposition to stem cell research (and hESC research and NT experiments in particular), is a relatively recent phenomenon. In this section, I lay out a snapshot of North American stem cell activism in civil society from the "top down." I begin with science movements, which are organized groups and/or coalitions of actors who push for pro-science agendas. A critical component of these movements are patient advocacy groups (PAGs) organized

around a focal disease or condition. This is one level down from coalitional forms of national and global science activism. Finally, PAGs are made up of individuals with diseases or conditions, and their supporters, care givers, and affiliated actors. By describing the activism in this form, I do not mean to imply that direction or resources flow from the top down. The flows of knowledge are multidirectional, vertical and horizontal. This overall structure is a *decentered ensemble* of actors that the Yes on 71 campaign was able to work with in order to achieve success in California.

There are two central points that delimit stem call activism from other forms of health activism currently on the scene as described in Chapter III. *The first, and most important, is that the therapeutic object itself, the hESC, is a deeply controversial object.* This is different from other forms of disease activism. For example, while AIDS activists had to confront many barriers in their work, drug therapies (such as AZT), while potentially harmful, were not considered controversial in themselves. That is, while the controversies around AZT were focused on its toxicity, these controversies were inflected through discourses of inequality and justice (for example, see Gamson 1989; Treichler 1991 for early takes on these issues). AZT, while later discredited, was neither derived from controversial sources, nor was the molecule itself accorded any special significance. By contrast, the hESC is extremely significant. Since it is currently derived from human embryos or embryo-like precursors that are destroyed in the process of collecting hESCs, many actors have uneasy feelings, ranging from mild concern to effusive outrage, some seeing the process as similar to abortion as the wrongful taking of life. In addition, many non-religious actors also express discomfort regarding human embryo experimentation. Given this wide array of in types of opposition, hESCs cannot be constructed as mere

research tools or possible therapeutics by supporters. It is their very existence that is the source of controversy; thus for some actors, this precludes any work being done with them.

The second point is that stem cell activism is affiliated with field of research that is currently in formation. This is significant for activists who appeal to science for their arguments and credibility. Unlike AIDS activism, which was located around relatively older and well-established sciences like immunology, epidemiology and pharmacology, stem cell activism is located around an emerging and still very fluid and unstable field of stem cell research. Today it is really a collection of quasi-disciplines, emergent technological approaches and institutions that lack an overall form. "Stem cell research" thus appears in public in forms like new professional organizations (the ISSCR being one), conferences, and seminars or public hearings (see also Chapters II and IV for more on the public lives of stem cell research). This state of the research provides opening for non-scientific actors, and facilitates the flows of knowledges that animate stem cell politics.

Science movements and stem cells: The AAAS and CAMR

Science movements, in the sense used here, have both older and newer forms in the terrains of contemporary biopolitics. By science movement, I am referring to organized groups and/or coalitions of actors who push for a pro-science agenda. A pro-science agenda is comprised of multiple concerns, including increasing government funding for scientific research, relaxing regulatory oversight on scientists or their work, and/or increasing public visibility of scientific endeavors and concerns. Several of these

groups are currently active in the United States. There are organizations, such as the American Association for the Advancement of Science (AAAS) founded in 1848, that seek to influence federal science policy. The AAAS has also weighed in on the stem cell issue (Teich 2002). In November 1999, the AAAS, in conjunction with the Institute for Civil Society, released a report entitled *Stem Cell Research and Applications: Monitoring the Frontiers of Biomedical Research*. The report begins by summarizing the findings and recommendations of the committee. There are fourteen claims made, which range from the vague to the seemingly obvious: "This research raises ethical and policy concerns, but these are not unique to stem cell research" (1999:iv), to specific calls for federal funding of human stem cell research, and equitable access of the research, and relatively open intellectual property structures around the technology (1999iv-xi). Overall, the report recommended that all forms of human stem cell research should move forward with funding because the science is fundamentally sound. The report sanctioned the earlier distinction made between "derivation" and "use" of hESCs (see Chapter II), and recommended that no public funding go to the derivation, and the derivation of hESC from "spare embryos" from IVF procedures was the "most ethical source of human primordial stem cells" (1999:viii).

At different points, the report attempts to fit human stem cell research into pre-existing regulatory structures: "Existing policies cover all aspects of [human stem cell] research, from the use of cell lines in laboratories, to human subjects protections, that will surface in the consideration of stem cell research;" and, "At present, stem cell research raises no unique ethical or policy issues" (1999:v-ix). This is an important rhetorical move for several reasons. First, it positions the federal government as a critical actor in

the field of stem cell research. It is important to remember that the AAAS report was cumulated and written at the end of the Clinton administration, which was enjoying fairly high approval ratings at the beginning of 1999. It is an open question what the report would look like if it were written under different political conditions. Second, this move positions human stem cell research as no different than advances in other areas of biomedical research. This deemphasizes the novelty of human stem cell research. However, this is paradoxical, in that the report also states that, "The current excitement over potential stem cell therapies emanates from new understandings of genetics and developmental biology" (1999:1). Human stem cell research is both new and not new. Finally, this rhetoric ratifies existing oversight laws and agencies, including the Federal Common Rule (commonly referred to as "45 CFR 46," or Code of Federal Regulations), which outlines human subjects protection, and the Food and Drug Adminstration (FDA), and the National Bioethics Advisory Commission (NBAC). This "governance by citation" is common in human stem cell discourse. That is, regulatory bodies charged with oversight of human stem cell research have difficulty fitting human stem cells into their pre-existing classification systems (see Chapter II). In order to account for this slippage, and without recourse to either change existing laws or creating completely new institutions, agencies cite each other's reports and writings in order to govern by deferring governance. In the human stem cell field, agencies wait for others to issue reports, which are then cited as the existence of some kind of regulation or authoritative statement. In the end, no one branch of government, agency, or institution has total jurisdiction over the regulation of human stem cell research.

Another important pro-science group in the stem cell debates is the Coalition for the Advancement of Medical Research (CAMR). CAMR emerged in 2001 out of the ashes of an earlier coalition known as Patient's Coalition for Urgent Research (Patient's CURe). Patient's CURe formed in 1999 to lobby Congress to support human stem cell research, using patient's narratives as a primary tool to convince politicians to support the research, or at least oppose legislation that would place restrictions on the research (Bonnicksen 2002:87). Patient's CURe was comprised of "three dozen national non-profit patient organizations," and had two central goals: expediting public funding of human stem cell research through the NIH, and transparency in public oversight and accountability (Perry 2000). After Patient's CURe's dissolution, several former members of that coalition formed CAMR, which has taken an active role in lobbying for ESC research as well as therapeutic (as opposed to reproductive) cloning. Coalition politics are not new to the social movement scene. William Gamson (1990) pointed out their significance over fifteen years ago. Recently, Nella Van Dyke (2003) argued that external threats are important mobilizing conditions for coalition formation. In this case, the threat of federal legislation banning or severely restricting hESC research was the impetus for CAMR's formation.

CAMR's website is both informational/educational and pro-activism. It lists a series of editorials and articles about hESCs from different media sources. It also offers a link to a proprietary letter-writing engine, which has a sample letter that can be automatically faxed to the U.S. Congress via the website. There is a link to a page identifying local media outlets, such as newspapers, TV, radio stations, online services, magazines and political publications. After a zip code is entered in the appropriate field,

the user is directed to a page that will generate a sample letter to the editor. The letter can then be sent to up to five different media outlets. This engine is owned by a company called Capitol Advantage. Thus, through electronic means, CAMR and its associates, vendors, and subcontractors facilitate the expansion of the number of circulated statements regarding hESC research.

An activist involved with CAMR, Stephanie, described their organizing efforts to me. She spoke about how CAMR attempts to produce a unified message:

> So, as a coalition, we were able to get the message out, not to just our membership, but the memberships of everyone involved. So CAMR for instance is developing a set of talking points, that could then be passed along to every CAMR member and CAMR's database of advocates, who we've collected over the years, that could then also be sent out to…Christopher Reeve for Paralysis Foundation could send it out to their advocacy network. Juvenile Diabetes Research Foundation could send it out to their members. Parkinson's Action Network…So you're getting this consistent voice with a consistent message of why it is that this is important and why it is that we all need to weigh in. So it's extremely complimentary to have a coalition advocating on behalf of science, all having the same message and advancing the potential to the best of our abilities
>
> Interview 5/23/03

CAMR's work thus produces two important effects: amplification of the same message through repetition, and ramification of that message into the smallest corners of civic life. The first is accomplished, as we have seen above, through new electronic formats, but also through the structuring of specific arguments. The second happens through reaching out to the ever-expanding number of PAGs, including the smaller orphan disease groups.

The first effect has been termed *frame amplification* (Snow et al. 1986). Frame amplification is an important step in the process of *frame alignment*. Frame alignment is a concept that captures the various processes of *micromobilization*, "the interactive and communicative processes" (1986:464) by which individual frames about an issue get synched with the frames that a SMO is constructing and deploying. The result of

successful frame alignment is the production of a *collective action frame*, or a shared interpretation of a situation by the different participants, audiences or stakeholders collective involved in the situation. Looking at how a frame is constructed, how it is interpreted and used, how it does or does not work, has become a well-established wing in social movement theorizing (for a recent summarization of the field, see Johnston and Noakes 2005).

Frame amplification has two elements: *value amplification*, which elevates some core value from the background to organizing prominence; and *belief amplification*, which foregrounds some belief about the social world. Both elements draw off of the stock of tropes, metaphors, narratives and objects that are already present in focal social worlds. That is, amplification works through resonance, or connecting the meanings of a collective action frame with older, extant meanings that animate the different social worlds. This is a difficult process for several reasons. First, social worlds are structured by "universes of discourse," (Clarke 1990b; Clarke 2005; Mead 1972; Strauss 1978) and thus, by definition, are structured through different symbolic systems. This does not automatically rule out overlapping discourses and points of connection between social worlds. But it does mean that resonance across social worlds or sub-worlds is quite difficult, and thus, extremely important. Second, entrepreneurs are one of the core constituencies of any social world (Clarke 2005). It is critical that these entrepreneurs accept the terms of the collective action frame. If they do not, it can cause problems such as rejection of the movement, or perhaps the segmentation of the social world (Strauss 1984). In either case, the outcome is not helpful for the movement, which is at the minimum seeking more supporters for its cause. Finally, some frames are deeply

controversial in themselves. For example, framing a movement around support for "human reproductive cloning" is currently very difficult. Many different and powerful social worlds oppose this kind of cloning. However, cloning, defined as an experimental process that produces identical copies of an object (such as molecules, software programs or model organisms) is a common and vital research technique. In the arena of human stem cell research, the word cloning has undergone several waves of differentiation. There are "reproductive," "therapeutic," and "research" forms of cloning. There is "somatic cell nuclear transfer" (SCNT) and its shorter cousin "nuclear transfer" (NT). Prop 71 mentions only "reproductive cloning," which it prohibits (see Chapter IV).

As I stated, amplification works with pre-existing tropes, metaphors, narratives and objects in order to resonate across social worlds. During the course of recent hESC controversies, the value that CAMR has amplified is the importance of scientific research. This is articulated through the understandings of hESCs versus human adult stem cells (hASCs). Some groups opposed to hESC research attempt to drive a wedge between hASCs and hESCs, claiming that hASCs offer better hope for therapeutics, or are morally preferable experimental objects. CAMR, on the other hand, supports both hASC and hESC research by seeing both as part of the same continuum:

> The reason why you're hearing so much more lately about new discoveries in adult stem cells is because of what we're learning from embryonic stem cells, and they're actually transferring that knowledge…We'll actually have more breakthroughs in embryonics by looking at the pre-embryonic state. Well, if you learn how to turn them on and off from a pre-embryonic state, you can apply that to embryonic, you can apply that to umbilical cord, you can apply that to adult. All the advances, the knowledge can be transferred. And it's only going to help everything to move forward faster and smarter by obtaining as much knowledge
>
> Interview 5/23/03

Stephanie locates hESCs within an ever-expanding stock of knowledge over cellular life, and emphasizes the importance of translatability across objects for regenerative medicine. This sets up a relation of equivalency between these objects of research. Thus, hASCs and hESCs are equally important for biomedical science, and the forfeiture of one ultimately impedes research on the other.

Belief amplification is the second aspect of frame amplification. The belief that follows from the value of unencumbered research is the assertion that hESCs represent the beginning of a new paradigm of medicine:

> We think these are the early steps to new treatments. I would say the way that we understand pharmaceuticals today—you know, pharmaceuticals are for the 20th century what cell transplantation will be for the 21st century. It will be a new avenue of medicine. I don't think it will ever be in the way of pharmaceuticals the way we know them now
>
> Interview 5/23/03

Here, Stephanie consolidates the history of hESC research within the scope of medical progress writ large. This sets hESCs apart from other forms of treatment, while still locating them within the historical flow of biomedical treatment. Both the value of unrestricted scientific research and the belief in the transformation of medicine through the production of new knowledge are amplified as they move through the coalitional circuitry that comprises CAMR.

By organizing around a single issue, or closely related issues such as hESCs and cloning, CAMR has been able to build a coalition that houses different PAGs, as well as universities and trade organizations. Smaller PAGs, or those that represent "orphan diseases" or diseases that strike a small number of people[i], benefit from coalitions like CAMR in that their members are able to potentially obtain the benefits acquired by larger, more well known organizations. At first blush, this arrangement appears to be a variant of the classic "free rider paradox" (Ferree 1992; Gamson 1990; Oberschall 1973;

Olson 1965). Developed by economist Mancur Olson, this paradox can be illustrated using a PAG. Lets say there is a person named Jill suffers who from Parkinson's disease (PD). Jill's time and money are valuable to her, as they are to anyone, but Jill's situation is slightly different in that a larger share of her resources must go to pay for her relatively costly medications. Jill is approached by a representative from a PAG that lobbies Congress on behalf of PD patients, which includes working to lower the costs of PD medications. The PAG representative asks Jill to join the group, and help support their activities with a $1000 donation. The representative says that while this is a lot of money, it will bring Jill a greater benefit in the end, as if they are successful, Jill will save thousands every year with lower medication costs. This seems like good logic, and Jill reaches for her checkbook.

However, as Jill is looking for her purse, she begins to realize something different. The PAG is working to lower drug costs on PD medications, and if they are successful, that victory will benefit everybody, regardless if that person is a member of the PAG or not. In Olson's terms, the victory is a *collective good*, or some benefit (like lowered drug costs) that cannot be withheld from individuals who did not contribute to its realization (Olson 1965:14-15). In other words, Jill thinks to herself, "Whether or not I contribute my $1000 will make little difference to the overall outcome, since many things have to happen in order for PD drug prices to get lowered. What happens if I do not give the money? If the PAG is successful, I benefit whether or not I gave my share. If they are not successful, I have saved $1000, which I need to pay for my medications." Jill decides that it makes more sense not to contribute than it does to contribute. She has talked

herself into becoming a *free rider*. The power of Olson's argument is to underscore that this is a rational outcome of thinking through whether or not to join an organization.

Olson's larger project was to understand why, given the free rider paradox, anybody would join a PAG in the first place? Part of his answer was that lobby organizations usually have other, usually economic functions, such as unions which deal with owners and organize work places in addition to lobbying that facilitate their collection of resources (what he referred to as the by-product theory, 1965:134-35). However, if an organization was mainly a lobbying institution, Olson argued that they are forced to offer some kind of inducement in order to overcome the free rider problem. He referred to these inducements as *selective incentives* (1965:51), such as a one time gift, or periodic newsletter. This is usually not a problem for large organizations. The real problems are for smaller organizations or movements. They are forced to use a part of every donation to go to the selective incentive, rather than the operation of the organization. Given that they have a smaller membership base, these groups can find themselves squeezed out of existence. CAMR does not offer any selective benefits to PAGs that join the coalition. So the question is why group would join the coalition in the first place? The answer has to do with CAMR's strategy of using patient's narratives as political tools.

Social movement scholars have researched the conditions that help or hinder coalition formation both within a particular movement and across different movements (Croteau and Hicks 2003; Jones et al. 2001; Manweller 2005; Meyer and Corrigall-Brown 2005; Rochon and Meyer 1997; Van Dyke 2003). This research has revealed different divisions of labor, which produce different coalitional forms. Forms include

network assistance, which is a coalition formed by a professional agency or organization; an *alliance* in which the division of labor of planning, recruitment, framing and mobilization is shared by different social movement organizations (SMOs); and a *network invocation*, in which a focal SMO plans and frames an event, but relies on supportive SMOs to mobilize support (Jones et al. 2001:209-10). CAMR is somewhere between an alliance and network invocation. It is composed of activists who are paid staffers of other organizations. CAMR has produced a *consonant frame pyramid* through its use of patient narratives. A consonant frame pyramid is frame resonance between individuals, SMOs and a coalition (Croteau and Hicks 2003:253). This condition is achieved because patient narratives, the public representation of personal suffering, are powerful political tools. For example, one of the creators of the Stem Cell Action Network (SCAN), Idelle Datlof, a retired social worker from Ohio, described her reaction to the personal narratives of others:

> Well, I have MS, and I've had MS since 1978, and I looked around over all those years to see what kind of research—and there was never anything, in my opinion, very exciting. I started hearing about regenerative medicine with words like repair, and it was quite an amazing word, because all of the medicine for MS is to shut off the disease process, and it didn't do it very effectively. No one was talking about repair. So I was pursuing that interest in listening to it, and finding out about it. Then when I heard President Bush's speech, that was clearly going to delay it, I just couldn't take that [unamused laughter]. That was it! I have not been particularly been an activist in my life before, but that just felt like it was a fantastic potential, and he was going—I don't even want to go into my feelings about that. And I can tell you what I did. Oh, meanwhile six months after 9/11, I was sitting at home every day reading the New York Times. The New York Times had "Portraits of Grief". I don't know if you saw those. It got syndicated in some of the papers. It was a thumbnail—a photo and a few paragraphs of each person who died in 9/11. And of all the reporting, I felt enormously effected by—they had it every day, and I would read the Times and cry. And it occurred to me that it was the faces—it was the personal that really got to people. And I thought, let's do that for stem cell research. I got the idea of "Portrait of Hope"—I stole it from "Portraits of Grief" [laughter]. As I started talking to people, I heard about CAMR in Washington, and I called them up and said I had this really good idea, and they should stop everything that they're doing and go forward with this. And whoever I spoke to said, "You know there are four or five other people around the country who are doing things, and maybe you'd like to talk to them". And I said, "Great!" They gave me four or five people's names—Raymond's being one of the names. Don Reed's being the second. Richard Arvedon being the third. I called everyone up cold, said, "Hi! Here's my idea". They said 'we like that – let's do that!' Even though they were each doing things, in their own way, we came together and then

> somehow, in ways that I don't even remember, we were having like monthly phone calls—conference calls. People just kept showing up.
>
> Interview 6/17/05

Here, she takes a framing technique from one context ("Portraits of Grief" following the September 11, 2001 terrorist attacks in New York City) and reformulates it for her own purposes; rather than grief, the activating element becomes "Hope." However, as this chapter will argue, hope is a complicated rhetorical concept.

Coalitions are not without internal disputes. In the case of CAMR, there have been some squabbles and difficulties. For example, the American Cancer Society (ACS), in a well-publicized dispute with Patient's CURe, pulled out of the coalition, due to pressure from opponents of hESC research who were also donors to the ACS (Wade 1999). This withdrawal was explained several ways in the *New York Times* article: as a protest at a fund-raising event; as a response to pressure from the ACS membership base; and as a disagreement with Patient's CURe over policy. The withdrawal was given to Patient's CURe by the president of the National Health Council, a lobby organization formed in 1920 that focuses on health care policy.[16] The ACS is not part of CAMR.

A second high profile PAG that did not join Patient's CURe was the American Heart Association (AHA). In early 1999, the AHA commissioned a panel to determine if the organization should support the funding of hESC research. Initially supportive, the AHA national office began to hear about dissension over support of the research, and calculated potential losses over this issue: "Reconsidering public opinion, officials made a new damage assessment: Funding [human embryonic] stem cell research would cut donations by $9 million to $15 million in the first year and by $45 million to $50 million

[16] Taken from NHC "About Us" webpage http://63.77.221.40/aboutus/about_index.htm (4 April 2006).

the next" (Zitner 2001). The AHA decided to cut its losses, and did not support Patient's CURe. Currently, the AHA does not support hESC research: "The American Heart Association funds meritorious research involving human adult stem cells as part of our scientific research grant program. We do not fund any research involving stem cells derived from human embryos or fetal tissue."[17] The AHA is not part of CAMR.

Free riders and expensive research

I argue that coalitions are able to overcome the free rider problem by the construction of collective identities. That is the success of consonant frame pyramids depends critically that individuals *come to see themselves* within the "coalition frame" (Croteau and Hicks 2003:253). By "seeing," I do not mean a disembodied or abstract perception. Rather, by virtue of the construction of a shared identity, stem cell activists developed deep commitments to the success of Prop 71. The centrality of commitment to a movement has been persuasively argued by Nathan Teske (1997) in his monograph on North American social activism. Teske interviewed full-time pro-life, environmental, social justice and business organization activists in an effort to move beyond the self-interest/altruistic dichotomy that he felt was hindering analyses of political participation. That is, rather than seeing political participation as either rational self-interest or altruistic selflessness, he argues that participation is better understood through the production of an activist identity. This production process has four central themes.

The first is the cultivation of a personal style, or "concerns about one's character" (1997:122). This style or character was a set of dispositions that determine how an

[17] Taken from AHA "Policies" webpage http://www.americanheart.org/presenter.jhtml?identifier=4757 (5 April 2006).

individual was to act in a specific situation. These dispositions were important for an individual, and were self-reflexively emphasized, tested and modified as the individual moved deeper into activism. This led to a shared dispositions despite the plurality of movements and goals of the activists Teske interviewed. He claims the most important of these dispositions is the necessity to act when "confronted with morally troubling situations" (1997:123)

The second is the notion shared by activists of very different stripes that activism was deeply meaningful social action. That is, the activists Teske interviewed connected their objective work of changing the world with their subjective enjoyment of their action (1997:123). In other words, activism, while demanding and frustrating at times, is validated and reinforced precisely because of these difficulties, and the activist's subjective fulfillment at overcoming these difficulties. Activism is important not solely because the work is morally good, but because the work is also about what kind of person the activist is, and is becoming.

The third theme is what Teske calls the "whole-life perspective," (1997:126-27) or imagining oneself looking backwards over a biography at the end of one's life. This gives an activist (or anybody) a "view from outside," but not an impersonal perspective from impartiality. It is a view that is deeply concerned with "my life," and my relations with other people. It is a view that is neither fully self-absorbed nor completely selfless, but incorporates both self and others into an imaginary future.

Finally, Teske wrestles with the complex theme of choice. That is, it is paradoxical that the activists he spoke with often claimed that they had "no choice" in their activism. This is also a common theme in narratives from those who rescued Jews

in Nazi-controlled Europe (1997:129). It is a paradox because the activists are not forced by anyone or anything to take on their beliefs or make the kinds of stands that they make. However, Teske argues that the moral commitments that one makes are inextricable from the identity that one cultivates over time. Therefore, the language of "no choice" does not mean that there is some kind of external coercion, but that given my commitments to my identity, to not act is not an option.

Teske's work underlines the importance of identity by looking at how activists themselves describe their identities. For stem cell activists, points three and four are the most salient. Stem cell activists supporting Prop 71 had biographies that were intersected by biomedical events, including diagnoses and treatments. As I will argue below, from diagnosis onward, stem cell activists gained a "view from outside" in Teske's formulation, as the loss of world is replaced by something else. The technoscientific identities (Clarke et al. 2003) embodied subsequent to diagnosis are shaped by the moral commitments that follow. On one hand, Teske excavation of the language of "no choice" is apt for stem cell activists, as many activists use this discourse. On the other, stem cell activists were also strategic in their use of this discourse. That is, as I will make clearer, stem cell activists combined moral commitments and public performances to synthesize collective identities.

I will now move down one level from coalitions to a focal PAG, and how the organization brings people together to do collective work. This "bringing together" is not just instrumentally valuable in terms of "raising the numbers" for lobbying, for example. Coming together under the identity of patient activists has important effects for strengthening and elaborating that identity.

Patient Advocacy Groups (PAGs) and stem cells: the case of the Parkinson's Action Network

Patient advocacy groups (PAGs) take a variety of forms and perform different functions, both across and within specific disease and/or injury conditions as discussed more generally in Chapter III. Specific to stem cell activism in California is the Parkinsons's Action Network (PAN), founded in 1991 in Northern California. It works on multiple fronts in the fight against Parkinson's disease (PD), a neurodegenerative condition that results in the death of specific neurons which release a neurotransmitter called dopamine. According to the PAN website (www.parkinsonsaction.org), PD affects "approximately 1 million Americans, approximately 40% are under the age of 60." This means that PD affects a relatively small population compared to other afflictions, such as cancer or heart disease, or even other neurodegenerative diseases like Alzheimer's disease, which strikes "approximately 4 million Americans" (www.alz.org). However, because of the nature of PD, it has become a major candidate for potential cellular therapies, including ESC-based interventions (Arenas 2002; Borlongan and Sanberg 2002; Brundin and Hagell 2001; Lindvall and Hagell 2001). Thus PD is often mentioned in conjunction with ESC research. PAN, as an organization, is an enthusiastic supporter of ESC research, and is considered by some as the "stem cell organization" (interview 5/8/03).

PAN is a national office, but also has a very active California caucus. PAN's work includes supporting legislation at a federal level intended to help cure PD, as well as organizing on grassroots levels to increase awareness about PD and potential therapies

or cures for PD. PAN's grassroots organizing is closely tied to its legislative agenda, as local fieldworkers play a central role in coordinating various political functions, such as letter writing or phone calling campaigns. Thus, the majority of PAN's work is decentralized, and tailored to the local political environment.

John and Carol (all names are pseudonyms), two PAN activists, both spoke with awe and excitement over the possibilities of ESCs for curing PD. This excitement has been fostered by the potential of ESCs to be coaxed into forming dopamine-producing neurons. But their enthusiasm also has to do with the conjunction of biography, etiology and politics. As a neurodegenerative disease, PD is very idiopathic: different people are affected in different ways at different times. While PD can ultimately lead to death, there is typically a long period of time from initial onset or diagnosis to death. This affords a window of opportunities, including for activism. As Carol pointed out, activism is as much work as her former career, which was truncated by the disease:

> It [PD] takes away your ability to just move along the path that you've been on. Virtually everyone at some point has to stop working because of it. It's not that you can't work, it's become unreliable. You can't work all the time. You don't know when you'll be able to work, you can't work as fast. You've become unemployable, more than not being able to work. I mean, we work a lot, but it's at all hours of the day and night… So it's important to realize that you can "work". You can do things, and advocacy is one of the important things you can do because it's so self-fulfilling. So that's why it's an important distinction
>
> Interview 5/8/03

For Carol, taking part in PD activism is part of the process of forming a politicized collective illness identity (Brown et al. 2004). This process allows her to not only meet other activists, but also to understand the significance of ESCs as a potential therapy. Through interaction with others afflicted with PD, Carol and John went through a process of self-redefinition. That is, the self begins to understand itself as *similar to* a group of

others, perhaps formerly viewed as foreign. For example, Carol used the metaphor of the leper colony to articulate the connectedness she feels:

> But I think of other communities, like leper colonies. I mean, generally leper colonies, they weren't voluntary by any means, but I'm sure there were consolations of living with each other. Because when we get together with other "Parkies", inevitably someone will say, 'Oh, God! It is so nice. I don't have to explain myself.'
>
> Interview 5/8/03

Feeling at home, not having to explain oneself, one's disposition or one's instabilities, creates the conditions for a *proto-citizenship*. Warwick Anderson (1998) studied Culion, a leper colony in the Philippines. He argues that medical authority was enmeshed within a process of citizenship, which for the residents of the colony, directed them "toward a contained, therapeutic future". Anderson argues that the leper colony was a "miniature…both bounded yet infinitely expandable" of the colonial control of the Philippines by the USA. While Carol's future has more degrees of freedom than those at Culion, for whom full citizenship was always deferred, the domains of health, potentiality and citizenship are brought together within the field of biotechnology. Rather than miniaturizing power relations, PAN cultivates the unfolding of the illness experience, and its recoding within the potentializing political technologies (Faubion 2000:403) of social movements.

