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Studying Stigma, Medicine, and Huntington's Disease

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# Studying Stigma, Medicine, and Huntington's Disease



**M**Y CURRENT WORK continues the study of stigma, medicine, and Huntington's disease that I began in 1995 with *Mapping Fate: A Memoir of Family, Risk, and Genetic Research* (UC Press, 1995).<sup>1</sup> But whereas *Mapping Fate* is autobiographical and contemporary, my most recent book, *The Woman who Walked into the Sea: Huntington's and the Making of a Genetic Disease* takes a more historical approach. Published in 2008 by Yale University Press and awarded the American Medical Writers' Book Award for 2008, this book traces the ways in which an unusual form of "St. Vitus's dance" became Huntington's chorea and

then Huntington's disease (HD)—a fatal hereditary neurological and psychiatric disorder characterized by involuntary movements and cognitive and emotional decline. In tracking these changes over the nineteenth and early twentieth centuries, I argue that influential medical and historical narratives of the disease made women a source and scapegoat for Huntington's—although the disease affects males and females in equal numbers. These narratives also defined HD families as undesirable citizens, thereby encouraging the family secrecy and denial that medicine ostensibly sought to overcome. I also aimed to

capture something of the lived historical experience of this illness through the story of Phebe Hedges, a white woman in early-nineteenth-century East Hampton, New York, who committed suicide in 1806. A certain dread and secrecy surrounded this malady at least by Phebe Hedges's time. However I suggest in the book that the stigma associated with it in the late 20th century owes much to the early 20th century eugenics movement, which influenced not only popular perceptions and medical discourse but also priorities for research on this disease, up through the 1970s. The eugenic emphasis on limiting or preventing procreation in families with Huntington's targeted women in specifically onerous ways. Only when families with Huntington's, and most notably women such as Marjorie Guthrie and Nancy Wexler, began speaking on their own behalf, within the context of late 1960s social movements, the 1970s recombinant DNA revolution, and new developments in neuroscience, did these derogatory images begin to change.

Continuing my study of stigma, I published an article in the British medical journal *The Lancet* on "Stigma, Secrecy, and Huntington's Disease," July 3, 2010. Currently I am examining



representations of Huntington's disease in popular culture. Since 1983, when a genetic marker for HD was identified and highly accurate predictive testing became possible—the first ever for a lethal, late-onset disorder—Huntington's has had a considerable presence in television dramas, for example “Marcus Welby,” “St. Elsewhere,” “House,” “Everwood,” and in fiction—Kurt Vonnegut's *Galapagos*, Ruth Rendell's *House of Stairs*, Octavia Butler's “The Evening and the Morning and the Night,” and Ian McEwan's *Saturday*. Drawing on feminist and disability studies perspectives, I am exploring the ways in which these writers have imagined the existential possibility of knowing one's fate without being able to change it, and also the ways of living with a steadily worsening brain disability for which there is no cure.

I am also working on a short paper analyzing the medical contribution of Neil Glendinning, a general practitioner who in 1975 completed, but never published, a medical thesis on previously undocumented families with Huntington's in Somerset, U.K., where he lived and practiced medicine. In the summer of 2010 I traveled to Somerset to interview Glendinning and his wife Gillian, also a

physician who collaborated with him. Neil Glendinning himself acknowledged that, as one of the few writers since the eponymous George Huntington to live and practice medicine in the same district as the HD families whom he studied, he was able to see aspects of the disease that were much less visible to clinic or hospital doctors. For example, since he got to know entire families in their daily lives, he was able to diagnose persons whose late onset or mild symptoms had gone unrecognized. He was able to trace the great variability of the disease within as well as between families over multiple generations. He also described the ways in which affected persons' quality of life depended heavily on the unpaid labor of women, a point often overlooked in clinical accounts at that time. I argue that his thesis is also remarkable for its sensitivity to family perspectives at a time when the legacy of eugenics lingered among some influential neurologists and geneticists.

During the past two years I have also spoken about all these projects at a number of colleges and universities (Emory, University of Wisconsin, Columbia, University of Redlands, Whittier College), conferences (American

Association for the History of Medicine, World Federation of Neurology), and meetings of HD advocacy groups (Huntington's Disease Society of America and the Hereditary Disease Foundation). I continue to work with the Hereditary Disease Foundation on its program of organizing scientific workshops and awarding grants and postdoctoral fellowships for research to find effective treatments for Huntington's disease.

**Alice Wexler has been a CSW Research Scholar since 1994. She received her Ph.D. in History from the Indiana University in 1972 after completing a dissertation entitled “Historians, Society, and the Spanish-Cuban-American War of 1898.” She taught for many years at Sonoma State College (now University) as well as at Claremont Graduate School, UC Riverside, and UCLA.**

## NOTES

1. *Mapping Fate* has been discussed in a number of recent books including Kathleen Woodward's *Statistical Panic: Cultural Politics and Poetics of Emotion* (2008), Monica Konrad's *Narrating the New Predictive Genetics: Ethics, Ethnography and Science* (2005), and Thomas Couser's *Vulnerable Subjects: Ethics and Life Writing* (2004).