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IRVINE

Gestational Surrogacy: Participants' Discussion and Decision Making Regarding Pregnancy Management, Including Prenatal Testing and Pregnancy Complications

THESIS

submitted in partial satisfaction of the requirements
for the degree of

MASTER OF SCIENCE

in Genetic Counseling

by

Susy Malca

Thesis Committee:
Professor Maureen Bocian, MD, MS, Chair
Professor Kathryn Steinhaus French, MS, LCGC
Professor Kathryn Osann, PhD, MPH
Professor Meredith Jones, MS, LCGC

2016

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ABSTRACT OF THE THESIS

Gestational Surrogacy: Participants' Discussion and Decision Making Regarding Pregnancy Management, Including Prenatal Testing and Pregnancy Complications

By

Susy Malca

Master of Science in Genetic Counseling

University of California, Irvine, 2016

Professor Maureen Bocian, MD, MS, Chair

While gestational surrogacy has grown in popularity in the last decade, the surrogacy process is far from homogeneous. This lack of standardization can cause problems between surrogates and intended parents and can be troublesome for healthcare providers.

The purpose of this study was to understand the current practices regarding discussion of potential pregnancy complications and prenatal testing in an attempt to determine how these decisions are made. This study also examined how comfortable surrogates felt expressing their opinions with the intended parents regarding these topics.

Surveys were distributed through four surrogacy agencies and included several topics that could pose a potential conflict between the surrogates and intended parents. One hundred and eleven participants were included in this study. Decisional topics included carrier screening, fetal anomalies, and screening/testing options. The number of topics discussed by the surrogates varied, with about 1/3 of participants reporting that they discussed most or all of these topics before being matched with the intended parents. Decisions during the pregnancy were most often made by medical professionals, followed by the gestational surrogate and intended parent(s) together. Most participants felt comfortable voicing their opinions and that their opinions were

considered throughout the surrogacy experience. These results indicate that surrogates generally feel comfortable and empowered throughout their experience.

The results of this study revealed overall positive experiences for the surrogates. Having standardized guidelines may increase satisfaction with the surrogacy process and be beneficial in preventing serious conflicts between surrogates and intended parents. Given the recent increase in prenatal screening and testing options, standardized guidelines are needed to assist genetic counselors with facilitating discussions between surrogates and intended parent(s).

1. Introduction

1.1 Gestational Surrogacy: Definition and Historical Background

1.1.1 Defining Gestational Surrogacy

Gestational surrogacy is an arrangement in which a woman (gestational surrogate) carries a pregnancy for another individual or couple (intended parent(s)) (Ashagouni, 2011). There are two categories of gestational surrogacy. *Traditional surrogacy* involves a woman carrying a pregnancy conceived with her own oocyte. In traditional surrogacy, the gestational surrogate is genetically related to the fetus. By contrast, *gestational carrier surrogacy* uses an embryo created from another woman's oocyte; gestational carrier surrogates are not genetically related to the embryo (Ashagouni, 2011; Conklin, 2013; James et al., 2010). Gestational surrogacy gives couples who otherwise may have been unable to have a biological child the chance to have a child who is genetically related to one or both parent(s) (Miller, 2004).

1.1.2 Historical Background of Gestational Surrogacy

While gestational carrier surrogacy is a fairly new concept, examples of traditional surrogacy are evident as far back as biblical times. In the Bible, Sarah was unable to conceive, so Abraham impregnated Hagar, their servant. Hagar was meant to serve as a surrogate, donating her egg and carrying the pregnancy for Sarah. The resulting child was intended to be raised by Abraham and Sarah.

The foundation of modern gestational surrogacy in the United States began in 1976 with the establishment of the first formal contract between a surrogate mother and a married couple. This agreement was brokered by Noel Keane, a lawyer who went on to found the Infertility Center, which arranges surrogacy agreements to this day. Keane spent much of his career

promoting and defending gestational surrogacy. The first surrogacy contract involving financial compensation was created in 1980, and the surrogate was paid $10,000 for her services (Behm, 1998; Conklin, 2013; Spivack, 2010).

Gestational surrogacy made headlines in the late 1980's with the New Jersey case of "Baby M." In 1986, Mary Beth Whitehead agreed to serve as a traditional surrogate for William Stern and his wife, Elizabeth. Whitehead agreed to $10,000 compensation and was artificially inseminated with William Stern's sperm. The agreement stipulated that Whitehead would carry the pregnancy to term and then terminate her parental rights and surrender the baby to Stern. However, after delivering a baby girl, Whitehead rescinded the initial agreement and fought for custody of the baby. The Supreme Court of New Jersey ruled that the contract was illegal and unenforceable. Custody was granted to Mr. Stern on the basis that it was in the child's best interest, but Whitehead's parental rights were acknowledged as well and she was awarded visitation rights (Spivack, 2010). The case of "Baby M" brought some of the complex issues that may arise in a gestational surrogacy arrangement to public attention (Conklin, 2013).

Another important case with a very different outcome—*Johnson v. Calvert*—occurred in California in 1990. Mark and Crispina Calvert hired Anna Johnson to serve as a gestational carrier surrogate for the couple and relinquish her parental rights after delivering the baby. In return, the Calverts would pay Anna $10,000 and a $200,000 life insurance policy. During the pregnancy, both Anna and the Calverts filed suit for custody of the baby. The California Court ruled that the Calverts were the legal parent(s) because Anna was not genetically related to the fetus, and the surrogacy contract was regarded a "personal service" contract rather than a parentage contract. They also approved the financial compensation (Conklin, 2013; Spivack, 2010).

Gestational carrier surrogacy became possible with the advent of artificial reproductive technologies (ART), such as *in vitro* fertilization (IVF) in 1978 and egg retrieval and donation in 1983 (Ashagouni, 2011). The first documented gestational carrier surrogacy arrangement was carried out in 1985. Today, gestational carrier surrogacy is more common than traditional surrogacy in the United States (Brezina & Zhao, 2012). In fact, traditional surrogacy is no longer offered by many gestational surrogacy programs.

1.2 Process of Gestational Surrogacy

Gestational surrogacy is typically initiated in one of two ways. The first involves the intended parent or parents commissioning a person whom they know, such as a family member or friend, to serve as their gestational surrogate. The second involves the assistance of a surrogacy agency, which matches the intended parent(s) with a gestational surrogate.

The process of becoming a gestational surrogate through a surrogacy agency in the United States is extensive and comprehensive. Gestational surrogacy is considered to be appropriate for women who have been unable to carry a pregnancy or who have a medical condition for which pregnancy is contraindicated, but not for social reasons or for convenience (Brinsden, 2003; Raziel, 2000; Sharma, 2006). Surrogacy agencies have strict prerequisites for their gestational surrogates. While each agency has slightly different requirements, some qualifications are common to most of them. A woman applying to be a gestational surrogate must typically be between the ages of 21-40, have had at least one pregnancy with no complications, and have a child whom she is raising. The experiences of a previous pregnancy and child rearing ensure that the surrogate has an understanding of what pregnancy entails and what giving up the child she carries to the intended parent(s) may feel like. In addition, having had a previous pregnancy with no complications may reduce the likelihood that the gestational

surrogate could be predisposed to complications during pregnancy and delivery. In the United States, gestational surrogates must be citizens or permanent residents of the United States, must be in good economic standing, must not be receiving financial assistance from the government, and must pass a criminal background check. Surrogates are also required to have a medical and psychological evaluation; they must be at a healthy weight and not smoke (James, 2010). Finally, if the gestational surrogate is in a relationship, her partner may also be required to fulfill the applicable requirements (Center for Surrogate Parenting, n.d.; Creative Conception, Inc., n.d.; Conceptual Options, n.d.; Surrogate Parenting Services, n.d.; The Surrogacy Program, n.d; West Coast Surrogacy, n.d.).

Once the intended parent(s) and gestational surrogate have been matched, the gestational surrogate and commissioning couple should independently seek counseling regarding the surrogacy process (Sharma, 2006). Both parties should also seek out a legal expert on surrogacy, and a legal agreement between the two parties should be established (Binsden. 2003; Sharma, 2006). If and when that agreement is complete, the process of pregnancy conception can begin. *In vitro* fertilization (IVF) is performed in gestational surrogacy when the oocytes of the intended mother or of a donor are utilized. This process is demanding on the body of both the oocyte donor and the gestational surrogate. First, the woman whose oocytes are being utilized takes fertility medications that cause her to produce multiple oocytes. These oocytes are retrieved and fertilized using the sperm of the intended father or a donor, forming one or more embryos. The embryos are left to divide until they enter the blastocyst stage. Meanwhile, the gestational surrogate takes exogenous hormones in preparation to establish and support the pregnancy. The blastocyst is transferred into the gestational surrogate's uterus and allowed to implant (Ashagouni, 2011). The gestational surrogate is expected to attend frequent follow up visits with

the fertility specialist until care can be transferred to an obstetrician (Ethics Committee of the American Society for Reproductive Medicine, 2013). Throughout the process, the intended parent(s) may or may not be present at the medical appointments.

1.3 Potential Benefits and Complications in Gestational Surrogacy

Whether gestational surrogacy should be available or not is still a point of contention. Supporters of gestational surrogacy advocate for the possible benefits it can bring, while opponents worry that the potential complications outweigh the benefits. Interestingly, Fortin and Abele (2015) found a positive association between acceptance of artificial reproductive technology (ART) and length of awareness of ART, suggesting that views towards ART are not static. Thus, in time, people's attitudes towards gestational surrogacy may become more positive as exposure to it increases.

1.3.1 Potential Benefits of Gestational Surrogacy

While adoption has been a viable option for many couples, gestational surrogacy provides the opportunity to have a child to whom the couple may have a genetic link. Gestational surrogates can carry a pregnancy for couples who can produce viable embryos but are unable to carry the pregnancy (Adams, 2003); they also can carry a pregnancy conceived with one intended parent's gamete and a donor's gamete (if the couple is unable to produce viable embryos together) or with gametes donated by egg and sperm donors. Gestational surrogacy also gives single fathers or men in same-sex relationships the opportunity to have biological children. Gestational surrogacy is currently available for women who have been unable to carry a pregnancy or for whom pregnancy is medically contraindicated, for single men, and for men or women in same sex relationships (ACOG, 2016: Corson et al. 1998; Greenfeld, 2015; Smotrich, 2008)

Advocates of gestational surrogacy believe the process is beneficial to both the gestational surrogate and the intended parent(s). The completion of gestational surrogacy results in a child for the desiring intended parent(s) (Milliez, 2008). Additionally, it permits the gestational surrogate to help others begin or expand their family, which may bring her satisfaction and purpose. Prohibiting gestational surrogacy would limit the autonomy of intended parent(s) to procreate as well as the autonomy of the gestational surrogate to provide a service to them (Sharma, 2006).

Proponents of gestational surrogacy argue that women who desire to serve as gestational surrogates are capable of acting in their own interest and that prohibiting gestational surrogacy based on the notion that women would be taken advantage of by intended parent(s) or the system is paternalistic (Macklin, 1991). While precautions must be taken to ensure that gestational surrogates truly understand what surrogacy entails and consent to the process, women who are interested are likely to be capable of deciding whether this would be a suitable experience for them.

1.3.2 Potential Complications in Gestational Surrogacy

Despite the aforementioned potential benefits, the concept of gestational surrogacy is complex and raises a number of concerns. Opponents of gestational surrogacy question whether the process of surrogacy is ethical. This concern stems from the fear that a gestational surrogate will be regarded as a vessel. The depersonalization of the gestational surrogate can initiate a harmful perception of them in which their wishes and needs are overlooked or ignored. This view could potentially evolve into objectification of women in general (Macklin, 1991, Sharma 2008).

As with other assisted reproductive technologies, gestational surrogacy elicits concern for the child who is being conceived and carried. In the case of gestational carrier surrogacy, there is concern that the lack of genetic link between the child and his or her parent(s) may be detrimental to their relationship (Ashagouni, 2011; Chatzinikolaou, 2010; Grodin, 1991). There is also a question of whether or not children born with the help of a gestational surrogate should be made aware of the circumstances of his or her gestation and how this information would impact the child (Chatzinikolaou, 2010). This unorthodox model of conception could be confusing to the child and may cause him or her to feel atypical.

Opponents of gestational surrogacy believe it could also be harmful to the child for other reasons. First, legislation regarding gestational surrogacy is neither comprehensive nor standardized. If the gestational surrogate were to decide that she no longer wanted to relinquish her parental rights to the child, a long and difficult custody battle possibly could ensue between the gestational surrogate and the intended parent(s) (Sharma, 2006). There is also a fear that, due to the atypical circumstances of the conception and pregnancy, the baby could be rejected by both the gestational surrogate and the intended parent(s) if he or she were born with an abnormality or a disabling disorder (Chatzinikolaou, 2010).

There are some similarities between these aspects of surrogacy and adoption. In adoption agreements, the birth mother is given a period of time postpartum during which she can choose to retain her parental rights over the child. However, gestational surrogacy differs from adoption in several ways. First, the intent of parental rights for the commissioning parent(s) in gestational surrogacy is established prior to conception rather than during pregnancy or after delivery. In addition, while the birth mother in adoption agreements (and in traditional surrogacy) is genetically related to the child, gestational carriers are not genetically related to the child.

Opponents of gestational surrogacy also state concern for the wellbeing of the gestational surrogate's other children and family. The process of gestational surrogacy is demanding for everyone involved, and the stress of gestational surrogacy could negatively affect the surrogate's family (Sharma, 2006). Furthermore, seeing their mother serve as a surrogate may give her children the impression that reproduction is a business and that women and babies are objects that can be purchased (Ashagouni, 2011; Sharma, 2006).

Another issue involves the subject of compensation. While surrogates ideally offer their services for the purpose of helping others and not for financial compensation, pregnancy is a complicated and expensive process. Some believe that gestational surrogates should be compensated only for their expenses during pregnancy, such as medical bills. Others believe that surrogates not only should be compensated for their expenses during the surrogacy process but also should receive additional compensation. Still others believe that any compensation for gestational surrogates should not be permitted. One reason for opposing compensation is fear that it would transform the process of surrogacy into "baby selling." (Ashagouni, 2011; Brezina & Zhao, 2012; `Macklin, 1991). In this view, compensation in situations involving adoption is illegal, and so it should not be permitted in gestational surrogacy arrangements. In addition, commercial surrogacy may lead to the impression that bodies are commodities to be sold, which might be considered degrading by some (Macklin, 1991). If monetary compensation is permitted, it could lead to the exploitation of women who are in need of financial help (Brezina & Zhao, 2012; Chatzinikolaou, 2010). This concern stems from the assumption that, in general, women of lower socioeconomic status would serve as surrogates, while wealthy couples would commission them. There is also disagreement regarding what should be considered appropriate compensation. If the compensation is too high, it could be seen as a form of coercion and could

push women in economic need to pursue surrogacy for the wrong reasons rather than pursuing other options for which they may be better suited and which ultimately may be more beneficial to them (Macklin, 1991). Excessive financial compensation may persuade potential surrogates to lie about their health or other qualifications in order to appear eligible to be a gestational surrogate. Excessively high compensation to surrogates could cause intended parent(s) to seek surrogacy elsewhere, such as in other countries where the costs may be lower (Ashagouni, 2011). Alternatively, if compensation is too low, this could lead to exploitation of the services provided by gestational surrogates. Low compensation might undermine the gestational surrogacy experience as well as all of the challenges encountered and sacrifices required of the gestational surrogate. In India, where gestational surrogacy is largely unregulated and inexpensive, women of lower socioeconomic class are sometimes pushed into surrogacy by their families as a means of helping out financially (Brugger, 2011). In these situations, risks are often ignored, and the woman's opinions and safety often are not taken into account.

While the gestational surrogate and the intended parent(s) usually are not acquainted prior to the matching process, intended parent(s) may elect to proceed with surrogacy through a family member (Ethics Committee of the American Society for Reproductive Medicine, 2012). The personal relationship between the gestational surrogate and the intended parent(s) may make both parties feel more comfortable. Alternatively, in traditional surrogacy, a surrogate from the intended parent's family would provide the ovum as well. As a result, the fetus and the intended parent would share some genes.

Intrafamilial gestational surrogacy possesses some issues of its own (Marshall, 1998). A situation in which a woman serves as a gestational surrogate for a male family member may be perceived as incest, even though intercourse between relatives does not actually occur, and may

complicate the family relationships with respect to the child (Ethics Committee of the American Society for Reproductive Medicine, 2012). Furthermore, in the case of traditional surrogacy, if a female relative of the intended father provided the ovum and carried the pregnancy, the child's biological parent(s) would actually be consanguineous, and the risks for birth defects and other genetic disorders in the baby would be increased. It is, therefore, recommended that sisters do not serve as traditional surrogates for their brothers (Ethics Committee of the American Society for Reproductive Medicine, 2012). Consanguinity and the perception of incest are not relevant when a woman serves as a gestational carrier surrogate for a female family member. In these cases, the relationship between the gestational surrogate and the intended parent(s) should be examined to determine if, socially, such an arrangement would be beneficial or problematic.

