MY 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). 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

The art of medicine
Stigma, secrecy, and Huntington’s disease

Until she herself was diagnosed with Huntington’s disease, my mother never mentioned that her father and three brothers had all died with this disease. Perhaps that missing family history was why I became a historian. I wanted to understand my mother’s shame, and the origins of her devastating silence. My first insight came at one of the public hearings organised in 1977 by the USA Congressional Commission for the Control of Huntington’s Disease. A woman from an affected family offered testimony that reverberated throughout the hearings and still resonates today. “If I had one wish that this Commission could accomplish”, she said, “It would be to take away the stigma of Huntington’s disease and take it out of the closet.” Another witness explained, “there is a shame associated with the disease, and they [family members] are so embarrassed by the whole thing that they just want to forget it.” A third person recalled that “one of the recommendations our first neurologist made was that we all ought to be sterilized. That was the first thing he said after he announced the diagnosis.”

Stigmatisation is often attributed to ignorance, which in the case of Huntington’s disease means unfamiliarity with the involuntary movements (chorea), behavioural disturbance, cognitive impairment, and autosomal dominant inheritance pattern. Yet history suggests that while knowledge in the context of democratic values can help overcome prejudices, scientific and medical knowledge apart from such values can coexist with, or even contribute to, increased stigmatisation and rejection. For instance, with the rediscovery of Mendel’s theory in 1900 came a more precise understanding of the inheritance pattern of Huntington’s disease. The British geneticist William Bateson established definitively in 1909 that it was inherited as a Mendelian autosomal dominant disease. At the same time with the emergence of eugenics, Huntington’s chorea, as it was called, became subject to calls for surveillance and control. In 1931, the North American biologist Charles B Davenport—director of the prestigious Biological Laboratory at Cold Spring Harbor, New York, USA, founder of the Eugenics Record Office, and an early proponent of Mendelism—hired a physician, Elizabeth B Muncey, to undertake the first large-scale pedigree study of families with Huntington’s disease in New York and New England, going back nearly 12 generations. He then used her data as the basis for a 1916 paper, in which he claimed that from just a few progenitors came a vast number of victims and called for immigration restrictions, surveillance of families, and compulsory sterilisation. Published in the American Journal of Insanity, “Huntington’s Chorea in Relation to Heredity and Eugenics”, was routinely cited in the biomedical literature on Huntington’s as one of the foundational texts on the disease.

In an era when eugenics attracted scientists, physicians, and intellectuals of all political stripes, Davenport spoke with the authority of science. So too did a Connecticut psychiatrist named Percy R V esse, whose 1932 paper became part of the Huntington’s disease canon. Building on Muncey’s pedigrees, V esse traced the genealogy of one of his own patients back to her 17th-century New England immigrant ancestors, identifying three married couples from the English village of Burons in Suffolk as the most likely progenitors of Huntington’s disease in the USA. For V esse, witchcraft accusations against one woman and her relatives indicated possible symptoms of the disease. The supposed “misconduit” of the men also pointed to the possibility of affliction, and indicated their disreputable character. Indeed, V esse portrayed all these individuals more as villains than as victims. The men were “illiterate and arrogant, and none attained recognition or respectability”. The women were the “austentable” cause of introducing Huntington’s to the USA. The “true story” of Huntington’s disease in the USA, according to V esse, was “revealed in the witchcraft trials of women in the Burons group”. Because they showed no inclination to remain childless, he wrote in 1939, the only way to stop their tainted legacy was “to warn all such chorics and their children against propagation” and to implement “rigid sterilisation”.

These recommendations were not merely theoretical. They were published in major medical journals at a time of widespread involuntary sterilisations in the USA and the move from sterilisation to outright murder of psychiatric patients and people with disabilities in Nazi Germany. Moreover, soon after it appeared in the Journal of Nervous and Mental Disease, V esse’s portrait gained traction in other prestigious medical and popular publications, where its eugenic resonance was emphasised. In 1935, the Lancet abstracted V esse’s paper, boosting that “we [Britons] may congratulate ourselves on their loss, for...there can be no doubt that Wilkie, Nichols, and Jeffers [V esse’s pseudonyms for the three men] and their progeny were undesirable characters, and would nowadays be classified as belonging to the social problem group.” The Literary Digest, a popular US magazine, in turn summarised The Lancet’s version under the prejudicial title “The Witchcraft Disease.”

Upping the ante, the young British neurologist MacDonald Critchley claimed, in 1934, that all members of families affected by Huntington’s disease were “liable to bear the marks of a grossly psychopathic taint, and the story of feeblemindedness, suicide, criminality, alcoholism and drug addiction becomes unfolded over and over again”. The distinguished American geneticist, James V Neel, argued in the first issue of the American Journal of Human Genetics, in 1949, that “even the most hesitant of us to
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 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).