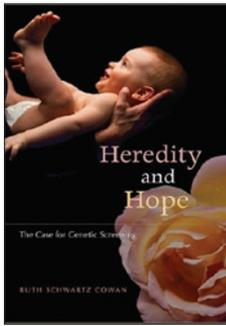


## Without apology

**Heredity and Hope: The Case for Genetic Screening**

By Ruth Schwartz Cowan

Harvard University Press, 2008  
292 pp., hardcover, \$27.95  
ISBN 978-0674024243

Reviewed by Robin Bennett

The electric tapping of the keyboard has an almost audible hum as messages fire across the National Society of Genetic Counselor's list-serv. "Did you see it?" Another article in the popular press concluding that genetic counseling is eugenic—a move to create a perfect race. The hackles of many genetic counselors bristle, and the comments fly—"Absolutely not true! We advocate for personal and reproductive choice; we discuss genetic options in a non-directive manner, encouraging reflection as to what will be the best choice for that person or couple, which is not necessarily the choice that we would make. It is not our role to judge."

The latest flurry occurred following Michael Gerson's article "Trig's Breakthrough" in the September 10th *Washington Post*, celebrating vice-presidential running mate Sarah Palin's son who has Down syndrome as a civil rights leader. Gerson writes, "Yet when Down syndrome is detected through testing, many parents report that genetic counselors and physicians emphasize the difficulties of raising a child with a disability and urge abortion. This is properly called a eugenic abortion...". With Ruth Cowan's *Heredity and Hope*, we now have data to counteract editorials like Gerson's. Cowan summarizes multiple lines of historical evidence that genetic counselors and geneticists are hardly the flag wavers of a eugenics movement; in fact, a higher percentage of couples at high risk of having a child with a genetic disease have chosen to have the child since the advent of genetic counseling than prior to the availability of informed advice about genetic testing.

Dr. Cowan, a professor of History and Sociology of Science at the University of Pennsylvania, intends to provide guidance as to how to think through thorny genetic decisions. She notes, "Genetic testing promises us a rose garden—the prevention of devastating diseases and profoundly disabling conditions—but unfortunately, there are precious few role models to help us make the unprecedented decisions that the testing forces upon us." She uses the "historian's tools to resolve bio-ethical questions regarding the gut-wrenching decisions that are made

*Robin Bennett is in the Division of Medical Genetics, University of Washington Medical Center, Seattle, Washington 98195, USA, and is a past president of the National Society of Genetic Counselors.  
e-mail: robinb@u.washington.edu*

regarding genetic testing and genetic screening. These are not only personal but social and political questions as well."

The historical road that Cowan takes us on begins with the rise of the "beautiful inheritance" of the eugenics movement and the simultaneous growth of classical genetics. The roots of current genetic counseling practice began with mendelian principles and expanded with biochemical analysis and molecular diagnostics. As a US citizen, it is sobering for me to learn that the eugenics movement was most effective in the United States, where mass sterilization laws were enacted. Cowan adeptly reviews the horror of this time, but clearly documents the separation of modern clinical genetics from this misshapen movement based on sloppy science to 'breed' a glorified race.

The next perspective is that of the growth of prenatal diagnosis in the early 1980s where "changes in abortion law were as important in the diffusion of amniocentesis as changes in laboratory techniques and discoveries in classical genetics... The first provider of prenatal diagnosis was a physician who wanted to help the carrier of a genetic disease *have* a baby; the first patient was a woman who, absent the test, would have probably terminated her pregnancy." The hoped-for outcome of prenatal diagnosis—having an unaffected child even when at high risk of having a child with a severe genetic disorder—is anti-eugenic. In contrast, carriers of genetic diseases were the very people targeted by the eugenics movement; eugenicists proposed to curtail their reproduction with mass sterilization, sexual segregation or, at the extreme, mass extinction.

Several chapters are devoted to gene mutation carrier screening, particularly the failure of sickle-cell anemia carrier screening in African Americans and the legacy that continues today of mistrust between African Americans and their physicians. This is in contrast to the success of carrier screening and prenatal diagnosis for B-thalassemia in Cyprus (a mandated program) and the approach to carrier testing in the US Ashkenazi Jewish population for Tay-Sachs disease.

At the conclusion of *Heredity and Hope*, I felt vindicated that the work of genetic counselors remains essential, and ever more so as the opportunity for genetic testing for individuals of all ages expands. Genetic counselors and medical geneticists have the unique ability to meld the science of genetics and the knowledge of the spectrum of genetic disorders with the skills to counsel individuals as they make unprecedented choices. Cowan concludes, "As a result of my historical research, the ethical and political foundation on which the current practices of medical genetics have been built is one to which I now feel capable of giving my full assent, without guilt, without ambivalence, and without apology... the time has come for prospective parents to stop feeling guilty about participating in screening, and for historians, social scientists, and journalists to stop warning about its hidden eugenic evils. These evils do not exist—and continuing to insist that they do is an attempt to further a political agenda by making good people feel unnecessarily guilty about their fundamentally wise and moral behavior."

*Heredity and Hope* will be a tattered book on the library shelf of every genetic counseling and medical geneticist training program, and a useful reference for students of molecular genetics, the history of science, medical ethics and public health. Perhaps it will also reach the hands of the continued naysayers of genetic counseling and testing.