Using a gestational surrogate who is related to either of the intended parent(s) may create conflicts within the family and may confuse social roles. The family may pressure the woman to serve as a gestational surrogate for her relative (Marshall 1998). There may also be family pressure for the gestational surrogate to conform to the wishes of the intended parent(s), regardless of her personal beliefs or preferences (Ethics Committee of the American Society for Reproductive Medicine, 2012). There are also potential implications for the child, who may be affected socially and/or emotionally by the news that he or she was carried and delivered by a relative other than his or her mother. Moreover, since the gestational surrogate would be biologically related to the fetus and, therefore, more likely to remain in contact with the child, she may feel entitled to play a parental role in the child's life. Alternatively, the gestational surrogate may be uncomfortable having contact with the child, whom she carried and delivered, and the child's parent(s), who have legal rights over him or her. In general, separate counseling for intended parent(s) and their gestational surrogate is recommended to ensure that all of their

wishes and concerns are being addressed adequately. This recommendation is, perhaps, more critical if a familial relationship exists between the intended parent(s) and gestational surrogate.

In 2012, the American Society for Reproductive Medicine released the following opinion regarding intrafamilial surrogacy: "The use of intrafamilial gamete donors and surrogates is generally ethically acceptable when all participants are fully informed and counseled, but arrangements that replicate the results of true consanguineous or incestuous unions should be prohibited, child to parent arrangements are generally unacceptable, and parent to child arrangements are acceptable in limited situations. Programs that choose to participate in intrafamilial arrangements should be prepared to spend additional time counseling participants and ensuring that they have made free, informed decisions." (Ethics Committee of the American Society for Reproductive Medicine, 2012).

Currently, gestational surrogacy is typically used for couples who are unable to conceive for medical reasons. However, there is the potential for couples who are medically able to conceive to elect gestational surrogacy for other reasons, such as having the intended mother avoid the inconveniences and potential complications associated with pregnancy. Due to the many possible concerns associated with gestational surrogacy, its use for reasons other than infertility or medical contraindications to pregnancy is controversial (Binsden. 2003).

1.3.3 Issues for Medical Providers involved in Gestational Surrogacy Arrangements

In addition to the issues that may arise during gestational surrogacy between the intended parent(s) and gestational surrogate, the medical providers involved in this type of arrangement may be faced with a number of complicated questions.

Healthcare providers, such as physicians, nurses, and genetic counselors, are required to make medical recommendations in the best interest of the patient and the fetus. In traditional

pregnancy, when the needs of the fetus and the mother differ, medical providers discuss potential conflicts with the intended parent(s) whenever possible in order to decide how to proceed with care (Sharma, 2006). In a surrogacy arrangement, however, the medical provider may encounter a situation in which the intended parent(s) and the gestational surrogate disagree about medical management (Grodin, 1991). The gestational surrogate is the person for whom the medical appointments are typically made and who is under the care of the medical professional. If there is disagreement between the intended parent(s) and the gestational surrogate about pregnancy or delivery management, the provider must decide how to proceed, ideally depending on the stipulations of the contract between the gestational surrogate and intended parent(s). However, the medical provider is not always familiar with the contract or agreement. Typically, it is the gestational surrogate who makes the final decision (Sharma, 2006).

While the gestational surrogate is technically the medical provider's patient, she is not the intended parent of the fetus. Typically, medical providers are obliged to maintain confidentiality with their patients unless they are given explicit permission to share medical information with others. In a situation in which there are pregnancy complications or in which the fetus is found to have congenital anomalies or dies *in utero*, the question arises as to whether the medical provider can or should report this information to the intended parent(s) (Sharma, 2006). Furthermore, if the gestational surrogate requests a procedure that could possibly endanger the fetus, such as invasive prenatal diagnosis (chorionic villus sampling or amniocentesis), fetal transfusion or surgery, or pregnancy termination, the doctor must consider whether the gestational surrogate can make such decisions without the permission of the intended parent(s). Conversely, if the intended parent(s) request a medically appropriate invasive procedure, such as prenatal genetic diagnosis or cesarean section, for the gestational surrogate, is the provider obliged to take the

intended parent(s)' wishes into account? The patient has the legal and ethical right to direct what happens to her body and must have the opportunity to be an informed participant in her health care decisions and to understand and consent to any interventions. However, failure to comply with the expectations for physicians involved in these types of situation can lead to legal issues for the physician (James, 2010).

1.4 Considerations and Recommendations for Gestational Surrogacy

Due to the complex nature of gestational surrogacy, a number of professional organizations have released recommendations to help minimize the risk of controversy and disagreement during this process.

1.4.1 ACOG Committee Opinion: Family Building Through Gestational Surrogacy (2016)

The American College of Obstetricians and Gynecologists (ACOG) released a committee opinion in 2016 regarding the responsibilities of a physician involved in gestational surrogacy. Their recommendations are quoted below:

1. Because of the ethical, legal, and psychosocial complexities and potential medical risks to the gestational carrier, it is recommended that the use of gestational surrogacy be restricted to situations in which carrying a pregnancy is biologically impossible or medically contraindicated for the intended parent(s).
2. Because the legal status of gestational surrogacy varies from state to state, obstetrician–gynecologists who assist in gestational surrogacy arrangements should encourage their patients, whether they are the gestational carriers or intended parent(s), to seek guidance from appropriately qualified legal counsel (i.e., experienced in third-party reproduction arrangements and licensed to practice in the relevant state or states). To avoid potential

conflicts of interest, it is recommended that the gestational carrier and intended parent(s) are represented by separate and independent legal counsel.

3. Obstetrician–gynecologists should remain informed regarding the medical, ethical, and psychosocial complexities of gestational surrogacy because they may play one of several roles in gestational surrogacy arrangements, including counseling potential gestational carriers, caring for pregnant gestational carriers, and advising and referring infertile patients considering this treatment. Obstetrician– gynecologists participating in these arrangements may benefit from consultation with appropriately qualified legal counsel and colleagues with experience in reproductive endocrinology and infertility.
4. Pertinent medical risks, benefits, and alternatives should be discussed by the physicians treating the gestational carrier and intended parent(s), and these physicians should be separate and independent, whenever possible, to optimize patient advocacy and avoid conflicts of interest
5. Separate and independent mental health counseling should be strongly encouraged for all parties involved. Mental health counselors can assist the intended parent(s) in anticipating issues surrounding disclosure of the pregnancy and the child's genetic lineage. For gestational carriers, mental health counselors can assist in anticipating issues surrounding questions and concerns from family and community as well as potential attachment issues for the gestational carrier during pregnancy and after delivery.
6. In an attempt to decrease potential conflict during pregnancy, obstetrician–gynecologists who counsel women who are considering gestational surrogacy should encourage them to discuss with the intended parent(s) as many foreseeable decision-making scenarios in

pregnancy as possible, and the plans for addressing these situations should be formally documented in the gestational surrogacy contract.

7. Cross-border reproductive care refers to the rapidly growing practice of individuals seeking assisted reproductive technology treatment outside of their country of domicile. This practice includes Americans seeking gestational carrier arrangements abroad and foreign nationals seeking gestational carrier arrangements in the United States. Obstetrician– gynecologists should be aware of the existence of these types of gestational surrogacy arrangements, and those who counsel and care for these patients should encourage patients to seek legal advice from appropriately qualified legal counsel experienced in cross-border gestational carrier arrangements.
8. Obstetrician–gynecologists are not obligated to participate in nonemergent medical care related to either domestic or cross-border gestational surrogacy arrangements. However, physicians who choose to care for gestational carriers should provide the same level of medical care as they would to any patient, regardless of the complexities of gestational surrogacy and their personal beliefs regarding a particular parenting arrangement.

(American College of Obstetricians and Gynecologists, 2016).

1.4.2 Surrogacy. FIGO Committee for the Ethical Aspects of Human Reproduction and Women's Health

In 2008, the International Federation of Gynecology and Obstetrics (FIGO), chaired by Milliez, released a committee opinion including nine recommendations regarding surrogacy that are quoted below.

1. Surrogacy is a method of ART reserved solely for medical indications. It is unacceptable for social reasons.

2. Because of the possibility of psychological attachment of the surrogate to her pregnancy on behalf of others, only full surrogacy is acceptable. Furthermore, all efforts must be undertaken to reduce the chance of multiple pregnancy with the ensuing risk to the surrogate and future babies
3. The autonomy of the surrogate mother should be respected at all stages, including any decision about her pregnancy which may conflict the commissioning couple's interest.
4. Surrogate arrangements should not be commercial, and are best arranged by nonprofit-making agencies. Special consideration must be given to transborder reproductive agreements, where there is increased risk of undue inducement of resource-poor women from citizens of resource-rich countries.
5. The commissioning couple and surrogate potential must have full and separate counseling independently prior to their agreement, and be encouraged to address the question of eventual disclosure to the child before entering into the intended procedure. Counseling must include the risks and benefits of the technique to be used, and of pregnancy, including prenatal diagnosis. Such counseling should be factual, respectful of the woman's view, and noncoercive.
6. Where there is no national legislation, prospective parent(s) and the surrogate should be encouraged to seek independent legal advice. They should be encouraged to enter into a consent agreement that outlines the critical issues involved and delineates the rights and responsibilities of all parties. The disposition of all unused embryos should be agreed upon.
7. Surrogacy, if conducted by individual physicians, should be approved by an ethical committee and should be practiced strictly under medical supervision.

8. When the practice is performed it should take full regard of the laws of the country concerned and participants should be fully informed of the legal position.
9. Research about coercion and harm to collateral individuals, such as existing children of the surrogate, must be conducted to understand the harm or benefits of this reproductive model. (Milliez, 2008).

1.4.3. Consideration of Gestational Carrier: Committee Opinion ASRM

The American Society of Reproductive Medicine (ASRM) released a committee opinion regarding gestational surrogacy in 2013, including a recommendation that intended parent(s) and their gestational surrogate each receive independent legal counsel.

ASRM recommends that compensation for gestational surrogates should be ethical, based on the notion that compensation for gamete donation and other situations, such as medical research, is ethical. Compensation should be "fair and reasonable." Considerations for determining compensation should include the time, inconvenience, risk and discomfort associated with pregnancy, the possibility of illness and risk to employment, and the potential burden on the surrogate's family. Compensation should comply with state laws and should not exploit or incentivize the gestational surrogate to lie about her health in order to qualify. Finally, compensation should not depend on desirable characteristics, such as intelligence, race, or physical characteristics of the woman.

ASRM recommendations for medical considerations and informed consent for the gestational surrogate include making the surrogate aware of the risks and processes of pregnancy, including the risk of producing a multiple gestation, especially if more than one embryo is transferred. The gestational surrogate should have final say in medical decisions and should receive appropriate medical care, and the choice of an obstetrician should be agreed upon

by all parties. Both the intended parent(s) and the gestational surrogate should understand screening for infectious diseases and its limitations.

The report also states that gestational surrogates should fulfill certain requirements, including being "at least 21 years of age, healthy, have a stable social environment, and have had at least one pregnancy that resulted in a delivery of a child" (p. 3). The age requirement is in place to ensure maturity of the gestational surrogate due to the complex emotional tasks associated with gestational surrogacy, including negotiating a relationship with the intended parent(s). ASRM believes that having had a prior pregnancy and delivery is necessary to giving informed consent because of the unique nature of the pregnancy experience. Gestational surrogates should also take into account the implications of gestational surrogacy for their own children and spouse.

Lastly, ASRM recommendations regarding psychological considerations stipulate that the relationship between the intended parent and gestational surrogate should be collaborative and respectful, that each party should receive independent counseling including "issues related to antenatal testing, pregnancy termination, multiple pregnancy, multifetal pregnancy reduction, and selective reduction," and that the intended parent(s) and gestational surrogate should ensure congruent goals for the pregnancy relative to these issues. Ultimately, the gestational surrogate should have final say over her body, and the agreement should discuss the implications of the gestational surrogate making a decision that might contradict the conditions stipulated in the agreement (Ethics Committee of The American Society of Reproductive Medicine, 2013).

1.5 Surrogacy Laws

While surrogacy recommendations have been put forward by a number of organizations, laws and legislation are limited and vary from place to place.

One point of contention regarding gestational surrogacy is whether financial gain for the gestational surrogate should or should not be permitted. *Altruistic surrogacy* refers to an arrangement in which there is no financial gain for the gestational surrogate, although certain expenses incurred during the process may be covered. Alternatively, *commercial surrogacy* refers to an agreement in which the gestational surrogate receives financial gain. Certain countries, such as Russia, Ukraine, India, and Georgia, allow both altruistic and commercial surrogacy. Others, such as Netherlands, Australia, Canada, South Africa and Greece, permit altruistic surrogacy but not commercial surrogacy. Some countries, such as France, Iceland, Italy, Pakistan, and Switzerland, ban all types of surrogacy. Still others, such as Ireland, do not have clearly regulated laws (Families Thru Surrogacy, n.d.; Lee and Tedeschi, n.d.). Countries also differ in their regulation of foreign surrogacy. Greece only allows using surrogates who reside in Greece, and Thailand allows for the use of a Thai surrogate only for couples who are residents of Thailand. Spain does not allow surrogacy but does permit its citizens to go through surrogacy in a different country. The inconsistent laws and unregulated nature of international surrogacy has led to numerous legal disagreements and complications (Gamble, 2009; Mortazavi, 2011). In the United States, surrogacy laws are determined state-by-state (Spivack, 2010).

A handful of states, such as California, Connecticut, Delaware, Maine, Maryland, Nevada, Oregon, and Rhode Island, are considered “surrogacy-friendly” and allow all types of surrogacy. Others, such as Arizona, Washington D.C., Indiana, and New York, explicitly

prohibit gestational surrogacy or maintain that surrogacy contracts are void and unenforceable, and some even penalize individuals involved in gestational surrogacy. Other states permit gestational surrogacy only for certain people or have unclear regulations (All Things Surrogacy, n.d; Circle Surrogacy, n.d.; Creative Family Connections, n.d.; The Surrogacy Experience, n.d.). Residents of states with unclear or unfavorable laws regarding surrogacy may chose to seek surrogacy in a more favorable state. However, the inconsistencies among state regulations can be problematic when trying to bring a child into the intended parent(s)'state of residence.

Due to the limited legislation in many places regarding gestational surrogacy, courts must take a number of factors into consideration when settling surrogacy disputes, including the best interest of the child, the rights of the gestational surrogate, the genetic link between the parent(s) and the child, and the intent of the commissioning parent(s) to become parent(s) through surrogacy. As a result, legal cases regarding surrogacy are often complex.

1.6 Past Research

A number of studies have looked at experiences and outcomes of gestational surrogacy. Evidence indicates that, overall, intended parent(s) have positive experiences and, for intended parent(s) who are married, no negative impact on their marriage (Binsden. 2003; Greenfeld, 2015; Kleinpeter, 2002). Intended parent(s) also report pleasant relationships with their gestational surrogate (Jadva et al., 2012). Furthermore, there is typically no negative impact on children after learning about the surrogacy (Greenfeld, 2015; Jadva et al., 2012).

Biologic children of gestational surrogates appear to adjust well after their mothers serve as gestational surrogates. However, during the process, some expressed feelings of jealousy, unhappiness, anger, and confusion (Riddle, 2015). Thus, while gestational surrogacy may not affect biologic children of gestational surrogates negatively in the long term, the process can be

difficult for them, and their needs should be acknowledged and addressed to reduce these negative feelings.

Intended parent(s) typically want a close relationship with the gestational surrogate and want to be present throughout the experience. However, some intended parent(s) may have feelings of loss of control over prenatal care (Kleinpeter, 2002). There does not appear to have been any research regarding cases of fetal testing, fetal anomalies, or decision-making when maternal complications are encountered.

Gestational surrogates also report satisfaction with the amount of contact after the surrogacy experience, with most surrogates keeping in touch with the intended parent(s) (Imrie and Jadva, 2014). Contact tended to decrease over time (Jadva et al., 2012). Jadva, et al (2015) found that gestational surrogates did not regret their experiences 10 years later.

