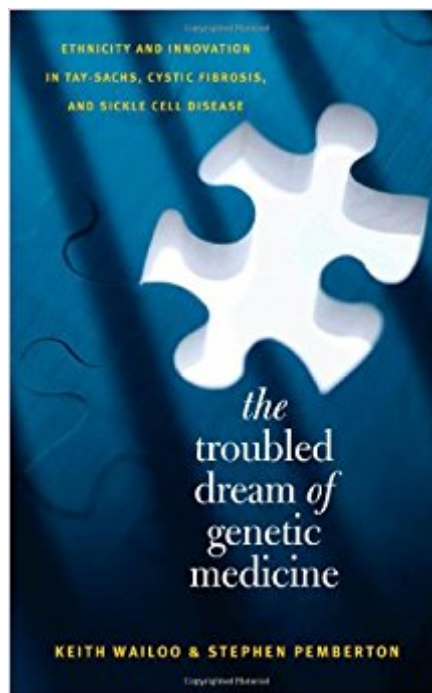




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# The Troubled Dream Of Genetic Medicine: Ethnicity And Innovation In Tay-Sachs, Cystic Fibrosis, And Sickle Cell Disease



## Synopsis

Why do racial and ethnic controversies become attached, as they often do, to discussions of modern genetics? How do theories about genetic difference become entangled with political debates about cultural and group differences in America? Such issues are a conspicuous part of the histories of three hereditary diseases: Tay-Sachs, commonly identified with Jewish Americans; cystic fibrosis, often labeled a "Caucasian" disease; and sickle cell disease, widely associated with African Americans. In this captivating account, historians Keith Wailoo and Stephen Pemberton reveal how these diseasesâ fraught with ethnic and racial meanings for many Americansâ became objects of biological fascination and crucibles of social debate. Peering behind the headlines of breakthrough treatments and coming cures, they tell a complex story: about different kinds of suffering and faith, about unequal access to the promises and perils of modern medicine, and about how Americans consume innovation and how they come to believe in, or resist, the notion of imminent medical breakthroughs. With Tay-Sachs, cystic fibrosis, and sickle cell disease as a powerful backdrop, the authors provide a glimpse into a diverse America where racial ideologies, cultural politics, and conflicting beliefs about the power of genetics shape disparate health care expectations and experiences.

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"Concise and well-argued... essential reading for anyone interested in genetics, disease, and the meaning of race." (Science)"Practitioners of the future will have to take these separate histories into account as this new era unfolds." (Doris Teichler Zallen, PhD JAMA)"Fascinating." (Jackie Leach

Scully Social History of Medicine)"Perfectly suited for use in teaching the history of medicine and health... At once concise, readable, and demanding in its parsimony. It should not be missed by anyone who cares about the emerging shape of health care in the age of genomic medicine." (Christopher Crenner Journal of the History of Medicine)"The book deserves to be read by a large publicâ and in particular by those who are in charge of, or concerned with, decisions about health politics." (Michel Morange Isis)"No book brings together contemporary understandings of genetics as a social rather than a biological project as nicely as The Troubled Dream of Genetic Medicine. This book, accessible to both scholars and general readers, greatly contributes to our understanding of the ways in which concepts developed in genetic medicine influence people's definitions of ethnicity and race." (Kaja Finkler, University of North Carolina at Chapel Hill)" The Troubled Dream of Genetic Medicine brings into focus intriguing concepts at the intersection of science and society... This book ought to encourage others to produce biosocial histories of this kind." (Abidemi Adegbola, M.D. Journal of the American Academy of Child and Adolescent Psychiatry)"The authors are two historians of health care policy and politics, and their well-researched account of the 'genetic revolution' reveals drama and intrigue rarely seen in descriptions of medical history." (PsycCRITIQUES)

Keith Wailoo is a professor in the Department of History and the Institute of Health, Health Care Policy, and Aging Research at Rutgers University. He is the author of Drawing Blood: Technology and Disease Identity in Twentieth-Century America (Johns Hopkins University Press, 1997) and Dying in the City of the Blues: Sickle Cell Anemia and the Politics of Race and Health (University of North Carolina Press, 2001). Stephen Pemberton is an assistant professor in the Federated Department of History at the New Jersey Institute of Technology and Rutgers University.

This book is an excellent, easy to understand introduction to its topic of the intersection of race and genetic medicine. I work in an area of clinical research adjacent to those discussed, and the various people and interests that drive this type of research were fairly and accurately represented as far as that representation went. The book does not go into great detail about how clinical trials are normally developed, funded, carried out, and reviewed in order to contrast these case studies with the norm-- something many people reading an introductory book may not understand. However, the three conditions discussed are well chosen and contrast with one another well enough that I think a layperson could come away from the book with a fair idea of the role research in genetic medicine has played for each. This book does not provide more than a very introductory idea of how racial

politics interact with the experience and treatment of these diseases. If you come to this book (as I did) from an interest in how race conditions experience of and access to clinical research, healthcare, and disease, you'll get a clear picture of how the material realities of each disease and treatment affect their communities. You'll get a less detailed picture of how each disease interacts with the affected community's cultures and histories with healthcare, research, and racial oppression. If you're interested in how anti-racist criticism and theory interact with the physical realities of any specific disease, you'll find food for your own thought but no real comment from the authors. There's no criticism intended in that-- this is a great introduction to the individual diseases and to the topic of genetic medicine and adjacent issues such as healthcare access in the U.S. and its relationship with clinical research. This book would make excellent undergraduate course reading in any of those topics. If you're more experienced in thinking and reading about race, this book can provide a good foundation for thinking about genetic diseases in that context. But don't make the mistake of thinking that's what this book is for. And if you already know a lot about racial and genetic medicine (I didn't), you probably don't need this book.

This was an extremely informative book about genetic diseases with some salient observations about the diseases, the incidences of the diseases within the specific communities, and common misconceptions that the uneducated have regarding these diseases. I would highly recommend this book for anyone who wishes a greater understanding of how these genetic diseases are inherited, treated, and the probability of unlocking specific cures within the future of discoveries in the human genome.

The Troubled Dream of Genetic Medicine: Ethnicity and Innovation in Tay-Sachs, Cystic Fibrosis, and Sickle Cell Disease provides a history of diseases which have been connected with racial makeup, sparking ethnic controversies in their discussion and analysis. The authors draw links between biology and social issues, examining underlying influences on research and perspective of modern medicine and how Americans ultimately come to embrace or reject projected breakthroughs. From therapy as social justice to media headlines and changing social perspectives, THE TROUBLED DREAM OF GENETIC MEDICINE is a powerful testimony to the power of prejudice even in the field of medical research. Diane C. Donovan California Bookwatch

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