Within liberal corporatist political institutions, such as in the United States, the "group" form is exceedingly important. That is, given the structure of North American political institutions, as well as the histories of activism in civil society (Skocpol), it is necessary for citizens to band together in order to leverage claims against other actors. Individuals seeking to influence public policy must develop affinities and alliances with others in order to move a project forward inside of the state. This is a major theme of

much writing on social movements. For example, for many North American writers, the civil rights struggle of the 1950s-1970s represents an archetypal social movement.[18]

For groups organized around the pole of health, rather than race, the situation is different. PAGs have found themselves in a double bind. They are not only facing the state as an opponent, they are facing other PAGs in a zero-sum game. For example, every NIH dollar that goes to cancer research, is constructed by many as one less dollar for Type I diabetes, PD, spinal cord injury research, etc. This structural opposition has mitigated against the formation of broad coalitions of PAGs.[19] However, stem cell research opened up a new possibility – the formation of coalitions around a specific technology. Stem cell research thus solved a major problem for PAGs– how to get people to work together.

What is a patient activist in the field of biotechnology?

For purposes of this project, I define a patient activist as an actor who has made public statements about a focal disease or condition that directly affects him or her, or someone close to him or her. This public activity includes actions like writing a letter, making a public statement at a conference or hearing, a public declaration at a meeting, or joining an organization that acts as a patient advocacy group (PAG).

While the decision to join a PAG is inflected by a wide variety of variables, such as biography, social class, race, gender, geography, etc., there is one variable that I will

[18] Characterizing the civil rights movement as a unitary phenomenon is difficult. While one could argue that an overall goal (if such a thing existed) was the attainment of equality between racially different groups, different streams of this movement utilized different framing techniques, repertoires of contention, recruitment and mobilization strategies, protest tactics and ideologies. Thus, the civil rights movement is better thought of as a heuristic for a multiplicity of movements.

[19] PAG coalitions would form around issues that would potentially benefit the entire field – for example, campaigning to increase the overall NIH budget, rather than specific disease or condition sectors, such as the NINDS vs. NHLBI.

foreground: diagnosis. That is, while the activists I interviewed for this project came from very different backgrounds, and had divergent views on many subjects, they shared the commonality of diagnosis of a disease or condition to either themselves, or an immediate family member. This key element does not of course exhaust the subject positions available within the field of patient activism. That is, there are actors who support hESC research who have neither been diagnosed, nor have close relatives with a disease or condition amenable to stem cell research. There are also actors who have a diagnosis that is a major candidate for hESC therapy, yet who deeply oppose this kind of research. Finally, there are those with PD or spinal cord injuries who do not become activists, and avoid the public activism of disease advocacy. While these are all important subject positions within public stem cell activism, my research does not address these trajectories. Rather, I focus on a convenience sample of activists who took public positions in favor of stem cell research and Prop 71.

Diagnosis of a serious condition is intuitively unsettling. The diagnosis shatters lived worlds. Others have thought deeply about the consequences of that moment, and it is not my intent here to analyze the phenomenology of diagnosis. There are also different pathways following diagnosis, and I also do not intend to catalog these experiences. But I do wish to raise the issues of transformation of identity that may be engendered through diagnosis.

For many people later diagnosed with PD, prior to diagnosis the pacing of events is uneven. Some experience vague feelings or flutters of slight symptoms that give them pause. Others experience an unexpected lack or deficit of functionality. Simple tasks may become more difficult or challenging; others make comments about perceived

changes, lack of energy, fluctuations in personality. Still others experience the changes in dramatic fashion. Spinal cord injuries for example, come as bolts from the blue. The commonality of all of the stem cell activists in this study was the confirmation of their condition by a medical diagnosis.

Following diagnosis, individuals face what Anselm Strauss (1997) referred to as a *loss of world*. Strauss points out that loss of world occurs when our existing "explanatory terminology" fails to agree with the social contexts in which it is occurring. The loss of world can be instantaneous; it can also be gradual. The early work of Anselm Strauss is helpful for understanding the synchronization of personal experiences of illness and disease with political frames and rhetorics. By the time *Mirrors and Masks* first appeared in 1959, Strauss had already written extensively on pragmatist philosopher and social psychologist George Herbert Mead. Mead's ideas about the self and its development over time were influential on Strauss, particularly the notion that the self has the capacity to reflect on itself, and retrospectively evaluates its action. Following through on this assumption in Mirrors and Masks, Strauss emphasizes that ongoing reevaluation is core to the self, and to the ongoing production of identities useful to one's life situations. Ongoing reevaluation is a social activity in that we evaluate our own activities as if we were someone else, or in Mead's words, we take the role of the other.

In the case of identity, we acquire new ways of naming our selves and our actions over time, some which supercede older versions, and some which complement the array of names we already possess. These names are strategically deployed at different times, and may also be placed upon us through what Strauss (1997) called *status forcing*

mechanisms, such as shaming or heroizing an individual, exiling or welcoming them into or out of a group, or diagnosis.

This opens up a set of interesting questions regarding identity and possession: In what sense do we mean we "possess" an identity? What are the terms of this possession? Telescoping out, what are the regimes of value that animate such possession, setting the conditions for us to be able to talk about the possession of an identity? Strauss was well aware of the provisional nature of possession of an identity, and the risks and dangers of dispossession.

A major analysis that built upon Strauss's insights on the relationships between identity and loss of world is Kathy Charmaz's (1993) *Good Days, Bad Days*. She argues that chronic illness is a kind of *interruption* that is defined in different ways: without a diagnosis; escalation of symptoms after an initial crisis; sudden onset; and information following a test or examination (1993:23). A diagnosis can be a relief, in terms of confirming intuitions and providing legitimation (1993:24). Yet, chronic illness is also an intrusion, which people respond to through ignoring the problems, struggling against them, reconciling with the illness, and/or accepting the illness (1993:46). Some patients will attempt to contain or "package" their chronic illness as distinct from other aspects of life (1993:66). This helps isolate acute attacks from affecting the deeper sense of a coherent self. Packaging is important as it helps shape the meaning of the illness for the individual. An important dimension of packaging is "passing" (1993:68-70). Drawn from the work of Goffman (1963), Charmaz points out that passing is "risky," and plays an important role in structuring social activity for the chronically ill. In terms of stem cell activism, as we will see passing may be strategically eschewed, similar to what

Gayatri Spivak (1988) referred to as "strategic essentialism." Stem cell activists who are chronically ill will often stage their symptoms or disability in highly public formats. Rather than attempting to pass, stem cell activists display their illnesses as a political tactic.

Charmaz also highlights the dilemmas of disclosing (Charmaz 1993:109-19). For stem cell activists who display their conditions in the process of doing representational work, this is a different set of concerns. Thus, rather than a set of risks and dilemmas over disclosure, displaying illness carries risks and dilemmas over authenticity and attributions of motivations. These dilemmas can be mitigated by appeals to proximate and distal goals. In the case of Prop 71, both the short-term event of a political campaign and the medium- and longer-term of promoting a controversial science help to rationalize the public display of illness.

Charmaz discovers two modes of disclosure or "telling;" protective disclosure and spontaneous disclosure (1993:119). They differ along the axis of control; that is, the protective form is staged by the actor, while in the spontaneous form, the actor is "outed" in some way. Charmaz also discusses "flaunting," or the attempt to manipulate a situation in order to provoke a response (1993:126-7). Flaunting is an interesting concept, but does not quite cover the public representations of stem cell activists. While they are strategically manipulating their appearance, it is not without its own set of risks. Display runs into a *politics of authenticity* that stem cell activists must negotiate.

Charmaz concludes her text by discussing the relationship between the self and structures of time, such as the past, present and future. She identifies three forms of the present: the "filled present," or a present filled with many activities (1993:241-2); the

"slowed-down present," or a present denuded of activity (1993:243-5); finally, the "intense present," or a present filled with "passion, authenticity and involvement" (1993:245). The intense present is the structure of time that stem cell activists choose to inhabit.

Charmaz's work is a detailed exploration of living with chronic illness. She reveals the day-to-day patterns, temporal flows and relations that individuals with a chronic illness inhabit and negotiate. While she considers modes of outing and flaunting, she never specifically connects these modes to institutions of authority. I want to use Charmaz's insights as the foundations from which to broaden modes of telling to consider changes in patient activism brought about by changing politics of representation and the forms of disclosure in political institutions. I will do this by analyzing a set of interviews conducted with patient activists who were mobilized during the Prop 71 campaign. These interview subjects were all active in some form of biomedical politics prior to their involvement in Prop 71.

Figure 5.1 lists the patient activists interviewed for this project. The table includes who was affected (self or relative), diagnosis, and date of diagnosis. All of these respondents were asked about how they became involved in stem cell activism. I next present narratives about a subset of four specific patient activists and their past political work. Their experiences helped to shape their stem cell activism.

Table 5.1: Stem Cell Activists

Name (all names are pseudonyms)	Subject of injury	Diagnosis	Date of diagnosis/injury	
Ed	Son	Type I diabetes	1999	

Victoria	Grandson	Type I diabetes	1999	
Susan	Daughter	Type I diabetes	?	
Paul	Self	Parkinson's disease	1998	
Steve	Self	Parkinson's disease	?	
Patricia	Self	Parkinson's disease	1990	
Julie	Self	Parkinson's disease	1988	
Jackie	Self	Parkinson's disease	1994	
Betty	Self	Multiple Sclerosis	1978	
Craig	Son	Spinal cord injury	1994	
Monica	Self	Spinal cord injury	1992	
Rachel	Self	Spinal cord injury	1992	
Walter	Self	AIDS	?	

Legacies of Superman: Getting state money for spinal cord injury research

On November 10, 1994, a parent's worst nightmare became reality. Craig watched his son, a star high school football player, go down on the field with a serious spinal cord injury. The event ended Craig's life as he knew it then, and initiated a new one. Over ten years later, he keeps the horror of that moment close to him:

> It was the worst thing that could ever possibly happen. Even death has certain advantages. You can at least walk away from this. But for your child to be tortured before your eyes is awful. The doctors gave us no hope. No chance that he would ever walk again or close his fingers. Almost no chance he would have a child. They told me my son would die young. So it was the worst.
>
> Interview 9/12/04

However, this terrible event was not an absolute end. To understand why, it is necessary to know Craig's biography to see what direction he was to eventually move in. Craig had

trained to be an Olympic weightlifter and, as an employee at FunLand, an amusement park, he took a stand to save the park after company officials decided that it should be closed. He recounted this event as a significant event in his political biography:

> It was important because - I remember the day they announced it, that this was going to happen. These people, a seven and a half billion dollar multi-national corporation, headquartered in [names country], I believe, came to our - we had a meeting of the workers who worked there, and told us what was going to happen, and showed us this lovely new shopping mall model, which - [FunLand] was like a little piece of Eden to us - was going to be replaced with. And when they finished, they asked for comments. I stood up and said, 'We're going to fight you on this.' That was kind of like a defining moment because I just had to decide; am I going to allow it to happen, something I love to be destroyed, or fight back? And we fought. And we won.
>
> Interview 9/12/04

Following his work at FunLand, Craig had moved into elementary school teaching. It was during his career as a teacher that his son's accident occurred. In order to raise money for spinal cord research, Craig wrote plays that the children at his school performed. Their efforts raised around $2,000. During this work, Craig heard about a police officer who was shot in the line of duty. While the officer was not permanently paralyzed, he had become instrumental in passing a state bill that added $15 onto every speeding ticket to go to spinal cord research. Craig eventually met this officer, and the two developed a friendship. Craig began to formulate a plan for a similar bill. He began first at the federal level, but soon realized that his efforts were falling on deaf ears. He then turned to the California legislature, and began to get some slight support, beginning with his district representative in the state assembly. Craig then began to elicit support from others, including seeking allies on various electronic listserves to look for allies. On one such list he met Monica.

Monica was paralyzed in a 1992 car accident, and her husband left her soon after the accident. She had been a successful real estate agent with two young daughters at the time. She described herself as not being an activist before her accident, but now readily

describes herself as one. She met Craig on-line on a paralysis listserve, as Craig was looking for help. Together, and with the help of a few other allies, they began the slow process of working through the California state government in Sacramento trying to get the bill that Craig originally thought up written and passed.

During his initial work with the California assembly, Craig realized that groups can be more influential than individuals. So he started "Californians for Cures" (CfC). Through CfC, Craig and Monica began the long, grinding work of lobbying. They attended hearings and committees meetings, wrote letters, and did the hard political work in Sacramento. Their work paid off. In September 2000, then Governor Gray Davis signed Assembly Bill 750, which allocated over one million dollars a year to research on spinal cord injuries for five years. The funding stream is to be managed by the Reeve-Irvine Research Center (RIRC) at the University of California, Irvine, which had been started in 1996. RIRC received a one million dollar gift from Joan Irvine-Smith, a philanthropist who teamed up with Christopher Reeve following his horse-riding accident.[20]

Creating a clinical tool: Starting California's PD Registry

Paul would have made Aristotle proud - he is a true political animal. He has worked for unions and mayors. On the wall of his office is a poster by radial artist Robbie Conal, whose posters of former United States Attorney General Edwin Meese and Supreme Court Justice Clarence Thomas could often be seen wheat-pasted in urban areas in the late 1980's and 1990s. He is currently a communications director for a large public

[20] Irvine-Smith was also a dedicated equestrian, and apparently she was impressed that Reeve did not blame his horse for the accident: http://www.capitolmuseum.ca.gov/english/remarkable/panel12.html

employees labor union. Diagnosed with PD six years ago, Paul described how he went through series of emotions before becoming active around this issue. Paul also acknowledged that his relatively young age at diagnosis played a role in his activism. Paul described the way these two variables, age of onset and political biography, critically intersected to shape his patient activism:

> There's this old Chinese saying: 'If you give a child a hammer, everything needs hammering.' It was just my approach to things, it's my profession. You go to a lawyer, everything needs lawyering; you go to PR person, everything needs PR. I came out of a political background, and I saw this as a political organizing issue. That was how I was going to approach it. The other thing is that I found that activism was therapeutic for me. It was a way of channeling some of my anger, and it was a way of making me feel more in control of my life. I wasn't going to be a victim. I am a person with PD, and I'm fighting for a cure, fighting for new therapies. I'm not going to sit and let the disease happen to me … I think activism is more the exception than the rule. People with PD experience symptoms such as depression, soft speaking voice, the Parkinson's mask, the shuffling, the types of symptoms that you don't like to be out in public with. So I think there's a natural tendency is to withdraw from your life. I think in the case of the young onset, where most of the activists are found, it's a therapeutic aspect of fighting the disease. And I think it is the relationships that get made with people who are sharing the experience of fighting the disease that motivate and keep somebody active. I notice at my Parkinson's association meetings that I have, I get about 15-20 people each meeting, and I have about 5 to 10 that come for just for one meeting. They usually have much more severe symptoms than I have, and don't really participate. They kind of watch. It's just difficult for people who are experiencing PD to be aggressive socially, so I think that slows people down.
>
> Interview 8/17/05

This description of PD activism is rich, and Paul has clearly reflected upon his position within the complicated fields of disease and other forms of political activism. His descriptions of public presentation are important, and we will return to them later in this chapter.

Paul's early onset and penchant for organizing also led him to consider whether there were other people with similar profiles. He pitched his ideas to the *Los Angeles Times* in order to get a story out about the increasing incidence of young-onset PD. When a member of the paper's staff asked him how many people are diagnosed, he realized that he didn't really know. Paul's goal was to try to get a figure of how many

people in California are diagnosed with PD. He discovered that nobody was keeping track of this kind of data. As luck would have it, his neurologist was located at UCLA. When MS repeated his thinking about tracking rates of PD in the state to his neurologist, the neurologist said that what would be really helpful is some form of systemized collection of data in the form of a confidential registry. The neurologist directed MS to his colleague in the School of Public Health who is an epidemiologist researching the incidence of PD in the San Joaquin Valley of central California. Paul contacted the epidemiologist, who corroborated MS's ideas that what is needed is some kind of method to collect the profiles of PD patients across the state. This could be best coordinated not by an individual university researcher but by the state. Paul's luck would continue:

> So, I lived 4 doors away from my state assembly member, who happened to be chair of the health committee. And one day I was out washing my car, and he drove by, and we stopped and chatted, and I suggested that he sponsor the registry bill. Using the contacts I made at PAN, and the involvement of the Parkinson's Institute, we successfully lobbied the bill through the state legislature, and the governor did sign it, over the objections of his staff. This was Arnold [Schwartzenegger].
>
> Interview 8/17/05

The registry is being set up at the time of this writing. It is only the second PD registry in the United States[21].

All in the Family: Kinship and Juvenile Diabetes

Victoria is a devoted grandmother, although you would not necessarily know that by talking with her. She is currently Vice President of Government Relations for a branch of the Juvenile Diabetes Research Foundation (JDRF) in California. JDRF was an instrumental organization in the development and passage of Prop 71. Like the activists mentioned above, Victoria comes from a deeply political background.

[21] The first was set up in Nebraska in 1996: http://www.hhs.state.ne.us/ced/parkinson/index.htm

> My parents always discussed politics and current events at dinnertime. We were very ordinary lower middle-class, but my parents were always very aware of what was going on. My mother is 88 and still talks politics and, you know, watches what's going on and reads what's going on. My great uncle Lou was one of the founders of the International Ladies' Garment Workers Union. I think we have always felt that it's important to participate. My grandmother, who was a tremendous influence in my life, came over from Russia at age 14, worked in sweatshops basically, and brought over her entire family of 8 brothers and sisters and her mother. And we just always felt that it's important to be involved in issues around you. I have an aunt who is my mother's big sister, who today is 92-years of age and still is president of her women's club at her temple, is involved in Hadasa, a women's organization that raises money for hospitals, and many charitable things that are in Israel. Our family has always felt it was important to be aware of what was going on in current situations, to think about it and to have a position about it.
>
> Interview 9/13/04

Unlike the other activists, Victoria did not work through political institutions to pass laws or develop programs, although her position as VP of GR kept her in contact with politicians at the federal, but not state level. JDRF targets increased funding for Type I diabetes through the NIH, so Victoria's work is more federally focused. However, JDRF is a federated organization, and members from the northern California branch was deeply active in the Yes on 71 campaign.

In 1999, at just under two years of life, Victoria's grandson was diagnosed with Type I diabetes. She became immediately involved in searching for information, and as an executive with a computer company, she was savvy with web searching. She was also unafraid to present herself to medical experts, and solicited help through a series of emails to diabetes researchers she discovered through web searches. Many of these emails recommended that she get in touch with the JDRF, which she did. The result for her was overwhelming, creating bonds between her and other people living with Type I diabetes, or supporting a family member or friend:

> We have what we call the extended family of people who have Type I Diabetes. [It] is an intense family feeling. I have no experience any other disease so I don't know what they experience but to give you an example, my daughter and I were in Beverly Hills one weekend. We were walking along and we saw Mary Tyler Moore sitting at an outdoor restaurant. My daughter said to me, she spotted her; I didn't even see her, my daughter

> said, "Mom, there's Mary Tyler Moore." Now she's a spokesperson for JDRF. My daughter walked a little ahead and I walked right up to Mary Tyler Moore, which I would normally never do. She was sitting with her husband who is very involved with JDRF, and another person, and I said, "I am really sorry to bother you but I just wanted to thank you for what you do for JDRF. My grandson has Type I Diabetes; this is his mom." Mary Tyler Moore put down her silverware, stopped her entire conversation, asked me questions about [names grandson]. How was he doing? Was he on the pump? Was he doing shots? Spoke to [names daughter]. I mean there was a really strong sense of family amongst people who deal with children or adults who have Type I Diabetes.
>
> Interview 9/13/04

Victoria's sense of relatedness to others sharing her experiences with illness is a potent organizing force. This sense helped her translate her past experience in politics and her professional work into becoming an executive in a PAG.

What's going on this weekend? The politics of PD communication

Patricia was diagnosed with PD in 1990, when she was 42 years old. Her marriage ended shortly after her diagnosis: "My marriage ended the same year, which is not tragic. It was just time" (Interview 8/19/05). She initially kept her PD hidden, but by 2000, she was walking in the Unity Walk in Central Park in Manhattan, an attempt to unite the many organizations that are involved with PD. Patricia said that she is an inveterate group joiner, but was unhappy about the fragmented nature of the field (something the Unity Walk attempted to address). The same year, she began to compile and organize the information related to PD organizations in Los Angeles county and surrounding areas. Her list is "hand-made," in that the information she collects is produced by other organizations, but she formats all the text, and has rules for its operation, such as inclusion and exclusion criteria:

> I try to keep my bulletin with the range of LA county and vicinity, and I don't put anything that has to do with for-profit, money gaining things. I just have this certain skepticism. It doesn't make any sense because some people do have speakers who are doing long-term planning, insurance, that kind of stuff. And that's fine. But I don't like to do ads, I don't want to have any strings. The whole point in what I'm doing is to try to

> be neutral but helpful. Parkinson's is, I think, unusual in that it has several different factions in terms of patient support and research support. They have little turfdoms.
>
> Interview 8/19/05

PDLA itself can thus be conceptualized a *workaround* – a piece of hand-made technology designed to fix a flaw in a complicated system, a flaw produced by the system through overloading, redundancy, or forms of miscommunication. PDLA is not simply a technical fix; it also reflects the politics of its sole designer. Specifically, Patricia excludes for-profit enterprises. While Patricia is not anti-capitalist, she understands that drug companies are commercial operations, which can lead to problems. For example, she talked about her participation in clinical trials:

> I volunteered for all the trials I could that didn't involve drugs or surgery. Things like memory or coordination, mostly at USC, some at UCLA. I was on L-depo when I was first diagnosed, and after a few years a few people, 5 people I think, died in England, and there was a scare that it was unsafe. So I was taken off that. But it had an amphetamine effect. I had that the first years I was working with PAN, and I got by with hardly any sleep for a long, long time. That was not good, I'm sure. So it was just as well I was taken off that. I was on mirapex after that, and that had horrible side effects too. The narcolepsy, especially when I would come to a stop sign in my car, I would suddenly be asleep. I usually could fight it when I was driving, but not when I was still. I was very dyskinetic. I had a compulsion. I was in a class action suit against mirapex with people who had compulsive gambling, drinking and sex, and mine was compulsive shopping on eBay! [laughs] As soon as I got off mirapex I stopped doing it! I just realized that instantly. I had a cookie jar in the shape of a shark, that when you opened it, it went [imitates theme from the movie *Jaws*]
>
> Interview 8/19/05

Some patient activists like Patricia, while actively looking at all their options for therapies, are critical of the organization of health in the United States. This includes a belief in the importance of single-payer health care, and a concern over the commercialization of knowledge production, in the case, the use of contract research organizations (CROs) for running clinical trials:

> Trials are by drug companies, but they are usually at universities, or a lot of them are. Some of them are done by clinical trial companies, and I've had very scary experiences with that, as have several of my friends. You're not paid for doing it, but you are paid expenses. When someone's really broke, that's a lot of money, getting $1000 for being in a drug trial. They've had neurologists monitoring them, but they haven't had movement specialists or Parkinson's specialists. And they got into really deep trouble, and had to be

> hospitalized, and had to have everything reworked in order to get back to the baseline they had before. I'm frightened about that, not for myself exactly, but it's exploitative without meaning to be. Whether it's meaning to be or not, it's exploitative [laughs]!
>
> Interview 8/19/05

These four brief sketches reveal the deep levels of commitment that patient activists have for political action. This includes working within established PAGs, starting new organizations and groups, lobbying and working with state and federal governments, working with scientists and clinicians, and developing forms of communication and participation. How then do individuals take the next step and become stem cell activists?

Becoming a stem cell activist

In order to become a stem cell activist, the two principles of stem cell activism that I mentioned earlier must be interpreted and represented: an individual must understand what is at stake in hESC research, and then must act publicly on the basis of these understandings. This is particularly salient during an electoral campaign like Prop 71. That is, since stem cell research funding was what was at stake, participants in the campaign had to make their positions public.

I do not consider this process of turning private beliefs or sentiments into public statements to be a simple matter of merely speaking in front a microphone. Instead I consolidate this complicated process under the concept of *developing an activist identity*. Identity is certainly something that is constructed by a subject in relation to a perceived identity norm. Gender, for example, has been thoroughly analyzed from this perspective. The construction of an activist identity is operative in the field of stem cell activism. This process is both hindered and facilitated by the controversial aspects of hESCs,

compared to becoming an activist in other HSMs (see Chapter III). That is, because human stem cells are always already controversial, the object itself of the activism cannot provide an unproblematic foundation for the subject. While this may seem at first a blockage to becoming a stem cell activist, it can also serve as a principle of mobilization. Before I discuss the making of a stem cell activist identity, it is necessary to explain what is it at stake in possessing an identity.

Theorizing collective identities

I concluded Chapter III by looking at five domains of controversy that cross-cut the Prop 71 arena. In Chapter IV, I argued that lay conferences were a crucial site where the debates that make up these controversies were articulated and contested. This public airing of claims and counter-claims serves to help construct salient identities. How does this process work? Before approaching this multifaceted question, I lay out my theoretical assumptions regarding the dimensions of identities and identifications.

The production processes, self-understandings and public performances that make up modern identities have been of concern to scholars in the social sciences and humanities for a great while. It is now axiomatic among these perspectives that *identities are irreducibly social*. That is, any focal identity category is formed in relation to others, is deeply context-dependent, is malleable and changes over time, is reflexively organized across social worlds, and must be displayed in public. Within this broad framework, however, there are important differences in theorizing identities and identification between and within disciplines.

I am not interested in making an argument about the status of identity as an ontological object. No individual "makes up" an identity *de novo*, but rather through socialization practices, comes to inhabit different identity categories. By inhabit, I mean to experience the effects of a category through the inclusions and exclusions that make that category possible. These identity categories are naturalized, so that individuals and groups come to see these categories as constitutitive of the groups themselves. At different times, the naturalization of a category itself is challenged, and occasionally the category itself disappears. Other categories, such as race, gender and sexuality are deeply enduring, and produce multiple forms of inclusion and exclusion which are historically variable. My specific interests here are identity categories and social movements.