1.7 Aim of Current Study

While gestational surrogacy has grown in popularity in the last decade, relevant legislation has not been adequately established in the United States. A number of organizations have published recommendations for utilizing gestational carriers that comprehensively address when the use of gestational carriers/surrogacy is appropriate, criteria for intended parent(s) and gestational surrogates, and legal issues that may arise, including compensation. Guidelines for the medical providers who work with gestational surrogacy have also been suggested. However, legislation regarding gestational surrogacy varies by county or state and is often not comprehensive.

Previous studies have analyzed various aspects of gestational carriers/surrogates, including experiences and emotional outcome for gestational carriers/surrogates and intended parent(s). However, no studies have examined the extent to which the possibilities of abnormal

prenatal testing results and fetal anomalies are discussed prior to pregnancy and how decisions regarding pregnancy management are made between the intended parent(s) and the surrogate. The purpose of this study is to understand current practices regarding discussions of potential pregnancy complications and of maternal and fetal testing and to determine how and by whom the related management decisions are made.

1.7.1 Statement of Hypothesis

Because of the lack of standardization of current practice regarding discussion of pregnancy complications and testing between intended parent(s) and gestational surrogates, there is considerable variability in how these issues are addressed. Decision making for these topics will also vary as a result of the variability in topics discussed. Guidelines for topics that should be discussed prior to conception are beneficial for intended parent(s), gestational carriers/surrogates, and their prenatal healthcare providers.

1.7.2 Significance

Lack of guided discussion and pre-conception agreement about what to do in the case of a fetal abnormality, abnormal prenatal test results, or pregnancy complications can cause conflict between gestational carriers/surrogates and intended parent(s) if these circumstances arise. The uncertainty can also be troublesome for the healthcare providers involved in the prenatal care. Specifically, physicians, nurses, and genetic counselors may find themselves caught between the wishes of the intended parent(s) and those of the gestational carriers/surrogate without a clear way to manage the situation. Identifying the areas of surrogacy that currently are not adequately discussed and agreed upon will aid in the creation of guidelines for future intended parent(s) and surrogates as well as for the genetic counselors and physicians who work with them.

II: Methods

2.1 Recruitment

Participants were recruited to partake in an anonymous web-based survey through SurveyMonkey, an online survey company. No researcher had direct contact with the participants. Recruitment was via four California-based surrogacy agencies: Growing Generations, Egg Donor & Surrogacy Institute (EDSI), Surrogacy Solutions Inc., and Center for Surrogate Parenting. Each agency was provided a copy of the survey to review. Once approved, each agency sent out a link to the survey via email to the gestational surrogates who have worked with their agency.

2.2 Participants

The participant population was composed of women who had previously served as a gestational surrogate at least once. Participants had to be at least 18 years old. Because women are only eligible to serve as gestational surrogates after the age of 18 (often not until the age of 21), no measures were taken to disqualify underage participants. The survey was only available in English, so participants were required to both read and understand English. Women who were on an agency's emailing list but had not yet served as surrogates were not eligible to participate. There was no discrimination based on age, religion, ethnicity, educational attainment, socioeconomic status, relationship status, or any other socio-demographic characteristic.

2.2.1 Protection of Participant Privacy

The participants' privacy was protected throughout the data collection process. No identifying information was collected from participants. Surrogacy agencies were not aware of which gestational surrogates had or had not participated in the study. All of the research data was stored securely and confidentially.

2.3 Informed Consent

Informed consent was obtained through an information sheet that appeared as the first page of the survey. By clicking "next," participants indicated that they consented to participate in the research study. The information sheet described the purpose, possible risks and discomforts, benefits, duration, participant eligibility, confidentiality, and participation associated with this study. Potential risks and discomforts included emotional reactions while answering questions. No direct benefits were anticipated for the participants. However, participation in this study could contribute to understanding the decision-making process of gestational surrogates. Participants were informed that their responses would remain confidential and that no identifying information would be collected.

2.4 Survey

The survey was presented using SurveyMonkey and was accessed through an online link. It consisted of 32 multiple choice and fill-in answer questions as well as 4 matrix-completion questions. The time needed to complete the survey was between 10-15 minutes. The major themes addressed in the survey included: 1) initial screening and communication with intended parent(s), 2) discussion of relevant topics with intended parent(s), 3) experience during the pregnancy, 4) medical visits and intended parent(s') involvement, and 5) demographics. The survey used skip logic technology, which prompted specific questions based on the participant's previous response. It was created by the researchers after exploring potential areas of conflict that may arise during surrogacy.

2.4.1 Survey Scoring

Discussion of relevant topics with intended parent(s) (items 13 and 14), included 16 topics that are relevant to the surrogacy experience and four possibilities regarding when they

may have been discussed: “Before being matched with intended parent(s),” “Prior to conception,” “During pregnancy,” and “Not Discussed.” Participants were asked to check all of the possible boxes that applied to each topic. Marked boxes were scored as 1, and unmarked boxes were scored as 0. The number of topics discussed was then added up for each possible time during which they may have been discussed for each participant. Then, the total number of topics discussed was added up for each participant. Each topic was classified as “discussed” or “not discussed,” regardless of the number of times the participant reported having discussed it. Participants were grouped by the number of topics discussed in total, before matching, prior to conception, and during pregnancy. For total number of topics discussed, participants who discussed 10 or fewer topics were given a score of 1, those who discussed 11-13 topics were given a score of 2, and those who discussed 14-16 topics were given a score of 3. For topics discussed before matching, prior to conception and during pregnancy, participants who discussed 6 or fewer topics were given a score of 1, those who discussed 7-13 topics were given a score of 2, and those who discussed 14-16 topics were given a score of 3.

Comfort responses (items 15, 16, and 17) were grouped due to small sample size. For each item, participants who marked “comfortable voicing my opinions and that my opinions were considered” were given a score of 1, and those who marked any of the other three options (“comfortable voicing my opinions but that my opinions were not considered,” “uncomfortable voicing my opinions but that my opinions were considered,” “uncomfortable voicing my opinions and that my opinions were not considered”) were given a score of 2.

Experience during the pregnancy (items 18 and 19) referred to the 16 topics from items 13 and 14**.** Participants were asked to mark all that apply for each topic: “No- not encountered during pregnancy,” “Yes-encountered during the pregnancy,” “Intended parent(s) made the

decisions alone," "Gestational surrogate made the decision alone," "The decisions were made by the intended parent(s) and the gestational surrogate together," and "Medical professional made the decision." Marked boxes were given a score of 1, and unmarked boxes were given a score of 0. For participants who marked one of the four boxes indicating how a decision was made but did not mark "Yes- encountered during the pregnancy," the "Yes" box was also scored as 1. Participants who indicated that a decision was made by the intended parent(s)/gestational surrogate alone AND by the intended parent(s) and gestational surrogate together were given a score of 1 for "intended parent(s) and gestational surrogate together" only. This decision was based on the assumption that participants had indicated the individual parties (ie. gestational surrogate and/or intended parent(s) prior to realizing there was an option for "intended parent(s) and gestational surrogate together." Participants who marked "medical professional" and something else were given a score of 1 for the other option that was marked. The rationale behind this scoring was that participants may have had medical professionals aid in the decision making process, but ultimately the decision would have been made by the intended parent(s) or gestational surrogate or all together.

Participants were asked how often intended parent(s) were present at medical appointments (item 21). Participants who marked "never" or "sometimes" were grouped together and given a score of 1. Participants who marked "Often," "Usually," or "Always" were grouped together and given a score of 2.

For "When intended parent(s) were not at an appointment, how was the information from the appointment disclosed to them?" (item 22), participants were asked to mark all of the answers that applied. Possible responses were "gestational surrogate informed them directly,"

“intended parent(s) obtained medical records,” “intended parent(s) spoke to medical professional involved,” “through the surrogacy agency,” “not discussed,” “N/A,” and “other.” “Intended parent(s) obtained medical records” and “intended parent(s) spoke to medical professional involved” were grouped together. “Not discussed,” “N/A” and “other” were not used in the analysis.

Participants were asked about their age during the gestational surrogacy experience (item 25). Those who indicated “18-25” and “26-30” were grouped together and given a score of 1. Those who marked “31-35” or “36 or older” were grouped together and given a score of 2.

Participants were asked about their personal relationship status during the gestational surrogacy experience (item 26). The answer choices included “single, never married,” “married,” “divorced,” “widowed,” “domestic partnership,” and “prefer not to answer.” Those who marked “married” were given a score of 1. Those who marked “single, never married,” “divorced,” “widowed,” or “domestic partnership,” were grouped together due to small sample size and given a score of 2.

Participants were asked to indicate their highest level of education (item 27). Those who indicated “high school or less” or “some college” were grouped and given a score of 1, and those who indicated “college graduate” or “graduate/professional degree” were grouped together and given a score of 2.

Ethnicity responses (item 28) were grouped due to small sample size. Participants who indicated “White/non-Hispanic” were given a score of 1. Those who indicated “American Indian or Alaska Native”, “Asian,” “Black or African American” or “Other” were grouped together into “Other/multiple ethnicities” and given a score of 2.

Religion responses (item 29) were grouped together due to small sample size. Participants who marked “Christian” were given a score of 1. Participants who marked “no religious affiliation,” “prefer not to answer,” or “other” were grouped together and given a score of 2. No participants identified as any of the other listed religions which included “Buddhist,” “Hindu,” “Jewish,” and “Muslim.”

Which one of their surrogacy experiences this represented (“number”) for the gestational surrogate (item 31) responses were grouped together due to small sample size. Participants who marked “first surrogacy experience” were given a score of 1. Those who marked “second surrogacy experience,” “third surrogacy experience,” or “fourth surrogacy experience” were grouped together as “second or more surrogacy experience” and given a score of 2.

Primary reason for serving as a gestational surrogate responses (item 32) responses were grouped together due to small sample size. Participants who marked “help a stranger” and “help a friend” were grouped together as “help another” and given a score of 1. Those who marked “financial compensation” or “other” were grouped together as “other” and given a score of 2.

State of residence of the gestational surrogate responses (item 33) were grouped together due to small sample size. Participants who indicated “California” were given a score of 1; those who indicated a state other than California were grouped together as “other” and given a score of 2.

Country of residence of the intended parent(s) responses (item 34) were grouped together due to small sample size. Participants who indicated “United States” were given a score of 1; those who indicated a country other than USA were grouped together as “other” and given a score of 2.

State of residence of the intended parent(s) responses (item 35) were grouped together due to small sample size. Participants who indicated "California" were given a score of 1; those who indicated a state other than California were grouped together as "other" and given a score of 2.

Time since the completion of the surrogacy experience responses (item 36) were grouped together due to small sample size. Participants who indicated "less than one year ago" or "I am currently pregnant—this is an ongoing surrogacy experience" were grouped together as "less than one year" and given a score of 1. Those who indicated "1-5 years," "6-10 years," "11-15 years," and "16 or more years" were grouped together as "1 year or more" and given a score of 2.

2.5 Statistical Analysis

Survey analysis was conducted using the statistical software Statistical Package for Social Sciences (SPSS). This is a descriptive study comparing data on information and topics discussed, comfort level, and decision making for gestational surrogates. Group differences in frequencies and categorical variables were examined using chi-square tests and Fisher's exact tests. Relationships among comfort and number of topics discussed, decision making throughout the process, how information was disclosed to intended parent(s) when they were not present at an appointment, decisions made without the intended parent(s), and presence of the intended parent(s) at the appointment were analyzed. The frequency distribution responses from each group to the attitude items were compared using Pearson's correlation models. A p-value less than 0.05 was used to indicate statistical significance.

III. RESULTS

3.1 Sample characteristics and demographic information

There were 136 participants who began the survey. Of those, 111 completed at least half of the survey and were eligible to be included in the analysis. There were no significant differences in the responses that were completed between those who were included in the analysis and those who were not. Ninety-five participants completed the survey entirely, including the demographic questions. Sixty-eight of the 95 (72%) were among the ages of 26 and 35, split evenly among 26-30 and 31-35. Eighty-seven percent (n=83) of participants were married, and 87% (n=83) had completed at least some college. Sixty-two percent (n=59) of participants reported identifying as Christian, and 25% (n=24) indicated no religious affiliation. Sixty-four percent (n=61) of participants reported using a donor egg, and 33% (n=31) used the egg of the intended mother. This was the first surrogate experience for 71% (n=67) of participants. Helping another person was the primary reason for serving as a surrogate for 74% (n=68) of participants.

Fifty-four percent (n=51) of participants lived in California during their surrogacy experience. Fifty-one percent of participants (n=48) reported that the intended parent(s) lived in the United States, and of these, 34% (n=21) lived in California. Forty-nine percent (n=48) of intended parent(s) lived in another county.

Eighty-three percent (n= 79) of participants reported that their surrogacy experience ended within the last five years, with 37.9% (n=36) having ended less than a year ago and 45.3% (n=43) ending 1-5 years ago.

Table 1 summarizes the sample demographics.

TABLE 1: Participant Characteristics	Total	
	n	%
AGE (n=95)		
18-25	10	9.0
26-30	34	35.8
31-35	34	35.8
36 or older	17	17.9
Prefer not to answer	0	0.0
RELATIONSHIP STATUS (n=95)		
Single, never married	3	3.2
Married	83	87.4
Divorced	5	5.3
Widowed	0	0.0
Domestic partnership	4	4.2
Prefer not to answer	0	0.0
LEVEL OF EDUCATION (n=95)		
High school or less	12	12.6
Some college (including completing an Associate's degree)	52	54.7
College graduate (B.A., B.S., or the equivalent)	24	25.3
Graduate/Professional degree (Master's degree, PhD, MD, JD)	7	7.4
ETHNICITY(n=95)		
American Indian or Alaskan Native	1	1.1
Asian	2	2.1
Black or African American	2	2.1
Hispanic	13	13.7
Native Hawaiian or other Pacific Islander	0	0.0
White/Non-Hispanic	82	86.3
Other *	1	1.1
RELIGION (n=95)		
Buddhist	0	0.0
Christian	59	62.1
Hindu	0	0.0
Jewish	0	0.0
Muslim	0	0.0
No religious affiliation	24	25.3
Prefer not to answer	4	4.2
Other	8	8.4
EGG (n=95)		
The intended mother's egg	31	32.6
The surrogate's egg	3	3.2
A donor egg from someone else	61	64.2
SURROGACY NUMBER (n=95)		

First surrogate experience	67	70.5
Second surrogate experience	22	23.2
Third surrogate experience	5	5.3
Fourth surrogate experience	1	1.1
Fifth or more surrogate experience	0	0.0
PRIMARY REASON FOR SERVING AS A GESTATIONAL SURROGATE (n=95)		
Financial compensation	5	5.3
Help a stranger	68	71.6
Help a friend	2	2.1
Help a family member	0	0.0
Other	20	21.1
GESTATIONAL SURROGATE'S STATE OF RESIDENCE (n=94)		
Arizona	3	3.2
California	51	54.3
Colorado	8	8.5
Florida	2	2.1
Georgia	1	1.1
Idaho	1	1.1
Iowa	1	1.1
Kansas	7	7.4
Nevada	1	1.1
New Hampshire	1	1.1
North Dakota	1	1.1
Ohio	2	2.1
Texas	3	3.2
Utah	6	6.4
Washington	3	3.2
Wisconsin	3	3.2
INTENDED PARENT'S COUNTRY OF RESIDENCE (n=94)		
USA	48	51.1
Unknown	0	0.0
Other country	46	48.9
FOR INTENDED PARENT(S) IN USA, WHICH STATE DID THEY LIVE IN (n=62)		
N/A	13	21.0
Arizona	1	1.6
Arkansas	1	1.6
California	21	33.9
Colorado	1	1.6
District of Columbia (DC)	1	1.6
Florida	2	3.2
Illinois	1	1.6
Maryland	1	1.6
Massachusetts	1	1.6
Nebraska	1	1.6
Nevada	1	1.6
New Jersey	1	1.6
New York	7	11.3
Pennsylvania/Rhode Island	1	1.6
South Dakota	1	1.6
Texas	5	8.1
Utah	1	1.6
Washington	1	1.6
TIME SINCE SURROGACY EXPERIENCE (n=95)		
Less than 1 year ago	36	37.9

1-5 years ago	43	45.3
6-10 years ago	4	4.2
11-15 years ago	2	2.1
16 or more years ago	2	2.1
I am currently pregnant-this is an ongoing surrogacy experience	8	8.4
IF THIS SURROGACY EXPERIENCE IS ONGOING, WHICH PART OF THE PROCESS ARE YOU IN? (n=8)		
Pre-matching with intended parent(s)	0	0.0
Matched but not yet pregnant	2	25.0
First trimester	0	0.0
Second trimester	2	25.0
Third trimester	4	50.0
Post-partum but still involved	0	0.0

3.2 Initial Screening and communication with intended parent(s)

Ninety-seven percent of participants were matched with the intended parent(s) through the surrogacy agency (n=107) and had a legal contract with the intended parent(s) (n=107). Eighty-five percent (n=94) of participants reported having the surrogacy agency involved in the process of making the agreement with the intended parent(s) and 91% (n=101) had a lawyer involved.

