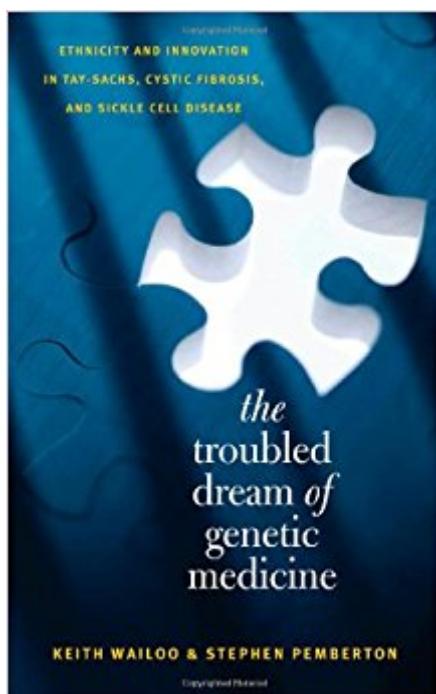


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# The Troubled Dream Of Genetic Medicine: Ethnicity And Innovation In Tay-Sachs, Cystic Fibrosis, And Sickle Cell Disease



## **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.

## **Book Information**

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## **Customer Reviews**

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.

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