Within social movement scholarship, the term *collective identities* has become an important analytic tool. In their recent review of the collective identities literature, Polletta and Jasper define the term as, "an individual's cognitive, moral and emotional connection with a broader community, category, practice or institution. It is a perception of a shared status or relation, which may be imagined rather than experienced directly, and it is distinct from personal identities, although it may form part of a personal identity" (Polletta and Jasper 2001:285). This definition is important for two reasons. First, the authors broaden the pathways through which actors come to see themselves as social movement participants and/or activists. Traditionally, the well-trodden pathway was primarily cognitive in nature. That is, individuals weighed the costs and benefits of social movement participation in rational ways before becoming active participants. For some, this logically led to inactivity, such as the free rider problem discussed above. However, rational thinking is only one way that individuals come to be involved with

social movements. In terms of identity categories, rationally accepting an identity is *one way* of cloaking one's self in an identity. However, there are other ways to come to possess an identity as well. For example, identities can be forced upon individuals, either coercively or chosen through immediate necessities of political strategies. Some of these identities are transitory; others become deeply enduring.

Second, the authors make a distinction between the (direct) experience of shared relations based on identity categories, and "imagined" relations between actors. Some identities have important corporeal aspects (for more on this see Chapter III). For example, social movements around racial and gender oppression have relied upon the direct experiences of exclusions based on immediately visible phenotypical statuses. These exclusions, often violent, have served to form identity categories from the outside, so to speak. That is, individuals who suffer forms of oppression based on phenotypes come to share *forms of consciousness*, or ways of experiencing reality. The *locus classicus* of this argument in North America is W.E.B. DuBois's (1999) notion of the "double consciousness" of African Americans during Jim Crow, as both phenotypically black and American citizens.

However, activism opposing racial oppression was not limited to just the victims of the exclusions. Many non-African Americans have aided in the struggles against exclusionary practices and institutions. In other words, non-African American individuals and groups could imagine what these exclusions were like, and subsequently mobilize on behalf of the appeals of social movements for racial justice. Thus there are points of overlap between the forms of consciousness between and among groups. Structurally, this is critically important for the formation of coalitional politics.

In terms of thinking analytically about identity categories, this attention to imagined relations helps dislodge more pernicious arguments that reduce identity categories to phenotypes, or experiences of exclusions suffered only by those bearing phenotypical markers. This strict account of identity politics reduces the (often contradictory) processes of identification to a simple reflex that has difficulty accounting for both the variable understandings of a focal identity within a group, and the degrees of salience of the same identity across groups. These latter concerns were, and continue to be, of great interest to sociologists.

This project is influenced by the latest round of analyses of *biomedicalization*: "the increasingly complex, multisided, multidirectional processes of medicalization that today are both being extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine" (Clarke et al. 2003:162). After reviewing the recent work on the concept of identity, I look at how technoscientific identities cross-cut political formations. Specifically, how the emergence of stem cell activism began entangled within Prop 71 and the institutionalization of controversial science.

Psychological and social psychological explanations

An early attempt to parse up the dense concept of identity was Johnston, Larana and Gusfield's (1994) typology of *individual*, *collective* and *public levels of identities*. This analytical typology is also helpful to sort out the historical and disciplinary bases of theorizing identities. The conceptual elaboration of individual identity has multiple long and deep histories. Psychology has historically taken an interest in identity-formation

over time through multiple theoretical and experimental approaches.[22] One powerful psychological explanation has argued that identities arise from group formation over competition for scarce resources (Jackson 1993; Monroe, Hankin and Van Vechten 2000). Known as *realistic group conflict theory*, the classic demonstration of this phenomenon is known as the "Robber's Cave experiment" (Sherif 1988; Turner 1990). Directed by Muzafer Sherif in 1954, two groups of twelve-year-old boys were randomly put into groups at a summer camp. After a week, the two groups were brought into contact, and unscripted forms of competition developed between the groups as they competed for rewards. In-group solidarity increased as a result of these activities. The groups were then brought together to mutually solve a problem (or "superordinate goals"), and the solidarities began to weaken (Sherif 1988:211). This experiment has been used as empirical evidence of the impact of competition between groups over resources determines identity formation.

In contrast to the realistic group conflict theory is *social identity theory*, which arose out of the work of Henri Tajfel (Robinson 1996; Tajfel 1974; Tajfel 1982). Tajfel argued that in-group and out-group identity formation happens regardless of the scarcity or abundance of resources. These "social identities" are important because under certain conditions, Tajfel argued, their salience overrides "personality characteristics," which can cause individuals to do things they would not "normally" do (Reicher 1982:43-44). Thus, social identities are, to a certain degree, independent analytical entities from personality (Ashmore, Deaux and McLauglin-Volpe 2004; Ellemers, Spears and Doosje

[22] Due to space constraints, I will not discuss Freudian, psychoanalytic, and post-Freudian approaches, such as Lacanian- and object relations-inspired theories, to the questions and problems around the concept of identity and identification. However, these perspectives have made valuable contributions to the theorization of identity formation.

2002). Social identities operate through conscious identification with existing social categories, and feelings of similarity or having a shared fate with others who inhabit those categories (Brewer and Silver 2000:153). This thread of psychological research shades easily over into sociological perspectives on identities and the processes of identity construction.

Social psychological cognates of social identity theory have produced a wealth of literature. Heavily influenced by the symbolic interactionist tradition, sociologically-oriented social psychologists have carved out their own body of work called *identity theory* (from a vast literature see Burke et al. 2003; Burke and Reitzes 1991; Callero 2003; Cerulo 1997; McCall 1978). One version of identity theory has become associated with the work of Sheldon Stryker (1994), which stresses the importance of *role identities*. Role identities are connected with a person's social structural position, and their salience to the self is predicated by interactions with others who within and across social structures (Howard 2000:371). Identity theory has moved now into different directions, with some direct engagement with psychological approaches (especially the work of Ralph Turner, 1976; 1988). While I do not draw from identity theory directly, it is important to recognize the work done in this area has migrated into neighboring enclaves, such as the study of social movements and collective behavior.[23]

Social movement theories and collective identities

Johnston, Larana and Gusfield's second type of identity is *collective identity* (Johnston, Laraña and Gusfield 1994:15). This concept has multiple valences, and has

[23] This project is influenced more strongly by the symbolic interactionist tradition oriented around the *negotiation of identities* rather than the social structural/role identity tradition .

found an important niche in contemporary theories of social movements. Alberto Melucci defines collective identity as, "an interactive and shared definition produced by several interacting individuals who are concerned with the orientation of their action as well as the field of opportunities and constraints in which their action takes place" (Melucci, Keane and Mier 1989:34) William Gamson defines it as the "mesh between the individual and cultural systems" (Gamson 1992:55). Sociologists (not all of whom are social psychologists) analyzing social movements have developed a set of approaches to the forms and functions of identities in and around social movements under the concept of collective identities. Within the study of social movements, the interest in collective identities peaked and waned over time. New Social Movement (NSM) theorizing of the 1980s led to one set of debates about the status of identity, especially with the work of Alberto Melucci. Like all debates, when looking backwards, the one between rational, "strategic" action and "expressive" identity formation appears clunky and reductionistic. As Polletta and Jasper point out in their review, these former poles are now part of more expansive perspectives that are able to incorporate both political economic and structural interests, and cultural formations and identities. This approach has antecedents in the social movement literature. For example, social theorists such as David Snow, William Gamson and Bert Klandermans have been interested in the dynamics of micro-mobilization, and the avenues by which individuals come to see (or not see) themselves as part of a broader movement.

Where do collective identities come from? They have their origins in the pre-existing identity categories that are salient in any society. That is, while collective identities serve to animate new political or cultural constellations of actors, these

collective identities are connected to older movements and identities. For example, Verta Taylor and colleagues have engaged in long-term studies of the women's movements (Rupp and Taylor 1987; Taylor 1989; Taylor and Whittier 1995), the lesbian and gay movements (Taylor and Raeburn 1995; Taylor, Rupp and Gamson 2004), and the historical intersections and resonances between these movements (Taylor and Rupp 1993; Taylor and Whittier 1992). In analyzing the construction of collective identities across these movements, Taylor and Whittier (1992), argue that attention needs to focus on three factors. The first is boundaries. Boundaries are important for creating social spaces for marginalized groups that incubate nascent identities around social categories that run counter to dominant social values, beliefs or ideologies. Boundaries are a critical component for any analysis because they "de-essentialize" theoretical assumptions (1992:111). Rather than positing an opposition identity grounded in natural propensities, for example, boundaries reveal the different ways that similar groups are constructed differently across geography. Thus, lesbian feminist organizing will be different in Tokyo, Atlanta and Moscow, but also retain commonalities that serve to foster transnational links.

Second is consciousness: "Boundaries locate persons as members of a group, but it is group consciousness that imparts a larger significance to a collectivity" (1992:114). Consciousness means that an individual within the social space of a marginalized identity comes to see the identity as meaningful, and a frame for interpreting aspects of the world. However, the concept of consciousness has been difficult for social movement theorists to embrace fully because of it reductionist and universalistic implications. That is, it has been assumed that everybody has the same form of consciousness, and that it is

ultimately a biological function. Recent work has begun to unpack these assumptions and explore multiple, non-identical forms of consciousness that are intersected by social categories and mechanisms of power (from a growing body of literature, see Mansbridge 2001; Sandoval 2000). Taylor and Whittier develop the idea of *oppositional consciousness* (Mansbridge and Morris 2001) to argue that lesbian feminists have different ways of interpreting social phenomena, such as sexual relations between women (Taylor and Whittier 1992:115). Consciousness provides a concept for exploring how actors not only make sense of the present, but conduct daily life and construct possible futures.

Finally they highlight negotiation as a species of political action. Negotiation has private (between other members of the movement or collective) and public (wider audiences), and explicit (direct confrontation with images and ideologies) and implicit (redefining existing symbols) dimensions (1992:118). This grid of possibilities makes clear how ostensively *personal* acts (wearing certain kinds of clothes or wearing makeup) are often *political* acts as well that emerge from negotiations within the collective, and among collectives.

Taylor and other's work on feminist and queer politics was instrumental in moving analyses on identities in/and social movements forward, and opened up new horizons of research: under what conditions are collective identities formed? What are their variations and dimensions? What are their "life histories?" Why are some enduring, and others transitory? How do collective identities work with other conceptual entities, like frames or opportunity structures?

Public identities and queer dilemmas

These questions overlap with Johnston, Larana and Gusfield's third type of identity: *public identity*. They define this identity as produced by "external publics" on social movement activists (Johnston, Laraña and Gusfield 1994:18). This is certainly important, but I would broaden this form of identity to include the representations that movement activists themselves construct and deploy over time across public settings. Mary Bernstein (1997) argues that the multiple public identities that gay and lesbian activists use at different times and places are in themselves important elements within political strategies. She refers to *identity deployment* as the use of identity characteristics as discursive objects (1997:538). Following Taylor and Whittier, she identifies *identity for critique*, which deploys aspects of identity in confrontation with established or dominant perceptions and norms, and *identity for education* which challenges dominant perceptions and norms through noncontroversial methods (1997:538). Components of an identity are strategically used depending on existing political structures, movement organizations and oppositional forms (1997:539).

Bernstein's work reveals how collective identities are constructed under different conditions. Joshua Gamson (1995) argues that strategies of *identity deconstruction* are also important for social movement theorists to consider. Gamson points out an important paradox: the collective identities that movements construct and deploy are also what serve as the basis of their oppression. While these movements certainly engage in boundary- and negotiation-work, they sometimes push to blur boundaries and make identity categories unstable (1995:393). Gamson, looking at the fights over the term "queer" in the early 1990s, argues that some social movements attempt to undermine the

logic of collective identity. This "queer dilemma" opens up different questions regarding collective identities: "for whom, when, and how are stable collective identities necessary for social action and change? Do some identity movements in fact avoid the tendency to take themselves apart?" (1995:403).

Gamson's point is well taken. Liberal forms of politics, such as federal government of the United States, requires that groups present grievances, which enhances "the political utility of solid collective categories" (1995:402). This has pushed social movement theorists to reconsider *identity politics* as a subset of social movements (for a review of this field of scholarship, see Bernstein 2005). Bernstein argues that distinguishing between identity politics and NSMs organized around identities, for example, is predicated on the argument that NSMs are fundamentally *inclusive*, while identity politics are fundamentally *exclusive* (2005:54). This may be mistaken. As research on the women's, and gay and lesbian movements has demonstrated, the inclusion/exclusion binary distinction is more complicated. Social movements face counterveiling pressures from two directions: pushes for the construction and deconstruction of identity categories emanates from both internal and external sources. What is more, a collective identity is itself exclusionary. That is, it is defined by what it is *not*, as much as by what its positive content. This can have multiple effects, as Gamson (following Foucault) points out, because systems of categorization are precisely the mechanisms through which power operates (Gamson 1989:358). It is difficult therefore for social movements to be either completely inclusionary or exclusionary.

For some, this set of relationships between an object (an identity) and on the conditions of possibility for the object (counterveiling pressures) means that the

conceptual status of the object is questionable. That is, why use identity as an analytic category when it is not capturing the deeper forces that are producing it in empirical situations? This is the question asked by Brubaker and Cooper (2000) in their critique of the concept of identity. They distinguish between the "hard" and "soft" usages of identity. The hard forms of identity are saddled with some "deeply problematic assumptions," such as a focus on the unity and permanence of identities (every person or group has, or should have, stable identities over the course of their existence), which while possibly latent or hidden, sharply differentiate individuals and groups (2000:10). What has happened is that responses to these (possibly faulty) assumptions is analyses based on "softened" versions of identity; versions associated with words like "multiple, unstable, in flux, contingent [the list goes on]" (2000:11). The net result is a term that does not do any useful work.

The authors propose three sets of terms to replace identity. The first is *identification and categorization*. This calls attention to the modes of identification, such as categorical (e.g., race or gender) or relational (e.g. kinship structures), as well as the internal and external loci of identification (2000:14-17). The second is *self-understanding and social location*. This set of terms emphasizes the "situated subjectivity" of social movement identities (2000:17-19). Finally, *commonality, connectedness, and groupness* comprise the third set. These terms are designed to be "sensitive to the multiple forms and degrees of commonality and connectedness" in a more differentiated analytic frame than the single term identity (2000:19-21).

While I am sympathetic with their desire for specificity and clarity, Brubaker and Cooper may be throwing the baby out with the bathwater in their call to go beyond

identity. While automatically ascribing a concept to empirical data should be avoided, I am not convinced that the concept of identity is no longer useful for social analysis even though the language "contingency and multiplicity" may be unsettling for some. The three alternatives the authors provide open up fruitful avenues to explore the countervailing pressures on social movement participants. However, this theoretical framing ignores movements in which *the viability of an identity is itself at stake*. This is an acute issue in the research on the women's movements and queer politics described above. That is, for some movements, the terms of struggle are sometimes precisely focused around an object called an identity. This may be a strategic decision by movement actors, or it may be a defensive reaction spurred by the tactics of various opponents, or an exigency of political conflict. However, this does not mean that *all the struggles* the movement is engaged in *all the time* are in these terms. Nor does this mean that conflicts over identity are proxies or reflections of other kinds of struggles. To follow Joshua Gamson's argument, the interesting analytical questions revolve around when, under what conditions, is a collective identity necessary (or not) as a political weapon?

Even if collective identities are "on the table" at a particular moment, this does not mean *in general* their forms tend towards instability or pure contingency. Again, following both Gamson and Anselm Strauss on identity, an important question is under what conditions is a collective identity produced, deployed and dissolved and/or re-produced? What are the consequences for gaining or losing this identity? The status of a particular collective identity (which includes the concepts used to represent it) may be in a transition phase, coming into or out of salience at the individual, collective and public

levels. Neither does it mean that analytical language must lapse into indeterminacy. In order to give the concept of collective identity some support, I argue that it is important to consider work being done in political theory. These vocabularies include questions of *publics* and *recognition* in modern social conflicts.

Recognition and exclusion

The work of Nancy Fraser in particular is important around questions of publicity. In an edited volume responding to the English translation Jurgen Habermas's *The Structural Transformation of the Public Sphere*, Fraser's chapter takes on Habermas's argument that foregrounds the bourgeois public sphere. While she is sympathetic to his overall project, Fraser (1992) contends that the notion of a singular public sphere needs to be expanded in order to account for contemporary social life[24]. Rather, she develops the concept of *subaltern counterpublics* that emerge coterminously with the bourgeois public sphere. Subaltern is drawn from Gayatri Spivak's (1988) argument about the possibilities and limits of representation[25], and counterpublics from the work of Rita Felski (1989). Fraser defines subaltern counterpublics as "parallel discursive arenas where members of subordinated social groups invent and circulate counterdiscourses to formulate

[24] Fraser's argument is not a rejection of Habermas's work. Rather, along with Habermas, she seeks to uncover the normative foundations for a critical theory of democratic social action. I do not have space to go into this normative approach, however, it is important to comment that it is organized around the idea of *participatory parity*. This involves thinking about how and why individuals and groups are included and excluded across political and economic institutions. Fraser's work is *critical theory* in that it theorizes "actually existing" social conditions, while simultaneously excavating the normative principles that both naturalize inequalities, and provide possible avenues for emancipation from forms of domination.

[25] Spivak's dense arguments begin with an exploration of how even the most critical of theorists, in her case Deleuze and Foucault, end up importing a damaging ethnocentric conception of the subject into their work. Spivak goes on to deconstruct this theoretical impulse, and argues that while these two are hampered by their inattention to the consequences of imperialism on European though, some conception of the subject is still important for intellectual production. This lead to a series of debates over what became known as *strategic essentialism*, a term that Spivak ultimately disowns . However, she does retain the force of this analysis on identities as, "a persistent critique of what one cannot not want" .

oppositional interpretations of their identities, interests, and needs" (1992:123). These counterpublics have a "dual character" (1992:124). They serve as both "retreats" and "training camps." In their retreat mode, a counterpublic offers a place where an individual can find commonality and solidarity with others who are, or want to be, similar. In their training camp function, counterpublics are pragmatic political actors who attempt to persuade other publics and counterpublics of the legitimacy and importance of their work.

Finally, Fraser marks a distinction between "weak publics," which are groups that help produce collective opinions, and "strong publics," which both produce opinions and have decision-making authority (1992:134). Subaltern counterpublics are generally weak publics by definition. However, they can and do interface with strong publics. For example, Daniel Brouwer (2001) demonstrates how AIDS activists with the group ACT-UP "oscillated" between the two faces of counterpublic life. This is critical for subaltern counterpublics in that this oscillation crystallizes collective identities. That is activists move across the social landscape, from organizational meetings, to street protests, to scientific meetings, to legislative forums, and the discourses of "counterpublicity" that occur shape collective identities (2001:89-90). Over the course of action, activists get "entangled" within governmental institutions (Callon and Rabeharisoa 2003). In Brouwer's argument, congressional committee and sub-committee hearings operate as a weak public nested within the strong publics of congressional decision-making bodies.

Brouwer argues that ACT-UP's testimonies at congressional hearings carry the risks and threats of co-optation and dis-identification (Brouwer 2001:98-99). However, the benefits of testifying, including increased public attention, amplification of the

message, possibilities of access to greater resources and strong publics outweigh these potential pitfalls. Thus subaltern counterpublics do not operate solely outside the state, or in civil society, but span the boundary between state and civil society.

In a similar vein, debates over the concept of recognition were rekindled by an important essay by Charles Taylor (1994), who argued that the refusal to recognize an individual or group as having a legitimate social status is at the heart of contemporary social conflicts. While Taylor ignored much social movement scholarship that argued that grievances alone are not sufficient to generate social movement activity, his essay was provocative, and along with Axel Honneth (Honneth 1992; 1995) stimulated a series of debates among political theorists between the statuses and functions of recognition and redistribution in structuring inequality, and responses to these inequalities, in modern social structures (Fraser and Honneth 2003; Hobson 2003). A particularly acute phase occurred in the pages of *New Left Review* (Butler 1998; Fraser 1997; Fraser 1998; Smith 2001b; Swanson 2005; Young 1997) as Nancy Fraser defended her "two-dimensional" conception of justice she refers to as the "parity of participation" model (fully explicated in Fraser and Honneth 2003, Section 1)[26].

What these debates over recognition indicate is the centrality of collective identities to contemporary political formations. Many of these perspectives take as given that collective identities are exclusionary; the pressing questions have to do with what

[26] For space reasons I present on a gloss of this model. The two-dimensional conception of justice analytically separates grievances over recognition (such as debates over gay marriage) from struggles over resource redistribution (economic injustices such as growing wage differentials and immiseration). Rather than claiming either pole is the singular cause for contemporary social conflict, Fraser argues for a synthetic perspective that is analytical and normative. This perspective (parity of participation) must account for *objective conditions* (removal of institutionalized barriers) and *intersubjective conditions* (dismantling of institutionalized value patterns that deny recognition to groups) in order to be possible .

kinds of liberal democratic institutions can support and maintain recognition struggles without being immolated in the process?

Technoscientific identities and stem cell activism

In their 2003 article, Clarke and colleagues argue that technoscientific identities can emerge in four distinct ways. The first is that the diagnostic and therapeutic tools being developed and used in biomedicine can help individuals to reach a desired identity that was previously denied or inaccessible. The authors use the case of IVF which transforms "individuals" into "parents" and "couples" into "families" (Clarke et al. 2003:182). These transformations also include the panoply of techniques that resculpt tissues and bodies, from plastic surgery to CABG (coronary artery bypass grafts) procedures to prosthetic advances to intersex surgical interventions, that provide *different kinds of lives*. Second, new subjectivities become possible as biomedical techniques foster practices of self-surveillance. Cancers of the reproductive system can be self-checked by both men (testicular cancers) and women (breast tumors). These practices of monitoring the body are incorporated into palettes of "health-promoting behaviors," and individuals are encouraged to think of themselves in these positive health frames. Third, imposed biomedical mandates can create new identities through the interactions of selves and the proliferating categories of health and risk (2003:183). Pharmacuetical development, for example, routinely extends and segments risk categories around the "pre-symptomatic" margins. Finally, emerging modes of interaction foster the conditions for new identities (2003:183). The authors use the example of telemedicine, or medical services done remotely through tele-communications channels, but other practices, like

medical tourism also fit this category. Medical tourism is the "offshoring" of marginal, controversial, and/or illegal medical and quasi-medical services. The traffic in patients and objects across borders reveals not a free-floating or indeterminate set of relationships, but rather a political economy of curing, deeply suffused with relations of power.

Do stem cell activists fit any of these categories? They certainly want to move from "being sick" to "being healthy," and seem to fit the first description best. Perhaps they are a new category; *biomedical counterpublics*. This category explicitly connects the production of technoscientific identities with the spaces and technologies of public representation that are necessary to produce legitimate claims. In other words, the identities that Clarke and colleagues lay out are "constructed by technoscientific means" (2003:182), and their salience and efficacy in a particular situation will depend on the degree that they are publicly recognized as legitimate identity categories. This means that biomedical counterpublics will come into and out of focus depending on their forms of involvement (Barbot 2006) with biomedical institutions, and the degrees of recognition afforded in public arenas.

How did this operate in the case of Prop 71? For the patient activists I interviewed on this project, there was a conversion of private involvements into public intimacies (Rapp and Ginsburg 2001). That is, the networks of patient support groups that interweave through California (and beyond) were not ostensively public political organizations. This political work on behalf of patients has been delegated to PAGs and science movements (see Chapter V). Following Fraser's conceptualization of subaltern counterpublics, these patient support groups focused both inward on private involvement, and externally in terms of connecting with professional and informal caregivers and allied

counterpublics. These patient support groups focused inward on private involvement. That is, while the forms on involvement varied both within and among patient support groups, the groups did not mount campaigns to influence California policy, for example. Their focus was the concerns of their own membership. A great example of this is Patricia. Patricia's PDLA list helped to provide Parkinson's disease patients in the Los Angeles area information on events or announcements pertinent to that area. As Prop 71 began to take shape, her list served as a conduit for the Yes on 71 campaign. She included information about Yes on 71 events on her list, but never relinquished control over the list. This work at the least helped draw yes votes, and may have even spurred other list members on to further activism on behalf of the Yes on 71 campaign.

The collective identity of stem cell activist flourished in both weak and strong publics. Stem cell activists in support of Prop 71 were operating both within and outside of the state. In the state of California, there was deep legislative support for human stem cell research (see Chapter IV). The California initiative process could be considered a strong public, in that a successful initiative carries the weight of law. It is a decision-making institution. What is interesting is that the work of activists in their weak publics also benefited the Yes on 71 campaign. While activists had concerns about the proposition and the campaign rhetorics, there was little concern about co-optation. The No on 71 campaign, on the other hand, could only conceive of supportive patient activists as dupes who were confused or mislead by the campaign. Empirically, this is unjustified, as many of the activists I interviewed had understandings and critiques of not only human stem cell research, but also the politics of biotechnology (disputes over intellectual property or the risks of human clinical trials for example), and the contradictions of

health care generally. Prop 71 was successful not because it was confusing or ideologically driven. In fact, if this were the case it should have failed. It was successful because weak and strong publics found *resonance* with both private involvements and public intimacies (for a recent explication of resonance, see for example Connolly 2005).

If the initiative process constitutes a strong public, what in this case are the weak publics? I have already highlighted the importance of groups organized around health and illness, from informal gatherings in living rooms to formal PAGs. A second important weak public was the series of public events over Prop 71 and human stem cell research more broadly. These ranged from large lay and scientific conferences to smaller town hall style meetings. These meetings brought together various experts from different disciplines to talk about human stem cell research, and they were important precisely because they juxtaposed very different discourses around the same object (for more on the importance of these events see Chapter IV).

The public intimacies that took shape on the Prop 71 campaign during the summer and fall of 2004 were not neutral. That is, the counterpublicities of being a stem cell activist were not without costs and benefits to different groups. For patient activists, this meant being confronted by a complicated set of biographical (or individual level) problems. I explore a subset of these problems in Chapter V. Despite their biographical difficulties, the public intimacies produced by patient activists afforded them a deep degree of public recognition. This public recognition revolved around *the form of suffering*. That is, supporters of Prop 71, and Yes on 71 staff, and *patient activists themselves* used suffering as a rhetorical strategy to promote Prop 71. This reflexive use of the form of suffering marks the conversion of private involvement into public

intimacy. Tracking the debates around this conversion reveals the "insides" of the identity of stem cell activist.

As I argued above, identity categories are also formed from the outside. In other words, the benefits for the Yes on 71 campaign of the conversion of private involvements into public intimacies were enormous. The public intimacies afforded by recognition of suffering from a disease or condition that might be ameliorated by stem cell research were one arrow in the quiver of the Yes on 71 campaign that was deployed against opponents. This tactic was not new. Prior to Prop 71, both SCAN, and before them Patient's CURe used patient's narratives and "Portraits of Hope" to produce public affect. The success of Prop 71 ratified this political technology.

In addition to the production of identity categories, this analysis foregrounds the *importance of technoscientific objects* in this particular health social movement. Like Clarke and colleagues typology of technoscientific identities, stem cell activists are oriented around an aspect of biotechnology. Through the public controversies over human stem cell research, activists both position themselves, and are positioned by others across arenas of conflict. Are stem cell activists "implicated actants?" (Clarke 2005; Clarke and Montini 1993) The answer is no. While they are represented by others, actual patient activists are usually present on the scene. For example, the structure of the California Institute for Regenerative Medicine has built-in patient advocacy. As Oudshoorn and Pinch (2003) make clear, users matter. In the case of Prop 71, stem cell activists played a central role in the public representations of what one form of regenerative medicine might look like.

