Does it Run in the Family?

A Consumer's Guide to DNA Testing for Genetic Disorders

by Doris Teichler Zallen
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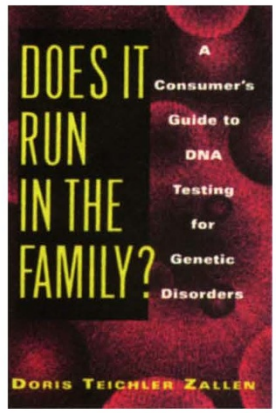
Reviewed by Dian Donnai
Department of Medical Genetics
University of Manchester
Central Manchester Healthcare Trust
St Mary's Hospital M13 0JH
United Kingdom

The public has an appetite for genetic and biotechnology matters — the meal that was made of Dolly confirms that. However, the often sensational way developments are portrayed by the media can lead potential users of genetic services to have unrealistic expectations or fears. *Does it Run in the Family?* by Doris Teichler Zallen aims to provide, for a general audience, information about genetic tests, how decisions are made and what resources are available to assist the decision making process.

There are nine chapters; the first sets the scene and leads onto the next four which focus on individuals and families and deal, in turn, with basic genetic facts, sources of genetic information and issues involved in decisions about testing. The remaining chapters examine the use society makes or could make of testing information, and consideration of the roles of lay organizations, the Internet and other resources, in the dissemination of genetic knowledge. The book ends with a useful glossary, recommendations for future reading and listings of ways to reach services or organizations (mostly North American).

I found the book as a whole to be eminently readable and reasonable. It is more like a novel than a textbook presenting, in an early chapter, details of four families faced with a genetic diagnosis in a relative and then relating facts and issues discussed in later chapters back to these families. Nevertheless, the book still manages to be comprehensive and on almost all occasions when I thought " but she hasn't mentioned this or that possibility", the point in question was woven in later in the chapter.

I tried to think how helpful this book would be to various patients I see in a genetic centre. To begin with, most families at the time of presentation or diagnosis are concerned with the specific problem in their child or family member. What is the condition? What will happen to our child? Why did the problem occur? Will it happen again? What can we do? These are the questions we are asked. The immediate thirst is for relevant information and, whilst this book could help, it may be difficult for someone without prior knowledge to extract the relevant portions. This text is probably more helpful to families some time after diagnosis or to those with a family history of autosomal dominant or X-linked disorders. These people are faced with choices about carrier, predictive and prenatal testing, and I cannot think of a better source than this book where the issues involved are so fairly and well laid out. Zallen has balanced discussion of possible wishes and feelings of consumers with consideration of safeguards (e.g., predictive testing protocols and caution in testing children), which the genetic service must employ. Some of the more technical information would be beyond the easy understanding of some people — an example is the section on linkage analysis — but throughout the author refers to various sources of information, including genetics centers, other professionals, lay organizations and the family.



I also considered whether the book would be useful to professionals involved with families with genetic disorders. I believe it could be very valuable to many groups: I shall certainly recommend it to be read by clinicians, nurses and other coworkers when they first join the genetic service because the partnership between 'consumers' and professionals is so well presented, as well as the impact a genetic disorder can have on all aspects of a person's life. Other professionals such as obstetricians, pediatricians, primary care physicians and associated teams would gain from reading this book too.

There is evidence that local and national healthcare and government policy makers are beginning to address the issues relating to genetics for society and for individuals. The UK Departments of Health have established an Advisory Committee on Genetic Testing with, amongst others, the task of establishing a code of practice and guidance on human genetic testing services supplied directly to the public. Discussions are ongoing in various countries between government, the insurance industry, lay organizations and the genetic community. Zallen, in this book, covers issues for families in relation to healthcare insurance, which is mostly relevant to countries without a nationalized health service, and life and property insurance in general. Real life examples are given including the tale of the woman with Charcot-Marie-Tooth disease who at first was denied healthcare insurance payment on the grounds that dental care was not covered!

My criticisms about the content are few; I felt that not enough attention was paid to consumers, preconceptions about heredity and genetic disorders. All too often, we professionals forget that we are not giving genetic information into a void, rather we are adding to a fund of family beliefs, which may include the view, for example, that if a woman looks like her mother who has hereditary breast cancer she is more likely to get the disease than her sister who "takes after" her father. Such misconceptions can hinder understanding of the real risks. I also felt that, although the book is best read cover to cover and not dipped into like a text book, readers will go back to individual parts and it could have been improved by a table or box at the end of each chapter summarizing the key points.

My main criticism however is directed at the publisher, who I feel has let down an author who has a real talent in communicating complex facts and issues to a general audience. The book is clad in a dull black cover, the illustrations, and particularly those of chromosomes, are drab and technically poor, and the diagrams of inheritance patterns are cramped. I really feel that an opportunity to present an important text in an appealing and accessible way to a wide audience has been missed. I hope, however, that this does not hamper its success and that the next edition, surely necessary as knowledge and technologies change, will address the presentational aspects.