Eighty-seven percent (n=96) of participants reported that they had their family history taken. Participants who answered “no” to having a family history taken were not asked the three follow-up questions about family history. Of those who had a family history taken, 78.4% (n=76) had it taken by the surrogacy agency; only 2.1% (n=2) of participants had it taken by a genetic counselor. Ninety-seven percent (n=95) of family histories were taken via a questionnaire. Of those who had their family history taken, 95% (n=91) were asked about their children, 97% (n=93) were asked about their parent(s), 89% (n=85) were asked about their siblings, 34% (n=33) were asked about their aunts and uncles, 12.5% (n=12) were asked about their nieces and nephews, and 65% (n=62) were asked about their grandparent(s).

When asked if they had been offered carrier screening, 37% (n=41) reported that they had. Participants who answered “no” to having been offered carrier screening were not asked the four follow-up questions about carrier screening. Only 4.8% (n=2) of participants who were

offered carrier screening reported having it offered for a specific condition. Carrier screening was required for 50% (n=21) of surrogate mothers who were offered it. Fifty-eight percent (n=23) of gestational surrogates who were offered carrier screening actually had carrier screening done; however, only 22% (n=5) of those who had carrier screening knew how many conditions they were screened for.

Table 2 summarizes the results of initial screening and communication with the intended parent(s).

TABLE 2: Initial Screening and Communication with Intended Parent(s)	Total	
	n	%
HOW WERE YOU INITIALLY MATCHED WITH THE INTENDED PARENT(S)? (n=111)		
Personal	0	0.0
Surrogacy agency	107	96.4
IVF Center	0	0.0
Personal relationship with intended parent(s)	2	1.8
Other	2	1.8
WHICH OF THE FOLLOWING AGREEMENT(S) WAS/WERE MADE AMONG YOU AND THE INTENDED PARENT(S)? (n=111)		
Legal contract	107	96.4
Informal contract with intended parent(s)	2	1.8
None	1	0.9
Other	0	0.0
WHO WAS INVOLVED IN HELPING CREATE THE AGREEMENT(S) AMONG YOU AND THE INTENDED PARENT(S)? (n=111)		
Surrogacy agency	94	84.7
IVF center	11	9.9
Lawyer	101	91.0
Genetic Counselor/other health care professional	6	5.4
N/A	1	0.9
Other	2	1.8
WAS A DETAILED FAMILY HISTORY TAKEN? (n=111)		
Yes	96	86.5
No	15	13.5
WHO TOOK THE FAMILY HISTORY? (n=96)		
Genetic counselor	2	2.1
Doctor/nurse	6	6.3
Surrogacy agency	76	78.4
IVF center	6	6.2
Other	7	7.2
HOW WAS THIS INFORMATION GATHERED? (n=96)		
Questionnaire	95	99.0
Pedigree	2	2.1

WHICH OF THE FOLLOWING FAMILY MEMBERS WERE YOU ASKED ABOUT? (n=96)		
Children	91	94.8
Parent(s)	93	96.9
Siblings	85	88.5
Aunts/uncles	33	34.4
Nieces/nephews	12	12.5
Grandparent(s)	62	64.6
None of the above	0	0.0
WERE YOU OFFERED CARRIER SCREENING TESTS FOR GENETIC CONDITIONS? (n=111)		
Yes	41	36.9
No	70	63.1
WERE YOU OFFERED CARRIER SCREENING FOR SPECIFIC REASONS, SUCH AS ANCESTRY OR FAMILY HISTORY OF A GENETIC SYNDROME? (n=41)		
Yes	2	5.9
No	39	95.1
WAS CARRIER SCREENING REQUIRED FOR YOU TO BE A GESTATIONAL SURROGATE? (n=35)		
Yes	21	60.0
No	14	40.0
DID YOU HAVE ANY CARRIER SCREENING TESTS? (n=40)		
Yes	23	57.5
No	17	42.5
HOW MANY GENETIC CONDITIONS WERE YOU TESTED FOR? (n=23)		
Less than 5	4	17.4
Among 6 and 50	1	4.3
Not Sure	18	78.8

3.3 Discussion of relevant topics with intended parent(s)

3.3.1 Discussed Topics

Participants were asked whether they had discussed certain topics before being matched with the intended parent(s), prior to conception, during the pregnancy, or if that topic was never discussed. Sixteen topics were listed that related to carrier screening, fetal anomalies, and screening/testing options. Participants could provide multiple responses to each.

Most topics related to prenatal screening and testing were discussed at some point in the process with at least 90% of the surrogates. Preterm labor, labor induction for medical reasons, and pregnancy termination due to the gestational surrogate's personal reasons were discussed with fewer than 85% of the surrogates. Labor induction for personal reasons was discussed with 66% of participants. Decision making was discussed with almost all participants.

Table 3 summarizes the frequencies of the potentially discussed topics.

TABLE 3: Topics Discussed Throughout the Process	Total	
	n	%
ULTRASOUNDS (n=111)		
Before being matched with intended parent(s)	64	57.7
Prior to conception	62	55.9
During pregnancy	75	67.6
Not discussed	7	6.3
Total discussed at some point	104	93.7
THE POSSIBILITY OF ULTRASOUND ABNORMALITIES AND FOLLOW UP (n=111)		
Before being matched with intended parent(s)	67	60.4
Prior to conception	60	54.1
During pregnancy	54	48.6
Not discussed	10	9.0
Total discussed at some point	101	91.0
ROUTINE PRENATAL SCREENING (n=111)		
Before being matched with intended parent(s)	71	64.0
Prior to conception	63	56.8
During pregnancy	66	59.5
Not discussed	9	8.1
Total discussed at some point	102	91.9
NON-INVASIVE PRENATAL SCREENING (n=111)		
Before being matched with intended parent(s)	68	61.8
Prior to conception	61	55.0
During pregnancy	60	54.1
Not discussed	8	7.2
Total Discussed	103	92.8
CVS/AMNIOCENTESIS (n=110)		
Before being matched with intended parent(s)	73	67.0
Prior to conception	53	48.6
During pregnancy	40	36.7
Not discussed	13	11.9
Total discussed at some point	96	88.1
TERMINATION OF PREGNANCY IN CASE OF FETAL ANOMALIES (n=111)		
Before being matched with intended parent(s)	92	82.9
Prior to conception	59	53.2
During pregnancy	27	24.3
Not discussed	3	2.7
Total discussed at some point	108	97.3
TERMINATION OF PREGNANCY FOR YOUR PERSONAL REASONS (n=110)		
Before being matched with intended parent(s)		
Prior to conception	79	71.2
During pregnancy	36	32.4
Not discussed	11	9.9
Total discussed at some point	22	19.8
	90	81.8
TERMINATION OF PREGNANCY FOR THE INTENDED PARENT(S)' PERSONAL REASONS (n=111)		
Before being matched with intended parent(s)	87	78.4
Prior to conception	48	43.2
During pregnancy	16	14.4
Not discussed	8	7.2

Total Discussed	103	92.8
PRETERM DELIVERY FOR YOUR SAFETY (n=111)		
Before being matched with intended parent(s)	61	55.0
Prior to conception	55	49.5
During pregnancy	40	36.0
Not discussed	18	16.2
Total discussed at some point	93	83.8
PRETERM DELIVERY FOR THE SAFETY OF THE BABY (n=111)		
Before being matched with intended parent(s)	61	55.0
Prior to conception	55	49.5
During pregnancy	42	37.8
Not discussed	16	14.4
Total discussed at some point	95	85.6
C-SECTION VERSUS NATURAL BIRTH (n=111)		
Before being matched with intended parent(s)	65	58.6
Prior to conception	53	47.7
During pregnancy–	55	49.5
Not discussed	10	9.0
Total discussed at some point	101	91.0
LABOR INDUCTION FOR YOUR MEDICAL WELL BEING (n=111)		
Before being matched with intended parent(s)	54	48.6
Prior to conception	44	39.6
During pregnancy	58	52.3
Not discussed	18	16.2
Total discussed at some point	93	83.8
LABOR INDUCTION FOR THE BABY'S MEDICAL WELL BEING (n=111)		
Before being matched with intended parent(s)	56	50.5
Prior to conception	44	39.6
During pregnancy	54	48.6
Not discussed	17	15.3
Total discussed at some point	94	84.7
LABOR INDUCTION FOR YOUR OWN PERSONAL REASONS (n=111)		
Before being matched with intended parent(s)	44	39.6
Prior to conception	30	27.0
During pregnancy	40	36.0
Not discussed	38	34.2
Total discussed at some point	73	65.8
LABOR INDUCTION FOR THE INTENDED PARENT(S)' PERSONAL REASONS (n=111)		
Before being matched with intended parent(s)	43	38.7
Prior to conception	31	27.9
During pregnancy	37	33.3
Not discussed	43	38.7
Total discussed at some point	68	61.3
DECISION MAKING DURING THE PREGNANCY (AMONG GESTATIONAL SURROGATE AND INTENDED PARENT(S)) (n=111)		
Before being matched with intended parent(s)	84	75.7
Prior to conception	81	73.0
During pregnancy	71	64.0
Not discussed	1	0.9
Total discussed at some point	110	99.1

Sixteen topics were asked about in the survey. For each topic that was discussed at some point during pregnancy, the participant received a score of 1. If the topic was not discussed, the participant received a score of zero. These scores were then added up for each person, with a maximum possible score of 16. The total number of topics discussed was then grouped. For the total number of topics discussed, participants were grouped as follows: 10 or fewer, 11-13, and 14-16. For topics discussed before matching, prior to conception, and during pregnancy, participants were grouped as follows: 6 or fewer, 7-13, and 14-16.

The total number of topics discussed at some point in the process ranged from 6-16, with 68.5% (n=76) discussing 14-16 topics at some point (tables 5 and 6). The median number of total topics discussed was 15, and the average was 13.9. Before matching, the median number of topics discussed was 11,and the average was 9.8. The median number of topics discussed prior to conception was 7, and the mean was 5.0. During the pregnancy, the median number of topics discussed was 7, and the average was 2.6. Topics were most likely to be discussed before being matched (14-16: 34.2%; n=38) and least likely to be discussed during pregnancy (0-6: 47.7%; n=53) (table 6).

Tables 4-11 summarize the number of topics discussed and the grouped number of topics discussed.

TABLE 4: Number of Topics Discussed								
Number of topics	Total (n=111)		Before being matched (n=111)		Prior to Conception (n=111)		During Pregnancy (n=111)	
	n	%	n	%	n	%	n	%
0	0	0.0	8	7.2	17	15.3	20	18.0
1	0	0.0	3	2.7	9	8.1	5	4.5
2	0	0.0	4	3.6	5	4.5	5	4.5
3	0	0.0	2	1.8	5	4.5	4	3.6
4	0	0.0	7	6.3	3	2.7	5	4.5
5	0	0.0	3	2.7	5	4.5	8	7.2
6	3	2.7	7	6.3	4	3.6	6	5.4
7	1	0.9	5	4.5	8	7.2	8	7.2
8	1	0.9	8	7.2	1	0.9	7	6.3
9	4	3.6	4	3.6	8	7.2	8	7.2
10	6	5.4	3	2.7	9	8.1	10	9.0
11	4	3.6	5	4.5	7	6.3	3	2.7
12	11	9.9	11	9.9	7	6.3	6	5.4
13	5	4.5	3	2.7	2	1.8	1	0.9
14	16	14.4	7	6.3	4	3.6	6	5.4
15	15	13.5	6	5.4	4	3.6	5	4.5
16	45	40.5	25	22.5	13	11.7	4	3.6

TABLE 5: Grouped Total Number of Topics Discussed (n=111)		
Number of topics	**n**	**%**
10 or fewer	15	13.5
11-13	20	18.0
14-16	76	68.5

TABLE 6: Number of Topics Discussed						
Number of topics	Before being matched (n=111)		Prior to Conception (n=111)		During Pregnancy (n=111)	
	n	%	n	%	n	%
0-6	34	30.6	48	43.3	53	47.7
7-13	39	35.2	42	37.8	43	38.7
14-16	38	34.2	21	18.9	15	13.5

The number of topics discussed (0-6, 7-13, 14-16) were compared by time during the process at which they were discussed (before matching, prior to conception, during pregnancy). A significant difference was found (p<0.001), with fewer topics being discussed later in the pregnancy (Table 7).

TABLE 7: Number of Topics Discussed by Time in the Process

Time in the Process	6 or fewer (n=135)		7-13 (n=124)		14-16 (n=74)		p-Value
	n	%	n	%	n	%	
Before Matching	34	25.2	48	35.6	53	39.3	<0.001
Prior to Conception	39	31.5	42	33.9	43	34.7	
During Pregnancy	38	51.4	21	28.4	15	20.3	

Respondents were compared by demographics and surrogacy experience for the number of topics discussed. For total number of topics discussed, significant differences were found by gestational surrogate state of residence (p=0.016). Gestational surrogates living outside of California were more likely to report discussing 14-16 topics than gestational surrogates living in California (83.7% ; n=36 v. 56.0%; n=26) (table 8). No significant differences were found by age, education, ethnicity, religion, whose egg was used, primary reason for serving as a gestational surrogate, state of residence of the gestational surrogate, country of residence of the intended parent(s), state of residence of the intended parent(s) if in the United States, or time since completion of surrogacy experience. For number of topics discussed before being matched with the intended parent(s) (table 9), no significant differences were found by demographics. The number of topics discussed prior to conception differed by time since surrogacy ended (p=0.012); 27% of participants whose surrogacy experience was ongoing or ended within the past year recalled that 6 or fewer topics were discussed prior to conception, and 57% of participants who completed the surrogacy experience over a year ago reported having discussed

6 or fewer topics (20.5%; n=9 v. 15.7%; n=8) (table 10). Number of topics discussed during pregnancy did not differ significantly by demographics (table 11).

Tables 7-10 summarize these results.

TABLE 8: Respondent Characteristics by Total Number of Topics Discussed								
Participant demographics		10 or fewer (n=15)		11-13 (n=20)		14-16 (n=76)		p-Value
		n	%	n	%	n	%	
Age								
	18 to 30	5	11.4	7	15.9	32	72.7	0.696
	31 and over	8	15.7	10	19.5	33	64.7	
Education								
	Some college education or less	7	10.9	15	23.4	42	65.6	0.097
	College graduate or higher degree	6	19.4	2	6.5	23	74.2	
Ethnicity								
	White	9	11.7	13	16.9	55	71.4	0.384
	Other/multiple ethnicities	3	20.0	4	26.7	8	53.3	
Religion								
	Christian	11	18.6	11	18.6	37	62.7	0.166
	Other	2	5.6	6	16.7	28	77.8	
Egg								
	Intended mother	4	12.9	6	19.4	21	67.7	0.939
	Donor	8	13.1	10	16.4	43	70.5	
Surrogacy Number								
	First	7	10.4	11	16.4	49	73.1	0.252
	Second or more	6	21.4	6	21.4	16	57.1	
Primary Reason								
	Help another	11	14.5	14	18.4	51	67.1	0.849
	Other	2	10.5	3	15.8	14	73.7	
Gestational surrogate state of residence								0.016*
	California	10	20.0	12	24.0	26	56.0	
	Other	3	7.0	4	9.3	36	83.7	
Intended parent(s) country of residence								
	USA	8	16.7	10	20.8	30	62.5	0.489
	Other	5	10.9	7	15.2	34	73.9	
Intended parent(s) state of residence								
	California	4	19.0	4	19.0	13	61.9	0.483
	Other	2	4.3	4	16.0	19	76.0	
Time Since Surrogacy Experience								
	Less than 1 year	4	9.1	5	11.4	35	79.5	0.095
	A year ago or more	9	17.6	12	23.5	30	58.8	