Finally, this analysis points towards the *importance of events* in the life histories of identities. Proposition 71 was not written and campaigned for in order to help consolidate the identity category of stem cell activist. This happened "behind the back" of Prop 71. Identity categories emerge, and some fade away over time. The punctuated time of political life in California (and beyond) helped to sharpen the contours of the identities of stem cell activists. The relatively short amount of time to campaign, and the frenetic pace of modern politics can be juxtaposed to longer campaigns, such as the North American civil rights movement, that sought to make strong, enduring identity claims.

Back to stem cell activism and Prop 71

I argue that stem cell activism during the Prop 71 campaign can be understood through the concept of a biomedical counterpublic. That is, patient activists became stem cell activists through the cultivation of an identity category created through technoscientific means, namely, a potential beneficiary of regenerative medicine. In addition, they publicly produced this identity category by displaying their illnesses across social worlds. Rather than hiding stigmatized conditions, they engaged different modes of disclosure (Charmaz 1993) as representational tactics.

The importance of Prop 71 to the formation of stem cell activism is two-fold. First, active elite support of this identity category came along with massive material donations. The Yes on 71 campaign spent over 34 million dollars during a professionally run campaign. A major thrust of this campaign was foregrounding patients and their conditions as potential beneficiaries of this campaign (for more detail on this see Chapter IV). Second, though the initiative process, the Yes on 71 campaign consolidated different

claims, including scientific, moral and economic arguments within a single political vehicle. In other words, stem cell research was presented as having scientific, moral and economic value that deserved public support.

These are sufficient conditions for the formation of a biomedical counterpublic. The necessary condition is people who want to become members of a counterpublic. However, becoming a member of this counterpublic, in other words becoming a stem cell activist, confronted potential activists with a series of problems. These problems are neither absolute barriers to activism, nor are they one-time "check-points" on the terrains of struggle. Rather, they are on-going negotiations whose outcomes bring people into, and out of, stem cell activism.

1. *Managing the ambiguities of hope.* HESCs as objects of discourse provide no secure foundations for action. They are *scientifically and morally difficult*. The identity of a stem cell activist emerges through the working on these difficulties. This constitutes a murky domain called the *ambiguities of hope*. That is, while "hope" is a critical concept for animating social action, it does not impinge directly upon a subject. Rather hope is fomented and mediated through the *discursive formation of curing*.
2. *Producing relationality and affinity.* Activists had to develop relationality to each other across very different diseases and conditions. This means overcoming historical perceptions of difference. Relationality does not occur spontaneously. While individuals certainly use others as referents in

the quotidian construction of life, this form of relationality is dependent upon the *public production of affinity.*

3. *Displaying illness authenticity.* As diseases and conditions have become appropriate objects of political discourse, they now embody new faultlines. That is, as objects of politics, diseases and conditions must be performed in the proper political institutional settings. This creates a set of problems around the *public display of claims to illness authenticity*.

The ambiguities of hope: You got your hyperbole in my rhetoric!

Certainly one of major reasons for the astronomical rise in attention given to hESCs is their potential to ameliorate a wide variety of conditions or illnesses. As I discussed in Chapter II, stem cell research has experimentally revealed the remarkable plasticity of human cells, tissues, and even organs that was at first only a contested theoretical possibility. Despite the excitement that pervades regenerative medicine, stem cells derived from human embryo precursors, whether "surplus" or "fresh," is deeply ethically controversial, as well as institutionally proscribed.

Patient activists have looked to stem cell research, like fetal tissue research before it, as a possible avenue of cure. This is the case largely because the scientific literature has affirmed this possibility. However, hESC research remains at a very early stage at the present moment. Moving a possible therapeutic from idea to market is a long, costly, and highly risky endeavor. Given the technical and political uncertainties around hESC research, the necessary large, institutional investors have not opened the tap.

Despite the mammoth difficulties around the clinical development of hESC technologies, there is an incessant stream of statements – from news reports to institutional assessments, from official white papers to web logs ("blogs") – reiterating, developing, challenging, supporting and/or worrying about the implications of hESCs as precursors to possible therapeutics, and the social futures that might arise if regenerative medicine continues to develop. I refer to this stream, following Foucault, as a *discursive formation*. A discursive formation is a set of statements that orient around an object, and produce that object as an *object of discourse.*[27] For example, Timothy Lenoir (1997:49) argues:

> The idea of clinical medicine as a discursive formation, for example, attempts to capture the connections that emerged in the nineteenth century among statements concerning pathological anatomy, comparative anatomy, tissues, lesions, autopsy, percussion, auscultation, case histories, the hospital, hygiene, statistical method, etc…The discursive formation is, accordingly, a historically conditioned system of regularity for the coexistence of statements.

One could create a list similar to Lenoir's regarding stem cell research. This list would include objects that are historically specific, such as venture capital or PET imaging devices, as well as the objects from Lenoir's inventory. One crucial object is the patient.

Patients are a critical object in what I will call *the discursive formation of curing*[28] for several reasons. First, they are the target of the intervention. Patients are framed as the primary potential beneficiaries of regenerative medicine. Second, patients are neither inert nor passive, but active in the production of this discursive formation. Patient activists utilize social institutions on their own terms and for their own benefit, unlike model organisms for example, they can represent themselves, as well as being

[27] This is of course to distinguish between objects of discourse and "objects-in-themselves." That is, this argument does not claim that discursive formations create objects in the empirical world. The latter is a kind of naïve realism.

[28] This formation would take account of statements that take on the possibilities of stem cells as curative agents. This would thus include a wide territory, including, scientific, medical, political, economic, religious and secular civil society organizations, to name a few general categories.

represented by others[29]. Third, as human subjects, patients are supported by formal and informal system of legal assumptions, decisions, rights, and responsibilities that necessitate specific technologies of participation (such as informed consent). This mitigates against potential instrumental involvement, but does not preclude it from actually happening. Finally, as political actors, patients accomplish tasks across a variety of social worlds and traffic and translate statements between these worlds. In other words, they can spread the message, organize, lobby, make demands of and/or protest against different actors at different times outside of the logics of formal political or technical directives. For example, science movements and PAGs have become incredibly sophisticated in the public realm, and can be more nimble than professional organizations or other formal institutions representing scientists and their interests.

It is obvious that patient activists represent themselves across different social worlds. At the same time, they are being represented in different discourses. That is, in the above example, patient activists are simultaneously beneficiaries of medical progress, subjects in legal structures, and socio-political actors. Corresponding to each of these subject positions are groups of statements that delineate the contours of that particular subject position. For example, in their examination of the relationships between human subjects and researchers in a clinical trial, Morris and Balmer (2006) argue that subjects take on a variety of identities, including "potential beneficiary," "collaborator," and "guinea pig" during their participation in the trial. The authors emphasize that the processes of negotiating these identities are not isomorphic with other clinical encounters,

[29] This opens up a series of interesting questions about the status of models in the biological sciences. For example, what are the differences/similarities between *model organisms* and *human subjects* in terms of the *kinds of models* that they are? What do these differences/similarities say about the nature of models within science?

such as the patient-doctor relationship: "Invoking and moving between multiple roles and identities is part of the process of navigation through unfamiliar social territory and active negotiation of a socially satisfactory researcher-subject relationship" (2006:1006). In other words, these identities are situational (Clarke 2005). However, identity categories like potential beneficiary or guinea pig which make sense within the context of the clinical trial, are also understandable in other situations. What is more significant for my argument is that the subjects in clinical trials self-reflexively turn themselves into discursive objects. Patients understand their identity as collaborator, or conversely as guinea pig, as precisely an identity produced by the position of being a subject of biomedicine. In order to achieve "socially satisfactory" relationships across social worlds, patient activists use statements that provide provisional utility ("I am a potential beneficiary of regenerative medicine") that are constellated within more general claims ("Regenerative medicine is potentially beneficial for many kinds of illnesses and conditions.") The identity of potential beneficiary or guinea pig is not mechanically imposed by institutional processes, but discovered by the subject through participation.

A second object of interest within the discursive formation of curing is *hope*. I focus on hope as an object not because hESC is inherently hopeful, but because it was a key rhetorical framing in the Yes on 71 campaign. Hope is an important "framing strategy" for biomedicine in general for several reasons: it legitimates medical intervention by offering a curative future; it helps ensure patient compliance with often difficult, and potentially lethal therapies; finally, it enrolls support from outside formal biomedical institutions and professions in the political support of biomedical work. In other words, the existence of the discursive formation of curing does not automatically

create belief in it. That is, simply hearing about the potential of hESCs is insufficient in itself to create stem cell activists. An actor must take a stand. Hope itself provides an important position from which to speak publicly. For example, the following exchange occurred after I asked LF if she felt that Prop 71 played up the curative aspects of stem cell research:

> Jackie: There was a [names conference] on stem cells, did you go to that?
>
> INT: I was there.
>
> Jackie: Yes, I went to that too. In fact, I stood up and made a comment at it about that duping in particular, and I stood up and said something like "I have this disease, I live this disease, I understand the reality. I'm not foolishly following and I'm not being duped. I know what's the potential and it's important we go ahead with it and do it." So I – it's the same reproductive health argument that drives me crazy. "These women are going to be duped into giving their eggs." I mean women are smart enough, they're not – I have a belief in me – the wisdom of people as more than just dumb sheep that are forced into following bad advice. We're smart people, we can figure these things out.
>
> Interview 7/28/05

Jackie's statement comes out of a biography of deep involvement in reproductive politics. She studied both agricultural economics and maternal-child public health at a graduate level, and was an executive with a prominent reproductive services organization. She was diagnosed with PD in 1994, at the age of 32. Her background is important for framing her assertions of the "wisdom of people." She translated her understanding of living with PD into public action – speaking at a lay conference on stem cell research. The hope of a cure provided an opening for her beliefs to be translated into political claims in a public venue.

The hope for hESCs providing a "miracle cure" was tempered by understandings of the uncertainties associated with scientific research, drug development, and the political economy of biomedicine. I refer to this as the *ambiguities of hope*. Here I do not mean that that the feeling of hope was unclear; rather, hope was strategically

segmented and qualified in various ways. Another example is Paul, whose statement regarding stem cells and other kinds of therapies was repeated by other subjects:

> I think in the heat of political campaigning, you get a little hyperbole in your rhetoric. *One of the things that I have been strongly advocating is that we don't put all our eggs in the stem cell basket, and other research [should]continue and be well funded and not neglected, because stem cell research is in its infancy, and there's no telling what it will yield, or what the timetable is for finding the breakthrough discoveries.* I think it's going to be incremental, and even breakthroughs are going to answer some questions but raise a slew of others. There's really so much to learn about how these cells interact. I would love for them to find a cure within my lifetime. I wouldn't be surprised if it takes 10, 15, 20 years before stem cells can be used therapeutically, but I think people hold onto the hope, and I hold onto that hope too. But on political campaigns you say 'this will make your teeth whiter, and grow more hair.' Those things happen.
>
> Interview 8/17/05

This statement reveals several aspects of one stem cell activist's engagement with the discursive formation of curing. First, stem cells are made therapeutically equivalent; they are one modality of cure among others that should be pursued. Second, human stem cell research is brought within a temporal horizon. One of the elements of the discursive formation of time is the deferral of time. Potential treatments are constantly assigned a potential future, usually in years. This is, of course, simply guessing. Nonetheless the form of this statement has become naturalized. Paul indicates this deferral through his stated desire for immediate cure, as he also realizes that no therapy will be available to help him in his lifetime. Third, the production of statements about human stem cell research is always already contested. In this case, Paul understands that the production of claims about therapies is tied to the political structures of an electoral campaign. Claims are clearly inflated for political purposes, and he understands the rhetorical nature of this inflation.

Another PD activist (Patricia) echoed these elements:

> I think it was necessary to have that 'save lives' [rhetoric] to counter the opposition who were saying 'don't kill.' There's no questions there's a potential – there's all kinds of reports, in different animals, that seem like really good responses. That's a big step. But it might be that [a cure] – that's the key word, it might be. I have some concern that all

> this effort has only gone this one direction, when there are so many other directions, if they're looking for something that will help in general, lots of different people, I can't object to that.
>
> Interview 8/19/05

Patricia's remark does the work of equivalency, in a slightly different way. She understands that like any potential therapy, hESC research could be a failure. If patient activists yoke their hope to this potential without any qualifiers, or "side bets" in Howard Becker's (1960) terminology, then they run the risk of giving up support of human stem cell research completely. That is, human stem cell research becomes an all or nothing proposition, which in the worlds of biomedical science is an extremely risky position to take. This is due to the erosion of the generalized belief in the authority of science (see Chapter III). Thus hope for a cure was always accompanied by its shadow, doubt about the possible curative future of regenerative medicine.

In the context of Prop 71, the ambiguities of hope were also reflected through criticisms of the Proposition itself. For example, this occurred in asymmetries between rhetoric and experience. One activist (Jackie) found some of the framing techniques used by the Yes on 71 campaign to be unsettling:

> In fact, one of my other complaints about the campaign was that there was – they'd say "49 days and counting, 31 days, etc.," and make a push, a big countdown. And every time I'd hear the countdown I was saying, "You know, the disease is not ending for me in 31 days, in 8 days, whenever." And it would just kind of irk me a little bit every time I heard the countdown, the big push because it's – that was not my reality. It was important but it's – the disease goes on and so you got to do what you can to live with that, and there's kind of a normalcy that I have to have that you don't have in a campaign.
>
> Interview 7/8/05

Also present were understandings of the difficulties of a controversial biomedical technology in terms of popular rhetorics:

> I mean, if I didn't have Parkinson's disease, my taste for new and brave new advances and progress and so forth would be less sharp, would be less intense, and I think part of me would react like the average person does. Where the hell is this going? What's next? If you can clone a mammal like Dolly [the sheep], can you clone a person? Now recently

> there's been a study that they think for specific scientific, biological reasons it may be impossible to ever clone a human being…It is that idea that we're all sort of comfortable in our present and we're all sort of uncomfortable with what the future may hold. It's not 1925 any more. Every bit of technological progress is not seen as a godsend. There's that late 20th century, early 21st century fear of the future. What's going to happen? Is this going to be a runaway thing? You know, eugenics, and can I have a baby with blond hair and blue eyes—all that stuff. It's understandably scary.
>
> Interview 5/8/03

The reference from John, a PD activist, to eugenics is interesting, as this is one of the major concerns of left-leaning critics of human stem cell research. Other stem cell activists raised similar concerns about the science:

> I'm not up on the specifics of the science, but I'm understanding more and more how it works. And also the dangers of it. Animals that have weird growths, and teeth coming out of their socks [laughs] that kind of grotesquery. The danger for patients is to put all their hopes on it. Given the complexity of it, and the length of time it would require to have a clinical trial, it's going to be years and years, before we have anything clinical. I think it would be really long. Cancer has been a focused effort for a long time. Of course we know a lot of things that people do, their environment, the lifestyles that lead to cancers sometimes, but it's taking a long time. The war on cancer has been going ever since I can remember, started in the 60's.
>
> Interview (Patricia) 8/19/05

Given the technical, ethical and political difficulties of human stem cell research, stem cell activists highlight hope within the discursive formation of curing for multiple reasons. This includes rhetorical moves against hope's shadow, doubt, which is always present whenever hope is invoked. Hope also operates rhetorically to combat opponents of human stem cell research who sought to derail the Yes on 71 campaign and/or arrest the research in general.

During the Prop 71 campaign, hope did not operate as an objective, abstract interest that activists accepted without reservation. While hope was constantly reiterated by the Yes on 71 campaign, human stem cell research, and in particular hESC research, is not repeated without question or concern, or awareness for grave complications, by stem cell activists. In this sense, stem cell activists were not fusing their present or future lives

with the imperatives of research (Callahan 2006). They were not falling victim to the "therapeutic misconception" (classic statement is Appelbaum et al. 1987). Appelbaum and his colleagues identified an important conflict between the clinician's duty to provide the best care possible to individuals, and the demands of research protocols to treat groups of people identically. This can lead to a difficult problem: research subjects "misinterpret the risk/benefit ratio of participating in research" because of deficits in knowledge and the inability of researchers to dispel these deficits (1987:21). What is different with stem cell activists is that they are speaking about a future state, rather than an actual clinical trial, which is Appelbaum's interest.

The data presented here indicates that the stem cell activists I interviewed were well aware of not only the scientific and clinical problems of human stem cell research, but also the controversies in economic and political realms as well. Hope is used as a discursive object in these different debates strategically, rather than operating as a marker of a deficit.

Relationality and affinity

A second set of problems that face stem cell activists concerns forming a (somewhat) unified front in support of hESC research. Even though individual activists were wrestling with the hope/doubt dilemma, this did not prevent them from acting politically and joining organizations to further the cause of human stem cell research. The production of a unified front has been helped by several developments. First was the level of priority given to hESC research by several high-profile PAGs, such as the Michael J. Fox Foundation (e.g. MJFF), Christopher Reeve Foundation (CRF), and the

Juvenile Diabetes Research Foundation (JDRF). Second, the emergence of science movements have helped to structurally focus attention at key targets in government. Third, new organizations, such as the Genetics Policy Institute (GPI) and the Stem Cell Action Network (SCAN), have arisen to promote precisely hESC and nuclear transfer technologies. Finally, efforts by members of scientific and biomedical social worlds to work with patient activists and others through workshops, conferences and meetings to promote hESC as a legitimate curative enterprise have been quite significant.

The discursive formation of curing is critical to successfully producing a united front. For example, scientific articles about stem cells will often list the benefits of the research to various populations of patients (for example, one of the early papers detailing hESC culture techniques, Thomson et al. 1998, listed a litany of diseases and conditions that could be ameliorated with hESCs). This is an important rhetorical move because it *brings different diseases and conditions into proximity*. As a technology, stem cell research has a potential benefit to many different kinds of end users, and this rhetorical proximity evokes a "we're all in this together" spirit.

However, these different end users have been historically at odds, and even in competition due to the funding mechanisms of the NIH. Procedurally, the President prepares the NIH's budget, and the Congress approves the actual amounts of money that go to a particular area (Dresser 2001:75-6). Congress also relies on testimony from NIH leaders who have close understandings of public health needs and the state of the science (Institute of Medicine 1998). In addition, patient activists visit Congressional offices in order to directly lobby for their condition. Stem cell activism provides a way around this

competition problem. A Type I diabetes activist (Victoria) articulated this idea, which was repeated by others:

> I haven't done much with CAMR, I've done quite a bit with SCAN. That was actually a new association, when they had their first meeting in Berkeley, and JDRF was very involved with that. And that's a new thing, because it's bringing together a lot of different organizations, and selfishly we are competing for the same dollars out there from the public. And I thought it was very exceptional to have all of these organizations come together and say "We need to focus on something that is common to all of us and not be as concerned about our own parochial interests in fundraising"… We're all fundraising organizations, and that will continue but I think that we have definitely joined hands and said, let's try to pass this initiative, and make that work because it affects all of us. But that doesn't mean we give up our individual fundraising efforts.
>
> Interview 9/13/04

Since PAGs must raise some level of funds in order to exist, this competitive fund-raising situation is a serious problem. Biomedical technologies can mitigate this problem somewhat if they operate at a suitable level across multiple physiological problems. Another Type I diabetes activist (Ed) framed this problem through multiple organizations' lobbying of politicians for increased research support:

> A few things are happening. One is autoimmune diseases are skyrocketing across the board. An autoimmune disease is obviously one that attacks another part of the body. So those seem to be absolutely skyrocketing and no one quite understands why that is. It's starting to look that some of the things, for example, that are going on in Type 1 diabetes Research funding for blocking the auto-immune attack, they will have great benefit with other auto-immune diseases. So the NIH, for example, in the last few years did their first conference on auto-immune disease in general, so there may be a situation where, I wouldn't be surprised to see some more direct cooperation with other groups. Then research matures related to all kinds of research, whether it's embryonic stem cells or other types of mechanisms for blocking auto-immune attack. So it was a pretty interesting, I was in a lobbying tour through Washington State, and the group ahead of us was the ALS group. Research that indicated that a certain blocking mechanism for Type I might be helpful with ALS. And so it's that kind of thing where I can see in the future… In this case it was in Senator Feinstein's office, rather than first the ALS group, and then the next group is JDRF, and the next group is some other disease group, that you might see a coalition going forward.
>
> Interview 10/7/04

This activist is keying into the ways in which stem cell research, as a technology, has the potential to intervene at a variety of levels. At the level discussed above, auto-immune

disorders, the pathological process effects different types of cells and tissues. Arresting or reversing the disease process is thus of avid interest for a variety of PAGs. This has benefits for PAGs; for example, rather than each group saying something relatively similar, they can save resources by creating a coalition that represents all auto-immune sufferers. Consequently, this coalitional form provides rhetorical support for a controversial technology by enlarging the pool of potential beneficiaries.

The organizational proximity around Prop 71 was both transitory and enduring. The transitory elements were associated with tactics around the immediate goal of getting the initiative passed. This included signature gathering, volunteer recruitment, and strategizing sessions during the campaign (see also Chapter IV).

The enduring elements were new organizational forms that brought patient activists together with each other, as well as scientific, clinical, political and economic actors. The interactions among patient activists with different diagnoses set the conditions for thinking about shared experiences across these differences, and the possibilities of concerted political action. Thinking across difference is a critical step for mobilization. The case of disability activism makes this clear (see Chapter III). For example, a stem cell activist with a spinal cord injury (Rachel) described how she balanced her hope in the curative potential of stem cell research with the different institutional hurdles that dampen her enthusiasm:

> So how do I balance the two? [being a stem cell activist while understanding the uncertainties] I think I stay focused on the potential of how it can help other people as well. It's not really the central point of advocating, the way I look at it, is there are millions of other people out there that - although I have what some people might look at it - "Oh, my God! That's horrible! I'd hate to be in your position." To me, I'd rather be in the position I'm in than, God forbid, having a progressive disease. Because then what do you do? Then it becomes a little bit more—it's scary. And that's why I'm fighting so hard, because I want to help those people that are progressively getting worse. People that have Parkinson's or cancer.
>
> Interview 6/17/05

For Rachel, a progressive neurodegenerative disease posits a much different future than her now relatively stable spinal cord injury. In contrast, for Patricia, who has a progressive neurodegenerative disease, it was a different reference population that made her think about her activism:

> For example, I was in a fundraiser once, I don't remember for what cause. But there were different disease groups, and on one side of me there were the blind children, and the other side were the paraplegics or something. And I just couldn't speak up [laughs]. PD is a difficult disease, and everybody calls it devastating, but God, blind children? What am I doing trying to compete with them?
>
> Interview 8/19/05

Proximity with others is central to the formation of stem cell activism. The perspectives it offered played a role in the construction of the identity of stem cell activist. The Yes on 71 campaign directly fostered these relationships through actions by Yes on 71 staff and supporters (see Chapter IV for more detail on this work), forging the coalition, holding meetings and fundraisers with different PAGs simultaneously, and continuously reiterating the list of diseases and conditions that could be potentially ameliorated with human stem cell therapy.

The on-going re-evaluations by stem cell activists were inflected through proximate relationships, as well as more distal ones. Telescoping out from face-to-face interactions, stem cell activists also display their illnesses and conditions to wider, more dispersed publics. However, interactions at broader levels of social organization introduce new problems. I characterize these problems under the heading of authenticity.

The politics of authenticity

A third set of problems confronting stem cell activists is a direct result of the intense public nature of contemporary biomedical politics. That is, the questions of

relationality discussed above are predicated by public performances to one's self and others. These performances are important as they determine which disease-focused groups get how much and how soon. However, performances are not risk-free; that is, they are not merely an act that one puts on in an ironic manner. Rather, they are connected to corporeal states. They have a *physiological authenticity* to the performer. My intent here is not to explore the experience of this authenticity phenomenologically. It is my assumption that the corporeal states under discussion here are real; that is, I am not interested in proving the existence (or non-existence) of these states. Rather, I am interested in the *public interfaces* between corporeal states and institutional forms, which are spaces for the legitimate performance of stem cell activism, and the enactment of biomedical counterpublicity. I will call the claims made within this tangle *the politics of authenticity*.

What is at stake in the politics of authenticity? On one level, a successful performance can lead to the allocation of material and symbolic rewards. However, the status of the performance became a question for those in the process of becoming stem cell activists. For example, consider this exchange:

> Julie: One of the reasons I would be glad to go and speak is that I can show people – by the way, I'm Italian. I can show people what a person looks like when the medicine's working because I'm "normal."
>
> INT: Why do you think that's important to show?
>
> Julie: So they can see the fluctuations and see what we – what it's like to wear our shoes. Because right now I'm okay. This is my Italian in me [demonstrating gesticulating].
>
> INT: That's not the PD [laughs].
>
> Julie: Yes [laughs]. They need to be able to see that Karen has times when she's "normal" but she also has times when she can barely move. So I feel that in one person they can see the great fluctuations that we live with.
>
> INT: Why is it important to show them? What will that give them?

> Julie: In today's world I'm not sure how much it would give them but I would hope that they could see that it's not easy and that the medicines and the pills that we take are not the answer. Because a lot of people will say, "Oh, but you can take the pills." Yes, I can take the pills, I know how to swallow, I know how to drink a glass of water, I can take the pills. But to try to show them that the pills are not the answer, that we need something else, and right now the only something else would be embryonic stem cell research. We've lost already five years with your friend and mine, Mr. Bush, because of his Christian background. I'm not being facetious, I consider myself a Christian but I believe in helping people not unhelping people and he's just the opposite. I mean I've been a Christian longer than he has! So that's what I would hope to be able to show people because all the research up to this point has been new pills and the new pills do this. This pill, if you take it, will enhance this pill, which will enhance this pill, which will – you know. They cause hallucinations, they cause lowering of blood pressure, they cause dyskinesias. They're not the answer.
>
> Interview 7/12/05

Julie is in a difficult situation. On the one hand, she wants to display to an audience her normal state (which is the result of a very complicated schedule of medicines) in order to accentuate the radically varying symptoms of PD. On the other hand, this performance of normality is directly intended to undermine the rationale of her medications. That is, the regime of pills that she takes (she also carries a timer with her at all times to remind her when to take a pill) is only partially helpful. It takes up much of her time and attention, requires constant maintenance, does not always work as planned, and sometimes produces deleterious side effects.

In sharp contrast, stem cells offer the possibility of a cellular transplant, and NT offers the possibility of a cellular transplant of her own tissue. For Julie, this technology would do away with her dependency on pills, and their accompanying side effects. In order to present this argument *in an embodied form*, Julie presents herself as normal in certain public spaces in order to talk about the deficits of pills. This is one modality of the politics of authenticity.

