BOOK REVIEWS

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In the preface to this report Sir Patrickairn (Chairman Nuffield Council on Bioethics) stressed that:

"Genetic research differs from many areas of medical advances in three distinct ways: first, the astonishing speed of its development; second, the irrefutable effect not only on individuals, but also on their families and societies generally; and third, the fear it arouses that it may be interfering with the basis of life itself."

The rapid development of medical and scientific knowledge generates new and con- 

suming ethical challenges but it is suggested that certain ethical principles will remain un-

changed. Appropriate responses will be re-

quired from the health professions, from 

health administrators, from the insurance 

industry, from employers, and from the 

Government.

The report therefore addresses four im-

portant areas: the difficulty in assessing individual's health risks exposed by genetic screening; the increased complexity of the ethical aspects of confidentiality; the demands made by professional and health resources by the required ethical procedures; the broad framework provided as a safeguard against 

eugenic abuse.

The contents of the report are best sum-

marised by quoting the recommendations which cover six main areas:

(1) Providing information and obtaining consent. The report stresses that genetic screening must be voluntary and informed by the availability of adequate information. It is recognised that there would be difficulty in providing "full" genetic counselling at present for all patients considering entering ex-

panding genetic screening programmes be-

cause of the small number of trained genetic counsellors currently available. The report suggests that this problem is best addressed by training large numbers of practice nurses and health visitors within the wider context of expansion and extension of primary care. Special safeguards are recommended for individuals who are unable to give properly informed consent (minors, the mentally ill, and those with severe learning difficulties).

(2) The results of genetic screening and confidentiality. The spread of genetic screening may cause tensions between the interest of an individual and those of relatives and further discussions are required with health pro-

fessional bodies. The report emphasises that individuals should normally be fully informed of the results of genetic screening, including the implications for other family members, but that the accuracy of the result and the confidentiality of medical information should be followed as far as possible. When an in-

dividual is reluctant to release information about genetic susceptibility to other family members, that the information may be considered to be vital to the interests of relatives, the report recommends that health professionals "... should seek to reassure individuals ... to allow the dis-

closure of information to other family members." In rare circumstances "... the individual's desire for confidentiality may be overridden".

(3) Employment. The report found little concern that current genetic screening pro-

grammes were being misused by employers but recommended that the Department of Employment keeps under review the potential effect of genetic screening and employs and notes the conditions under which genetic screening of employees might be con-

templated.

(4) Insurance. British insurance com-

panies should adhere to their current policies of not requiring any genetic tests as a pre-

requisite of obtaining insurance. This was based upon the current difficulty of assessing evidence of genetic susceptibility to common disorders, the danger that companies would be overcautious in their assessment of risks, and of the possibility of abuse. The Working Party also recommended that there should be early discussions between the Government and the British Insurance Industry and that in the meantime there should be a mora-

torium on requiring the disclosure of genetic data unless it is clear from the routine family history that there is a genetic risk. The mora-

torium should apply only to policies of moderate size.

(5) Public policy. To avoid the possibility of eugenic abuse of genetic screening the Working Party recommended that every effort should be made to improve public under-

standing of the potential limitations of genetic screening and that there are limits to the effects of edu-

cational work and therefore strongly reiterated its recommendations on adequately informed consent, confidentiality, and the central coordination and monitoring of genetic screening programmes.

(6) Implementation of screening pro-

grammes. The Working Party recommended that genetic screening programmes should be regarded largely as pilot programmes gov-

erned by the ethical codes applying to research procedures. However, it was also recom-

mended that the Department of Health in consultation with the appropriate pro-

fessional bodies establish a central co-

ordinating body to review genetic screening programmes and to monitor their im-

plementation and outcome. Detailed criteria for introducing screening programmes are given in the report.

The report is generally an excellent document which is concerned with genetic screening for serious disease and, although acknowledging that there is serious concern about genetic screening for human traits that are in no sense diseases, the issues have been deferred for further "... discussion by professionals with skills other than those represented in our Working Party". The membership of the Working Party, chaired by Dame June Lloyd, is certainly competent to deal with the issues raised by screening for serious genetic disease with representatives from the full range of genetic endeavour from laboratory to clinic and community. They are to be congratulated on a comprehensive, authoritative, and interesting report.

Most important issues are addressed squarely although there is no definitive state-

ment about the propriety of withholding in-

formation on CF carrier status when couple testing. There is a clear introduction to the basic facts of genetics with appropriate stress on the importance of non-directive genetic counselling "where possible". In a report on screening a little more explanation would have been appropriate to the predictive power and accuracy" and of "sens-

itivity and specificity".

RODNEY HARRIS


Had the word encyclopedia been incor-

porated somewhere in the title, this book would have lived up to any resultant ex-

pectations. Thirty three chapters and three appendices contain comprehensive coverage of the molecular genetics of haemostasis and its inherited disorders. The introductory chapter gives a clear, concise account of co-

agulation and fibrinolysis, followed by brief resumés on some general topics in the context of haemostasis, such as evolution, muta-

genesis, and the role of mutation research. Although brief, these sections provide a suit-

able foundation for the more detailed con-

siderations in the ensuing chapters. The thirty two chapters which follow the Introduction expound on the different key proteins of haemostasis: the constituent proteins of both coagulation and fibrinolysis and the proteins which modulate the functions of these haemostatic processes. Generally, one chap-

ter deals with one protein and is, in effect, a mini-review. Indeed, many of the chapters would stand review修订 since the authors have gone to great lengths to leave hardly a stone unturned in discussing their subject, and yet the chapters are not drawn out or rambling, they are succinct and to the point.

Each chapter is similarly structured with a short, informative introduction putting the protein which is about to be discussed into its physiological context. This is followed by sections which can be broadly grouped into two subject areas: protein biochemistry and molecular genetics. The topics covered within these two broad groupings depend upon what is currently known of the protein being dis-

cussed and include such areas as structure, function, physiology, post-translational modi-

fication, mechanism of action, intermolecular interactions, operation of activation, cDNA cloning, genomic cloning, sites of synthesis, restriction fragment length polymorphisms, and mutations (the latter including database.

These topics are general indicators of the coverage of the book; however, there are many extras peppered throughout which give it a deeper interest. For example, the history of haemophilia is overviewed in chapter 2 (factor VIII and haemophilia A) and the pro-