BOOK REVIEWS

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In the preface to this report Sir Patrick Nairne (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 inescapable 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 controversial ethical challenges but it is suggested that certain ethical principles will remain unchanged. Appropriate responses will be required from the health professions, from health administrators, from the insurance industry, from employers, and from the Government.

The report therefore addresses four important 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 genetic abuse.

The contents of the report are best summarised by quoting this section which covers 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 expanding genetic screening programmes because 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 broader 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 tension between the interest of an individual and those of relatives and further discussions are required with health professionals. 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 acceptance of the confidentiality of medical information should be followed as far as possible. When an individual is reluctant to release information about himself, then there is information to be vital to the interests of relatives, the report recommends that health professionals "... should seek to persuade individuals . . . to allow the disclosure of medical 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 programmes were being misused by employers but recommended that the Department of Employment keeps under review the potential of genetic screening and notes the conditions under which genetic screening of employees might be contemplated.

(4) Insurance. British insurance companies should adhere to their current policies of not requiring any genetic tests as a prerequisite 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 that in the meantime there should be a moratorium on requiring the disclosure of genetic data unless it is clear from the routine family history that there is a genetic risk. The moratorium 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 understanding of screening, that there are limits to the effects of educational work and therefore strongly reiterated its recommendations on adequately informed consent, confidentiality, and the central coordinating and monitoring of genetic screening programmes.

(6) Implementation of screening programmes. The Working Party recommended that genetic screening programmes should be regarded largely as pilot programmes governed by the ethical codes applying to research procedures. However, it was also recommended that the Department of Health in consultation with the appropriate professional bodies establishes a central coordinating body to review genetic screening programmes and to monitor their implementation. 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 statement about the propriety of withholding information 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 demonstrate the predictive power and accuracy and of "sensitivity and specificity".

RODNEY HARRIS


Had the word encyclopedia been incorporated somewhere in the title, this book would have lived up to any resultant expectations. 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 coagulation and fibrinolysis, followed by brief resumes on some general topics in the context of haemostasis, such as evolution, mutagenesis, and the role of mutation research. Although brief, these sections provide a suitable foundation for the more detailed considerations 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 these two processes. They provide a comprehensive, up to date account of the molecular genetics of haemostatic processes. Generally, one chapter deals with one protein and is, in effect, a mini-review. Indeed, many of the chapters would stand as reviews for those who have not seen the work 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 discussed and include such areas as structure, function, physiology, post-translational modification, mechanism of action, intermolecular interactions, regulation of activity, cDNA cloning, genomic cloning, sites of synthesis, restriction fragment length polymorphisms, and mutations (the latter including database). The topics are general indicators of the coverage of the book, however, there are many extra peppers dispersed 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-