Julie also speaks about the importance of presenting herself *with* symptoms at times:

> It's just like – my doctor has said to me – I was having trouble writing again, and I didn't want to up my medicine and so forth, and so I thought about going on disability and I was a year away from 65 at the time. So in order to get Medicare disability you have to see one of their doctors and whatever. And my doctor said to me [whispers] "Don't take your medicine. And then you'll fail the test." Because it's like she said, I worked sixteen years with the disease and so, yes, a lot of us will do that. When I spoke that day over in [names city] I had let my medicine wear off a little bit and you could hear the tremor in my voice, and you could see me tremoring and whatever, and I did that on purpose because it really doesn't hurt you that much if you don't do it every day. But I think he – I agree with Michael J. Fox, people have to see, they have to wear my shoes for one day.
>
> Interview 7/12/05

One could argue that Julie's choice of mode of self-representation is opportunistic. That is, she chooses which embodied presentation to make, normal or symptomatic, based on immediate political exigencies or longer-term agendas. This argument is based on the assumption that symptoms can be presented at the subject's volition. In this sense, it similar to forms of self-representation in public forums that seek a scripted emotional response for the audience. For example, an individual who is guilty of some transgression will appear humble, speak in low, measured tones, and ask for forgiveness or appeal to the magnanimity of his or her audience. This scripted response allows audiences to understand what is happening, although different audiences interpret scripts differently.

However, Julie's form of politics is more complicated. Rather than reducing these forms of self-representation solely to a calculating political rationality (which on one level they are), we should think of them also as *the presentation of disease identities in public interfaces*. That is, they are embodied performances, like the example above, but they require cultivation, practice and organization. In short, they require *identities*. Julie cannot completely control her embodied performance, so it is not isomorphic with other kinds of self-representation. That is, the symptoms of PD should not be considered performance. The body twitches, squirms or shakes outside of conscious control.

Symptoms have a physiological authenticity. This produces different responses from subjects, ranging from deep seclusion to intense engagement. Audiences respond differently as well. The unease associated with strange, and sometimes disturbing bodily symptoms can lead to stigmatization (Goffman 1963). Various disability movements, as we have seen above, directly challenged these processes of stigmatization by foregrounding symptoms in political protest. Julie, and other stem cell activists, strategically display symptoms, yet they are not performances like other public forms of self-representation. In order to pull off the performance, activists need to understand what is at stake. They require an identity as a stem cell activist. Lack of this identity precludes public activism. As an example, one that Julie cited above, I turn to the case of Michael J. Fox.

Lucky man? On turning into a pumpkin

In recent years in the United States and elsewhere, PAGs have been started, endorsed and/or supported by celebrities. Individuals such as Christopher Reeve, Mary Tyler Moore, and Muhammad Ali have taken public positions as spokespeople for different diseases and conditions. Some scholars have argued that celebrities get involved with social movements "in which they can claim legitimate standing" (Meyer and Gamson 1995:190). Celebrity involvement will also effect the rhetoric of movements, including using more general rights-based discourse despite the specific claims of a movement in order to appeal to larger groups of people, utilizing a charity framing strategy for the movement, and appealing to wider collective benefits above

movement goals (1995:190). In short, sustained and engaged celebrity participation transforms social movements.

In 2002, Canadian actor Michael J. Fox's self-styled memoir entitled *Lucky Man* came out in publication. Fox, known for television and movie acting, was on the way to becoming a major film star when in 1991 he was first diagnosed with PD. Fox (2003:152) writes how he initially hid his diagnosis and symptoms through a variety of mechanisms, until 1998, when he disclosed his diagnosis in a Barbara Walter's interview on the popular evening news program *20/20*, and the celebrity-oriented magazine *People*. Fox's actions revealed to him, through an unexpected outpouring of letters and other contacts, a vast underground world of individuals like himself, diagnosed with PD under the age of 65, living in "closets" in fear of the repercussions of being known as a person with PD (2003:230).

Lucky Man recounts Fox's struggle with his diagnosis and its sequelae, namely the threat it poses to his life, career, and family. As a trained actor, he is skilled in masking the effects of PD in order to "pass" (Goffman 1963) in his everyday activities. However, he describes in painful detail the costs of his attempts to pass, to himself and loved ones. Fox describes his awakening to the notion that his disease wasn't "personal," that there were others like himself, struggling with similar problems. Through the voice of his neurologist, Fox reframes his acting vis-à-vis his emerging identity as a person with PD: "Being an actor makes you inherently very observant about your behavior. The manner in which you felt and expressed the experience is very different from most patients. It puts you at an advantage in managing it" (Fox 2003:179). For Fox, being an

actor meant being skilled at passing, but also skill at presenting oneself in a scene. This is an example of *emotion work*.

In her pioneering work, Arlie Hochschild (1983) argues that different occupations, in her case flight attendants, engage in a kind of acting; they imagine themselves as acting a role, which in turn depends on how the airline presents itself, in order to meet the demands of the occupation without reacting in professionally inappropriate ways. Hochschild understands the flight attendants' reactions through the metaphor of method acting. That is, the flight attendants cope with difficult in-flight situations by acting as if something else was actually occurring. They re-framed difficult situations in new ways by acting as if something else was really happening. In terms of Michael J. Fox, he never stopped acting. Rather, he adjusted his identity to fit the demands of the new role – being "out" with PD.

Prior to his public announcements, Fox engaged in a repertoire of carefully timed practices: tapping a pencil to mask the hand tremors; leaning against walls; having to miss appointments to take "important phone calls" in private; and a meticulous schedule of secret ingested medications, as well as making sure he always had extra Sinemet pills with him at all times. This was all in the effort to avoid the most dreaded moment, "turning into a pumpkin" (Fox 2003:222), or having his symptoms appear at the worst possible moment: the middle of shooting a scene. For his segment with Walters, she asked him to put on and take off his leather jacket in order to demonstrate the difficulty PD patients have with everyday activities (Fox 2003:224-25). This shot never occurred because Fox was "on" his meds (as opposed to being "off," or displaying symptoms due to lowered levels of medication in the bloodstream). Following his announcements, Fox

became more active, and eventually began his eponymous foundation. He would testify before House and Senate subcommittees "off," in order to display what living with PD entailed. This was less difficult for Fox than for others because of his profession.

Celebrity participation in HSMs present different challenges than participation with other movements. Primarily this is because the celebrity generally shares the disease or condition with a population. This gives celebrities legitimacy that may elude them in other struggles (Meyer and Gamson 1995, especially the Amendment 2 struggle in Colorado). Celebrities, especially actors, are beneficial to HSMs precisely because of the comfort of being on display. For patient activists not trained in acting, it is more difficult to display the physiological authenticity of a disease or condition at a public interface. For some it may be impossible, and this precludes public activism.

Public presentations

Before his organization of his PD activist identity, Michael J. Fox struggled with the tasks of keeping his condition hidden. The lack of an identity not only arrested his activism, but also lead to open conflict with those around him. Making his activist identity public fostered different interpretations from supporters. For example, John and Carol spoke about the unintended consequences of Fox's public identity:

> Carol: And also we were incredibly fortunate from Mike's [Michael J. Fox] misfortune—he's got to be one of the most beloved men in the country.
>
> John: God knows why. I mean, he's a nice guy.
>
> Carol: But the people who have said, "Oh, I really have a thing for Mike Fox" - everyone from secretaries in offices to computer, biker nerds that we've had fixing our machines. They all had a thing for Mike Fox. And I think his personality, in particular, lent itself

> to—it reflected well on the rest of us. It made the rest of us seem as nice as Mike Fox [laughter].
>
> John: That's true. And he's so young. And that doubles the 'really nice guy gets tragic illness' [narrative]. We're all watching him on TV progress, and rooting for him and the whole thing. And his decision to really run with the ball has enamored him to people. It's brought people out of the closet in a way that just is astounding.
>
> Carol: I don't know if this is way off the track, but you mentioned earlier the gay community, and somehow it was an inspiration for the Parkinson's community once Mike came out. There's a lot commonality and terminology about coming out of the closet. Do they know what works? How it is accepted? Do you get rejected by some of your family and accepted by the rest? Actually I don't mention that a lot in the community, because it makes people uneasy, but in fact there are a lot of commonalities.
>
> Interview 5/8/03

Relationality, or seeing one's self in others, carries risks as well as benefits. The identities and affinities produced through biomedical identifications lead not just to happy families, but also to relations that cause unease, and sometimes conflict. For example, in their field work to get a piece of legislation passed, DR recounts an incident involving a spinal cord injury activist attempting to get support from disabled individuals at an independent living center:

> Well, there's people in the paralyzed community that don't support the research. I think mainly it's because when you're hanging on by your fingernails—which everybody that is paralyzed basically is—their lives are hell. You don't want any ripples. You don't want any earthquakes when you're hanging on by your fingernails, even if they could be good. So one of my people that was working with me went into an independent living center, which tries to give help to paralyzed people. She tried to get [a paralyzed individual] to support the Roman Reed Bill. And he said, "Don't you think I'm as good as you, you blankety, blankety, blank." Started cussing her out. So she said, "Hey, my son is paralyzed." He wouldn't hear it. He bumped her with his wheelchair and drove her out of the place. So some people—not so much now as things are starting to happen positively, but especially at the beginning, it was very hard.
>
> Interview 9/12/04

Attempts to produce affinities fail, or produce the opposite of the intended outcome. Organizing a stem cell activist identity means becoming comfortable with the contradictory outcomes of the performance. One way of doing this was through

reconciling the performance as a legitimate way to access power. Consider this exchange with Jackie when I asked her how she thinks about testifying while "off:"

> Jackie: I've become – not jaded but I've become more accepting of using whatever legitimately – like my daughter going [with me] to Washington. You could say I was using a 9-year-old but she was into it, and I was into it, and it was genuine and heartfelt and if that's what works with the politicians. It's all a big game of political manipulations. That's a strong word, but I'll do what works. And if apple pie and motherhood and children and babies and all – as long as you're using it with integrity. I mean I think that's the key thing. If you have integrity, whatever works.
>
> INT: What does "integrity" mean?
>
> LF: I mean not using something at – for whatever cost. Not lying, cheating, and stealing to get your way even if it's for a good reason. I think you need to be a good, honest person even if you're – the ends do not justify the means. I think there has to be consistency between the means and the end because it's a good end, but you got to have integrity with it.
>
> INT: So Michael J. Fox has mentioned that when he testifies before Congress he won't take his medication to physically demonstrate the bodily effects of Parkinson's.
>
> LF: Yes.
>
> INT: Do you think that's manipulative in the sense of what you've been describing?
>
> LF: It's manipulating it but so is taking medication to manipulate. Because we all have the disease, and the fact that we're functional more than not is being masked by the drug. So is that manipulating? The fact that I took drugs to be able to talk to you so we could talk, because we wouldn't be able to communicate otherwise? I mean it's just – it's practical, I think. That's a good example of the integrity issue. If not taking the drugs you're a certain way, if you have to act or exaggerate symptoms or not be what you really are, that I find manipulative. But not taking your medication? I mean when I applied for Social Security it was a real exercise for me because they – you need to emphasize what you can't do and I try to be optimistic and say what I can do but that doesn't work for Social Security. They don't want to know what you can do – they don't give you Social Security based on what you can do. And I've noticed there's generally a tendency toward optimism among – I think among Parkinson's patients. I don't know if that's an absolutely true generalization but I have noticed in a lot of people, and so if optimism is working against you – a friend called the other day and said her husband had to retire. I said, "Go to the dark side." When they ask you about him, think about when his medication's off. Because the fact that he's on part of the day is irrelevant. If he's off part of the day, have him describe the bad side. Just say, "No, but," not "Yes, but."
>
> INT: What did you mean, "Go to the dark side?"
>
> LF: I mean, what I try not to do as an optimist, I don't dwell in how bad off I am. I don't like to think about it, I don't like to be there. But the reality is I'm paralyzed for several hours a day, and that sucks. But I don't dwell there. But in way when you're filling out like Social Security forms and all this stuff it's like, be there, go there and talk about that, because it is a reality.
>
> Interview 7/28/05

The presentation of the symptoms of a disease or condition at public interfaces is an important political technology for biomedical counterpublics. Like Brouwer's (2001) analysis of ACT-UP's testimonies at congressional hearings, stem cell activists faced risks in this strategy. These risks included not only possible co-optation, but personal humiliation as well.

Not all PD activists agreed with this approach. For example, when I asked Patricia about this strategy, she replied that she felt that was "fraudulent:"

> Some people think they should not take their medication when they want to look sorry and sad, when they're applying for disability or whatever. I don't think that's a smart thing to do. It seems like fraud. You know that you can function better than that. You know that you have a serious condition; yet there's the opposite condition where people say 'Oh I'm fine,' and they're not. Everybody has their own way of coping with things, and that just isn't my way. If a diabetic didn't take his insulin, people would automatically think of that as fraud, I would think. They know to take it, and keep going.
>
> Interview 8/19/05

Patricia is not acting out of a stigmatized position, or attempting to pass in any way. Rather, she sees the public display of symptoms as inappropriate political action. This discrepancy between these two activists marks a tension that runs through stem cell activism, and animates the politics of authenticity. These politics, and how an individual positions oneself within it, are foundational for the production of the identity of stem cell activist. They are on-going and relentless.

Conclusions

My focus on identities in this chapter is an attempt to excavate the social foundations of stem cell activism. Patient activists, acting in concert with the Yes on 71

campaign, collectively constructed an identity that attempted to resolve some vexing problems: the ambiguity of a novel and controversial biomedical technology; the structural oppositions between PAGs; and the tensions around the self-representation of identities in public spaces. Like all identities, being a stem cell activist is bounded temporally and situationally. That is, an actor is not a stem cell activist all the time. This identity is foregrounded at certain times and in certain spaces, and backgrounded at others.

On the one hand, the structural conditions have propelled HSMs into an important position within formal and informal social institutions. HSMs are now not just a helpful form of organizing – they are necessary component for controversial sciences. Human stem cell research is controversial across different domains, which has helped to foment social movement mobilization. Singular PAGs, regional groups of PAGs, and larger coalitions of groups now work simultaneously to defend and move forward lines of biomedical research. At times this work becomes loosely coordinated around a shared goal. In the case of this project, it was the passage of Prop 71.

In this chapter, I argue that we can think of stem cell activists as the membership of biomedical counterpublics. This term moves analyses of technoscientific identities (Clarke et al. 2003) away from assumptions about fixed cultural positions and towards understandings of identities as formed both from the inside and outside of actors through different social processes. Biomedical counterpublics emerge at both the overlaps and gaps among and between discourses and organizations.

For individual stem cell activists, biomedical counterpublic participation carries with it both risks and benefits. A central element is the notion of public participation.

Drawing from recent concerns in political theory, it is claimed that actors should be given the egalitarian social conditions in order to articulate their claims. This implies that collective claims both should be, and must be, made public. For many social movements, this is a central goal. Public expression and affirmation of an identity is one crucial component in struggles by marginalized groups.

This public nature of movements presents different challenges than other movements for HSMs in particular. First, at a structural level, HSMs are organized around a single disease, condition or injury. These states are very different in terms of their symptomology and diagnoses, regimes of treatment and care, and levels of research towards therapies. HSMs historically have competed against each other, albeit within a recently expanding NIH budget. Getting HSMs to work together collectively presents a difficult problem. The case of Prop 71 reveals one solution: provisional unification around a single event. The Yes on 71 campaign was successful in forming and promoting their coalition, and the immediate political benefits included a large population of different HSMs supporting a single issue.

Second, at the meso-level, HSMs are always intertwined with other institutions, organizations and agencies within and outside levels of government. This means that public presentations are mediated through existing and potential alliances and oppositions. In other words, while HSMs act unilaterally, this action is filtered through different stakeholders. This is generally reflected in the reformist modes of politics HSMs engage in, although this has not historically always been the case. There is a radical streak that runs through HSMs that questions existing social relationships and demands new arrangements. This is exemplified in the women's health, disabilities, and

HIV/AIDS movements. In the case of Prop 71, stem cell activism was oriented around questions of justice through a reformist strategy. That is, stem cell activism was presented as supporting biomedical science, economic development, and the improvement of health care for all.

Finally, at an individual level, the public nature of politics is difficult for some actors. Outside of the obvious problems associated with the strains of public activity on corporeal states, there are interactional difficulties as well. Becoming a stem cell activist is not a single act or commitment, but rather involves repeated public acts around a controversial technology. In the case of Prop 71, it also meant doing the basic political work, which can be inherently distasteful for some. However, as I have argued, stem cell research is not a transparent, immediate interest for stem cell activists. It is a highly contingent form of technoscientific research that is riddled with social contradictions. Stem cell activists are not oblivious to these conditions. Many expressed unhappiness and outrage with the state of health care in the United States, and located some of the problems with human stem cell research in the structures of health care in general. At the same time, activists I interviewed expressed degrees of pleasure at uncovering and learning about the scientific, ethical, and commercial aspects of human stem cell research. Interactions with bench researchers and clinicians were described as meaningful and significant. For all the individuals I interviewed, becoming a stem cell activist was a complicated mixture of cognitive, expressive and corporeal elements.

Chapter VI: Stem cell scientists and Speculative Investments

In the United States, scientists have had varied relationships with political formations, including formal, institutional kinds of politics (such as serving in agencies and/or advisory committees), social movements, and/or electoral campaigns. Since World War II, scientific researchers (including laboratory-, field station-, and clinic-based

researchers) have been largely autonomous from direct government authority, with the major exception of the government as a source of funding. While they may receive material resources from the government through grants, contracts and awards through specific agencies, their day-to-day conduct generally falls under the jurisdiction of individual institutions and professional organizations dedicated to promoting scientists and their activities. Overarching organizations, such as the American Association for the Advancement of Science (AAAS) have worked with discipline-specific organizations and universities to promulgate codes of ethics, standards of laboratory and clinical practice, and other formal and informal regulations of how to do "good science." In addition, a deep and well-respected system of peer review has emerged as the appropriate method for the evaluation of the content of scholarly work.

During the 1970's the environment for the biomedical sciences began to change, when broad questions of citizen participation, research ethics and the risks of research to human subjects gathered increasing amounts of public attention. While the federal government was involved in the regulation of research involving humans and animals that it funded, it was not always with the consensus of the scientific communities. Provisions regulating ethics in scientific research relied on recommendations (and endorsement) from the communities of research scientists, as well as a broader, often worldwide, politics of responsible science.

At the same time, the biomedical sciences also went through a series of widening and deepening relations with economic organizations, including private financial, research, manufacturing, and public relations sectors, among others. While biomedical science has always been intertwined with capitalist logics in the United States and

elsewhere, the beginning of the 1970s marked a both an expansion of existing biomedical markets, and the emergence of new markets further "upstream" in clinical and, eventually, experimental research. Namely, scientific processes, beginning with recombinant DNA and monoclonal antibody technologies, opened up new ownership claims on biological objects. These changes gave biomedical scientists new experimental tools and questions, as well as opportunities to work with novel patrons.

As I discuss in Chapter V, stem cell activists have become central actors in the fields of regenerative medicine and were critical to the success of Prop 71. During the campaign, their work was complemented by assistance from a second group of key actors, stem cell scientists. These researchers contributed different kinds of support to the Yes on 71 campaign than the stem cell activists. As I argued in Chapter IV, Prop 71 was framed as credible through the direct support of major scientists who were listed on the Yes on 71 website and in campaign materials. The list was a veritable who's-who of elite researchers, clinicians and Nobel laureates, which was carefully pointed out by the Yes on 71 campaign during public presentations. This constituted scientists' *passive support* of the proposition, which required little from them other than signing on to a campaign that had already been legitimated as scientifically appropriate. Yet these scientists operated as more than conscience constituents or adherents (McCarthy and Zald 1980); they used their epistemic credibility to add legitimacy to the Yes on 71 campaign. But the involvement of bench researchers did not stop there. Some bench researchers were also *active supporters* of Prop 71. Scientists' active support took many forms: they spoke at rallies and press conferences, took the affirmative side in public debates, spoke favorably of Prop 71 during scientific conferences and seminars, and publicly displayed the

electoral paraphernalia such as buttons, stickers and placards. This passive/active distinction is an analytic distinction; that is, empirically, scientists were both passive and active supporters to different degrees.

Social movement involvement is nothing new for scientists. As I will describe in the next section, segments of scientists have organized themselves in relation to different movements and controversies throughout the 20th century. I will focus on three: atomic weapons scientists, reproductive biologists, and molecular biologists working with recombinant DNA.

Then, for the remainder of this chapter, I focus on a convenience sample of scientists who were active supporters of Prop 71. This sample was obtained through participant observation of conferences, debates and other venues in which stem cells and/or Proposition 71 was the topic. These scientists were then interviewed regarding their perceptions of the Yes on 71 campaign, including the tensions between the built-in skepticism of science, and the necessity to make positive claims within electoral political formats. This tension, I argue, is emblematic of the difficulties scientists in stem cell research find themselves in vis-à-vis controversial science in public worlds.

As I argued in Chpt. 4, scientists deployed what I call logics of representation during the Prop 71 campaign in order to ensure a coherent and meaningful position in support of the initiative. In that chapter, I examined the content of these logics. In this chapter, I locate scientists' activism on behalf of the Prop 71 campaign within longer histories of North American scientist activism in order to deepen an understanding of logics of representation. In the United States, scientists have long and rich histories of political engagement. It is not simply a matter of scientists becoming more political over

time; rather, it is useful to compare the different ways through which scientists have engaged with different publics, including sponsors, allies, supporters, dissenters and enemies, across time and disciplinary histories.

Scientists and controversial science

Scientists as active supporters of ostensible political claims or movements have multifaceted, if sometimes hidden, histories. Historian Peter Kuznick (1987) argues that the 1930s were a critical time for North American scientists. The decade between the Great Depression and WWII marked changes in the relationships between bench researchers and their publics, and set the path for debates in post-war science policy. Science and scientists were the objects of concern for many, for quite different reasons. One extreme view called for a moratorium or "holiday" from scientific research, in part from perceptions about the role of science in causing the horrors of World War I. While this proposal garnered little support, it did provoke a scathing reply in *The Scientific Monthly* from Stanford anatomy professor A.W. Meyer. Meyer (1928:544) adopting a tone of religious reverence, argues that science is not opposed to religion: "And if no one can, or tries to, outwit nature or the Creator, then why all this alarm, for the man of science, too, is a worker in the vineyard of the Lord, misunderstand and misuse him in war or peace though we may." His missive also reflected a Platonic image of the synchrony between the empirical and metaphysical: "A life in conformity with the laws of science, need give no one trouble, for it implies living in conformity with the laws of nature, which must be the laws of God. If there is a conflict between the laws of matter and those of the spirit, it must have been so ordained, and it cannot be the power of any

man to avoid that conflict" (1928:545). Meyer's dismissive response fed into a second, more widespread concern - that scientists were divorced from the problems wracking the social body, such as war, unemployment and inequality. Reinforcing this dim view of scientists, Kuznick (1987:41) argues, was the perception that basic science was being fundamentally shaped by the demands of business. Beyond business coffers, the other major sources of funding for basic science were government and philanthropies, which were both relatively small prior to WWII. One early government attempt to marshal funds for basic research resulted in the formulation of the National Research Fund organized in 1925 through the National Academy of Sciences (Davis and Kevles 1974). However this attempt failed, as Davis and Kevles (1974:217-18) explain, because the firms that contributed to the fund could not guarantee a return, since they could not make strong ownership claims on the results of their investments (namely the creation of new knowledge).

The Great Depression loomed large over basic science research, and the Roosevelt administration took a New Deal approach by creating the Scientific Advisory Board (SAB) in 1933 (Kuznick 1987:32-3). Roosevelt selected MIT president Karl Compton to chair the SAB, and in 1934, Compton gave a speech to the American Association for the Advancement of Science (AAAS) branch in Berkeley, California, in which he outlined his ideas regarding support of basic science research. First, basic science is responsible for many of the improvements in American's standard of living. Second, he noted that basic science could be brought to bear upon many problems, such as unemployment, natural resource planning and usage, and "hereditary weaknesses"[30]

[30] Compton followed the eugenic line popular at the time: "Hereditary weaknesses, both mental and physical, constitute a terrific annual drain on the happiness and on the finances of the country…If

(Compton 1934). Finally, the usefulness of science can be increased through a program of national taxation, since the beneficiaries of science would be the entire population. Compton's speech attempted to link social concerns with solutions drawn from basic research. He captured the pre-war position of many academic scientists: supportive of Roosevelt's New Deal programs and state sponsorship of science (1934:388, comparing the Roosevelt administration to "Maxwell's demon," a character created by physicist James Clerk Maxwell to help explain the kinetic behavior of molecules), while strongly resistant to political controls over the planning and coordination of basic science. Compton's vision was of a state agency that would operate like the Rockefeller Foundation or Carnegie Institution of Washington, but look like the National Academy of Sciences or National Research Council, funded by taxpayers (1934:393). While the SAB fell apart in 1939, Compton's dream began to take institutional form shortly after the war.

The decades from 1890 to the eve of WWII were important for the development of the biomedical sciences in the United States. Much has been written about nineteenth century medicine, and space prevents a deeper consideration of the "therapeutic revolution" that was to reshape the North American medical sciences. Jonathan Liebenau (1987) argues that the pharmaceutical industry was to go through a dramatic expansion and transformation during this period by becoming more "scientific" However, he argues that this scientization was not spurred on the clarification of scientific theory or quests for natural truths. Rather, he argues, pharmaceutical leaders realized that scientific

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incurable, and hereditary, the welfare of the race requires elimination, perhaps by some such means as have been found successful in repressing undesirable or developing desirable physical and mental traits in domesticated animals…Such controls as are here suggested will be found unpleasant to contemplate by many people. But think, on the other hand, of the terrible unhappiness of defectives and their families; remember that their number runs into the hundreds of thousands; remember that they constitute one of the greatest drains on our economic resources. If science can find effective means to cure such cases, or, if incurable, to prevent their occurrence, this alone would justify all the scientific work that has ever been done."

standardization, especially standards backed up by the force of law, would help bring stability to the volatile and confusing worlds of drug preparation, manufacture, and distribution. Scientific laboratories were beginning to appear in industrial settings with greater frequency, and scientists had incentives from pharma to collaborate and shuttle between academia and industry. The federal government passed laws in 1902 (the Biologicals Control Act) and 1906 (the Pure Food and Drugs Act), both with the support of large drug manufacturers, which ultimately gave, "legal support to the notion of scientific practice, and to rationalize the industry accordingly" (Liebenau 1987:97).

Scholars have examined scientists from different disciplines, and their organizational and political lines of work (for example, Goodell 1977; Gusterson 2004; Hermanowicz 1998; Kendall 2000; Kevles 1995; Kleinman and Vallas 2001; Kleinman 1995; Kleinman 2003; Kohler 1994; Kuznick 1987; Latour 1987; Primack and Von Hippel 1976; Smith 1965; Strickland 1968). This chapter draws from this literature, and in the following sections, I will briefly examine three examples of scientist activism, atomic scientists, reproductive scientists, and molecular biologists.

Scientists as critics: the case of atomic sciences

With the advent of WWII, national priorities regarding the funding of basic science shifted. By 1942, when recruitment for the Manhattan Project to develop an atomic weapon began, the economic, political and cultural changes in and around basic science funding began to undergo massive transformations. Scientists played a major role in all aspects of the creation of the atomic bomb, from the lab to the war-room to the halls of national policy-making. The war also drove many European physical scientists

towards elite universities of the United States, where these migrant scientists had colleagues and departments happy to receive them (Kevles 1995:280). Germany had become a leader in physics by this time, including important breakthroughs in atomic research. However, the Reich's labeling of theoretical physics as "Jewish science" and persecution of Jewish citizenry led many of their leading physicists, such as Albert Einstein, to leave (Badash 1995:12). The rise of organized fascist states galvanized newly-emigrated researchers to the United States to push for a defeat of the Axis powers through scientific and technological innovation. This included letters to President Roosevelt from Leo Szilard and Albert Einstein pushing for the development of atomic weapons (Kevles 1995:280).