TABLE 9: Respondent Characteristics by Number of Topics Discussed Before Matching								
Participant demographics		**6 or fewer (n=34)**		**7-13 (n=39)**		**14-16 (n=38)**		**p-Value**
		n	**%**	**n**	**%**	**n**	**%**	
Age								0.379
	18 to 30	14	31.8	13	29.6	17	38.6	
	31 and over	14	33.3	20	39.2	14	27.5	
Education								0.890
	Some college	20	31.3	22	34.4	21	32.8	
	College graduate or	11	35.5	10	32.3	10	32.3	
Ethnicity								0.297
	White	22	28.6	27	35.1	28	36.4	
	Other/multiple	8	53.3	3	20.0	4	35.1	
Religion								0.715
	Christian	21	35.6	20	33.9	18	30.5	
	Other	10	27.8	13	36.1	13	36.1	
Egg								0.793
	Intended mother	11	35.5	9	29.0	11	35.5	
	Donor	19	31.1	22	36.1	20	32.8	
Surrogacy Number								0.165
	First	18	26.9	26	38.8	23	34.3	
	Second	13	46.4	7	25.0	8	28.6	
Primary Reason								0.936
	Help another	25	32.9	27	35.5	24	31.6	
	Other	6	31.6	6	31.6	7	36.8	
Gestational surrogate state of residence								0.205
	California	22	44.0	14	28.0	14	28.0	
	Other	9	20.9	17	39.6	17	39.5	
Intended parent(s) country of residence								0.568
	USA	18	37.5	16	32.5	14	29.2	
	Other	13	28.3	17	37.0	16	34.8	
Intended parent(s) state of residence								0.180
	California	10	47.6	6	28.6	5	23.8	
	Other	5	20.0	9	34.0	11	44.0	
Time Since Surrogacy Experience								0.459
	Less than 1 year	14	31.8	13	29.5	17	38.6	
	A year ago or more	17	33.3	20	39.2	14	27.5	

TABLE 10: Respondent Characteristics by Number of Topics Discussed Prior to Conception								
Participant demographics		**6 or fewer (n=48)**		**7-13 (n=42)**		**14-16 (n=21)**		**p-Value**
		n	**%**	**n**	**%**	**n**	**%**	
Age								0.457
	18 to 30	19	43.2	15	34.1	10	22.7	
	31 and over	22	43.1	22	43.1	7	13.7	
Education								0.225
	Some college education or less	31	48.4	24	37.5	9	14.1	
	College graduate or higher degree	10	32.3	13	41.9	8	25.8	
Ethnicity								0.429
	White	32	41.6	29	37.7	16	20.8	
	Other/multiple ethnicities	7	46.7	7	46.7	1	6.7	
Religion								0.805
	Christian	27	45.8	22	37.3	10	16.9	
	Other	14	38.9	15	41.7	36	37.9	
Egg								0.661
	Intended mother	13	41.9	14	45.2	4	12.9	
	Donor	26	42.6	23	37.7	12	19.7	
Surrogacy Number								0.163
	First	29	43.3	29	43.3	9	13.4	
	Second	12	42.9	8	28.6	8	28.6	
Primary Reason								0.328
	Help another	30	39.5	32	42.1	14	18.4	
	Other	11	57.9	5	26.3	3	15.8	
Gestational surrogate state of residence								0.238
	California	24	48.0	20	40.0	6	12.0	
	Other	17	39.5	15	34.9	11	25.6	
Intended parent(s) country of residence								0.124
	USA	25	52.1	17	35.4	6	12.5	
	Other	15	32.6	20	43.5	11	23.9	
Intended parent(s) state of residence								0.982
	California	10	47.6	8	38.1	3	14.3	
	Other	12	48.0	9	36.0	4	16.0	
Time Since Surrogacy Experience								0.012*
	Less than 1 year	12	27.3	23	52.3	9	20.5	
	A year ago or more	29	56.9	14	27.5	8	15.7	

TABLE 11: Respondent Characteristics by Number of Topics Discussed During Pregnancy								
Participant demographics		**6 or fewer (n=53)**		**7-13 (n=43)**		**14-16 (n=15)**		**p-Value**
		n	**%**	**n**	**%**	**n**	**%**	
Age								0.052
	18 to 30	15	34.1	22	50.0	7	15.9	
	31 and over	30	58.8	15	29.4	6	11.8	
Education								0.684
	Some college education or less	32	50.0	23	35.9	9	14.1	
	College graduate or higher degree	13	41.9	14	45.2	4	12.9	
Ethnicity								0.425
	White	38	49.4	28	36.4	11	14.3	
	Other/multiple ethnicities	6	40.0	8	53.3	1	6.7	
Religion								0.406
	Christian	30	50.8	23	39.0	6	10.2	
	Other	15	41.7	14	38.9	7	19.4	
Egg								0.159
	Intended mother	17	54.8	8	25.8	6	19.4	
	Donor	26	42.6	28	45.9	7	11.5	
Surrogacy Number								0.710
	First	30	44.8	27	40.3	10	14.9	
	Second	15	53.6	10	35.7	3	1.7	
Primary Reason								0.844
	Help another	35	46.1	30	39.5	11	14.5	
	Other	10	52.6	7	36.8	2	10.5	
Gestational surrogate state of residence								0.670
	California	22	44.0	22	44.0	6	12.0	
	Other	22	51.2	15	34.9	6	14.0	
Intended parent(s) country of residence								0.726
	USA	24	50.0	17	35.4	7	14.6	
	Other	20	43.5	20	43.5	6	13.0	
Intended parent(s) state of residence								0.956
	California	11	52.4	7	33.3	3	14.3	
	Other	12	48.0	9	36.0	4	16.0	
Time Since Surrogacy Experience								0.481
	Less than 1 year	22	50.0	18	40.9	4	9.1	
	A year ago or more	23	45.1	19	37.3	9	17.6	

3.3.2 Comfort

Participants were asked to describe their level of comfort (items 15, 16, 17) at various times, including before being matched with the intended parent(s), prior to conception, and during pregnancy by choosing the response that most accurately reflected their experience. The results are summarized in Table 12.

TABLE 12 : Comfort Level	**Total**	
	n (n=109)	**%**
PRIOR TO BEING MATCHED WITH THE INTENDED PARENT(S) (n=109)		
Comfortable voicing my opinions and that my opinions were considered.	104	95.4
Comfortable voicing my opinions but that my opinions were not considered	2	1.8
Uncomfortable voicing my opinions but that my opinions were considered.	3	2.8
Uncomfortable voicing my opinions and that my opinions were not considered.	0	0.0
AFTER BEING MATCHED WITH THE INTENDED PARENT(S) BUT PRIOR TO CONCEPTION (n=109)		
Comfortable voicing my opinions and that my opinions were considered.	103	94.5
Comfortable voicing my opinions but that my opinions were not considered	3	2.8
Uncomfortable voicing my opinions but that my opinions were considered.	2	1.8
Uncomfortable voicing my opinions and that my opinions were not considered.	1	0.9
DURING THE PREGNANCY (n=109)		
Comfortable voicing my opinions and that my opinions were considered.	96	88.1
Comfortable voicing my opinions but that my opinions were not considered	6	5.5
Uncomfortable voicing my opinions but that my opinions were considered.	7	6.4
Uncomfortable voicing my opinions and that my opinions were not considered.	0	0.0

Overall, the majority of participants indicated being comfortable voicing their opinions and that their opinions were considered, although this decreased somewhat from before being matched (95.4%; n=104) to during the pregnancy (88.1%; n=96).

For comfort level before being matched (table 13), no significant differences were found by age, relationship status, education, ethnicity, religion, number of surrogacy experience, (i.e., was this their first or second surrogacy), primary reason for serving as a gestational surrogate, state of residence of the gestational surrogate, country of residence of the intended parent(s), state of residence of the intended parent(s) if in the United States, or time since completion of surrogacy experience.

For comfort level prior to conception (table 14), significant differences were found by religion (p=0.048), with participants identifying as Christian being more likely to have felt uncomfortable voicing their opinions and/or to have felt that their opinions were not considered (89.9%; n=53 v. 100.0%; n=36).

Comfort level during pregnancy (table 15) differed significantly by religion (p=0.047) and gestational surrogate's state of residence (p=0.010), with participants who identified as Christian or who resided in California being more likely to have felt uncomfortable voicing opinions and/or to have felt that their opinions were not considered (16.9%; n=10 v. 2.8%; n= 1 and 20.0%; n=10 v. 2.3%; n=1, respectively).

TABLE 13: Respondent Characteristics by Comfort Level Before Matching						
Participant demographics		**Comfortable and felt that opinions were considered**		**Uncomfortable and/or opinions not considered**		**p-Value**
		n (n=90)	**%**	**n (n=5)**	**%**	
Age						1.000
	18 to 30	42	95.5	2	4.5	
	31 and over	48	94.1	3	5.9	
Education						1.000
	Some college education or less	60	93.8	4	6.3	
	College graduate or higher degree	30	96.8	1	3.2	
Ethnicity						1.000
	White	73	94.8	4	5.2	
	Other/multiple ethnicities	14	9.3	1	6.7	
Religion						0.647
	Christian	55	93.2	4	6.8	
	Other	35	97.2	1	2.8	
Egg						0.660
	Intended mother	30	96.8	1	3.2	
	Donor	57	93.4	4	6.6	
Surrogacy Number						0.317
	First	62	92.5	5	7.5	
	Second	28	100.0	0	0.0	
Primary Reason						0.579
	Help another	71	93.4	5	6.6	
	Other	19	100.0	0	0.0	
Gestational surrogate state of residence						0.369
	California	46	92.0	4	8.0	
	Other	42	97.7	1	2.3	
Intended parent(s) country of residence						0.674
	USA	46	95.8	2	4.2	
	Other	43	93.5	3	6.5	
Intended parent(s) state of residence						0.457
	California	20	95.2	1	4.8	
	Other	25	100.0	0	0.0	
Time since						0.660
	Less than 1 year	41	93.2	3	6.8	
	A year ago or more	49	96.1	2	3.9	

TABLE 14: Respondent Characteristics by Comfort Level Prior to Conception						
Participant demographics		**Comfortable and felt that opinions were considered**		**Uncomfortable and/or opinions not considered**		**p-Value**
		n (n=89)	**%**	**n (n=6)**	**%**	
Age						
	18 to 30	42	95.5	2	4.5	0.683
	31 and over	47	92.2	4	7.8	
Education						
	Some college education or less	60	93.8	4	6.3	1.000
	College graduate or higher degree	29	93.5	2	6.5	
Ethnicity						
	White	73	94.8	4	5.2	0.252
	Other/multiple ethnicities	13	86.7	1	13.3	
Religion						
	Christian	53	89.8	6	10.2	0.048*
	Other	36	100.0	0	0.0	
Egg						
	Intended mother	29	93.5	2	6.5	1.000
	Donor	57	93.4	4	6.6	
Surrogacy Number						
	First	63	94.0	4	6.0	1.000
	Second	26	92.9	2	7.1	
Primary Reason						
	Help another	70	92.1	6	7.9	0.344
	Other	19	100.0	0	0.0	
Gestational surrogate state of residence						
	California	45	90.0	5	10.0	0.212
	Other	42	97.7	1	2.3	
Intended parent(s) country of residence						
	USA	44	91.7	4	8.3	0.678
	Other	44	95.7	2	4.3	
Intended parent(s) state of residence						
	California	18	85.7	3	14.3	0.318
	Other	24	96.0	1	4.0	
Time since						
	Less than 1 year	43	97.7	1	2.3	0.211
	A year ago or more	46	90.2	5	9.8	

TABLE 15: Respondent Characteristics by Comfort Level During Pregnancy						
Participant demographics		Comfortable and felt that opinions were considered		Uncomfortable and/or opinions not considered		p-Value
		n (n=84)	%	n (n=11)	%	
Age						
	18 to 30	38	86.4	6	13.6	0.750
	31 and over	46	90.2	5	9.8	
Education						
	Some college education or less	56	87.5	8	12.5	1.000
	College graduate or higher degree	28	90.3	3	9.7	
Ethnicity						
	White	70	90.9	7	9.7	0.206
	Other/multiple ethnicities	12	80.0	3	20.0	
Religion						
	Christian	49	83.1	10	16.9	0.047*
	Other	35	97.2	1	2.8	
Egg						
	Intended mother	28	90.3	3	9.7	1.000
	Donor	53	86.9	8	13.1	
Surrogacy Number						
	First	59	88.1	8	11.9	0.113
	Second	25	92.9	2	7.1	
Primary Reason						
	Help another	65	85.5	11	14.5	0.010*
	Other	0	0.0	11	100.0	
Gestational surrogate state of residence						
	California	40	80.0	10	20.0	0.212
	Other	42	97.7	1	2.3	
Intended parent(s) country of residence						
	USA	40	83.3	8	16.7	0.119
	Other	43	93.5	3	6.5	
Intended parent(s) state of residence						
	California	16	76.2	5	23.8	0.220
	Other	23	92.0	2	8.0	
Time since						
	Less than 1 year	43	84.3	8	15.7	0.211
	A year ago or more	41	93.2	3	6.8	

3.4 Experience during the pregnancy

Participants were asked which of the topics from items 13 and 14 were actually encountered during the surrogacy process (items 15 and 16). For those topics that were encountered, participants were asked to indicate by whom the decisions regarding that topic were made: the intended parent(s) alone, the gestational surrogate alone, the intended parent(s) and gestational surrogate together, or a medical professional.

The results are summarized in Table 16.

TABLE 16: Decision Making by Topic										
Topic	Intended Parent(s) Alone (n=93)		Gestational Surrogate Alone (n=31)		Intended Parent(s) and Gestational Surrogate Together (n=239)		Medical Professional (n=280)		Total Decisions (n=643)	
	n	%	n	%	n	%	n	%	n	%
Ultrasound	5	5.2	4	4.1	35	36.1	53	54.6	97	100.0
Ultrasound Abnormalities	7	14.9	1	2.1	11	23.4	28	59.6	47	100.0
Prenatal Screening	23	23.2	4	4.0	26	26.3	46	46.5	99	100.0
Non-Invasive Prenatal Screening	24	28.2	1	1.2	27	31.8	33	38.8	85	100.0
CVS/Amniocentesis	12	40.0	2	6.7	7	23.3	9	30.0	30	100.0
Termination for Fetal Anomalies	5	45.5	0	0.0	4	36.4	2	18.2	11	100.0
Termination for Gestational Surrogate Personal Reasons	0	0.0	2	100.0	0	0.0	0	0.0	2	100.0
Termination for Intended Parent(s)' Personal Reasons	3	60.0	0	0.0	0	0.0	2	40.0	5	100.0
Preterm Delivery for Gestational Surrogate's Safety	1	4.5	2	9.1	6	27.3	13	59.1	22	100.0
Preterm Delivery for Fetus's Safety	1	4.8	1	4.8	6	28.6	13	61.9	21	100.0
C-Section	1	2.0	5	10.0	14	28.0	30	60.0	50	100.0
Induction for Gestational Surrogate Medical Reason	0	0.0	3	9.4	12	37.5	17	53.1	32	100.0
Induction for Fetal Medical Reason	0	0.0	4	13.8	9	31.0	16	55.2	29	100.0
Induction for Gestational Surrogate Personal Reasons	1	100.0	0	0.0	0	0.0	0	0.0	1	100.0
Induction for Intended Parent(s) Personal Reason	4	20.0	1	5.0	10	50.0	5	25.0	20	100.0
Decision Making	6	6.5	1	1.1	72	78.3	13	14.1	92	100.0

Participants were asked which of the potentially discussed topics were actually encountered during the pregnancy. Ultrasound (n=97), prenatal screening (n=99), and non-

invasive prenatal screening (n=85) were most likely to have been encountered. Topics such as pregnancy termination for the gestational surrogate's personal reasons (n=2), termination for the intended parent(s)' personal reasons (n=1), and induction of labor for the gestational surrogate's personal reasons (n=1) were least likely to be encountered. However, these same topics for medical reasons were more likely to be encountered. Eleven participants encountered the issue of pregnancy termination for fetal anomalies, 32 encountered induction of labor for gestational surrogate's medical reasons, and 29 encountered induction of labor for fetal medical reasons. (The survey did not ask what actions were taken regarding these issues—only whether they were encountered.)

Surprisingly, the most common way that decisions were made for over half of the topics was by the medical professional. When comparing decision making by the intended parent(s) alone, the gestational surrogate alone, or the intended parent(s) and gestational surrogate together, decisions were made more often by both parties together for 12 of the 16 topics.

3.5 Medical Visits and intended parent(s)' involvement

Participants were asked about their medical appointments and the involvement of the intended parent(s) (items 20-24). Eighty-eight percent (n=83) of parent(s) reported never bringing their surrogacy agreement to medical appointments. Seventy-eight percent (n=72) of intended parent(s) were never or sometimes at the surrogate's medical appointments. The gestational surrogate informed the intended parent(s) directly about the information that was discussed during the appointment 90% (n=85) of the time. Permission to discuss information with the intended parent(s) was explicitly given to the medical provider 90.5% (n=86) of the time. Twelve percent (n=11) of gestational surrogates made at least one medical decision when the intended parent(s) were not present at the appointment.

Table 17 summarizes the results.

