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Moments of Truth in Genetic Medicine

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BOOK REVIEWS

MOMENTS OF TRUTH IN GENETIC MEDICINE

By Susan Lindee. 270 pp., illustrated. Baltimore, Johns Hopkins University Press, 2005. $40. ISBN 0-8018-8175-7.

In 1964, Victor McKusick completed the first of a series of field trips to the Amish communities of Pennsylvania. McKusick had two guides for his initial trips: David E. Krusen, a Lancaster physician who had noted a high incidence of achondroplasia among the Amish, and John Hostetler, a sociologist from Pennsylvania State University and an expert on Amish culture. Author Susan Lindee demonstrates that both of these guides were absolutely essential for McKusick's genetic surveys of the Amish. To detect hereditary patterns, McKusick had to enroll a social network among the Amish — his expertise had to extend beyond medical genetics to the local cultures and communities where the various maladies occurred.

Contributions from both research subjects and researchers lie at the heart of this engaging study of human genetics from 1955 to 1975. Whereas the history of phenylketonuria, familial dysautonomia, or even postwar twin studies could be treated solely from the perspective of the researchers who pioneered these investigations, Lindee offers a rich and nuanced history that gives voice to both subjects and scientists. As such, Lindee's analysis distributes scientific authority; and the ability to recognize scientific reality (the "moments of truth" that give the book its title) is shared by researchers, subjects, families, and communities.

Lindee presents five defining moments during the postwar period that collectively describe how the genetic bases of some diseases were recognized and how human genetics itself grew to include genetic disease as an important area of research. This book is not an exhaustive study of human genetics or genetic disease in the postwar period. Instead, it offers careful consideration of the development of blood tests for phenylketonuria; the construction of McKusick's social and genetic networks among the Amish as he investigated diseases such as the Ellis–van Creveld syndrome; the success of human cytogenetics and the reception of karyotype analysis; the creation of the Veteran Twin Registry and its application to human behavioral genetics; and the history of genetic research on familial dysautonomia. Each of these cases is fascinating and distinct. The involvement of family support groups in research on familial dysautonomia, for instance, is interwoven with the history of the genetic characterization of the disease and its diagnosis and treatment.

The challenge of diagnosing genetic disease is a theme that runs through each of Lindee's historical cases, but examples such as the development of the blood test for phenylketonuria, McKusick's pedigrees, and the display of chromosomes in karyotypes allow the reader to see important differences in how reliable diagnostics were established. Lindee's discussion of the diagnosis of zygosity in the Veteran Twin Registry is particularly interesting, since the twins themselves seemed to be better at recognizing zygosity than were the tests used at the time. The history of this "moment of truth" captures the complexities of research on genetic disease while prompting us to reconsider the distribution of scientific authority and the dynamics of knowledge production.

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ETHICAL DILEMMAS IN PEDIATRICS: CASES AND COMMENTARIES

Edited by Lorry R. Frankel, Amnon Goldworth, Mary V. Rorty, and William A. Silverman. 303 pp. New York, Cambridge University Press, 2005. $80. ISBN 0-521-84744-3.

The discipline of pediatric ethics is growing up. The conventional approach to bioethical analysis does not work with respect to children as it does for adults. The very foundations of bioethics are different when questions