The institutional framework created to coordinate wartime science in the United States included the National Defense Research Committee (NDRC) and the Office of Scientific Research and Development (OSRD) (Badash 1995:30). Vannevar Bush, a well-recognized engineer and vice-president of MIT, was appointed as chairman of the Manhattan Project Military Policy Committee, and was supported by James Conant, president of Harvard and chair of the NDRC (Smith 1965). Both Bush and Conant became pivotal post-war figures in the development of the NSF.

As historians of this period have shown, the physicists involved in the production of the atomic bomb were also deeply politically involved in multiple ways (Strickland 1968). They were in conversation with domestic political leaders, and often disagreed with what they perceived as the managerial style of the OSRD. For example, Smith (1965:33) pointed out that while Bush was a respected scientist, he was also "something of an autocrat." His position as speaking on behalf of Manhattan Project scientists to the

government was not always seen as beneficial, and conflicted with scientific norms of questioning received ideas: “Science has its own rigorous discipline, but this does not include, as in the military and to some extent the government bureaucracy, unquestioned adherence to decisions handed down from above” (1965:33). In addition, loyalty oaths and secrecy protocols forced scientists to change conventional communications patterns regarding aspects of their work.

The United States government coordinated the Manhattan Project across a series of different locations, including the Metallurgical Laboratory (“Met Lab”) at the University of Chicago, the Oak Ridge weapons complex in Tennessee, the weapons-grade material fabrication reactors in Hanford, Washington, and laboratories in Los Alamos, New Mexico (Badash 1995:30-47). Scientists were put in charge of administering these locations, and communicated with each other and the OSRD. As Donald Strickland makes clear, there were intense, on-going and high-level communications between the White House and Manhattan Project scientists, especially those at the Met Lab. Strickland (1968:25) pointed out the concern that many of the scientists at the Met Lab in particular were “younger men,” and had been politically active in pushing for international controls over atomic weapons. Met Lab scientists also debated the idea of a test detonation of a nuclear weapon to demonstrate its destructive power to Japanese leaders. Smith (1965:70) claims: “In the final two years of the war scientists individually or collectively made three overlapping requests: that long-range planning in the field of atomic energy be undertaken; that Russia be told about the general nature of the atomic weapon; and that a demonstration be attempted to induce Japan to surrender before the bomb was used in combat.”

The production of the atomic bomb required elaborate coordination between the different labs, and this coordination served as the foundation for political organization. Shortly following the end of the war, President Truman announced his administration's atomic policy, and Congress introduced the May-Johnson bill, which was met with mixed responses from scientists (Smith 1965:128-29). The bill called for the creation of a Presidential Commission to direct the nation's nuclear program. Many scientists were unhappy with this aspect of the bill, as well as the possibility of military officers being appointed by the President to oversee the program. In addition, many atomic scientists opposed the secrecy provisions, as well as the lack of attention to international control of nuclear technology (Smith 1965:130).

In mid-October 1945, various groups of atomic scientists traveled to D.C. for "science week" in an attempt to lobby politicians to stop the May-Johnson bill. Reactions to the atomic scientist's lobbying efforts and public opposition to May-Johnson bill were mixed (Smith 1965:175-76). Some periodicals ridiculed the activism, and a group of atomic scientists responded with an article in *Life* magazine entitled "The Atomic Scientists Speak Up," defending their activism and stances on international control and oversight (Smith 1965:178-79). Importantly, atomic scientists' activism began to attract support from other groups, both scientific and non-scientific (Smith 1965:181).

The former Manhattan Project scientists organized at each lab, building from prior networks of communication within and between sites, and eventually formed the Federation of Atomic Scientists (FAtS) to coordinate opposition to the May-Johnson bill. FAtS leadership, composed of delegates from the atomic labs, issued a "Joint

Declaration" pushing for international control and opposing secrecy of atomic power (Smith 1965:187-88). The "atomic scientist's movement" was a success, and the May-Johnson bill ultimately died in Congress.

Eventually FAtS was to join the Federation of American Scientists (FAS), which continues to exist today, and now attends to a variety of issues in international scientific security. Atomic scientists were also active in founding other organizations such as the Union of Concerned Scientists (in 1969 at MIT) (Kendall 2000). Albert Einstein eventually took part in the Pugwash Conferences on Science and World Affairs, which pushed for an end of nuclear weapons build up. Thus public activism by atomic scientists as critics of federal science and defense policies was central in altering the relationships and discourses about scientists and social issues. They helped create organizations that were to play important roles in the decades to follow regarding democratic control over science policy, and the priorities and outcomes of publicly-funded research.

Scientists as entrepreneurs: the emergence of the reproductive sciences

The relationships between disciplines and social activism are varied at both individual and collective levels. While atomic scientists engaged publics through controversies around nuclear weapons production and control, biologists took part in different types of controversies and movements. This is obvious from the concerns of each discipline, but also highlights the different ways through which scientists develop public positions, gather allies, combat opponents, and deploy frames and rhetorics in order to accomplish various goals.

For the atomic scientists, the key transformations occurred around wartime scientific organization. During this relatively brief period, they built enduring networks and social movement organizations around a core set of issues. American biology serves as an interesting comparison case of different styles of scientist activism. In her book *Disciplining Reproduction*, Adele Clarke (1998) examines the broad sets of transformations that reorganized the social worlds of American biology, medicine, and agriculture at the beginning of the 20th century. This was an exciting time for biological research, as it experienced a series of segmentations and growth spurts. The "new biology" that was taking shape was marked by important shifts, including a transition to controlled, quantitative experimental techniques, an emphasis on function over form, and a growing interest in the molecular or cellular scales of life (Clarke 1998:46). Life was beginning to be unfolded at more minute levels, which provoked novels programs for the "control" of life itself (Pauly 1987). For example, Clarke argues that two important lines of work facilitated the growing importance of biochemistry in the new biology: the study of "internal secretions" or "hormones" and biochemical analyses of living cells (Clarke 1998:48). These aspects of biochemistry were also to become important for human stem cell research (HSCR) and cell culture techniques, such as the elaboration of the cytokine system of cell signaling (see Chpt. II).

Clarke also highlights the importance of "scientific entrepreneurs" in the reproductive sciences (1998:51). Fund-raising is a major activity of research scientists, and as biomedical science has grown more complex, it has also grown more expensive. Like the reproductive scientists Clarke examines, human stem cell researchers have had to become entrepreneurial. Today, they work at the bench, in the classroom, clinics, at

policy tables, and at public meetings. As venues within which human stem cell researchers travel have grown, new constituencies must be enrolled, as well as combated, in the HSCR arenas.

Clarke argues the formation of the reproductive sciences was enhanced by its function as a device for translating among social worlds. Biology, medicine, and agriculture could autonomously pursue the reproductive sciences yet also benefit from the exchanges across professions (1998:157). One of Clarke's particular interests is the lateness of emergence of the reproductive sciences, which she argues was due to its "illegitimacy" through its association with sex and birth control, as well as biologists' more legitimated interests in other research domains, such as genetics and evolution (1998:88).

The reproductive sciences were to take a more obdurate form through three pathways: through links to the development of modern endocrinology via reproductive endocrinology(1998:134); establishing a "quid pro quo" with various health social movements (1998:163); and seeking funding through both established means, as well as forging new funding alliances among the academic, philanthropic and industrial sectors (1998:207). Bench researchers were key actors in all three pathways.

HSCR picks up where Clarke leaves off, with slight differences. For example, different aspects of stem cell research are controversial for different groups. Some religious conservatives argue that the human blastocyst is a complete human being. Any potential harms against the embryo are equivalent to the harms against humans in other stages of development. This argument has been taken up by some religious movements which, due to the ascendancy of the religious right in the United States, beginning in the

1980s, present a well-organized and formidable opposition to bench scientists seeking human research materials. One strategy that scientists have relied upon is what I call the *discourses of curing*. Biomedical researchers and their allies routinely assent the benefits for human health of vanguard cellular and molecular therapies – therapies that may still be at experimental levels. Discourses of curing are the statements, claims and arguments offered that serve as linking devices across different social worlds. They help to align different groups through the polysemic notion of a cure. For example, patient activists and health social movements today have become "entangled" with experimental systems in various ways (Rabeharisoa 2003). Such entanglements have benefited researchers, their institutions, and health social movements supporting the research (see Chapters III and IV).

As Clarke argues, the new biology of the twentieth century was deeply invested in controlling and manipulating the foundations of life itself. I argue not that these investments in control have dissipated, but rather that they have taken new forms. As I pointed out in Chpt. II, successes in stem cell biology and transplantation techniques have opened up new potentialities latent in human biologies and physiologies.

Scientists as policy-makers: the recombinant DNA controversies

Last, let me turn to the case of molecular biologists and the recombinant DNA controversies. Here I do not intend to explicate the emergence of molecular biology and biotechnology in the 20th century, as that has been skillfully done elsewhere (Bud 1993; de Chadarevian 2002; Gaudillière and Löwy 1998; Kay 1996; Kay 2000; Keller 2000; Morange 1998). Nor do I want to re-represent the North American and European

controversies over molecular biological approaches in the 1970s, which also have been brilliantly analyzed by many others (Gottweis 1998; Haraway 1997; Krimsky 1991; Lowy 1996; Rabinow 1996; Thackray 1998; Wright 1994). Rather, I will briefly describe the broad parameters of scientists' activism in and around recombinant DNA (rDNA) in the 1970s and 80s, with particular attention to scientists' involvement in the promulgation of NIH regulations.

By the 1960s, molecular biologists were experimenting on and with various plant and animal viruses (Krimsky 1982). One interesting set of experiments was proposed in the lab of Paul Berg at Stanford. Berg, a biochemist, proposed linking the DNA from one virus, simian virus 40 (SV40) with the DNA from another virus, called lambda phage. The lambda phage targets bacteria like E. coli, and Berg reasoned that the SV40-lambda hybrid would infect *E. coli*, and begin to replicate itself (Lear 1978:23-5). However, according to Lear, as Berg talked about this idea with other scientists in 1971-72, he began to worry about the risks of introducing DNA from a virus known to cause tumors into a common bacteria (1978:36-7). Those concerned included Nobel laureate David Baltimore (Krimsky 1982:81). At the 1973 Gordon Research Conference on Nucleic Acids, 122 out of the 142 scientists in attendance voted for sending a letter to the National Academy of Sciences and the Institute of Medicine urging high-level attention to these risks (1982:74-5). The NAS responded by convening the Committee on Recombinant DNA Molecules, Assembly of Life Sciences, and asked Berg to chair it (Gottweis 1998:94).

The committee met in April, 1974, and published their summary in *Science*, *Nature*, and *The Proceedings of the National Academies of Science* (Krimsky 1982:83).

The letter appeared in *Science* in the July 26, 1974 issue, and described rDNA techniques, as well as proposed steps for mitigating the hazards. What is interesting, in comparison with current hSC research debates, is that the letter does not accentuate the possible benefits of rDNA. It does mention that experiments are "likely to facilitate the solution of important theoretical and practical biological problems," but it does not talk about specific solutions or problems, or use the word "cure" in terms of biomedical applications (Krimsky 1982:83-4). Rather, the letter highlights the risks, and not the benefits, of this technology. Berg's group made four recommendations in the letter: a voluntary world-wide moratorium on certain rDNA experiments; scientific restraint on cross-species rDNA experiments; creation of an NIH oversight body; and an international scientific meeting to assess the risks of rDNA experiments. This meeting occurred as the now-legendary Asilomar meeting, held in February 1975.

Krimsky (1982:96) points out that the voluntary moratorium called for in the Berg letter was without serious challenge, largely because of the elite status of its authors. In one case, a microbiologist at the Scripps Institution in San Diego, CA argued that the moratorium and up-coming Asilomar conference were unnecessary, and would likely lead to a cumbersome bureaucratic response. Berg's reply had two salient elements among others. First, he was unsure that pharmaceutical companies would abide by the moratorium, and second when it came to the question of risk, he referred to U.S. government assurances, before Hiroshima, that there was little "appreciable" risk of cancers of the blood from atomic tests. Berg's rhetorical strategy was successful, in part because he positioned scientists as the only appropriate evaluators of rDNA safety. He

was unsure about both market and state forms of oversight, and thus scientific guidance was the only legitimate form of regulation (Krimsky 1982:114-15).

Much has been written about the Asilomar conference, and I will not recapitulate these descriptions and arguments (see above). Krimsky (1982:153) claims that scientists at Asilomar were concerned that regulation over rDNA experiments be in the hands of the NIH. For example, he reported that many scientists were alarmed when they were told that they could face liability if they were found negligent in the case of a workplace accident.

Gottweis (1998:89) argues that the representations of the risks of recombinant DNA discussed at Asilomar display a kind of circularity. That is, a risky technology is to be controlled by more technology, which itself has risks: "risk could be fought only with risky technologies." Risk is never dissolved into certainty, but only segmented into different categorical hazards. This was an important move for two main reasons. First, the risks of rDNA, which at the time were protean and murky, became codified and established within specific statements about risk containment. Second, since Asilomar was limited to natural scientists, and the topics and agenda were tightly controlled, it was the natural scientists in attendance who crafted and articulated these statements about risk, which were the first steps in rDNA policy for various states (1998:91).

Gottweis (1998:104) claims that the discourses of risk were important for facilitating "expert enclosures," or the concentration of expertise on a relatively bounded domain. The expert enclosure around the risks of rDNA research deeply influenced the regulations the NIH promulgated in 1976 (1998:93). Not all scientists were settled about the aftermath of Asilomar, especially upon policy-making by the NIH. In June 1976,

Science published a letter from renowned biochemist Erwin Chargaff entitled "On the Dangers of Genetic Meddling." In his letter, Chargaff questioned the wisdom of using *E. coli* as the host bacterium for rDNA research, as many strains of the bacterium reside in the human digestive system. Characterizing the research as a "destructive colonial warfare against nature," he claimed that, "The future will curse us for it," the "it" being rDNA research (Chargaff and Robinson Simring 1976:940). Chargaff also questioned the role of the NIH, and like the NSF debates nearly thirty years earlier, he called for congressional oversight, rather than expert governance (1976:938). Chargaff was joined by Francine Robinson Simring from the environmental group Friends of the Earth. Simring called for an expanded inquiry into all the possible hazards of rDNA research

A month later, Maxine Singer and Paul Berg responded to Chargaff and Simring in the pages of *Science*. Singer and Berg leapt to the defense of the NIH as the proper oversight agency, and framed the formation of NIH guidelines as "directed towards eliminating or minimizing real and imagined hazards, rather than balancing benefits and risks" (Singer and Berg 1976:186). They made no mention of possible benefits, except for one sentence: "The only certain benefit is increased knowledge of basic biological processes; the predicted benefits for medicine, agriculture, and industry will follow only upon this increased knowledge" (1976:186). This exchange is significant in that it demonstrated that by 1976 the terms of the debate were not about the possible benefits to be derived from rDNA research, but rather over the parameters of risk that the research posed to humans.

Despite these debates over risk, scientific work was on-going, and from 1976 to 1979 new discoveries regarding the structure and function of DNA in various organisms

were contributing to the status of molecular biology as an expert enclosure, as well as burgeoning financial resource (Wright 1986:326). Wright points out that an array of different economic organizations were also becoming interested in rDNA technique, identifying three distinct forms of commercial interest: venture capital; multi-national corporations; and fledgling biotechnology firms (1986:332). In California, venture capital and biotech firms began to conglomerate around the major research universities during this period, and relations among these organizations intensified and deepened.

In addition, rDNA was becoming a public spectacle. For example, two molecular biologists from the company Biogen announced at a press conference that they had developed a method for producing large amounts of interferon, even though they had only synthesized a small amount in the lab. One of the scientists later admitted that the purpose of the announcement was to drum up financial interest, which it clearly did (1986:344-45). This mode of fund-raising through (premature?) press release was successful, and became a useful strategy for scientists for several reasons. First, it is relatively cost-free, as the media were more than eager to cover the latest breakthroughs in what appear to be highly promising biomedical areas. Second, it helps to consolidate their expert enclosures. Scientists appear in newspapers and on television as the appropriate spokespeople for rDNA and other biotechnologies. Their epistemic credibility helps to provide them with broader public credibility. Third, these larger forms of public visibility and credibility facilitate jurisdictional enlargement of molecular biology. As Wright (1986:359) points out, the rDNA era greatly expanded the overlap between basic / experimental science and clinical research and applications. While in 1976 Singer and Berg were hesitant to speak about the potential benefits of rDNA, by

1998 the second paper on the successful culturing of hESCs spoke glowingly about the curative possibilities of these objects.

This short review of three instances of scientist activism reveals that scientists can be deeply engaged political and organizational actors. They have multiple lines of interests that are overlapping during episodes of mobilization, including:

- Self-interest: attempts for personal gain, either material or symbolic, or the biographical motivations for doing scientific work.
- Professional/disciplinary interests: the consolidation and expansion of disciplinary-specific concerns, questions and/or opportunities.
- Organizational interests: ensuring institutional homes and continuous and relatively stable sources of funding.
- Political interests: concerns over the futures of both specific research projects, as well as the fate of the sciences and humanity more generally.
- Rhetorical interests: concerns with public representations of science.

As Chapter II showed, the field of stem cell research as a distinct domain of scientific work in the United States is currently in the process of formation. Both experimental and policy aspects are proceeding, without generalized agreement between actors as to what it is that they are actually doing demonstrating what interactionists call "cooperation without consensus" (Clarke and Star 2007). For example, at several lay conferences a claim was made that reduced to the following form: stem cell research is moving so fast; it is so complicated and yet so promising that our current ethical understandings can not

keep up with the science.[31] This purported level of generalized ethical and/or political confusion reveals not paralysis, but a domain of intense activity. That is, the confusion is an artifact of many different people doing many different things.

In 21st century North American bench science, the basic organizing unit is the lab led by an individual principle investigator (PI). The professional advancement of junior scientists (graduate students and postdocs) offers the status of PI as the ultimate achievement within this scientific social world. This includes being lead author on papers, access to larger amounts of moneys from funding agencies, directorship of one's own laboratory space, access to institutional resources, and a heightened degree of credibility, or "claims-making capital," within both professional and lay settings. Becoming a PI offers tangible rewards, many of which are invisible to those outside of the structures of academic status hierarchies.

The PI is the nucleus of the research cell. This metaphor is helpful, but also covers up some critical dynamics that drive biomedical research. PI's are fiercely independent, and are only coordinated in large multi-institutional projects, and even then often very loosely. Elite scientists especially resist attempts to control or direct their work processes, and wax rhapsodic when describing their individual mechanisms for developing research questions, hypotheses, experiments and data-interpretation frames. Thus, in the United States in particular, basic science is not directed at the level of the PI. It is coordinated through funding priorities.

[31] The form of these conferences often recapitulated this problem. That is, they were structured to offer scientific facts in the morning, and ethics and policy concerns after lunch. One prominent bench researcher said: "Good ethics comes out of good science."

Funding Biomedical Research in the USA

Historically, the funders and sponsors of biomedical science are diverse, including the state, civil society organizations, market actors, industrial sectors, trade associations, and philanthropic foundations and organizations. Since WWII, for reasons outlined below, biomedical research in the United States has become the target of various *speculative investments*, which have played an increasing role in the steering function of scientific funding (Thompson 2005). Speculative investments are bets placed on research that is imagined to produce some kind of return for some delimited group. It is revenue that is targeted towards curing or ameliorating a disease or condition. This differs from Vannevar Bush's (1945) "endless frontier" of basic research, whose outcome was basic knowledge that may or may not be directly beneficial or translatable into immediate application. Rather, speculative investments are targeted towards "mission oriented" research. The success of the Manhattan Project raised hopes for many about the possibilities of directing money and time at a particular research goal or outcome.

This is a slightly different take on the traditional distinction between science and technology. In other words, the claim that some aspect of technical work is "pure" or "applied" always involves the use of categorical distinctions that are themselves at stake in the work itself. Following the work of actor-network theorists and others (Callon 1999; Latour 1987; Law and Hassard 1999), the categories of pure and applied, science and technology, take shape *after* the empirical, practical work of "getting things done" is accomplished. Thus my claim is not that speculative investments target applications at the expense of basic research, but rather that speculative investments help reformulate a field of research activity by acting on the social forms of knowledge production.

What does this mean? As I described above, speculative investments are resources laid on in order to solve a particular health problem for a defined population. The beneficiaries are a defined population, or sub-population such as "Type II diabetics" or "children with autism."[32] For example, in 1937 the federal government created the National Cancer Institute (NCI) as part of the NIH complex in order to move cancer research forward. In 1971, the Nixon administration broadened the scope and funding of the NCI to initiate a "war on cancer." The research done with NCI funds is targeted towards "cancer patients." Within the scope of this mission, researchers work on very different objects and systems: solid tumors and cancers of the blood, brains, skin or reproductive systems.

By the 1970s, biomedical research had become big science - big in terms not only of escalated funding, but also in terms of the configurations of the research teams. Cancer research operates at multiple levels of analysis: from the molecule, to the organ, to the person, up to the population. Cancer research teams now include multiple specialists from experimental, clinical, statistical and other technical worlds. Thus these worlds do not exist in absolute separation from each other. Since they are under the umbrella of cancer research, there is a flow of persons, objects, and knowledges among them. For example, in her description of a laboratory as a "processing environment," Karin Knorr-Cetina (Knorr-Cetina 1999:38-9 original emphasis) draws upon a phenomenology of space: "The traffic of objects, researchers, and information produces a *lifeworld* within which laboratories are locales, but which extends much further than the

[32] Recent work focuses on the power of knowledge production to proliferate diagnostic categories, for example. Thus there are earlier, sometimes asymptomatic stages of a particular disorder, which require testing and possible pharmacological intervention.

boundaries of single laboratories." The "lifeworlds" of biomedicine are expanding to include multiple labs, clinics, and other spaces.

Speculative investments can come from a variety of actors, private and public. In the United States following WWII, the federal government began to fund targeted biomedical research through the NIH. The "categorical" approach to institute creation was expanded by director James Shannon from 1955-1968. He (Shannon and Kidd 1956) defended this approach, but also became concerned that it was producing unintended consequences. Namely, targeted funding was creating a class of elite scientists more aligned with a particular institute than with their home university (Shannon 1964). This led to a weakening of universities and scholarly values: "The paragon of academic attainment today is not the scholar but the productive scientist" (1964:977-78). Shannon's concern would be born out over the 1970s and 80s, as industry now funds the majority of scientific R&D (Chpt. IV). In other words, the "productive scientist" produced by NIH funding was closer to the norms and expectations of private industrial science than university-based science.

Throughout the 1970s and 1980, financial institutions including venture capitalists became more interested in not only scientific institutions like universities and research centers, but also in the content of scientific knowledge. This content was under the jurisdiction of bench researchers. Historical and contemporary connections between scientists and industry have been well documented (Gaudillière and Löwy 1998; Keating and Cambrosio 2003; Krimsky 2003; Thackray 1998). Important legal and policy shifts in the early 1980s, such as the *Diamond v. Chakrabarty* case, which allowed the U.S. Patent and Trademark Office (USPTO) to issue patents on multicellular organisms that

had been genetically altered, and the Bayh-Dole amendment that gave broad control over patents developed by federally-funded research to the patent holder, have often been cited as contributing to a very positive environment for the capitalization of molecular biology (Krimsky 1982; Wright 1994).

At the same time, concerns were being raised about the implications of these transformations in academic life. Research teams at Harvard and Tufts investigated the possible problems, largely under the heading of "university-industry research relationships" (UIRRs) of the rapidly expanding networks between scientists, industry and the government. The Harvard team, led by David Blumenthal, concluded that UIRRs were generally beneficial to biotech companies, measured in terms of the number of patent applications per industry dollar invested in academic biotech research, as well as helping to keep the companies up to date in the latest research findings. In contrast, the results for universities were mixed. While UIRRs provided funding, some of the industry executives Blumenthal's team interviewed reiterated Shannon's concern that funding priorities were directing scientists away from "the broader goals of basic science" (Blumenthal, Epstein and Maxwell 1986:245). To counter the risks of UIRRs to universities, Blumenthal and colleagues recommended that universities pay closer attention to UIRRs, and only enter into relationships that are clearly beneficial to them and their faculties (1986:232).

One institutional response by many universities was to coordinate the administration and oversight of UIRRs through campus offices of technology transfer (OTT). OTTs have become important components of the "entrepreneurial university." At UCSF, for example, the Office of Technology Management is located within the Office of

Research, which also directs the Center for BioEntrepreneurship (CBE). The CBE regularly offers a quarter-long course that instructs graduate students, postdoctoral fellows and researchers in the details of intellectual property, and the legal and policy aspects of commercialization, essentially "Bioentrepreneurship 101."[33]

In the 1990s, scholarly attention to UIRRs blossomed, and different theories attempted to explain these changes. Michael Gibbons and colleagues argued that knowledge production is transitioning from a "Mode 1" to "Mode 2" type of organization (Gibbons 1994; Nowotny, Scott and Gibbons 2001). In Mode 1, problems are defined and solved by professional communities which are a discipline-based and hierarchically organized with enduring form, controlled by professional experts. Mode 2, in contrast, is transdisciplinary, "transient," with broader forms of "social accountability" (Nowotny, Scott and Gibbons 2001), closer to what today are called "assemblages" (Marcus and Saka 2006; Ong and Collier 2005). Henry Etzkowitz and colleagues described the "triple helix" of government-academia-industry relations (Etzkowitz and Leydesdorff 1997; Etzkowitz, Webster and Healey 1998). The triple helix metaphor is designed to indicate the deep structural intertwining of these institutions. Shelia Slaughter and Larry Leslie (1997:8) defined "academic capitalism" as "institutional and professorial market or marketlike efforts to secure external moneys." All of these perspectives detail the extensive connections between academia, the state, and market organizations.

While the status and effects of UIRRs remains controversial, this dissertation demonstrates that the academic biomedical sciences of the 21st century have undergone

[33] For research purposes, I enrolled in the course as a credit/no credit student, and I received "credit." The course was taught in a lecture-style format, with guest speakers from local businesses and law firms. At the end of each class, food was provided and students were encouraged to "network" and continue informal conversations with the speakers.

deep structural transformations since WWII. These transformations have helped to facilitate the emergence of the "productive scientist" in James Shannon's (1964:978) words, as individual researchers in academic research centers now capitalize their own research, with ready assistance from OTTs. The influx of industrial revenue, coupled with legal and regulatory changes, is one causal force behind these transformations. However, private financiers did not warp a field of purportedly pure science. As I have argued, biomedical research was already "mission-oriented." The growing centralities of what I have called "speculative investments" are deeply tied with the development of regenerative medicine as an institutional project.

