Book reviews

Gene mapping: using law and ethics as guides

Edited by George J Annas and Sherman Elias, New York, OUP, 1992, xxiv+292 pages, £35.00

The subtitle of this excellent collection of essays draws our attention to the fact that in the case of the Human Genome Project money has been allocated through the National Center for Human Genome Research in the United States specifically to a programme examining the ethical, legal and social issues (ELSI). Hence, unusually in scientific research, the ethicists and lawyers have an opportunity to ‘guide’ the research.

This volume takes the reader through all the main ethical aspects of the project: to map the human genome; the question of the moral distinction between somatic and germline gene therapy (here regarded as difficult to uphold); privacy and control of genetic information, including the possible consequences of genetic testing for insurance and employment, and the danger of the reinforcement of racial prejudice.

The strength of the collection lies neither simply in that it has assembled many of the big names in the American bioethics community, nor in the range of ethical issues covered, but in the way the issues are set in historical context and related to underlying philosophical questions. For example, articles by Swazy, Proctor and King examine precedents and the lessons they can teach the policy-makers of the present. As King points out, the American experience of sickle-cell screening is hardly reassuring. She argues that those involved with gene mapping should make efforts to ensure that the beneficial results of the work are not denied to ethnic minorities. In one of the most interesting contributions, Proctor compares ‘genomics’ (a term that covers mapping and sequencing) and eugenics, and suggests that it is over-optimistic to believe that abuses are necessarily a thing of the past, when we survey contemporary developments in different parts of the world.

Proctor further argues that whereas many people are anxious about the social control that may result from the genome project, the illusion of control is what we should fear. The mapping enterprise may lead to the view that people’s problems are thought to be essentially genetic. The theme of biological reductionism and determinism is taken up in a number of essays and is illuminatingly discussed by Shuster, who says, ‘the emergence of life escapes the model intended to explain it’.

In addition to this philosophy of science strand, Caplan points to the necessity for conceptual clarification of the concepts of health, normalcy and disease. What we consider to be a disease, he says, will be important in shaping the way the results of the project are utilised.

The paper by Walters urges the formation of a national advisory committee on genetic testing and screening. He notes that although both gene therapy and genetic screening involve applications of recombinant DNA techniques, the two technologies have been treated quite differently, gene therapy receiving by far the greater share of attention from policy-makers.

He cites Capron, however, as saying that screening is the more probable source of harm with its potential threats to individual interests in insurability, employment and reproductive freedom.

As regards the latter, although the prevailing view is that genetic counselling should be non-directive, there has been recent questioning of traditional ethical principles in the genetic context, and King points out that ‘non-directive counseling may not be an achievable goal for future counseling programmes’. This is because non-directive counselling may depend on counsellor and counsellee sharing value assumptions.

Although this book arises out of the American scene the issues have relevance for those in Europe considering these questions. It is not possible to discuss all the contributions here but the volume will be of considerable value to all who are working in this area.

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Practical medical ethics

Alastair Campbell, Grant Gillett and Gareth Jones, Oxford, Oxford University Press, 1992, 177 pages, £15.00 pb

Three eminent members of the University of Otago have combined to produce a text in medical ethics that is primarily, though they hope not exclusively, for medical students. The material is generally clear and well presented and, in terms of its principal intended audience, covers a good range of problems. Naturally, the expected topics such as abortion, euthanasia, AIDS and mental health are there, but there are also chapters on the foundations of medical ethics, the status of the body and its parts, medical research, needs and justice, and the problems of etiquette, malpractice and compensation. The welcome discussions of treatment
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