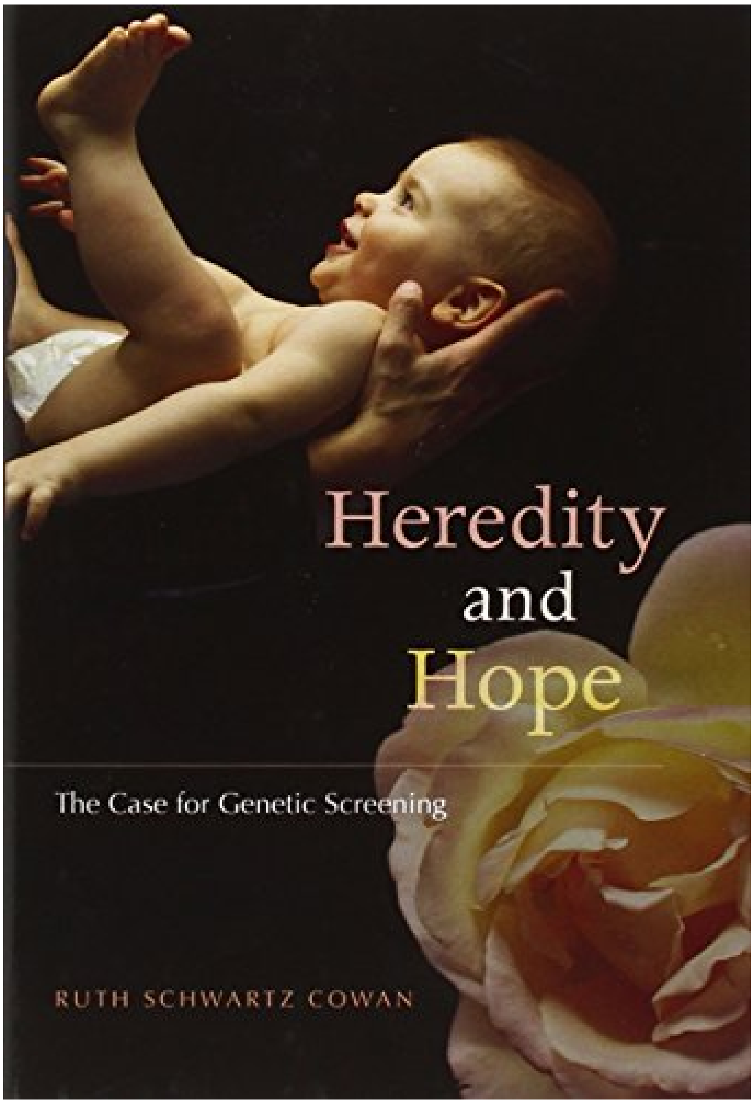
Heredity and Hope: The Case for Genetic Screening

Ruth Schwartz Cowan



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Ruth Schwartz Cowan : Heredity and Hope: The Case for Genetic Screening before purchasing it in order to gage whether or not it would be worth my time, and all praised Heredity and Hope: The Case for Genetic Screening:

2 of 4 people found the following review helpful. Making the case for genetic screeningBy Dominique TobbellIn this extensively researched and well-written book, Cowan explores the history of genetic testing, paying particular attention to the meaning of genetic testing to those who developed it and those who experienced it. In doing so, Cowan deftly undermines the arguments made by opponents of genetic screening who see the technology as inexplicably linked to the eugenics movement, who see it as a form of discrimination against the disabled, and who see the routinization of prenatal genetic testing as an example of a paternalistic medical profession diminishing women's