TABLE 17: Medical Visits and Intended Parent(s)' Involvement	Totals	
	n (n=95)	%
HOW OFTEN DID YOU BRING YOUR GESTATIONAL SURROGACY AGREEMENT TO A MEDICAL APPOINTMENT? (n=95)		
Never	83	87.4
Sometimes	9	9.5
Often	1	1.1
Usually	0	0.0
Always	1	1.1
N/A	1	1.1
HOW OFTEN WERE THE INTENDED PARENT(S) PRESENT WITH YOU AT MEDICAL APPOINTMENTS? (n=95)		
Never	14	14.7
Sometimes	58	61.1
Often	7	7.4
Usually	10	10.5
Always	6	6.3
N/A	0	0.0
WHEN THE INTENDED PARENT(S) WERE NOT AT AN APPOINTMENT, HOW WAS THE INFORMATION FROM THE APPOINTMENT DISCLOSED TO THEM? (n=95)		
Gestational surrogate informed them directly	85	89.5
Intended parent(s) obtained medical records	3	3.2
Intended parent(s) spoke to medical professional involved	28	29.5
Through the surrogacy agency	38	40.0
Not discussed	0	0.0
N/A	1	1.0
Other	12	12.6
WHEN THE INTENDED PARENT(S) WERE NOT PRESENT AT THE APPOINTMENT, DID YOU CLEARLY GIVE THE MEDICAL PROVIDER FULL PERMISSION TO DISCUSS THE VISIT WITH THE INTENDED PARENT(S)? (n=95)		
Yes	86	90.5
No	5	5.3
N/A	4	4.2
DID YOU MAKE ANY MEDICAL DECISIONS WHEN THE INTENDED PARENT(S) WERE NOT PRESENT AT THE APPOINTMENT? (n=95)		
Yes*	11	11.6
No	79	83.2
N/A	5	5.3

How the intended parent(s) were informed about visits at which that they were not present was analyzed by demographics (table 18-20). For "When intended parent(s) were not at an appointment, how was the information from the appointment disclosed to them?" (item 22), participants were asked to mark all of the answers that applied. Gestational surrogate as the informant (table 18) differed by ethnicity (p=0.032) and by the intended parent(s)' state of

residence (p=0.002), with participants who identified as white/non-Hispanic and those involved with intended parent(s) living in the United States but not in California being more likely to have had the gestational surrogate inform the intended parent(s) directly 92.2%; n=71 v. 75.3%; n=11, and 100.0%; n=25 v. 66.7%, n=14, respectively).

When intended parent(s) obtained medical records or spoke to an involved medical professional (table 19), significant differences were found with the intended parent(s)' state of residence (p=0.040) in that intended parent(s) living in the United States but not in California were more likely than those residing in California to have obtained medical records or to have spoken to an involved medical professional (48.0%; n=12 v. 19.0%;n=4).

Intended parent(s) informed by the surrogacy agency (table 20) differed by the state of residence of the gestational surrogate (p=0.006) and by time since the surrogacy experience. Gestational surrogates residing in California and having had surrogacy experiences that ended over a year ago were more likely than those with recent surrogacy experience to have obtained information from the surrogacy agency (52.0%; n=26 v. 23.3%; n=10, and 51.0%; n=26 v. 27.3%; n=12, respectively).

TABLE 18: Respondent Characteristics by Gestational Surrogate Informed Intended Parent(s) Directly						
Participant demographics		**Yes**		**No**		**p-Value**
		n (n=84)	**%**	**n (n=11)**	**%**	
Age						0.537
	18 to 30	40	90.9	4	9.1	
	31 and over	44	86.3	7	13.7	
Education						0.745
	Some college education or less	57	89.1	7	10.9	
	College graduate or higher degree	27	87.1	4	12.9	
Ethnicity						0.032*
	White	71	92.2	6	7.8	
	Other/multiple ethnicities	11	73.3	4	26.7	
Religion						1.000
	Christian	52	88.1	7	11.9	
	Other	32	88.9	4	11.1	
Egg						0.486
	Intended Mother	29	93.5	2	6.5	
	Donor	53	86.9	8	13.1	
Surrogacy Number						0.726
	First	60	89.6	7	10.4	
	Second	24	85.7	4	14.3	
Primary Reason						0.688
	Help another	68	89.5	8	10.5	
	Other	16	84.2	3	15.8	
Gestational surrogate state of residence						0.213
	California	42	84.0	8	16.0	
	Other	40	93.0	3	7.0	
Intended parent(s) country of residence						0.199
	USA	40	83.3	8	16.7	
	Other	43	93.5	3	6.5	
Intended parent(s) state of residence						0.002*
	California	14	66.7	7	33.3	
	Other	25	100.0	0	0.0	
Time Since Surrogacy Experience						0.537
	Less than 1 year	40	90.9	4	9.1	
	A year ago or more	44	86.3	7	13.7	

TABLE 19: Respondent Characteristics by Intended Parent(s) Obtained Medical Records or spoke with Medical Professional						
Participant demographics		**Yes**		**No**		**p-value**
		n (n=29)	**%**	**n (n=66)**	**%**	
Age						0.272
	18 to 30	16	36.4	28	63.6	
	31 and over	13	25.5	38	74.5	
Education						0.484
	Some college education or less	18	28.1	46	71.9	
	College graduate or higher degree	11	35.5	20	64.5	
Ethnicity						1.000
	White	24	31.2	53	68.8	
	Other/multiple ethnicities	4	26.7	11	73.3	
Religion						0.819
	Christian	19	32.2	40	67.8	
	Other	10	27.8	26	72.2	
Egg						1.000
	Intended mother	9	29.0	22	71.0	
	Donor	19	31.1	42	68.9	
Surrogacy Number						1.000
	First	21	31.3	46	68.7	
	Second	8	28.6	20	71.4	
Primary Reason						1.000
	Help another	23.0	30.3	53	69.7	
	Other	6	31.6	13	68.4	
Gestational surrogate state of residence						1.000
	California	16	32.0	34	68.0	
	Other	13	30.2	30	69.8	
Intended parent(s) country of residence						0.264
	USA	17	35.4	31	64.6	
	Other	11	23.9	35	76.1	
Intended parent(s) state of residence						0.040*
	California	4	19.0	17	81.0	
	Other	12	48.0	13	52.0	
Time Since Surrogacy Experience						0.180
	Less than 1 year	10	22.7	34	77.3	
	A year ago or more	19	37.3	32	62.7	

TABLE 20: Respondent Characteristics by Intended Parent(s) Obtained Information from Surrogacy Agency

Participant demographics		Yes		No		p-Value
		n (n=38)	%	n (n=57)	%	
Age						0.208
	18 to 30	21	47.7	23	52.3	
	31 and over	17	33.3	34	66.6	
Education						0.826
	Some college education or less	25	39.1	39	60.9	
	College graduate or higher degree	13	41.9	18	58.1	
Ethnicity						1.000
	White	6	40.0	9	60.0	
	Other	29	37.7	48	62.3	
Religion						1.000
	Christian	24	40.7	35	59.3	
	Other	14	38.9	22	61.1	
Egg						0.826
	Intended mother	13	41.9	18	58.1	
	Donor	24	39.3	37	60.7	
Surrogacy Number						0.218
	First	29	43.3	38	56.7	
	Second	9	32.1	19	67.9	
Primary Reason						0.601
	Help another	29	38.2	47	61.8	
	Other	9	47.4	10	52.6	
Gestational surrogate state of residence						0.006*
	California	26	52.0	24	48.0	
	Other	10	23.3	33	76.7	
Intended parent(s) country of residence						0.139
	USA	15	31.3	33	68.8	
	Other	22	47.8	24	52.2	
Intended parent(s) state of residence						0.755
	California	7	33.3	14	66.7	
	Other	7	28	18	72.0	
Time Since Surrogacy Experience						0.022*
	Less than 1 year	12	27.3	32	72.7	
	A year ago or more	26	51.0	25	49.0	

3.6 Comfort level and intended parent(s)' presence at medical appointments

The relationship between the gestational surrogate's reported comfort level and the intended parent(s)' presence at medical appointments was analyzed (table 21). Participants who marked "never" or "sometimes" were grouped together, and those who marked "often," "usually," or "always" were grouped together.

No significant differences were found among having the intended parent(s) present at medical appointments and comfort level before being matched, prior to conception, or during pregnancy.

TABLE 21: Comfort Level by How Often did Intended parent(s) attend Medical Appointments

Comfort Level		Never/Sometimes		Often/Usually/Always		p-value
		n (n=72)	%	n (n=23)	%	
Comfort level before being matched						
	Comfortable and felt that opinions were considered	70	77.8	20	22.2	0.090
	Uncomfortable and/or opinions not considered	2	40.0	3	60.0	
Comfort level prior to conception						
	Comfortable and felt that opinions were considered	69	77.5	20	22.5	0.150
	Uncomfortable and/or opinions not considered	3	50.0	3	50.0	
Comfort level during pregnancy						
	Comfortable and felt that opinions were considered	66	78.6	18	21.4	0.128
	Uncomfortable and/or opinions not considered	6	54.5	5	45.5	

IV. DISCUSSION

The introduction of gestational surrogacy has allowed couples who would otherwise be unable to have biological children to achieve parenthood. While its use has increased in the last

ten years, legislation and regulation regarding gestational surrogacy have not been adequately established.

Previous studies have looked at the level of satisfaction and at short- and long term effects of gestational surrogacy for the surrogate, the intended parent(s), and the child conceived through surrogacy (Binsden. 2003; Greenfeld, 2015; Imrie and Jadva, 2014; Jadva et al., 2012; Jadva et al., 2015; Kleinpeter, 2002; Riddle, 2015). No studies have examined the surrogate's comfort level throughout the process or the extent to which issues relevant to the gestational surrogacy process are discussed between parent(s) and surrogate. The purpose of this study was to understand the current practices regarding discussions of potential subjects such as maternal genetic screening, fetal testing and pregnancy complications and to determine how decisions regarding these issues are made. This study looked at the initial screening and communication between gestational surrogates and intended parent(s), discussion of relevant issues, the surrogate's experience during the pregnancy, and the intended parent(s)' involvement with medical visits and pregnancy management decisions.

4.1 Initial Screening and Communication with Intended Parent(s)

Almost all of the participants were matched with intended parent(s) through a surrogacy agency and had a legal contract that a lawyer was involved in creating. The homogeneity of the responses with respect to initial screening and communication with intended parent(s) may be due to the method used to recruit participants for this study. Surveys were sent out to surrogates through their surrogacy agencies. These results may not be representative of initial screening and communication practices for gestational surrogates who were matched with the intended parent(s) in other ways, such as through a personal relationship or a lawyer. It will be important

to assess if these groups differ and if surrogacy arrangements not made through an agency are likely to have legal counsel and a legal contract.

The low number of gestational surrogates who were offered carrier screening for genetic disorders may be related to the fact that the majority of gestational surrogates did not use their own eggs for conception. When the intended mother's egg or a donor egg is utilized, the gestational surrogate is not genetically related to the fetus, so the gestational surrogate's carrier status would be irrelevant to the child's genetic makeup.

4.2 Discussion of Relevant Topics with Intended Parent(s)

4.2.1 Discussed Topics

Participants were asked to indicate which of 16 possible topics were discussed and at which point of the surrogacy process they were discussed. Decisional topics included screening/testing options, termination of pregnancy, and labor/delivery options. Screening/testing topics were most likely to be discussed. Furthermore, routine issues commonly encountered in pregnancy, such as ultrasound and cesarean section, were more likely to be discussed than others, such as labor induction. The possibilities of induction of labor and termination of pregnancy for medical reasons were more likely to be discussed than the possibilities of those events due to personal reasons.

Topics were most likely to be discussed before being matched and least likely to be discussed during pregnancy. This trend may reflect diligence in the process of matching gestational surrogates with intended parent(s); if issues are adequately discussed early in the process, they may not have to be discussed again later.

Gestational surrogates living outside of California were more likely to report discussing 14-16 topics than those living in California. This result is somewhat surprising, since California

is one of the states most accepting of surrogacy (All Things Surrogacy, n.d; Circle Surrogacy, n.d.; Creative Family Connections, n.d.; The Surrogacy Experience, n.d.). Because the surrogacy agencies that distributed the surveys were based in California, these results may reflect a more thorough discussion of pregnancy-related issues with surrogates who do not reside in the same state as the agency or intended parent(s). Having the participants located in different geographic regions can predispose to lack of personal contact and reduced communication. Surrogacy agencies may take this into account and may actually ensure a more thorough discussion with such clients. Alternatively, these differences may reflect an intentionally more thorough discussion with these participants because their states of residence may have more stringent regulations, and thus extra efforts may have been made to avoid conflict and misunderstandings during the surrogacy process. This could also reflect a response bias in which participants based in California who discussed all or most topics were less likely to participate in the study.

The number of issues discussed prior to conception differed by time since surrogacy ended, with participants whose surrogacy experience was ongoing or ended within a year recalling more topics having been discussed. This may represent a difference in recall; gestational surrogates who more recently discussed these topics may recall discussing more of them than those who discussed them years ago. Alternatively, this difference may represent an increase over time in the number of topics discussed with surrogacy participants prior to conception. No differences by demographics were found when analyzing the number of topics discussed before matching or during pregnancy.

During pregnancy, fewer topics were likely to have been discussed with participants over 30 than with those 30 or under. This difference approached significance. Perhaps younger

women tend to have less experience in pregnancy and surrogacy than women over 30 and thus more of a need to discuss the various topics of concern.

In order to prevent exploitation through gestational surrogacy, it is imperative to ensure informed consent. One essential facet of informed consent is having a thorough understanding of the process, including the associated risks and benefits, potential complications, and optional genetic testing (Austin & Brisman, 2013). Standardization of items to discuss with gestational surrogates prior to beginning the process would reduce the likelihood that gestational surrogates might enter into the experience without a clear understanding of what it may entail.

4.2.2 Comfort Level

Participants were asked to describe their level of comfort at various times during the surrogacy process, including before being matched, prior to conception, and during pregnancy. Overall, the majority of participants indicated being comfortable voicing their opinions and feeling that their opinions were considered, although this decreased somewhat throughout the process. These findings are consistent with past research that has found that most gestational surrogates have positive experiences and feel comfortable in the process (van den Akker, 2005; Jadva, Imrie, & Golombok, 2015)

Comfort level was analyzed by demographics, and no differences were found for comfort before being matched. For comfort after matching but prior to conception, significant differences were found by religion, with participants identifying as Christian being less likely than those who identified as "other" to report comfort with the process and feeling that their opinions were being considered. Comfort level during pregnancy differed significantly by religion and gestational surrogacy's state of residence, with participants identifying as Christian or residing in

California being more likely to have felt uncomfortable voicing their opinions and/or feeling that their opinions were not considered.

The lower comfort level reported among Christians may reflect the moral arguments against surrogacy put forward by certain Christian denominations. While ART is not prohibited, third-party reproduction may violate a number of Christian principles (Zoloth & Henning, 2014), including that procreation should be accomplished within a marriage and that the participation of an outside individual in procreation violates the sacredness of marriage and intimacy (Assemblies of God, n.d.; Hemayatkhah, Hemayatkhah, & Johromi Farahi, 2014). Because procreation out of wedlock is may be prohibited, ART for single individual(s) may not be permitted (Assemblies of God, n.d; .; Hemayatkhah, Hemayatkhah, & Johromi Farahi, 2014). Furthermore, if infertility is perceived as a decision made by God, then pursuing ART or surrogacy may be perceived as an offense against the will of God (Assemblies of God, n.d). Even though women who are willing to be gestational surrogates may not hold these beliefs, a Christian upbringing may make discussion of these topics uncomfortable. Comfort level of Christian participants could not be compared to comfort level of participants who identified with other religions due to the small number of participants who identified with a religion other than Christian. This difference could thus possibly reflect a lower comfort level among participants who identify with religions in which surrogacy is prohibited or controversial compared with those who identify as being unaffiliated with any religion.

This result indicates that, while overall gestational surrogates tend to feel comfortable with the process, certain groups may be likely to feel less comfortable. This study was limited by the small number of participants who reported having a low comfort level during surrogacy, but

future studies may be able to identify the characteristics of surrogates who are less likely to be comfortable and explore the cause of it.

4.3 Experience During the Pregnancy

Participants were asked which of the potentially discussed topics were actually encountered during the pregnancy. Routine items, such as ultrasound, prenatal screening, and non-invasive fetal genetic screening were more likely to be encountered. Topics such as pregnancy termination for the gestational surrogate's personal reasons or for the intended parent(s)' personal reasons and induction of labor for the gestational surrogate's personal reasons were least likely to be encountered. These same topics were more likely to be encountered when related to medical reasons. That topics involving the personal reasons of the intended parent(s) or of the gestational surrogate are less likely to be encountered during the process may suggest that the surrogacy agreements and discussions between gestational surrogates and intended parent(s) adequately explore these issues in advance and prevent them from becoming problematic. Issues such as fetal anomalies or medical complications in the gestational surrogate are more likely to actually be encountered because conflict regarding these issues may be unpredictable and inadequately explored until they actually arise.

