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## Review of Reproductive Genetics and the Law

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## REPRODUCTIVE GENETICS AND THE LAW

Sherman Elias & George J. Annas  
Year Book Medical Publishers, 1987  
323 pages, \$35.00

**Reviewed by  
Judith Areen\***

How many goodly creatures are there here!  
How beauteous mankind is! O brave new world,  
That has such people in 't!

—Miranda, *The Tempest*, Act V:Sc 1

For many, the phrase “brave new world” evokes images of the chilling society envisioned by novelist Aldous Huxley in which human beings are engineered in the laboratory. But as Professor Albert Jonsen reminds us in the introduction to *Reproductive Genetics and the Law*, the phrase was first used by Shakespeare in *The Tempest* when Miranda first sees normal human beings on the remote island where she has been reared along with the monstrous Caliban, the spirit Ariel, and other creatures of her father’s magic art.

The authors of *Reproductive Genetics and the Law*, Sherman Elias and George Annas, introduce us to a brave new world that is closer in spirit to Shakespeare than Huxley, peopled as it is with parents, infants, and physicians striving to be “goodly creatures” in the sense of being free from fatal genetic defects. The decision to place the extraordinary advances that have occurred in our understanding of human genetics in the familiar world of medicine enables the authors to underscore the enormous potential for relief of pain and suffering offered by recent advances in genetics without sacrificing the opportunity to criticize aspects of the new science that could lead to abuse.

The authors announce at the beginning that their goal is to avoid the profes-

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sional bias so common in the literature: medical and scientific writers tend to ignore social policy issues, and lawyers and ethicists tend to misunderstand or ignore relevant scientific facts (p. xi). This fruitful, interdisciplinary collaboration of obstetrician/geneticist and health lawyer/medical ethicist more than lives up to the goal, containing as it does concise, accurate and useful information about human genetics and relevant areas of law. The scope of the book is remarkably ambitious, moreover, for it covers not only such matters as genetic screening and gene therapy, but also contains a chapter on "Reproductive Liberty," one on "Treatment of Handicapped Newborns," and one on "Gene Therapy." There is even a chapter on "Noncoital Reproduction" that discusses such new reproductive technologies as in vitro fertilization and surrogate mothers. The authors have included a judicious selection of illustrations and photographs and chapter references that serve to guide the interested reader to much more detailed discussions of both scientific and legal matters.

Although the emphasis is on scientific and legal facts, ethical and policy issues are not neglected. In some of the more contentious areas, the authors present the arguments on both (or more accurately, all) sides of an issue. On other points, however, they take a very clear stand. Thus, they accurately note that although "we have strongly argued in favor of attempting to identify and cure genetic diseases, we have consistently urged that this only be done with the informed consent of individual patients, and with informed public discussion of the myriad issues and interests involved" (p. 270). Some readers may be disappointed by the evident preoccupation with what might be termed procedural values, but the choice may also make the book a more useful source for policy-makers.

My only complaint is that the book came out too soon to wrestle with what is likely to be the biggest (at least in terms of dollars spent) genetic undertaking of our lifetime: the decision whether to commit as much as three billion dollars to sequencing (mapping) the human genome. The human genome project is intended to determine the identity, position, and function of the more than 100,000 genes in the human body. The map could thus significantly advance our understanding of how specific gene defects produce diseases such as cancer.

There are a growing number of signs that the project will go forward. Early this year, the National Research Council of the National Academy of Science issued a report recommending that the project go forward, and recommending that Congress approve an additional \$200 million annually for fifteen years to fund the project.<sup>1</sup> Congress has already appropriated more than \$17 million to the National Institutes of Health (NIH) to formulate long-range plans for the project.<sup>2</sup>

The only objections to the project until very recently have been raised by

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<sup>1</sup>The Washington Post, Feb. 12, 1988, at A3, col. 1.

<sup>2</sup>Palca, *NIH Gearing Up to Tackle the Human Genome*, 332 NATURE 99 (1988).

researchers who fear that such a huge project will divert funding from other biomedical research.<sup>3</sup> Yet as the National Research Council report noted, “a concerted effort to map and sequence the human genome would have profound social significance.”<sup>4</sup> For example, “diagnoses that trace diseases to our genes can also convey stigma and set the scene for social prejudice.”<sup>5</sup> The committee also cautioned that gene maps might be used by companies or insurers to screen out individuals who present occupational or insurance risks. The human genome project thus raises far more significant issues than the proper balance of power between large and small research projects.

Fortunately, a coalition of individuals and organizations representing civil rights groups, organized labor, disability rights, women’s organizations, public interest organizations, consumer and health organizations, and religious groups has been formed to seek the establishment of a congressional board and citizens committee to address the public policy implications of the project.<sup>6</sup> Surely we need to develop a public policy as sophisticated as our science on these fundamental human matters. The Elias-Annas collaboration demonstrates that it is possible to link the two. I hope they will undertake a second edition of this fine volume in order to give us the benefit of their thinking on these latest developments.

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<sup>3</sup>The Washington Post, Feb. 12, 1988, at A3, col. 1.

<sup>4</sup>National Research Council, NEWSREPORT 5 (March 1988).

<sup>5</sup>*Id.*

<sup>6</sup>Coalition Seeks Panel to Study Impact of Mapping Human Genome, CHRONICLE OF HIGHER EDUCATION, April 27, 1988, at A8, col. 1. The author is a participant in the coalition.