Stem Cell Scientists and Prop 71

I am arguing here that Proposition 71 is a speculative investment. Why is this claim significant? As I have demonstrated, the relationships between scientists and their funders are complex, and do not reduce to scientists' (or others) mere self-interest. That is, I reject the argument that scientists supported Prop 71 simply because they wanted more funding for research or larger incomes. While it is certainly true that they will receive more funding for stem cell research, I argue that scientists' support of Prop 71 marks the growing importance of speculative investments. In other words, rather than arguing that scientists are simply an interest group seeking to maximize resources, it is more interesting, and arguably more accurate, to connect arguments in support of Prop 71 with the emergence of regenerative medicine, the use of the initiative process in the policy context of California, and the multifaceted roles of scientists inside and outside the lab today.

My argument here is consonant with Daniel Lee Kleinman's (2003) claim about the importance of the indirect influences of commercial norms on academic biology. These influences include the purchase and use of standardized, proprietary tools and reagents, as well as intellectual property agreements. Kleinman claims that the PI in the lab he observed desired to separate the "scientific" work or designing and executing experiments from the "social" work of getting funding and negotiating patent agreements, but could not pull off this separation because of the structural position of the laboratory scientist in academia today (2003:159).

Here, I want to extend Kleinman's argument beyond the lab. I am interested in how the changes described above have positioned stem cell scientists vis-à-vis the controversies regarding human stem cell research. That is, the social ties that have been elaborated and deepened between scientists and their patrons are opening up new spaces for scientists to do new kinds of work. In terms of activism, this helps both older forms to thrive, and produce new networks and affiliations, such as scientists and patient activists working together on the Yes on 71 campaign.

At the same time, this activism is not without dangers for stem cell scientists. That is, their public defense of human stem cell research on behalf of the Yes on 71 campaign had to be articulated in formats that would accrue public support. I referred to these formats as logics of representation. Opponents of Prop 71 made arguments that questioned the speculative investments of stem cell scientists, and implied that they stood to gain as a class from the passage of the initiative. While stem cell scientists rejected these claims, they do pose new problems for the public representations of scientists and

their work. I now turn to my analysis of data collected from interviews with ten scientists, eight of whom were active in support of Prop 71.

Stem cell researchers joined the Yes on 71 through different avenues, and did different kinds of political work over the course of the campaign. While no data was collected on how many biomedical scientists joined the Yes on 71 campaign versus the No on 71 campaign, or not getting involved at all, anecdotal evidence demonstrates that few professional scientists or clinicians were involved on the No side. One organizational wing of the No on 71 campaign, called "Doctors, Patients, and Taxpayers for Fiscal Accountability" (henceforth Fiscal campaign), listed thirteen individuals as campaign directors. Four of these individuals had either a Ph.D. or M.D., one of whom was a social scientist. The Yes on 71 campaign listed 35 Nobel prize winners, 159 medical doctors, and 203 other "Professors, Researchers and Scientists" (http://www.yeson71.com/ coalition.php). This vast disparity may reflect the capabilities of the Yes on 71 campaign organizers to actively recruit doctors and scientists, rather than the spontaneous political action of any individual to affiliate with a particular campaign. Nonetheless, this gulf was constantly reiterated by Yes on 71 staffers who commonly cited its existence as evidence of the credibility of their campaign.

Stem cell scientists also spoke in support of Prop 71 at different events. A central theme that was repeated in interviews and at public events was the importance of human stem cells, and especially hESCs, as biomedical tools. HESCs are not easy to obtain, and difficult to maintain in vitro. Scientists who are interested in working with hESCs have different disciplinary backgrounds. For example, one PI from a northern California research university (Bay Tech) named Tonya (all names are pseudonyms) has spent

considerable time studying the human placenta. In humans, the placenta arises from cells of the early blastocyst known as trophoblasts. These cells become the placenta, infiltrate the maternal blood vessels, and provide the conduits that keep the developing embryo alive:

> We started studying everything we could about the placenta, and we learned how to isolate, I wouldn't call them stem cells, but it's a progenitor population in the placenta. We learned how to put them in culture, and we ask all kinds of questions about these purified cells. We ask questions related to tumorigenesis; in human pregnancy they do this amazing thing where they go into the uterine wall, and they line all the mother's blood vessels, so they shunt uterine blood to the placenta. They have half the genes of the father, but they are not immunologically rejected. They do all these magic, magic things, so I was just completely hooked. As part of that, we have been going back earlier and earlier, and we've discovered some mechanisms of how the cells adhere to the uterus that we think are involved in the first steps of implantation. So through our placenta work we have been working on human development for a very long time.
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> Interview 9/7/05

Tonya's work with the placenta locates her research in a liminal space in both the body and in time. The placenta arises from cells of the early embryo, fuses with maternal vasculature, and supports the embryo, but is not rejected by the mother's immune system. It is a fascinating organ, neither entirely embryonic nor maternal. It is an outside that is on the inside, between two outsides. It is essential; many early pregnancy complications are caused by malformed or improperly functioning placentae, yet following birth it is often consigned to the category of waste or left-over. It is currently being investigated as a possible source of objects that are called cord blood stem cells (Waldby and Mitchell 2006).

Tonya's work on the placenta locates her research at institutional junctures as well, and her questions about embryonic development have lead her to work with objects that might be called embryonic stem cells. Developmental biologists have been involved in what is now being called stem cell research for some time:

> So when, I think somewhere around 1999-2000, since we did everything you could possibly do with a placenta, Marcus [colleague at Bay Tech] came to me and said, 'you guys got a lot of expertise in human embryology, a lot of reagents we needed, from sequences for DNA and RNA work, to antibodies and all that kind of stuff.' He said 'Would you be a co-investigator on this grant, this [names] grant with Cells, Inc. [names biotechnology company]?' I said sure, it sounds like fun. So he sent me a copy of the grant, and I realized in the grant, was part of this bit about how they were looking for some kind of cell as a feeder to replace the mouse embryo fibroblasts. So I said to Marcus, I think this might be relatively simple, because there are fibroblasts component of the placenta; we can get really early gestation ones, and I bet that these fetal fibroblasts are going to be really good feeders. So Marcus said that sounds like a great idea, so let's try that. We were about to try this when Marcus shows up in my office one day and says he's leaving to go to [another university]. He said will you take over this project, this deriving stem cell lines? I said I'm going to have to ask the people in my group because this is a big deal! So I asked the people in my group, and because of our interest in embryos and placentas, I always have a couple of IVF people in my group, or people who have IVF in their background. So I asked these people and they were extremely enthusiastic. I had one woman who created the first IVF baby in [states country], and she is one of these people who is incredibly enthusiastic about everything, and we were both like this would be a wonderful thing to do. So we got a team of people together, and started deriving stem cell lines. To tell you the truth, we weren't particularly interested in just deriving lines and feeders, it's not particularly intellectually interesting. We wanted to learn the fundamentals of the cells, which our experiences have allowed us to do. We wanted to make good cell lines that we had a lot of confidence in. The cells on the NIH registry, nobody's really certain about their history; they've had a pretty hard life. In human cells, we worry about genetic effects and mutations. The DNA is very fancy, and has all these very fancy decorations, chemical moieties, hanging off of it that can change everything. So we've been very fastidious about our cells, and we have a lot of confidence that they are very good.
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> Interview 9/7/05

In this passage, Tonya talks about several important aspects of bench research. First, the development of teams of heterogeneous experts. She was approached by a colleague because of her expertise in human embryology, and after getting involved she relied on the expertise of members of her team with IVF. Biomedical scientists usually work in teams, and require colleagues, postdocs and grad students, and technicians with different skills and capabilities. Tonya's answer shows the importance of having varyingly skilled personnel for the production of hESC lines.

Second, after her colleague departed, she took over the project of deriving the hES cell lines. As she states, the instrumental aspect of the project, namely constructing a tool, is "not particularly interesting," but it will lead to two interconnected outcomes: the production of basic knowledge about hESCs, and the creation of new, and more robust,

hES cell lines for further research. Certainly molecular biology has its background in "biological materials processing" (Kenney 1986:131), and tools are some of its most important outcomes. In this case, the tool produced is a hESC line. However, unlike PCR or monoclonal antibodies, hESC lines have many unknown aspects (Cambrosio and Keating 1995; Rabinow 1996). While a cell line can be a tool for drug discovery, it is also an object of study per se. Thus, the better this tool is in terms of being well characterized, reproducible and standardized, the more confident scientists are of the knowledge derived from it.

In addition to being useful for bench research, hESCs could be important sources for the creation of transplantable tissues. Of course, a key problem here is access to research materials. Another researcher who was active on the Prop 71 campaign, Brad, expressed his involvement as based in the need for more cells and tissues, in this case islet cells which produce insulin in humans. A pioneer in diabetes research, he knew that there is a shortage of donor pancreases, despite recent advances. One technique, referred to as the Edmonton protocol, emerged in the 1990s as a possible breakthrough solution for this problem. Brad stated that despite the small number of technical changes the Edmonton protocol made, including stopping the administration of steroids as an immunosuppressive, dramatic results were observed in diabetics. This was a huge step forward, but islet cell transplantation remains limited by the number of available cells:

> We have our own islet transplant unit. We have obviously some trials going on in treating type I diabetics. We have a strong developmental biology program interested in how the pancreas develops in trying to make islets. So the philanthropic group, would hear me talk all the time about these subjects, and one of my slides always is, "If I could make islet transplantation work tomorrow, 100% of the time, with the best possible scenario, I could treat maybe 0.1% of all people with diabetes because the fact of the matter is that there are just not enough islets out there." I told you all the reasons. You've got to put a lot in, sometimes you need more than one donor. There are only about 4000 people in the world that donate their pancreas a year if you want them to, so you just can't do this.

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Another stem cell researcher, Thomas, made similar "supply and demand" arguments, but in a different field. Thomas works in neurobiology, and his dissertation focused on a specific kind of cell called an oligodendricyte which insulates neurons with a substance called myelin. He argued that this process is relatively simple, compared to what other cells have to do, and has great potential for repair of spinal cord injuries as opposed to other diseases or conditions:

> It's an easier thing to treat [spinal cord injuries] because we can generate a high purity population [of oligodendricytes]. A high purity population of insulin producing cells has not been generated; cardiomyocytes, not been generated; dopaminurgic cells, not been generated. That still has to come. In addition, once you get the final transplant population, what does it have to do? Is it a dopaminurgic cell that somehow has to get to the right diseased, dying area of the brain, not be killed off itself by the endogenous disease process, make axonal extensions over long distances in the adult human brain that is diseased? Being adult and diseased both put up barriers towards the growth of axons. And then functionally integrate into an extraordinarily complex circuit. What an oligodendricyte has to do in a spinal cord injury is one heck of a lot easier. You put it where you need it, right at the site of trauma, and all it has to do is find a naked axon…A naked axon in the adult does release signals that say 'myelinate me,' and it just has to wrap that thing. It doesn't have to integrate into a complex electrophysiological circuit. It just simply has to wrap fat around a wire.
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> Interview 9/7/05

These three examples demonstrate that for scientists who supported Prop 71, human stem cell research represented possible solutions for a variety of problems, including the need for cellular tools, supply and demand issues, and the development of exciting new cellular therapies.

All of these scientists receive speculative investments. Brad's department receives money from a variety of sponsors, including the philanthropic organization he mentioned (the Diabetes Cure Organization, DCO). DCO made a huge push in the 1990s to cure juvenile diabetes. As Brad sees it,

> The [DCO] is a perfect example. It is very much a political machine, more so than any [other] foundation that I can imagine. Their thing, they have mottos. The 90s was the "decade of the cure." The biggest mistake they ever made! When I walked in here in 2000, and I had a bunch of donors who had been [DCO] donors, and they wanted to give me money, they said, "[DCO] let us down. They said that the 90s was going to be the decade of the cure." There is incredible risk in making promises. But on the other side of it, and I truly believe this, that unless, if you believe in this type of science, unless you are committed to that as an endpoint; look, 9 out of 10 experiments I do fail. That just the way science is. But unless I continue every day to walk in here thinking I'm going to cure diabetes, I don't think I'm going to put as much of my heart and soul into this thing. If my science is all about getting enough preliminary data for the next grant, or getting recognition for the next paper, or being a productive researcher, I don't feel like I have achieved what I want out of my career.
>
> Interview 9/9/05

Brad is clearly committed to being a scientist, and he sees it as his work as an attempt to cure diabetes. His stakes are also deeply personal; he even donated a kidney to his father who has the disease. But he must explain to his sponsors that 90% of his work is a failure. This kind of failure rate is difficult for some sponsors to hear as they expect a greater return on their investments.

Researchers face other kinds of risks as well. HESC research is closely monitored by many groups of people, and opponents are always ready to leap on any transgression of protocol or procedure. Tonya told this story:

> [P]olitics is really changing the way we work on a day-to-day basis in the lab. I'll give you a very graphic example. We published this paper on implantation, and it was published electronically at noon on a Thursday. By 4:00 pm I had an email from this congressional staffer, who said, "OK these are your NIH grants; which one of those supported your embryo work?" Took them 4 hours to put this paper together with our NIH funding, and set up an entrapment situation. I think they are patrolling; I absolutely think they are patrolling. They're absolutely looking for key words. Grant profiles are public information, but you have to be pretty sophisticated to go into the NIH websites and do this stuff. Because we had used human embryos in this work, I sent it to my program officers at NIH, and I explained to them that we had used private funds for the actual embryo work, it had been done off-campus in the laboratory of a former IVF Fellow of mine. One of the NIH institutes, where the money had supported the work, tried to get me to take that grant, and their institute, the attributes, off that paper! Because they were so afraid of the flack!
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> Interview 9/7/05

These examples are intended to display the complicated situations that scientists must negotiate in order to do human stem cell research. In other words, stem cell scientists are not only attempting to get material resources, they are also engaged in other negotiations with different organizations. They have multiple lines of interests which blend and overlap in actual practice, including:

- Self-interest: attempts for personal gain, either material or symbolic; and/or personal biographical motivations for doing scientific work.
- Professional/disciplinary interests: the expansion and consolidation of disciplinary-specific concerns, questions and/or opportunities.
- Organizational interests: ensuring an institutional home with continuous and relatively stable sources of funding.
- Political interests: concerns over the futures of both specific research projects, as well as the fate of the sciences more generally.
- Rhetorical interests: the public representations of science.

I turn next to the last category, rhetorical interests. Specifically, I will focus on the activism by scientists on behalf of Prop 71 through television commercials and public speaking.

The "commercial" world of human stem cell research

In the Yes on 71 campaign, bench researchers did many things and were involved in every step of the campaign, from its genesis and drafting, through the state-wide campaign. One important campaign tool is television commercials. In a state as large as

California, media such as television, radio, and the internet play critical roles in the success or failure of a campaign. The Prop 71 campaign used all three. The Yes on 71 campaign ran a series of commercials, with patient activists, celebrities, and stem cell scientists each and all endorsing the campaign.

The scientists who appeared in commercials were all elite scientists, many of them leaders of large laboratories and/or research units. They included Nobel Prize laureate Paul Berg (Stanford), as well as Jeffery Bluestone (UCSF) and Irving Weissman (Stanford). The scientists spoke briefly, sometimes inside what appeared to be a lab or clinic, and expressed support for Prop 71 and the hope that stem cells will save lives. The commercials were immediately attacked by various groups as misleading. Brad responded to these criticisms:

> After my ad, I was chastised in a [local newspaper] editorial. It basically was to highlight things in campaigns that were not being truthful. Truth in advertising kind of thing, and they challenged my commercial. They basically said that I was overselling stem cells. What I had said in it was that I thought that in 10 to 20 years, that there would be therapies coming out of stem cell research for diabetes. I think that's quite a reasonable expectation, I still believe today that is true. If in 20 years from now, we're not using some form of stem cells in diabetes, I'd be shocked.
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> Interview 9/9/05

Brad did not make the commercial out of a cynical view of publics, or of politics. Since human stem cell research was at the time in a very early stage relative to the production of therapeutic objects, there was much uncertainty regarding the status of a cure. At the same time, Brad was not naïve or unaware of the other interests at stake during the campaign:

> My view of Prop 71 was there were all kinds of issues there. There were people who would make statements because they were trying to pass the thing, and that was it. There were people that went out there and over-promised because they knew they could line

> their pockets with more money if they did it, because there were some folks out there that clearly had an agenda, that they figured a big chunk of that money's going to come back to them. There were people out there that were as interested in the political process as they were in the political outcome. I don't begrudge anybody, what their reasoning for it was, because I think no matter what the reason for getting into it was, the fundamental notion of what Prop 71, or any research-driven initiative has for this country, is enormous. There are always going to be people that challenge the motivation of people, but the cause is a good one.
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> Interview 9/9/05

This response indicates that he was aware of the other sets of interests that were also at work during the campaign season. However, for Brad these other interests were consolidated within a view of biomedical science as directed towards making some kind of impact in the lives of patients:

> I should say one other thing. Scientists are skeptical and cynical about this stuff, but I think good scientists have to believe that there is something you're striving for. There are really different kinds of scientists. Some kinds of scientists believe that just understanding, knowledge of biology, knowledge of science, is in and of itself sufficient to be doing what we do. And I think those guys are great, and I think that there is a lot of science to do for science's sake. Without any kind of need for an outcome. I'm not that kind of scientist. I happen to be a scientist that believes that we're in this business in part to make a difference in people's lives, a traceable and tractable difference. So even though I'm a basic Ph.D. scientist, so much of my research is geared towards, "I've made this discovery, how can I do this in humans." So for me, I don't find it paradoxical that scientists would be political. That really doesn't, for me, offer any kinds of real concerns.
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> Interview 9/9/05

For Brad, being political was deeply tied to many aspects of his personal and professional lives. His support of Prop 71 on behalf of the possible outcomes for patients is contiguous with his arguments regarding the conduct of science. That is, mission-oriented biomedicine will likely lead to some kind of therapy, and this should be supported by financing from public and private sources.

At the same time, Brad did not argue that all biomedical science should move in mission-oriented directions:

> I don't like line item designated money for certain things. I've certainly benefit from it, but I think that if we lose the serendipity of basic science, and we don't allow people the chance to discover knowledge for knowledge's sake, we will have done a disservice to the community. So I am not suggesting that science needs to move in the direction that I did, and I describe myself as a certain type of scientist, but not necessarily something that I think everyone should be or strive to be. One of the terrible things that has happened in the last decade is that the NSF, which is truly the knowledge driven arm of our scientific community, has been decimated. Its budgets have been cut as a consequence of this push towards disease-oriented research, and I think that's terrible. I'm certainly someone who benefits from and believes strongly in translational research. When I look at the various organizations that I interact with, I have no problem with the [DCO] being very monomanical about its approach to its disease. That should be their mission, job, all of that. The NIH should not be that. The NIH should remain still the source, the scaffold, the fundamental underpinnings of what our research base is, so that companies, foundations, medical institutes can spend a chunk of their money, if not most of their money, talking about that next layer of translation.
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> Interview 9/9/05

Brad, as director of a major research center, with many years in biomedical science, and familiar with the dilemmas of speculative investments, offered reflective, thoughtful answers about a very complicated and contradictory system. Other scientists echoed this argument. Garth, a neuroscientist who was heavily involved with the Yes on 71 campaign, argued that human stem cell research was at much too early a stage to talk about cures:

> The wrong directions I see as being directed principally towards therapies, without a knowledge of the diseases or a knowledge of stem cell biology. Simply hurling things in an untutored, unsophisticated manner at diseases, and being therapeutically-driven rather than biologically-driven. My belief was that to be driven by therapies was the wrong way to go. Particularly in the early days of a field…You don't start with a disease, and go after cures in cafeteria style. I didn't want stem cells to be simply be one of the choices on the menu. I wanted to make sure that stem cell biology was guided by people studying the biology.
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> Interview 11/04/05

Garth points out the shortcomings of scientific research that done in ignorance of basic biological functions. He is responding to the clinical problems with gene therapy, which has produced several spectacular failures, including the much publicized death of a research subject. These failures had detrimental effects on gene therapy in the United

States, including tighter regulations by the FDA on further clinical trials (Cavazzana-Calvo, Thrasher and Mavilio 2004). Garth is also attempting to consolidate authority of human stem cell research within specific scientific disciplines. He argues that the field of stem cell biology should be "guided" by scientists, and not those closer to the clinic.

Scientists also claimed that they were hemmed in by the structural requirements of media. Garth claimed that it was difficult to talk about Prop 71 with specificity because of the time constraints of a commercial or talk show:

> First I think political campaigns bring out the worst in both sides, particularly political campaigns in this high-tech media age where there's very little time for making an argument. Things need to be communicated in bumper-sticker language, and in sound bites. This forces complex issues to be debated in black and white…I remember vividly being on PBS, public TV, the [names city] PBS station, which was a half hour shoe devoted to Prop 71, and you would think, well, public TV, there you have plenty of time to flesh out an argument. That's what they are looking for. They're looking for intellectual discourse. By the time you have your half hour show, and they show 10 minute clips, and the moderator gets to ask her list of questions, and it's just me and this other guy, it still came down to having to give answers in telegraphic form.
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> What's very interesting is that the stem cell biologists sometimes, especially when you had a biologist, not a lay person, would try to give thoughtful answers, and if we didn't give long, nuanced answers, we were criticized. On the other hand, the opponents as you remember, used to throw out real slogans, just slogans. I remember my opponent in the debate would say, "Stem cell biology is killing babies for nothing more than padding the pocketbooks of the biotech industry." Which is 20 words he could say in a nanosecond. That registers with the listener as sounding horrible. For me to then dissect everything that he just said, with a thoughtful complete answer, takes a few minutes. Which I didn't have, but I would try. We would never try to sink to that level. On the other hand, it was very difficult to give your nuanced answer. Then you become better at coming up with your own little slogan. I use to personally come up with a slogan that I could say quickly, but that would not commit me to say things that are outrageous, like 'Stem cells can cure anything.' I used to say things like, 'everything you just heard is false because it came from somebody who does not understand the intricacies of stem cell biology. If you want to know more ask me.' It came down to that. Politics brings out the worst in everybody. It forces people to say things without the sophisticated nuance that is required. And that was a problem.
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> Interview 11/04/05

Garth understands that political representations put him into a difficult position. Given the limited amount of time available, his opponents can make hyperbolic claims (in his opinion) that he is forced to respond to in a structurally hyperbolic way, namely exerting his expertise and denigrating his opponent as a non-expert. At the same time, the

controversies around human stem cell research are appealing to media organizations because they attract viewers. However, these solicitations were not without risks. Thomas understood his involvement as helping his multiple interests, but that being a public scientist can have repercussions:

> I get involved in anything that serves my means and ends. I have my hands in science, in business and in politics, and I maintain a number of contacts in all three pillars of society, because all have unique benefits. Being a little bit politically astute, I think, serves a scientist extremely well because it's for the greater good. None of that benefited me directly, not a single bit of it. In fact it was likely detrimental to me, because no scientist likes to see another scientist parading across the pages of the Wall St Journal, and every other major magazine out there. And I was written up in them all, and largely as a result of media following politics. Otherwise they wouldn't follow the sciences closely, so all of that was a personal sacrifice on my part because it doesn't do a scientist any good to be on the front page of all these papers.
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> Interview 9/7/05

I asked him why he considered his visibility during the campaign a "sacrifice:"

> A lot of it is professional jealousy, and that's just silly. But there's a very real concern in that senior scientists that have seen careers come and go, they understand the sexy lure that media has on younger scientists, and older scientists, and they're afraid of good scientists turning into Hollywood scientists, putting out crap research, following media-friendly but "scientifically-light" research avenues. Any time they see a young scientist in the news they worry that scientist for their 15 minutes of fame lightening their scientific integrity. So [about] what I had to do was get out there, jump on that campaign bandwagon to help the greater good, but then also publish rock solid science. I feel that I have succeeded in that, because in the past year I have published a great deal of articles in very top notch journals, and very hard core science, much of which is completely media-unfriendly. So I have been very careful to keep my solid, basic research component very intact, because that is indeed where my heart lies. I'm really not interested in being a media face. It just so happens that my work is media friendly, and people like to comment on my age or looks or something.
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> Interview 9/7/05

Thomas argues that a scientist's reputation is important, and while the public debates were possibly detrimental to individual scientist's reputations, they also had benefits "for the greater good.". One of the most important was public support of Prop 71. I want to now turn to another important interface among the different groups of actors involved in the struggles over Prop 71 - lay conferences.

Lay Conferences and Public Speaking

Commercials which appeared on television and the internet were only one way that scientists publicly defended human stem cell research. A second was *public speaking*. Public speaking is conceptualized as a social form of claims-making that can happen anywhere, even in private. Public speaking is largely the recitation of collective claims vis-à-vis desired ends. The basic form is a politician giving a stump speech, and promising to lower taxes or increase public funding for education in order to win votes. However public speaking also involves affective connections: the same politician implies "I am like you," and "We are not like them." There is a process of identification that must occur in order for public speaking to be effective. If the different segments of the audience do not imagine themselves within the frame of the public speech, the speech becomes empty rhetoric or propaganda, and is seen as an attempt to manipulate or "spin" words and persons. This is an actively negative outcome.

Bench scientists take great care in their public speaking, including using precise terms when talking about specific objects. The anatomy of this kind of talk reveals a dense vocabulary and long chains of arguments, connected by visual forms of proof. This kind of talk is understandable to members who share the presuppositions of the speaker, and there are many presuppositions at play in any particular instance of this kind of talk.

The most heightened instance of this kind of talk happens at scientific conferences, which bring together members of an epistemic community (Knorr-Cetina 1999) to engage in a specific kind of public speaking. Within a context of shared claims, individual PIs, and those desiring to become PIs, present their arguments. There are

others who listen in as well, perhaps with a shared understanding, but different desired ends. There are also both the loyal opposition and the peanut gallery in attendance. During a talk people listen attentively, scribble notes, murmur to each other, or appear disinterested. There are smiles, scowls, laughter, expressionless stares and/or applause. Action may be fast and furious.

During the summer and fall of 2004, I collected participant observational data were collected at three major stem cell conferences. These conferences all shared the same structure, and were framed as events that were open to everyone, regardless of their level of knowledge about stem cell research. Their pedagogical function was foregrounded. I refer to them as "lay conferences" as distinct from scientific conferences because the audience was not assumed to be largely scientists. In the first segment, bench researchers presented their work, attempting to "explain" what stem cells are, what they do, and why they might be significant. This public speaking involved a deconstruction of the kind of talk that happens at scientific conferences; while an object was talked about in a similar way, the significance of aspects of the object had to be made explicit. For example, it was still somewhat difficult to visually mark what a "stem cell" was when it was *in vitro*. How do we know what we are looking at under a microscope is in fact a stem cell? This is difficult to explain, given that stem cells have a similar morphology to non-stem cells. Therefore, researchers do all kinds of manipulations to isolate the signal from the noise. They use techniques called assays that measure the products of a reaction or biochemical process. For example, they insert a gene that when activated or "turned on," produces a protein that fluoresces under ultraviolet light. This is called a green fluorescent protein (GFP) assay. Scientists also have a remarkable system of tracking

cells by using receptors on the cell surface called CD (cluster designation) markers. There are over 250 characterized CD markers on human cells. These CD markers bind to molecules known as antibodies. An antibody can be joined (or conjugated) with a fluorescent molecule, then exposed to a cell culture. The antibodies will bind only to those cells that have the appropriate CD marker. The cell culture can then be run through a machine that uses optics to pick out those cells that have bound with the fluorescent antibodies. This is known as a fluorescence-activated cell sorter, or FACS assay. FACS and GFP can produce dramatic visual images that display the cellular population or process being explained.

