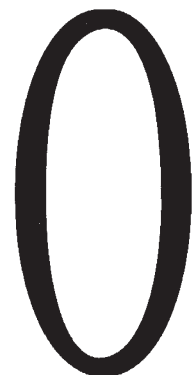


## /BOOK REVIEW

## Mapping the Human Genome

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ne of the underlying tenets of scientific endeavor is that gaining knowledge is good. Recent medical advances have shown that the application of new technologies raises countless legal and ethical issues such as who should decide when patients in permanent vegetative states should be "allowed to die," and

who should control the fate of frozen embryos conceived outside the womb. However, few question the worthiness of the underlying knowledge that permits the development of these technologies. After all, the same medical knowledge, the identical machine, that prevents an elderly comatose patient from being allowed to die "a natural death" can also preserve the life of a young mother during surgical procedures that will restore her to full health.

Is the human genome project, which seeks to map and sequence all three billion base pairs of the human genome, any different? This is one of several provocative questions raised in the collection of insightful essays compiled in *Gene Mapping Using Law and Ethics as Guides*. While many of the essays focus on specific practical problems that might arise as the project nears completion (e.g., fears of eugenics, patent issues, insurance problems), the broader philosophical issues are addressed as well. The editors' introductory and concluding chapters are quite effective in bringing together both the philosophical and the more practical levels of analysis. *Gene Mapping's* essays frequently praise the fact that the ethical, legal, and social implications of the project are being considered in tandem with the project's development. They also reflect the inherent difficulties of such an early analysis by raising a litany of such issues, but with little ability to predict which are or will most likely become significant.

*Gene Mapping* is on stronger footing when addressing some of the philosophical issues that the project raises. Most striking is the question of whether the thrust of the project and its powerful hold on some of the best minds in the scientific community will impose too reductionist a perspective on the workings of human anatomy. Thus, several essays focus, at least in part, on what Evelyn Shuster terms a fundamental "'paradigm shift' in genetics and an aggressive, simplifying, reductionist perception of genetic knowl-

edge and of humans." Shuster argues that "no model can enable us to predict how the genes will respond to challenges, interact with the milieu, and restructure themselves to ensure their survival."

Beyond concerns about the intentional or unwitting imposition of a reductionist perspective on modern medicine, compelling issues arise from the overall implications of more detailed genetic knowledge. How valuable is genetic knowledge that leads not to treatment but to increased medical and social uncertainty? Will a focus on genetic diagnosis cause a reevaluation of what we define as disease? Will a predisposition unaccompanied by symptoms become perceived as a type of sickness itself, thereby attempting to justify, one suspects, further expenditures of limited health care resources?

It is here that *Gene Mapping* would have been more rewarding if it had taken a more expansive view of the potential implications of the project. Certainly the notion of societal redefinition of sickness is not new, yet a change toward more broadly defining predisposition as a form of sickness could have very far-reaching effects. For example, might an increase in one's risk to cancer caused by exposure to carcinogens become an actionable tort, even if one does not suffer from the cancer itself, as it would increase the risk of getting cancer? What would this do to society's notions of damages or of culpability?

Societal notions of culpability may also be affected by the project's impact on the definition of what is "normal." As Arthur Caplan points out in his essay, abnormality is not in itself bad—in fact, variation is normal. But how will science define the "normal" human genome? This issue is particularly vexing, especially when one considers the role that biological definitions play in imputing fault and responsibility. Frequently, definition of a characteristic as having biological roots (e.g., alcoholism) becomes a rationale for relieving the "victim" of responsibility for his or her actions, at least in part. What attributes currently perceived as reflective of moral or legal culpability will be redefined as biologically derived? And, as several essays note, to what extent might biological causes or predispositions become a rationale for explaining why it is "natural," and therefore acceptable, that certain groups thrive while others do not?

In short, *Gene Mapping* successfully raises numerous provocative issues and questions. While its focus on philosophical concerns such as the reductionist implications of the project and its effect on societal definitions of normality is effective, it would have been even more successful if it had considered in greater depth several of the broader implications of the project. ///

## Gene Mapping

Using Law  
and Ethics  
as Guides

Gene Mapping:  
Using Law and  
Ethics as Guides,  
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