There are currently no studies that explore which issues are actually encountered by surrogates during pregnancy. Each of the sixteen topics asked about in this study was encountered by at least one participant, confirming the importance of discussing them with gestational surrogates and intended parent(s) prior to beginning the process in order to prevent disagreements and complications between the two parties.

Surprisingly, the most common way decisions were made for over half of the topics was by the medical professional. Medical professionals were the most likely to make decisions

regarding screening/testing (ultrasound, ultrasound abnormalities, prenatal screening, non-invasive prenatal screening) and labor/delivery management for medical reasons (preterm delivery for gestational surrogate's safety, preterm delivery for fetus's safety, induction for gestational surrogate medical reasons, induction for fetal medical reasons). This study did not assess who the medical professional was for each of these scenarios (i.e., physician, nurse, genetic counselor, etc.). Genetic counseling is based on being non-directive with patients and allowing them to make their own decisions, and thus this would be an unexpected finding. Genetic counselors are specifically involved in helping patients make decisions regarding genetic screening and testing, such and prenatal screening of parents for genetic disease carrier status, non-invasive screening for fetal chromosomal disorders, and invasive fetal testing. These results may indicate that genetic counselors were not involved in these surrogacy cases. Alternatively, they may indicate that patients perceived genetic counselors to be more directive than they really are. Further studies are needed to determine the extent of genetic counselors' involvement during surrogate pregnancies.

When comparing decision-making by intended parent(s) alone, gestational surrogate alone, or intended parent(s) and gestational surrogate together, decisions were made most often by both parties together for 12 of the 16 topics. These results indicate generally good cooperation between the intended parent(s) and gestational surrogate. However, one or both parties may feel overwhelmed or unqualified regarding medical management issues and may defer to the professional to make a decision.

This study did not explore whether the gestational surrogates were satisfied with the number of decisions that were made by the medical professionals. That the majority of decisions were made by medical professionals could indicate confidence in their physicians, pressure to

conform and hesitation to speak out, or a preponderance of purely medical management issues. This study revealed that most gestational surrogates were comfortable voicing their opinions during the pregnancy, indicating that this trend reflects confidence in the physician. However, due to the limited number of responses indicating a low comfort level, analysis to identify whether participants were less comfortable when medical professionals made decisions was not possible.

4.4 Medical Visits and Intended Parent(s)' Involvement

Participants were asked several questions concerning the involvement of the intended parent(s) during the surrogates' medical visits. Most participants reported that the intended parent(s) were not always present at medical appointments, and the majority of participants never brought their gestational surrogacy agreement to their appointments. The majority of participants reported that when the intended parent(s) were not present, they disclosed the information discussed at the medical appointments to the intended parent(s) afterwards. About one tenth of participants reported having made a medical decision when the intended parent(s) were not present at the appointment, but the study did not ask for detailed information regarding the nature or severity of the related issues, so some may have been relatively minor.

How the intended parent(s) were informed about medical appointments that they did not attend was analyzed by demographics. Participants who identified as white/non-Hispanic and those involved with intended parent(s) living in the United States but not in California were more likely to have informed the intended parent(s) directly. Intended parent(s) living in the United States but not in California were more likely than intended parent(s) living in California to have obtained medical records or to have spoken with a medical professional. Gestational surrogates residing in California and gestational surrogates involved in a surrogacy experience that ended

over a year ago were more likely to have had intended parent(s) obtain information from the surrogacy agency than were gestational surrogates residing in other states and gestational surrogates whose experiences were ongoing or had ended less than a year ago.

To our knowledge, this is the first study to explore the intended parent(s)' involvement with the surrogate's medical visits. These results support the need for standardization and discussion of these aspects of surrogacy. It is important that gestational surrogates bring their agreements to medical appointments in case the medical professional has doubts as to how to proceed, especially if the intended parent(s) are not present. Gestational surrogates and intended parent(s) should determine who will inform them about the medical appointments at which they were not present. It is also imperative that gestational surrogates and intended parent(s) discuss the circumstances in which it would be appropriate for the gestational surrogate to make a decision without them, for instance, when the issue is minor or the decision is time sensitive. Consequences for making decisions that contradict the stipulations of the contract should also be outlined in the agreement.

4.5 Surrogate comfort level and Intended Parent(s) Presence at Medical Appointments

No differences by presence of the intended parent(s) at medical appointments were found in comfort level throughout the surrogacy experience. The analysis was limited by the small number of participants who reported being uncomfortable and/or that their opinions were not considered.

4.6 Limitations of this Study

While this survey was available to gestational surrogates in general, the study sample was skewed due to the way in which the surveys were distributed. The survey was distributed by four California agencies to surrogates with whom they have worked. This limited participation almost

exclusively to individuals who began and went through the process through a surrogacy agency. The agencies may have set procedures for the surrogacy process that could have c0ontributed to the homogeneity of the responses. The low variability in respondent characteristics and comfort level may reflect the way in which participants were recruited and limited the statistical power of the data analysis.

The high comfort levels reported in this study may be due to participants who had a positive experience being more likely to maintain contact with the surrogacy agency and, therefore, to participate in this study. Gestational surrogates who felt uncomfortable or had a negative experience may have been underrepresented due to a lower likelihood of having access to, and participating in, the survey.

This study was also limited by the small sample size. At times, very small responses were found for certain options, so analysis of those items was limited.

4.7 Future Studies

While this study illustrates some important characteristics of the gestational surrogacy experience from the perspective of the surrogate, it did not examine these aspects from the perspective of the intended parent(s). Future studies should evaluate many of these issues from the perspective of intended parent(s).

This study evaluated the experiences of gestational surrogates who were matched through a surrogacy agency. Further research including gestational surrogates who did not go through a surrogacy agency is necessary to explore whether their experiences differ.

While many decisions were made by the intended parent(s) and gestational surrogate together, the most common way decisions were made during pregnancy was by the medical professionals. It is important to explore this process in more detail and to assess the gestational

surrogate's and intended parent(s)' satisfaction. These results are contrary to what would be expected with genetic counseling, which is founded on the principle of educating individuals about their options and guiding them through the decision-making process in a nondirective manner. However, not all medical management decisions may lend themselves to such a process. Future studies exploring gestational surrogates' and intended parent(s)' experiences and perception of decision making with genetic counselors may be considered.

4.8 Conclusion

Our results provide insights into the gestational surrogacy process from the perspective of the surrogates themselves, including which relevant issues are likely to be discussed at various points in the process, how comfortable gestational surrogates are throughout the experience, how and by whom decisions are made, how often intended parent(s) are present at medical appointments, and how information from the appointments is transmitted to the intended parent(s).

Gestational surrogates reported being comfortable voicing their opinions and that their opinions were considered the majority of the time. This counters the argument that women often may be objectified and taken advantage of during the surrogacy process. While this result was encouraging, some of the other data indicate a need for improvements in the gestational surrogacy experience. The number of issues discussed varied greatly by participant, suggesting the need for standardized guidelines regarding subjects to be considered by the participants prior to a surrogacy agreement. Gestational surrogates and intended parent(s) were more likely to make decisions together than individually; however, the party most likely to make a decision was the medical professional. This may indicate that intended parent(s) and gestational surrogates may feel uncomfortable voicing their opinions to medical professionals. Alternatively, this may

reflect the facts that in most cases, the intended parent(s) were not present at medical appointments and that the majority of participants never brought their gestational surrogacy agreement to their appointments. Medical management of surrogate pregnancy is complicated because of the number of parties and delicate issues involved. When the intended parent(s) do not have the opportunity to discuss management questions together with the surrogate and the physician or when their wishes are not known, conflict among the parties may arise. Practitioners and surrogates can consider methods of including intended parent(s) in the medical visits by inviting them into the office for discussion after the surrogate's examination has been completed or by including them electronically, such as with video chat or 3-way telephone conversation. Bringing the surrogacy agreement to the appointment could help medical practitioners become familiar with the parent-surrogate relationship and manage potential conflicts more easily. Because of their influential role, medical professionals involved in gestational surrogacy may benefit from training in dealing with issues that may arise during the surrogacy process.

Based on these results, it is suggested that the National Society of Genetic Counselors propose guidelines that include the following:

1. Which issues should be discussed prior to being matched with the intended parent(s) and after being matched but prior to conception.
2. The comfort level of potential gestational surrogates in discussing those topics should be assessed. Measures should be taken to ensure that they feel confident in expressing their opinions and views.
3. The presence of the intended parent(s) at medical appointments should be discussed with the intended parent(s) prior to conception.

a. Will the intended parent(s) be present? How often? In what manner will they be included?
b. How will the intended parent(s) be informed about what is discussed during an appointment that they miss?
c. Should the surrogacy agreement be taken to all medical appointments? Should the healthcare provider(s) be given a copy of it?
d. How and by whom will decisions be made if the intended parent(s) are not present? Specifically, how will emergency management decisions be made?
e. Giving medical providers permission to discuss the surrogate's medical management with the intended parent(s).

4. The pre-surrogacy counseling should include a portion about the participants' comfort with medical professionals. Specifically, both the intended parent(s) and the gestational surrogates should be empowered to participate in decision-making rather than simply allowing the medical professional to make certain decisions that they may not agree with. Situations in which the health and safety of the surrogate are more important than possible risk to the fetus should be considered. Having the parties meet together with the selected obstetrician before the contract is written could be advantageous to all those involved.

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Gestational Surrogacy and Decision Making

Welcome to My Survey!

Gestational Surrogacy and Decision Making

Purpose: This study is designed to examine the ways in which gestational surrogates and intended parents make decisions during pregnancy. Specifically, it explores which genetic and prenatal screening methods are discussed and how decisions are made. We are conducting this study to learn more about this question since it has not been studied much in the past. Participation in the study involves completion of a survey that asks you questions about yourself and about your experience as a gestational surrogate.

Risks and Discomforts: No risks or discomforts are anticipated from participating in the study. Potential risks or discomforts include possible emotional reactions while filling out the survey.

Benefits: The anticipated benefit of participation is the opportunity to contribute to understanding of decision-making during the process of being a gestational surrogate.

Duration: This survey should take 10-20 minutes to fill out.

Eligibility: You must be 18 years or older and must have acted as a gestational surrogate at least once. If you have acted as a gestational surrogate more than once, please fill out one survey for each time.

Confidentiality: The information you provide during this study will remain confidential. Only the researchers will have access to the study data and information. There will be no identifying information on the survey and your personal information will not be revealed. The results of this study may be published as a research paper in a professional journal or be presented at a professional meeting. The data you provide may be collected and used by Survey Monkey as per its privacy agreement. Note: There is no reasonable expectation that data is anonymous.

Participation: You will not be compensated for your participation in this study. Participation in this study is voluntary. Refusal to participate in this study will involve no penalty. You are free to withdraw from this study at any time by closing the survey prior to submitting it.

Further Questions and Follow-Up: You may ask the researchers any questions that occur to you during the survey or interview. If you have further questions once the survey is completed, you are encouraged to contact the researchers using the contact information given below.

Susy Malca, Genetic Counseling Graduate Student (Lead Researcher)
(714) 456-5837 or smalca@uci.edu

Meredith Jones, Faculty Sponsor
UCI Department of Pediatrics
101 The City Drive, ZC 4482
Orange, CA 92868-3298

If you have other questions or concerns about the study please contact UCI's Office of Research by phone, (949) 824-6662, by e-mail at IRB@research.uci.edu or at 5171 California Avenue, Suite 150, Irvine, CA.

By clicking ''Next' you are indicating you consent to participate in this research study.

Gestational Surrogacy and Decision Making

Section I: Initial Screening and Communication with Intended Parent(s)

This section focuses on your initial screening and communication with the intended parent(s). For the following questions, please choose the answer that best describes your experience. More than one option may be selected if the question states "check all that apply."

1. How were you initially matched with the intended parents?

- ◯ Personal
- ◯ Surrogacy agency
- ◯ IVF center
- ◯ Personal relationship with intended parents
- ◯ Other (please explain)

2. Which of the following agreements was made between you and the intended parent(s)?

- ◯ Legal contract
- ◯ Informal contract with intended parents
- ◯ None
- ◯ Other (please explain)

3. Who was involved in helping create the agreement between you and the intended parent(s)? (Mark all that apply)

- [ ] Surrogacy agency
- [ ] IVF center
- [ ] Lawyer
- [ ] Genetic counselor/other health care professional
- [ ] N/A
- [ ] Other (please explain)

4. Was a detailed family history of your family taken?

- ○ Yes
- ○ No

Gestational Surrogacy and Decision Making

Section I: Initial Screening and Communication with Intended Parent(s)

This section focuses on your initial screening and communication with the intended parent(s). For the following questions, please choose the answer that best describes your experience. More than one option may be selected if the question states "check all that apply."

5. Who took the family history?

- ○ Genetic counselor
- ○ Doctor/nurse
- ○ Surrogacy agency
- ○ IVF Center
- ○ Other (please specify)

6. How was this information gathered (mark all that apply)?

- [ ] Questionnaire
- [ ] Pedigree (a "family tree" drawing with symbols that indicate each member of your family)

7. Which of your family members were you asked about (mark all that apply)?

- [ ] Children
- [ ] Parents
- [ ] Siblings
- [ ] Aunts/uncles
- [ ] Nieces/nephews
- [ ] Grandparents
- [ ] None of the above

Gestational Surrogacy and Decision Making

Section I: Initial Screening and Communication with Intended Parent(s)

This section focuses on your initial screening and communication with the intended parent(s). For the following questions, please choose the answer that best describes your experience. More than one option may be selected if the question states "check all that apply."

8. Were you offered carrier screening tests for genetic conditions [for example, cystic fibrosis (CF), spinal muscular atrophy (SMA), Tay-Sachs disease, etc.]?

○ Yes

○ No

Gestational Surrogacy and Decision Making

Section I: Initial Screening and Communication with Intended Parent(s)

This section focuses on your initial screening and communication with the intended parent(s). For the following questions, please choose the answer that best describes your experience. More than one option may be selected if the question states "check all that apply."

9. Were you offered carrier screening for specific reasons such as ancestry or family history of a genetic syndrome?

○ No

○ Yes (Please Specify)

[ ]

4

10. Was carrier screening required for you to be a gestational surrogate?

- ◯ Yes
- ◯ No
- ◯ N/A

11. Did you have any carrier screening tests?

- ◯ Yes
- ◯ No

12. How many genetic conditions were you tested for?

- ◯ 0
- ◯ 1
- ◯ Less than 5
- ◯ Between 6 and 50
- ◯ Between 51 and 100
- ◯ More than 100
- ◯ Not sure

Gestational Surrogacy and Decision Making

Section II: Discussion of Relevant Topics with Intended Parent(s)

This section focuses on relevant topics that you may have discussed.

13. For each topic, indicate when in the process it was discussed by marking the appropriate box. You may mark more than one box for each topic if it was discussed at different points in the process. If this topic was never discussed, please mark the box that indicates "Not Discussed"

	Before being matched with intended parents	Prior to conception	During pregnancy	Not Discussed
Ultrasounds	☐	☐	☐	☐
The possibility of ultrasound abnormalities and follow up	☐	☐	☐	☐
Routine prenatal screening (maternal blood tests to screen for fetal abnormalities during pregnancy)	☐	☐	☐	☐
Non-invasive prenatal screening (blood test to screen for chromosome anomalies in the fetus)	☐	☐	☐	☐
Chorionic Villus Sampling (CVS) and/or Amniocentesis	☐	☐	☐	☐
Termination of pregnancy in case of fetal anomalies	☐	☐	☐	☐
Termination of pregnancy for your personal reasons	☐	☐	☐	☐
Termination of pregnancy for the intended parents' personal reasons	☐	☐	☐	☐

14. For each topic, indicate when in the process it was discussed by marking the appropriate box. You may mark more than one box for each topic if it was discussed at different points in the process. If this topic was never discussed, please mark the box that indicates "Not Discussed"

	Before being matched with intended parents	Prior to conception	During pregnancy	Not Discussed
Preterm delivery for your safety	☐	☐	☐	☐
Preterm delivery for the safety of the baby	☐	☐	☐	☐
C-section versus natural birth	☐	☐	☐	☐
Labor induction for your medical well being	☐	☐	☐	☐
Labor induction for the baby's medical well being	☐	☐	☐	☐
Labor induction for your own personal reasons	☐	☐	☐	☐
Labor induction for the intended parents' personal reasons	☐	☐	☐	☐
Decision making during the pregnancy (between gestational surrogate and intended parents)	☐	☐	☐	☐

Gestational Surrogacy and Decision Making

Section II: Discussion of Relevant Topics with Intended Parent(s)

For the following questions, please choose the option that most accurately reflects your experiences when you were discussing the topics from Question 13.