In addition to displaying these exciting visual images of stem cells, the scientists had to explain *what they mean*, and *how they were made*. At scientific conferences, these aspects are understood and not talked about, unless if there is a disagreement.[34] At the lay conferences, these techniques had to be made explicit, and the scientists verbally took their experiments apart to reveal how they produce proof. This did not undermine their credibility; in fact it enhanced it. Usually these scientists were congratulated as "being able to speak English," or be able to easily translate their public speaking to address broader publics.[35]

One of the most convincing assays was what I will call the "rat assay." The visuals of this assay were so powerful that some researchers have stopped using it at lay conferences. The assay is shown as a digital video clip of a rat over a series of time sequences. It usually began with the rat post-induced spinal cord lesion. The video would show a rat in a defined space, struggling with paralyzed hind legs and loss of tail

[34] This can lead to a dilemma known as "experimenter's regress" .
[35] A future analysis will compare this form of public demonstration with Robert Boyle's .

function. Sometimes the rat would be on a slowly turning rotor, and struggled to stay on top. Other times the rat was viewed from below on an elevated ladder. Often the rat was simply shown in close-up in a pen, slowly crawling across the ground. There were also video images of a "knock-out mouse" (a mouse with a defined genetic mutation) that had a condition that was similar to amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease as it is called in the United States). This mouse is known as a "shiverer mouse," as it displays incessant bodily shaking caused by the lack of certain cells called oligodendricytes (the cell responsible for insulating the neuron with fat).

The next scene involved a series of images, sometimes GFP and FACS results, displaying that a subset of cells were nearly pure cultures of a specific cell, such as an oligodendricyte. This cell population was then injected into the site of the rat's lesion or pathology. The next set of digital images displayed the same animal, following the injection of the cell population. The results were dramatic. The animals had reduced shaking, and were able to perform with much improved ability on ladders and rotors. The images were dramatic, and presented results that appeared obvious. These animals had been healed with stem cells.

Some scientists stopped using the rat assay at public events. One admitted to me that he felt that audiences were coming away from his presentations with the wrong idea – namely that it was a short step to replace rats with humans. Even though scientists would stress that therapeutics were still far away from the clinic, the rat assay demonstrated proof of principle. However, as critics of hESC research charged scientists for producing hype through the use of these images, some scientists decided to stop using these images in public.

Conclusions

Stem cell scientists were very active on behalf of Prop 71. As I have detailed here, their participation was invaluable for the success of the initiative. However, the participation of bench researchers in this campaign was not only the mobilization of a group on behalf of its own interests. Nor was it scientists simply seeking resources to continue their pursuit of cures. Rather, as I have argued, scientist activism on behalf of Prop 71 can be understood as a downstream outgrowth of the growing importance of speculative investment in the biomedical sciences. These forms of science funding are complex and, I am asserting, have both direct and indirect effects. While others have focused on the direct effects of speculative investments (Bok 2003; Geiger 2004; Washburn 2005), I have centered on what might be called the indirect effects. These include the possibilities that have opened up for scientist activism as a result of the institutional changes in the sponsorship of knowledge production in the U.S. across the twentieth century.

Scientists certainly organize within and among scientific disciplines. For example, Scott Frickel (2004:141-42) shows how genetic toxicologists organized within scientific communities, labs, and classrooms to instantiate a "politics of environmental knowledge." In contrast, stem cell scientists, while in some cases having deep biographies of ostensive political involvement, mobilized relatively rapidly and successfully in and for public venues. While they have been aided by their allies in related social movements and organizations, the actual clear and concrete support of scientists was critical for the credibility of the Yes on 71 campaign.

Also in contrast to Frickel's example, stem cell scientists engaged on a different terrain, namely electoral politics. This required that stem cell scientists take public stands of affirmation, something that can be at odds not only with the "organized skepticism" of scientific knowledge production, but also the evaluative structures of institutional status hierarchies that confer professional advancement, and the personal rivalries of lab groups and individual scientists. Again, stem cell scientists benefited from their networks of organizations with other groups, especially patient activists who were constantly invoked as the direct beneficiaries of therapeutic developments.

Why is it important to focus on scientist activism in terms of speculative investments? I am arguing that it is because one of the major unintended consequences of these investments is to make scientists more, and not less, politically active. Electoral politics demand that groups represent their goals and agendas publicly. Stem cell scientists were not afraid to do this, and spoke in defense of Prop 71 at numerous opportunities. The multiple sources of funding that scientists use and rely upon, now including Prop 71 and the California Institute for Regenerative Medicine, routinely bring them out of the laboratory and into closer contact with different, and sometimes competing, constituencies and publics. Significantly, this increased political activism is not only characteristic of contested research domains such as stem cells, but much more generally in terms of setting rational scientific research agendas.

One of the consequences of this increased activism is that scientists are now forced to publicly discuss their work. In one sense, they always do this, but it is usually limited to professional journals and/or conferences (Latour and Woolgar 1979). In contrast in the case of Prop 71, stem cell scientists had to appear in public and carefully

explain what it is that they do, why it is important, and the possible implications and consequences. These public representations of science have different effects vis-à-vis different groups. For scientists, it is a method for gaining the support of allies, namely patient activists and their supporters. However, it also has risks. Opponents can publicly challenge scientific expertise and/or the legitimacy of certain lines of work. For example, one could imagine an individual who is opposed to hESC research learning developmental biology, and promoting hASC research, not just as an ethically preferable alternative, but as scientifically more valid and/or promising. Indeed, some groups opposed to embryo research have deployed these arguments. Or, an individual or group opposed to hESC research could scrutinize the claims, data, or experimental systems used by stem cell scientists for signs of errors or fraud.

In sum, this chapter has attempted to connect the funding of science through speculative investments with the public forms of stem cell politics. I do not claim that speculative investments have caused these forms to take the shapes that they currently possess. Rather, as a diffuse set of background practices and tacit knowledges, as well as through the processes of training and becoming a scientist, and the on-going struggles for resources, speculative investments have moved to the heart of biomedical knowledge production and can move scientists beyond the laboratory.

Chapter VII: Project Summary and Conclusions

In a relatively short time span, essentially since 1998, human stem cell research has jumped into public imaginations, and become a fixture in print and electronic media. In this dissertation, I have argued that stem cell research is part of a larger constellation of actors, practices, discourses and institutions called regenerative medicine that is currently becoming a major domain of experimental and clinical research. This project is an empirically grounded analysis of one of the early skirmishes around the institutionalization of regenerative medicine, California's 2004 statewide initiative, Proposition 71, The California Stem Cell Research and Cures Initiative. Regenerative medicine, as a social formation, is a messy mixture of the old and the new, an emerging assemblage (Marcus and Saka 2006). Chapter II detailed how the disciplines within which human stem cells became epistemic objects (experimental hematology, immunology, neurobiology, and developmental reproductive biology) each and all have deep historical lineages. My own analysis began post-WWII, while other research has investigated much earlier histories (Bud 1993; Creager 2002; de Chadarevian and Kamminga 1998; Kohler 2002; Maienschein 1991). In this sense, regenerative medicine is not an absolutely new technical system. Its fragments lie among the scattered disciplinary histories of the modern natural sciences.

However, regenerative medicine in general, and human stem cell research in particular, is constantly represented today as presenting novel ethical or commercial problems. To be sure, strong ownership claims over human biological objects are of particularly recent interest to a variety of actors. One helpful way of sorting out the old and the new in any technological object or system is to trace historically the narrative

framings of objects and systems (White 1973). Historian of technology David Nye (1994; 2003) has written extensively about the social character of large technical systems, including the narratives of "new beginnings" in the United States. Nye (2003) has identified three main discourses or "foundation stories" about nature, technology, and nation. The first is what he calls the "wilderness tale," or the idea of wilderness as oscillating between a chaotic, malevolent place that must be tamed by technical superiority, or as "the other" of civilization, a place of wondrous beauty to be used as an escape from the alienation of modern life (2003:297-98). Emerging at the beginning of westward expansion by North American white colonists, a new discourse of a "second creation" animated understandings of the relationships among people and technologies, like the axe and the mill, space and citizenship (2003:5-6). Though this narrative had lost most of its explanatory power by the 1920s, Nye claims that Americans did not want to let go of it: "The narrative has become so deeply embedded in American thinking that it has ceased to be merely a story. It has become a national myth of origin" (2003:292). The dominant narrative that has gradually replaced America as "second creation" is the "recovery" story which framed and animated the North American conservation movement in the second half of the 20th century. The "recovery" story asserts that human intervention and management of nature is salvational, becoming "a managed site that seeks to recoup the virtues of the first landscape while making it accessible to tourists and profitable for private enterprise" (2003:294-95). Nye argues today that these three discourses are contemporaneous; they continue to frame arguments and haunt different positions taken vis-à-vis nature today.

Nye's analysis is applicable to cuurent debates over human stem cell research generally and Prop 71 specifically. During the campaign, human stem cell research drew heavily on tropes of both second creation and recovery narratives that Nye analyzes. Human stem cell research was framed as offering hope to millions of Californians and their families and loved ones. As this project has argued, hope was framed as a cure developed from human stem cell precursors, embodied in the Yes on 71's campaign slogan: "Save Lives with Stem Cells."

The Yes on 71 campaign also relied heavily on the recovery narrative. In this sense, stem cells, as technically constructed and mediated objects, redeemed not only patients, but also economic development and out-of-control health care costs (on redemption see Hogle 1999). Recovery in Nye's (2003) description is the remediation of despoiled landscapes and watersheds by the benevolent forces of the state and market. Stem cells also represent a form of remediation, not only of human bodies but also of economies of commodities and knowledge production. The fear of a stem cell "brain drain" – scientists leaving California and/or the U.S. for better cell lines - was constantly invoked, along with mythic tales of the successes of recombinant DNA, microcomputers and Silicon Valley. California's support of Prop 71 would create an economic renaissance. Indeed, the major biotech regions of the state, San Diego and San Francisco, both pushed hard to become the headquarters of the California Institute for Regenerative Medicine (CIRM) after the passage of Prop 71, offering reduced-rent space in prime locations, as well as numerous other benefits. The success of Prop 71 was due to the resonances of these discourses with the voting publics of the state.

I conclude this project with two areas of interest that have emerged as a result of executing this dissertation, and will guide my future research agenda – biological citizenship and technoscientific identities.

Biological Citizenship and the Promise of Cures

The first research question that guided this project was, "What are the institutional contexts and processes through which regenerative medicine is being made a legitimate form of medicine?" As Paul Starr (1982) points out, professional scientific medicine became dominant in the United States through assistance by the state through medical school and practitioner licensing, for example. As Chapter VI argued, the state remains a key actor for biomedicine, as funding priorities have played a major role in shaping postwar research trajectories. Regenerative medicine is heir to this political capital. The tools and techniques of these forms of medicine were already being discussed by the 1970s and, by the 1990s, human stem cell research took off as described in Chapter II. However, as Chapter II also argues, human embryo research as highly contested science has proven to be extremely difficult to support at the federal level. This barrier, combined with a friendly biomedical research environment in California, led to the genesis of Prop 71.

It is important to note that Prop 71 is not just a statutory change; it is also a constitutional alteration, inscribing human stem cell research as a right at a very fundamental level. In a sense, Prop 71 moved human stem cell research into the very heart of the state. This was ratified by voters even as opponents of Prop 71 asked why the same was not being done with basic health care, or some form of universal health care

insurance. Indeed, stem cell activists asked the same kinds of questions, yet supported Prop 71.

I argue that by becoming part of California's constitution, Prop 71 represented a form of "biological citizenship" (Petryna 2002; Rose and Novas 2005). That is, through its instantiation in the state's constitution, Prop 71 made regenerative medicine one of the ways that California fulfills is social contract with its citizens. In this sense, Prop 71 is the inverse of what Adriana Petryna (2002:107) called the "unstoppable dimension of illness" in her study of the aftermath of the Chernobyl nuclear disaster. She describes the complicated political economies of illness that have arisen in post-Soviet states, and the strategies that sufferers engage in to be granted forms of recognition by state and medical authorities. Petryna (2002:107) argues that the "randomness of the law (in the form of denials of access, exclusions, postponements) combined with economic instability" made Chernobyl-related illnesses and conditions sites of biosocial value production.

The "randomness of the law" haunts the institutionalization of "promissory biovalue" (derived from Thompson 2005; Waldby 2002). In contrast with individuals petitioning for state and medical recognition following a national trauma, Prop 71 asserted regenerative medicine as a future right for all California citizens. In contrast with Chernobyl sufferers who had to embody and perform a past harm, stem cell activists instead worked for a future curative state. These differing forms of biological citizenship can only be understood through the distinct social histories of each nation and region. However, despite the universalizing rhetoric of a "right to a cure," there are no guarantees that therapies, should they ever arrive, will be freely available to Californians. Currently, intellectual property and potential pricing mechanisms for human stem cell-derived

therapies are live disputes, as the CIRM attempts to move human stem cells from bench to bedside. The biosocialities that are yet to emerge will be different from those found in Ukraine.

Nonetheless, this project shares with Petryna an acute attention to the ways in which health activism is inflected through political economic structures. Chapter III analyzed the major forms of health social movements, and how some of these movements have become positioned around the controversies involving human stem cell research. Chapter IV then examined stem cell activism specifically on the Prop 71 campaign trail. Stem cell activists contributed the promissory biovalue of human stem cell research, and were well aware of the curative potential of this biotechnology.

Stem cell scientists are also important actors facilitating this kind of biological citizenship through their engagements with biocapital. Historically, scientists have proven to be relatively flexible in pursuing and incorporating different sources of research funding within their bench and clinical lines of work. This project examined recent history of science activism in the United States, focusing on the changes post-WWII. Chapter VI developed the concept of speculative investments to analyze the emerging institutional connections between scientists and their patrons, including economic organizations (corporations, banks, and financial institutions), civil society organizations (philanthropic foundations, patient advocacy organizations and health social movements), and the state and its agencies.

Scientists are clearly entrepreneurial vis-à-vis securing funding. They have also become remarkably adept at politics related to their work, especially struggles and conflicts over public representations of scientific research. Scientists today must contend

with crowded fields of actors, friends and foes alike, on their home turf of scientific debates. They have, as the case of Prop 71 demonstrates, benefited from patient activism. However, such support may also pose challenges to scientists. As Chapter V elaborated, stem cell activists do not unreflectively support scientific research and are keenly aware of the dilemmas and shortcomings of regenerative medicine. The genie of lay expertise cannot be put back into the bottle, and it will likely manifest in both anticipated and unanticipated ways in the future of stem cell therapeutics.

To win the battle of Prop 71, stem cell scientists deployed logics of representation in order to make human stem cell research understandable. They were provisionally successful. However, these logics operate in fields of "reversible" power relations (Foucault 1990). That is, while the logics of modularity, clinicality, and development were deployed in support of Prop 71, there are no guarantees that they will be permanently welded in support of regenerative medicine. That is, these logics can be reframed and targeted back at scientists and their allies with demands for "other" research. Indeed, this is already happening. For example, those who oppose the disaggregation of human embryos for this research argue that the embryo is a complete human being with all the potential capacities and subsequent rights of a fully developed human.[36] The formation of the human embryonic genome is a significant marker in this narrative, for even though the early human embryo is not corporally human (it has not differentiated from a single cell) it is genetically human. An easy dismissal of this perspective is the argument that those who oppose hESC research are anti-modern, or desire to replace science with metaphysics. However, those who argue for the genetically

[36] For a forceful statement of this position see a recent essay by Robert George, 'Human Cloning and Embryo Research: The 2003 John J. Conley Lecture on Medical Ethics', *Theoretical Medicine,* 25 (2004), 3-20.

human are clearly not anti-science. This is apparent both from their rhetoric, as well as the logic of their arguments. How would it be possible to defend life at a genetic level without recourse to molecular biology? It would not make any sense even to speak of genes as having importance in deciding who or what gets to count as human.

In sum, my analyses in this empirical research deepen our understanding of biological citizenships, and elaborate upon the different ways in which it takes shape in different sites with different histories. Certainly, my focus was extremely narrow. However, this work can now serve as a foundation for comparative efforts both within the United States, as well as cross-nationally. One empirical direction is to develop comparative analyses of human stem cell research both within the United States and internationally. The current regulatory patchwork of human stem cell research around the world presents both barriers and facilitators to the unfolding of regenerative medicine (Gottweis 2002; 2005). Research has documented the importance of stable and well-recognized standards for the development of scientific research. In the United States at least, the uncertainty and relative lack of comprehensive standards for human stem cell research in both private and public institutions has posed problems, largely in causing biocapital investors to hesitate to commit the funds necessary to start up and scale up research. On the other hand, the patchwork quality of regulations internationally allows mobile biocapital to move to places that appear to friendlier towards long-term human stem cell research. Therefore, state and national stem cell research programs need to be understood vis-à-vis the global situation of varied forms of regenerative medicine.

Technoscientific Identities in Public Spheres

The second research question that animated this research was, "What are the on-going, enduring effects of the intersections between controversial sciences and forms of liberal government?" While the state remains a central institution in modern life, not all social movement activity involves direct challenges to the state. Stem cell activism, while certainly involving the state, was structured by other dynamics as well. As Chapters V and VI argued, the histories of both lay experts and scientific experts involve institutional and biographical elements that do not fit easily with "state-centric" social movement analyses (McAdam, Tarrow and Tilly 2001). Stem cell activism shares elements with health social movements (Barbot 2006; Brown et al. 2004; Epstein 1996; Klawiter 1999), but also important differences.

This project has foregrounded the production of a new category of social movement activism – stem cell activism. Most such activism is triggered initially by a technoscientifically-based diagnosis, like a technoscientific identity (Clarke et al. 2003). Such identities may overlap and/or conflict with existing political identities. While technoscientific diagnoses produce numerous effects on individuals, the emergence of human stem cell activism has provided one channel for individuals to pursue. Of course, this does not mean that all related patients become stem cell activists. Quite the contrary; this project only examined a handful of stem cell activists across the state. However, patient activists who became stem cell activists, despite their differences, shared some common processes. Chapter V examined these processes, such as negotiating the ambiguities of hope, thinking about the relationality of diagnoses, and performing embodied illness identities.

These processes do not occur in isolation. They are deeply social, and can be analyzed as such. I developed the concept of a biomedical counterpublic in order to synthesize these scattered, uneven and contradictory processes into some kind of meso-level formation. Drawing from Nancy Fraser (Fraser 1992; Fraser and Honneth 2003), I argued that these biomedical counterpublics serve as staging grounds for collective identities. They are open-ended, sometimes transitory locations inside which certain forms of collective identities take shape. However, the construction of a collective identity is always fraught with difficulties, not the least of which involved "modes of disclosure" of an activist's illness or condition. During the Prop 71 campaign, stem cell activists publicly represented their corporeal states, which was neither a simple nor straightforward task, as "patient's voices." I argue that this form of activism is a critical junction point for moving controversial biomedical projects like human stem cell research forward. In this dissertation, I examine responses by patient activists to the predicaments of supporting this research, and in turn, how these responses play an important part in the construction of the collective identity of stem cell activist.

I argue that biomedical counterpublics are important for the mobilization and on-going activity of health social movements. Chapter III delineated the different types of health social movements, and their "biosocialities" and "forms of involvement" with different groups of actors. This opens up a series of questions for social movement theory, especially the political institutionalist or "state-centric" wings. For example, how can biomedical counterpublics be considered autonomous or outside the state, when the state plays such an important role in formatting the kinds of political responses that are

available to activists? My work raises two important areas for continued research in this regard.

First, the everyday politics of illness interfaces patients with a variety of social institutions, clearly involving the state. As Chapter V argued, many stem cell activists had previous experience with activism, including engaging with state actors and agencies. At the same time, stem cell activists are engaging with the discourses of regenerative medicine, and are thus taking on other forms of power and authority. My analysis is inspired by Joshua Gamson's (1989) research on HIV/AIDS activism associated with the group ACT-UP. Gamson argues that ACT-UP activists were not just challenging state or corporate power (which they certainly were), but also taking on "processes of normalization" (1989:352). In a similar way, stem cell activists are not only addressing state policy, but are also engaged in complex and contradictory processes of articulating new subject positions, analyzed in Chapter V.

Second, my research highlights the analytical importance of events. Events punctuate and perforate states and arenas. While Prop 71 was a state-sponsored event, its dynamics and effects are beyond the control of the state. As Chapter IV asserted, this is an important aspect of direct democratic techniques. Foucault (1972) called our attention to events long ago, and it is important to remember his arguments, especially as institutional arguments rise into theoretical prominence. Events are not reducible to the power of institutional dominance, but always exceed the efforts at direct control by the state or other actors. In highlighting events, I do not mean to imply that the state is unimportant; indeed, states can use events to enlarge the scope of their authority. Rather, I use the event in this project in an analogous way to the use of controversies in science.

Events serve as useful analytical wedges to examine how actors both (re)constitute their identities in relation to other actors, as well as in relations to shifting terrains of possibility.

Thus, unlike contemporary political institutionalist arguments which highlight the state in "channeling" dissent and opposition (Amenta 2005), this research backgrounded the role of the state. Stem cell activism is inflected by state power, but it is also percolating elsewhere and playing a role in reshaping aspects of the state. For example, my future research will examine the phenomenon of stem cell biomedical tourism - patients who travel to "offshore" medical research centers to receive purported human stem cell therapies. Such patients are willing experimental subjects, often taking part in highly risky, renegade biomedical clinical science. However, since they are willing subjects, the knowledge being produced by this form of research will be available for other biomedical researchers. In other words, the data from offshore biomedicine will not be ethically troubling in the same ways that data from Nazi medical experiments were. This is not to say that biomedical tourism for procedures unapproved as yet in the U.S. is not ethically difficult. It is indeed causing commentators to rethink the category of eugenics. Future work will examine these changes, and their effects on political institutions, as being fomented by transnational biopolitical activism.

Limitations of the Research

Like all research, this project has its limitations. The interviews were generated using convenience sampling, which has its own set of problems including respondent biases. While I was explicitly focused on stem cell activists who were public supporters

of Prop 71, this project would have benefited from interviews with individuals who were diagnosed with a candidate disease or condition for human stem cell research who nonetheless opposed Prop 71. Such opposition is especially interesting around the disability rights movement, where particular disabled identities may be highly valued. This project would have also been strengthened from interviewing patient activists who were mobilizing against regenerative medicine at the time of Prop 71.

Second, in a similar register, this project would have been more robust if it had included bench researchers who were opposed to Prop 71. I did heard rumors of natural scientists being pressured into supporting Prop 71, or at least remaining silent about their criticisms. However, I am skeptical about this being a widespread phenomenon, largely because there have been no subsequent revelations of such suppression of dissent since the election (now over two years). Moreover, there has been no audible criticism from scientific groups in California, or elsewhere, vis-à-vis the CIRM. Nonetheless, there was a spectrum of responses by physical, natural, and social scientists to Prop 71, and this research could have been strengthened by examining a wider range of positions taken by scientists from different fields and disciplines.

Despite these limitations, this project has raised some important points in both social movement theory and science, technology, and medicine studies. Future research will take into account the problems from this focal project, as well as new questions provoked by this project.

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Appendix A

Table 4.1 constructed from following data sets:

Year	Report
2004	NSF InfoBrief *U.S. R&D Continues to Rebound in 2004* [NSF 06-306] – Figure 1 (data file)

Table 4.2 constructed from following data sets:

Year	Report
2003	*2005 NSF Federal Funds for R&D, FYs 2003, 2004, 2005*, Volume 53 [NSF 06-313] - Table 86
2001	*2003 Federal Funds for R&D, FYs 2001, 2002, 2003*, Volume 51 [NSF 04-310] - Table C-84
1999	*2001 NSF Federal Funds for R&D, FYs 1999, 2000, 2001*, Volume 49 [NSF 01-328] - Table C-84
1997	California Science and Technology Indicators – Cohen, 1999
1990	California Science and Technology Indicators – Cohen, 1999
1980	California Science and Technology Indicators – Cohen, 1999

Table 4.3 constructed from following data sets:

Year	Report
2003	Total HHS Obligations – *2005 NSF Federal Funds for R&D, FYs 2003, 2004, 2005*, [NSF 06-313] – Table C-5
	Obligations in CA – *2004 NSF S&E State Profiles: 2003-04* [NSF 06-314] – Table CA FY 2003
2001	Total HHS Obligations – *2003 NSF Federal Funds for R&D, FYs 2001, 2002, 2003*, [NSF 04-310] – Table C-5
	Obligations in CA – *2003 NSF S&E State Profiles: 2001-03* [NSF 05-301] – Table CA FY 2001
1999	Total HHS Obligations – *2001 NSF Federal Funds for R&D, FYs 1996, 2000, 2001*, Volume 49 [NSF 01-328] – Table C-5
	Obligations in CA – *2000 NSF S&E State Profiles: 1999-2000* [NSF 02-318] – Table CA FY 1999
1998	Total HHS Obligations – *2000 NSF Federal Funds for R&D, FYs 1998, 1999, 2000*, Volume 48 [NSF 00-317] – Table C-5
	Obligations in CA – *1999 NSF S&E State Profiles* [NSF 01-317] – Table CA FY 1998

1995 Total HHS Obligations – *1997 NSF Federal Funds for R&D, FYs 1995, 1996, 1997*, Volume 45 [NSF 97-327] – Table C-5
Obligations in CA – *1997 NSF S&E State Profiles: Fall 1997* [NSF 98-315] – Table CA FY 1995

1994 Total HHS Obligations – *1996 NSF Federal Funds for R&D, FYs 1994, 1995, 1996*, Volume 44 [NSF 97-302] – Table C-3
Obligations in CA – *1996 NSF S&E State Profiles: Fall 1996* [NSF 97-306] – Table CA FY 1994

1993 Total HHS Obligations – *1995 NSF Federal Funds for R&D, FYs 1993, 1994, 1995*, Volume 43 [NSF 95-334] – Table C-15
Obligations in CA – *1995 NSF S&E State Profiles: Fall 1995* [SRS 95-406] – Table CA FY 1993

Table 4.5 constructed from following data sets:

Year	Report
2000	*2000 NSF R&D in Industry in 2000* [NSF 03-318] - Table A-27
1997	California Science and Technology Indicators – Cohen, 1999
1991	California Science and Technology Indicators – Cohen, 1999
1981	California Science and Technology Indicators – Cohen, 1999

Table 4.8 constructed from the following report:

Year	Report
2003	*Academic Research and Development Research Expenditures: Fiscal Year 2003* [NSF 05-320] - Table 1

Table 4.9 constructed from the following report:

Year	Report
2006	*National Science Board: Science and Engineering Indicators 2006, Volume 1* [NSB 06-01] - Appendix Table 5-5

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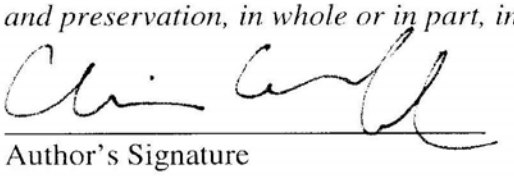

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