The Woman Who Walked into the Sea: Huntington's and the Making of a Genetic Disease

Author: Alice Wexler
Yale University Press (2008)
253 pp., $20.00 paperback.

Ever wonder how symptoms became recognized as a disease and then given a name that became widely known or how inheritance was described before patterns of inheritance were even elucidated? *The Woman Who Walked into the Sea* tells the interesting story of how this all occurred for Huntington disease, from acceptance as a "local peculiarity" to an internationally recognized clinical entity. The book's title comes from the description of the 1806 suicide of Phebe Hedges, who lived in East Hampton, Long Island, where the Huntington family also lived. This book does more than tell the history of Huntington disease (MIM 143100)—one also learns about life in the 1800s and early 1900s, the emergence of concepts of heredity, the establishment of neurology as a medical specialty, the eugenics movement, and the field work for Huntington disease that was conducted by Dr. Elizabeth Muncey under the direction of eugenicist Dr. Charles Davenport.

The book is written by Alice Wexler, historian and author of *Mapping Fate: A Memoir of Family, Risk, and Genetic Research*, whose mother had Huntington disease and whose family is well known in the genetics and Huntington disease communities for their work mapping the HD gene, writing about being at risk for Huntington disease, and launching the Hereditary Disease Foundation. Alice Wexler deftly traces generations of the Hedges' and the Huntington's family histories and shows how their living in East Hampton and encountering each other in community life helped contribute to Dr. George Huntington's awareness, keen observations, and understanding of this condition. Knowing the family members with and without the disease gave Dr. Huntington the insight to derive the specific pattern of inheritance of this hereditary chorea, before there were known patterns of inheritance, and led to his important observation of complete disappearance of the disease in one generation in unaffected family lines.

Dr. George Huntington was not the first to describe what is now known as Huntington disease, and in fact, he may not have even done so had he not been asked to give a talk at a meeting. Wexler shares the history of how this disorder was previously described and offers explanations as to why the 1872 paper written by Dr. George Huntington, 21 years old and just out of medical school, was so significant. She also discusses how this first description of hereditary chorea by an American gave Americans an identity and reputation in the newly established medical specialty of neurology, which had until then been dominated primarily by Europeans.

The "lived experience" of Huntington disease and community knowledge of members with this condition is explored. Wexler states that "As a historian, I had learned to see disability and disease as socially as well as biologically constructed and as conditions whose meaning could change over time and across place" (p. xix). She shows how in some communities, individuals with Huntington disease were accepted, lived like their neighbors, and even served in leadership positions, while in other places, they were less a part of community life, stigmatized, and even suspected of witchcraft. Wexler explores these differences in community attitudes toward individuals affected with Huntington disease over time and likely reasons for acceptance and exclusion. Wexler also addresses global issues of perceptions and treatment of disability, noting "Having a progressive fatal disease such as Huntington's is significantly different from living with a stable disability. Still, it does not preclude a worthwhile life, with the resources and support that can make this possible. Those of us at risk for this disease have learned to value our precarious relationship to the world, and the insights that it has given us" (p. 186).

One has only to read through the acknowledgments and footnotes to gain an appreciation for the impressive number of interviews conducted and documents reviewed to produce this well-researched book. Wexler's use of quotes from historical documents, particularly in early chapters, draws one into life in this East Hampton community and makes one feel present as the events unfold. Throughout the book, Wexler poses basic and thoughtful questions and then provides answers as best she can with the historical documents that she has found. The book also has photos, including a few of the historical documents, making it possible to read some of the words as they were actually written at the time.

Winner of the 2009 American Medical Writers Association Medical Book Award in the non-physician category, *The Woman Who Walked into the Sea* is packed with details, so it is a slower read, as would be expected for a historical book. It would have been helpful if the pedigrees of the Hedges and Huntington families had been placed at the beginning of the book for easier access. In addition,

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inclusion of a timeline, showing the key events described in the book regarding the history of Huntington disease and the time periods when different names were used, would have been helpful. Readers, particularly students, will find this book useful for learning about Huntington disease from historical, medical, and societal perspectives. The book also provides an important window into the practice of medicine for a hereditary, neurological condition in the 1800s and early 1900s and the early history of genetics. Clinician educators can use the book content to add some historical facts and insights into their lectures. Families with Huntington disease may also appreciate learning about the history of their disease. After reading this well-written and intriguing book, one wonders about the history of other inherited genetic conditions and hopes that Alice Wexler will lend her skills to uncovering these histories and telling the stories that need to be told.

Web Resources

The URL for data presented herein is as follows:

Online Mendelian Inheritance in Man: http://www.ncbi.nlm.nih.gov/Omim/

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