15. Prior to being matched with the intended parent(s), I felt:

- ○ Comfortable voicing my opinions and that my opinions were considered.
- ○ Comfortable voicing my opinions but that my opinions were not considered.
- ○ Uncomfortable voicing my opinions but that my opinions were considered.
- ○ Uncomfortable voicing my opinions and that my opinions were not considered.

16. After being matched with the intended parent(s) but prior to conception, I felt:

- ◯ Comfortable voicing my opinions and that my opinions were considered.
- ◯ Comfortable voicing my opinions but that my opinions were not considered.
- ◯ Uncomfortable voicing my opinions but that my opinions were considered.
- ◯ Uncomfortable voicing my opinions and that my opinions were not considered.

17. During the pregnancy, I felt:

- ◯ Comfortable voicing my opinions and that my opinions were considered.
- ◯ Comfortable voicing my opinions but that my opinions were not considered.
- ◯ Uncomfortable voicing my opinions but that my opinions were considered.
- ◯ Uncomfortable voicing my opinions and that my opinions were not considered.

Gestational Surrogacy and Decision Making

Section III: Experience during the pregnancy.

This section focuses on your experience during the pregnancy. For the following questions, please choose the answer that best describes your experience. More than one option may be selected if the question states "check all that apply."

18. Please mark “yes” for each of following topics that was actually encountered during the pregnancy, and “no” for those that were not.

For the topics marked “yes,” please indicate how decisions were made with respect to that topic (by intended parents alone, by the gestational surrogate alone, by the intended parents and the gestational surrogate together, or by a medical professional).

	No-not encountered during pregnancy	Yes-encountered during the pregnancy	Intended parents made the decisions alone	Gestational surrogate made the decisions alone	The decisions were made by the intended parents and the gestational surrogate together	Medical professional made the decisions
Ultrasounds	☐	☐	☐	☐	☐	☐
Ultrasound abnormalities and follow up	☐	☐	☐	☐	☐	☐
Routine prenatal screening (blood tests to screen for fetal abnormalities during pregnancy)	☐	☐	☐	☐	☐	☐
Non-invasive prenatal screening (maternal blood test to screen for chromosomal anomalies in the fetus)	☐	☐	☐	☐	☐	☐
Chorionic Villus Sampling (CVS) or Amniocentesis	☐	☐	☐	☐	☐	☐
Termination of pregnancy in case of fetal anomalies	☐	☐	☐	☐	☐	☐
Termination of pregnancy for your personal reasons	☐	☐	☐	☐	☐	☐
Termination of pregnancy for the intended parents' personal reasons	☐	☐	☐	☐	☐	☐

19. Please mark "yes" for each of following topics that was actually encountered during the pregnancy, and "no" for those that were not.
For the topics marked "yes," please indicate how decisions were made with respect to that topic (by intended parents alone, by the gestational surrogate alone, by the intended parents and the gestational surrogate together, or by a medical professional).

	No-not encountered during pregnancy	Yes-encountered during the pregnancy	Intended parents made the decisions alone	Gestational surrogate made the decisions alone	The decisions were made by the intended parents and the gestational surrogate together	Medical professional made the decisions
Preterm delivery for your safety	☐	☐	☐	☐	☐	☐
Preterm delivery for the safety of the baby	☐	☐	☐	☐	☐	☐
C-section versus natural birth	☐	☐	☐	☐	☐	☐
Labor induction for your medical well being	☐	☐	☐	☐	☐	☐
Labor induction for the baby's medical well being	☐	☐	☐	☐	☐	☐
Labor induction for your own personal reasons	☐	☐	☐	☐	☐	☐
Labor induction for the intended parents' personal reasons	☐	☐	☐	☐	☐	☐
Decision making during the pregnancy (between gestational surrogate and intended parents)	☐	☐	☐	☐	☐	☐

Gestational Surrogacy and Decision Making

Section IV: Medical Visits and Intended Parent(s)' Involvement

This section focuses on medical visits and the involvement of the intended parent(s) during the pregnancy. For each of the following questions, please choose the answer that best describes your situation. More than one option may be selected if the question states "check all that apply."

20. How often did you bring your gestational surrogacy agreement to a medical appointment?

- Never
- Sometimes
- Often
- Usually
- Always
- N/A

21. How often were the intended parents present with you at medical appointments?

- Never
- Sometimes
- Often
- Usually
- Always
- N/A

22. When the intended parents were not present at an appointment, how was the information from the appointment disclosed to them (check all that apply)?

- [ ] Gestational surrogate informed them directly
- [ ] Intended parents obtained medical records
- [ ] Intended parents spoke to medical professional involved
- [ ] Through the surrogacy agency
- [ ] Not discussed
- [ ] N/A
- [ ] Other (please explain)

23. When the intended parents were not present at an appointment, did you clearly give the medical provider full permission to discuss the visit with the intended parents?

- Yes
- No
- N/A

24. Did you make any medical decisions when the intended parents were not present at an appointment?

- ◯ Yes
- ◯ No
- ◯ N/A

If you checked "Yes," please describe the decision that was made:

[ ]

Gestational Surrogacy and Decision Making

Section V: Demographics

For this section, please select the answer that best describes you and your situation.

25. How old were you during this gestational surrogacy experience?

- ◯ 18-25
- ◯ 26-30
- ◯ 31-35
- ◯ 36 or older
- ◯ Prefer not to answer

26. Which of the following BEST describes your personal relationship status during this gestational surrogacy experience?

- ◯ Single, never married
- ◯ Married
- ◯ Divorced
- ◯ Widowed
- ◯ Domestic partnership
- ◯ Prefer not to answer

27. What is the highest level of education you completed?

- ◯ High school or less
- ◯ Some college (including completing and Associate's degree)
- ◯ College graduate (B.A., B.S., or the equivalent)
- ◯ Graduate/ professional degree (Master's degree, PhD, MD, JD)

28. What is your ethnic background (mark all that apply)?

- ☐ American Indian or Alaska Native
- ☐ Asian
- ☐ Black or African American
- ☐ Hispanic
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ White/Non-Hispanic
- ☐ Other (please specify)

29. What is your religious affiliation?

- ◯ Buddhist
- ◯ Christian
- ◯ Hindu
- ◯ Jewish
- ◯ Muslim
- ◯ No religious affiliation
- ◯ Prefer not to answer
- ◯ Other (please specify)

30. Whose egg was used during this pregnancy?

- ◯ The intended mother's egg
- ◯ The surrogate's egg
- ◯ A donor egg from someone else

31. This was my:

- ◯ First surrogate experience
- ◯ Second surrogate experience
- ◯ Third surrogate experience
- ◯ Fourth surrogate experience
- ◯ Fifth or more surrogate experience

32. What was your primary reason for serving as a gestational surrogate?

- ◯ Financial compensation
- ◯ Help a stranger
- ◯ Help a friend
- ◯ Help a family member
- ◯ Other (please specify)

33. Which state were you living in during the process of surrogacy?

34. Where did the intended parents live?

- ◯ USA
- ◯ Unknown
- ◯ Other country (please specify)

35. If the intended parents lived in the United States, which state did they reside in?

36. How long ago did you complete this surrogacy experience?

- ◯ Less than 1 year ago
- ◯ 1-5 years ago
- ◯ 6-10 years ago
- ◯ 11-15 years ago
- ◯ 16 or more years ago
- ◯ I am currently pregnant - this is an ongoing surrogacy experience

Gestational Surrogacy and Decision Making

Section V: Demographics

For this section, please select the answer that best describes you and your situation.

37. If this surrogacy experience is ongoing, which part of the process are you in?

- ◯ Pre-matching with intended parents
- ◯ Matched but not yet pregnant
- ◯ First trimester
- ◯ Second trimester
- ◯ Third trimester
- ◯ Post-partum but still involved (please specify in which ways you are still involved).

Gestational Surrogacy and Decision Making

End of Survey

Thank you for completing the survey. We appreciate the time you devoted to participating in this study. Your participation is very valuable to us!

APPENDIX B: Confirmation of Exempt Research Registration

UC IRVINE: OFFICE OF RESEARCH
INSTITUTIONAL REVIEW BOARD (IRB)
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CONFIRMATION OF EXEMPT RESEARCH REGISTRATION

March 8, 2016

SUSY MALCA
DEPARTMENT OF PEDIATRICS

RE: HS# 2016-2590 *Gestational Surrogacy and Decision Making*

The human subjects research project referenced above has been administratively registered with the UC Irvine Institutional Review Board (UCI IRB) as Exempt from Federal regulations in accordance with 45 CFR 46.101. This exemption is limited to the described activities in the registered UCI IRB Protocol Narrative and extends to the performance of such activities at the sites identified in your UCI IRB Protocol Application. Informed consent from subjects must be obtained unless otherwise indicated below. UCI IRB conditions for the conduct of this research are included on the attached sheet.

Information provided to prospective subjects to obtain their informed consent should, at a minimum, consists of the following information: the subject is being asked to participate in research, what his/her participation will involve, all foreseeable risks and benefits, the extent to which privacy and confidentiality will be protected, that participation in research is voluntary and the subject may refuse to participate or withdraw at any time without prejudice.

Questions concerning registration of this study may be directed to the UC Irvine Office of Research, 5171 California Avenue, Suite 150, Irvine CA 92697-7600; 949-824-0665 (biomedical committee) or 949-824-6662 (social-behavioral committee).

Level of Review: Exempt Review, Category 2

Valerie M. Sanchez, MA, CCRP
IRB Administrator

Registration valid from 03/08/2016 to 03/07/2021

UCI (FWA) 00004071, Approved: January 31, 2003

Informed Consent Requirements:

1. Signed Informed Consent Not Required
    a. Study Information Sheet Required

UNIVERSITY OF CALIFORNIA

APPENDIX C: UCI IRB Conditions for All UCI Human Research Protocols

UCI IRB CONDITIONS FOR ALL UCI HUMAN RESEARCH PROTOCOLS

UCI RESEARCH POLICIES:
All individuals engaged in human-subjects research are responsible for compliance with all applicable UCI Research Policies (http://www.research.uci.edu/compliance/human-research-protections/hrp-policy-library/hrppPolicies.htm). The Lead Researcher of the study is ultimately responsible for assuring all study team members adhere to applicable policies for the conduct of human-subjects research.

LEAD RESEARCHER RECORDKEEPING RESPONSIBILITIES:
Lead Researchers are responsible for the retention of protocol–related records. The following web pages should be reviewed for more information about the Lead Researcher's recordkeeping responsibilities for the preparation and maintenance of research files: http://www.research.uci.edu/compliance/human-research-protections/researchers/lead-researcher-recordkeeping-responsibilities.html
and http://www.research.uci.edu/compliance/human-research-protections/researchers/preparation-maintenance-research-audit-file.html.

PROTOCOL EXPIRATION:
The UCI IRB expiration date is provided on the exempt registration letter. **All exempt protocols are registered for a maximum period of five years**. If the study will continue beyond five years, a new Application for IRB review is required. No annual continuing renewals are required.

MODIFICATIONS & AMENDMENTS:
No changes are to be made to the registered protocol or the approved, stamped consent form without the prior review and approval of the UCI IRB. All changes (e.g., a change in procedure, number of subjects, personnel, study locations, new recruitment materials, study instruments, etc.) must be prospectively reviewed and confirmed by the IRB before they are implemented.

APPROVED VERSIONS OF CONSENT DOCUMENTS, INCLUDING STUDY INFORMATION SHEETS:
Unless a waiver of informed consent is granted by the IRB, the consent documents (consent form; study information sheet) with the UCI IRB approval stamp must be used for consenting all human subjects entered into this study. Only the current approved version of the consent documents may be used to consent subjects. **Approved consent documents are not to be used beyond the expiration date provided on the exempt registration letter**.

ADVERSE EVENT & UNANTICIPATED PROBLEMS REPORTING:
All unanticipated problem involving risk to subjects or others or serious adverse events must be reported to the UCI IRB in accordance with Federal regulations and UCI policy. See http://www.research.uci.edu/compliance/human-research-protections/researchers/reporting-of-adverse-events-unanticipated-problems-and-violations.html for complete details.

CHANGES IN FINANCIAL INTEREST:
Any changes in the financial relationship between the study sponsor and any of the investigators on the study and/or any new potential conflicts of interest must be reported immediately to the UCI Conflict of Interest Oversight Committee (COIOC). If these changes affect the conduct of the study or result in a change in the required wording of the approved informed consent document, then these changes must also be reported to the UCI IRB via a modification request.

CLOSING REPORT:
An electronic closing report should be filed with the UCI IRB when the research concludes. See http://www.research.uci.edu/compliance/human-research-protections/researchers/closing-a-protocol.html for complete details.

APPENDIX D: Recruitment Email

Dear Surrogate Mothers,

My name is Susy Malca and I am a genetic counseling student at the University of California, Irvine. I would like to invite you to complete a research survey for my Master of Science thesis entitled, “Gestational Surrogacy and Decision Making”

The goal of my thesis is to explore the ways in which gestational surrogates and intended parents make decisions before and during pregnancy.

This survey is open to women who are 18 and older who have served as a gestational surrogate at least once. The survey should take approximately 10-15 minutes to complete. The survey is anonymous and participation in this study is voluntary.

This study was reviewed and approved by the the University of California, Irvine Institutional Review Board.

To participate in this survey, please click on the link below:
(Link to Study Info Sheet and Survey will be placed here)

If you have any questions or technical difficulties, please contact me at smalca@uci.edu or 714-456-5837 or Meredith Jones, Faculty Sponsor, at merjones@uci.edu or 714-456-5796.

Thank you in advance for participating in my thesis research.

Susy Malca

APPENDIX E: List of “Other” Responses for “Primary Reason for Serving as a Gestational Surrogate”

LIST OF “OTHER” RESPONSES FOR “PRIMARY REASON FOR SERVING AS A GESTATIONAL SURROGATE”
“Help create a family,” ”enjoy being pregnant,” “giving deserving people their dream of being a family,” “to do something bigger than myself,” “I was going to help a family member, but she ended up not needing my help. So I decided to help someone else, since I was a good candidate,” “personal fulfillment,” “help give a couple a family,” “enjoyed pregnancy,” to help make a family,” “it was a calling from God to help another woman doing something I love doing. I love helping others and enjoying being pregnant,” “felt called to do so,” “help a couple’s dream of becoming parents a reality,” “to help a family out, and to pay for college loans,” “both helping someone and financial compensation,” “I love being pregnant,” “the experience, financial, help someone that wants a baby,” “help others complete the dream of having a family,” “pay It forward since we had fertility problems ourselves,” “to help someone in need.”

APPENDIX F: List of “Other” for “When the Intended Parent(s) were not at an Appointment, How was the Information from the Appointment Disclosed to them?”

LIST OF “OTHER” RESPONSES FOR “WHEN THE INTENDED PARENT(S) WERE NOT AT AN APPOINTMENT, HOW WAS THE INFORMATION FROM THE APPOINTMENT DISCLOSED TO THEM?”
“The caseworker for my last surrogacy handled all information. She didn't want me to talk to them about medical issues.” “They were on the phone with me during appts” “Intended Parents were usually on phone during appointment“ “I often had them on Skype video call during the appointments” “Myself” “Surrogate Agency went” “By phone or text message” “If parents weren't there the Surrogate Agency was there to tell the parents what had happened”4 “Face time during appointments” “Through me” “Skyping the appointment. My IPs are on the other side of the world.” “I would always let them know because they only went with me once.”

APPENDIX G: List of “Other” for “Did You Make Any Medical Decisions When the Intended Parent(s) were not Present at the Appointment?”

LIST OF “OTHER” RESPONSES FOR “DID YOU MAKE ANY MEDICAL DECISIONS WHEN THE INTENDED PARENT(S) WERE NOT PRESENT AT THE APPOINTMENT?”
”Intended parents lived out of the country. Twins were born early and I made decisions for the boys until their parents arrived.” “Certain blood tests.” “I decided to go V-BAC. I had discussed it with the IP’s already.” “Emergency C-section. I was asked due to risk I was taken, but I gave the parents the option first.” “Csection.” “Yes I would message them ASAP for approval. Parents lived out of country.” “Emergency Csection when parents were absent.” “To be induced for baby’s safety, they were on an airplane unable to con tact.” “Medical decisions involving my personal health only. All other decisions were made together such as medications, vaccines etc.”