autonomy.Instead, Cowan shows that for the researchers and physicians who developed prenatal genetic testing, their motives were pronatalist: these developers sought to reduce the number of unnecessary abortions being performed on fetuses at risk of being afflicted with a life-threatening genetic disease by providing parents with definitive information about the genetic (and thus disease) status of their fetus. In doing so, the developers of genetic testing and advocates of genetic screening were committed to reducing the amount of human suffering experienced by the children and families affected by fatal genetic conditions.Cowan shows clearly how individuals and couples at-risk of passing on genetic diseases to their children and the parents of children born with fatal genetic diseases have been some of the biggest proponents of genetic screening, raising money, supporting research, and lobbying federal governments to provide more support for genetic screening. Cowan argues that for governments to limit at-risk individuals' access to genetic screening is itself paternalistic, and makes the convincing case that genetic screening (in the form of prenatal testing, newborn testing, and carrier testing) for such fatal diseases as sickle cell anemia, thalassemia, phenylketonuria, and Tay-Sachs disease is at once morally right and politically acceptable.Heredity and Hope is an important book for anyone interested in the subject of genetic testing but especially for expectant parents considering prenatal diagnosis, individuals considering being tested for their carrier status, and physicians and policymakers who continue to debate the ethics of genetic screening.0 of 0 people found the following review helpful. You'll learn so much about medical genetics vs eugenics, two different beasts entirelyBy CustomerI checked this book out at my school's library randomly. I really didn't know much about genetic screening or counseling but after reading this book have learned so very much about medical genetics.This book is absolutely wonderful in that it isn't filled with too much jargon and that it does an amazing job of addressing the history of medical genetics vs the history of eugenics, which I originally thought was one in the same(SPOILER: they aren't)Anyhow, the author does a great job of addressing critics of genetic screening and the historical fallacious basis of their arguments , particularly at the conclusion of the book.I have had my misgivings about genetic screening/and testing and this book really changed my perspective. There are some parts that can get a little dry because of the scientific nature of the book and all the history- but in a way those parts also make it very interesting.At many instances I couldn't put the book down , but you'll probably want to take a break or two if you're not the most "science-cy" person.Ultimately I recommend this book 100%! I will definitely be getting a personal copy in the near future.1 of 4 people found the following review helpful. A Bit StrainedBy R. AlbinThis concise and essentially polemical book is aimed at clarifying and defending the present practice of medical genetics. Cowan, a historian, provides thoughtful and useful summaries of the histories of the eugenics movements, the development of modern medical genetics, and specific examples of modern genetic screening. She describes the emergence of screening for Tay-Sachs, and the very interesting and largely unfamiliar (to most readers at least)experience of thalassemia screening in Cyprus. These sections are quite well done. Cowan is particularly interested in rebutting criticisms of medical genetics from a variety of modern sources and defending modern medical genetics from association with past eugenics movements. Cowan also does well in distinguishing the humane intentions and individually oriented practices of modern medical genetics from the proposed and actual eugenic practices of the 20th century.This book suffers from 2 significant defects. While Cowan correctly differentiates modern medical genetics from 20th century eugenics, she pushes her argument too far in an attempt to erase the stigma of eugenics from genetic screening. The differences Cowan discusses are real and significant, but modern medical genetics is still primarily concerned with using genetic information to inform reproductive decisions and decisions about continuing pregnancies. Despite the major differences from historic eugenics, this is a major common feature. Whether this is called negative eugenics (as most would) or genetic screening (Cowan's preferred term) is more a matter of rhetoric than substance. Cowan also glosses over many of the significant ambiguities of genetic practice. Her major examples, thalassemia and Tay-Sachs, are relatively straightforward in the sense that these mutations consistently produce severe, early-onset phenotypes. But what about last onset, incurable genetic disorders? What about disorders with incomplete penetrance? DYT1 dystonia is an often severe disorder enriched in Ashkenazi Jews. We know from recent research that this mutation produces manifest disease in only about 50%-60% of its carriers. What happens if there is a significant degree of variation in the phenotypes associated with mutations in some genes and predictions of the severity of the phenotype are not possible? These are quite difficult issues and significantly complicate Cowan's somewhat uncritical endorsement of genetic screening.Review Addendum: I downgraded this review from 3 stars to 2 stars after reading Diane Paul's excellent introduction to the history of eugenics, Controlling Human Heredity. Paul's book, published in 1995 and not cited by Cowan, shows quite clearly that one of Cowan's central claims is wrong. Cowan argues that modern medical genetics is not historically connected to the eugenics movement. There is abundant documentation in Paul's book that this claim is erroneous.

The secrets locked in our genes are being revealed, and we find ourselves both enthused and frightened about what that portends. We look forward to curing disease and alleviating sufferingfor our children as well as for ourselvesbut we also worry about delving too deeply into the double helix. Abuses perpetrated by eugenicistsfrom involuntary sterilization to murdercontinue to taint our feelings about genetic screening. Yet, as Ruth Schwartz Cowan reveals, modern genetic screening has been practiced since 1960, benefiting millions of women and children all over the world.

She persuasively argues that new forms of screeningprenatal, newborn, and carrier testingare both morally right and politically acceptable. Medical genetics, built on the desire of parents and physicians to reduce suffering and increase personal freedom, not on the desire to improve the human race, is in fact an entirely different enterprise from eugenics. Cowans narrative moves from an account of the interwoven histories of genetics and eugenics in the first half of the twentieth century, to the development of new forms of genetic screening after mid-century. It includes illuminating chapters on the often misunderstood testing programs for sickle cell anemia, and on the worlds only mandated premarital screening programs, both of them on the island of Cyprus. Neither minimizing the difficulty of the choices that modern genetics has created for us nor fearing them, Cowan bravely and compassionately argues that we can improve the quality of our own lives and the lives of our children by using the modern science and technology of genetic screening responsibly.

Ruth Cowan, an unabashed supporter of genetic screening and prenatal diagnosis, explains how they have enabled parents at risk to have children free of debilitating or deadly genetic diseases. She is a masterful and altogether convincing guide. (Daniel Kevles, Yale University)Elegantly written and thoroughly researched, Ruth Schwartz Cowan's wisdom shines forth on every page of this critically important book. (Dr. Howard Markel, author of When Germs Travel)Cowanadeptly and persuasively shows why the normative foundation for contemporary genetic screening is sound, why it should not be tarred with the brush of racist eugenics and where the real challenges and conundrums lie for those involved in screening now and in the future. (Arthur Caplan, Director, Center for Bioethics at the University of Pennsylvania)Passionate, well-researched, and controversial, Heredity and Hope provides important historical illumination on an issue which activists and analysts from many perspectives will be eager to address. (Rayna Rapp, author of Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America)Modern healers may claim science to be the foundation of their work, but the key is, in fact, persuasion: to heed advice, to push and persevere, to hope. As the genome is further dissected and better understood, no family of diseases warrants more genuine hope for successful management than genetic conditions. Cowan understands that we must all share that hope for the campaign to be successful. (Hugh Young Rienhoff Jr. Nature 2008-05-22)About the AuthorRuth Schwartz Cowan is Professor of History and Sociology of Science, University of Pennsylvania.