clearly the most useful portion of the appendices. This appendix would have been strengthened by the inclusion of information on how to access the latest information on current gene therapy trials, principal investigators, and guidelines from both journals (listed in appendix A) and web sites (e.g., the NIH site Gene Therapy for Human Patients at http://www.nih.gov/od/orda/cover.htm). In summary, although this book is somewhat uneven, this edition is a valuable starting point for both physicians and patients with an interest in gene therapy, and it provides a useful overview of the state of ongoing gene therapy trials.

KAREN KOZARSKY

Institute for Human Gene Therapy
University of Pennsylvania
Philadelphia

0002-9297/97/6006-0044$2.00

Am. J. Hum. Genet. 60:1567, 1997

Life as We Know It: A Father, a Family, and an Exceptional Child. By Michael Bérubé. New York: Pantheon Books, 1996. Pp. 284. $24.00.

This is an extraordinary book. Bérubé, a professor of English at the University of Illinois at Urbana-Champaign, has written an intimate book about his family, comprised of himself and his wife, Janet Lyon, and their two sons, Nick and James. James has trisomy 21 and Nick does not.

In this beautifully written book, Bérubé explores and interweaves the intensely personal effect, on a family, of a child with Down syndrome; the effect of society on that child and family; and, in turn, the impact of that child on society. With skillful prose, always tempered with laugh-out-loud humor, Bérubé not only argues compellingly for Jamie's place at "our" table, but also demands that we look long and hard at our definition of table and at our definition of us. How do we define who and what is human? How do our societal values sculpt our willingness to engage and to embrace those who are "different," and what are our personal and societal obligations to do so?

Bérubé skillfully juxtaposes anecdotes and vignettes from Jamie's short life, with explorations of philosophy (the Wittgenstein is occasionally tough going, at least for this reader), legislation, science, and history. In the chapter "Genetic Destiny," Bérubé offers one of the clearest explanations of meiotic nondisjunction that I have ever read. He walks us through the excitement of his wife's second pregnancy, their decisions to eschew amniocentesis and prenatal diagnosis, their reactions to the birth of their son with trisomy 21, and their subsequent experiences throughout their son's stormy neonatal course and early childhood. The author's narrative is peopled with physical therapists, occupational therapists, teachers, friends, neighbors, and physicians. He discourses at length with regard to the issues of prenatal diagnosis and pregnancy termination, coming down clearly on the side of freedom of choice while, at the same time, recognizing that he and his wife have made a different choice with which they are comfortable.

I bought the book because I had heard Bérubé speak on National Public Radio and had thought that the book sounded interesting. I put it down once after I began reading, only because I needed to sleep. I have not stopped thinking about it since I first read it four weeks ago, and I expect that I will read it again. It has made me think deeply about my role, as a medical geneticist, in delivering diagnostic and prognostic information to parents. It has made me question my own values regarding quality of life and my own arbitrary assignment of humanity to others.

This is an honest book. I believe that the author has allowed me into the most intimate corners of his life and has bravely articulated his own conflicting ideas, feelings, and responses to his second son. This is a sweet book. It is laced with undeniable love. Bérubé has been most generous in sharing himself and his family with us. Bérubé states, "My task, ethically and aesthetically, is to represent James to you with all the fidelity that mere language can afford, the better to enable you to imagine him—and to imagine what he might think of your ability to imagine him" (p. 264). He has succeeded.

Buy this book and read this book. I think it should be mandatory reading for all of us who pretend to know what we are doing when we provide genetic counseling to families.

VIRGINIA P. SYBERT

Divisions of Medical Genetics and Dermatology
Children's Hospital and Medical Center
University of Washington
Seattle

0002-9297/97/6006-0045$2.00

Am. J. Hum. Genet. 60:1567–1568, 1997

Chromosome Abnormalities and Genetic Counseling. By R. J. McKinlay Gardner and Grant R. Sutherland. Vol. 29 in: *Oxford Monographs on Medical Genetics*. New York: Oxford University Press, 1996. Pp. 478. $59.50.

Genetic counseling in cases of chromosome aberrations can be very difficult and tricky, as is well known not only to insiders. Particularly difficult to handle are prenatal diagnoses, especially when they are based only on cytogenetic results without the support of molecular investigations. It is notoriously difficult to find adequate references and guidelines for the many unique situations that may occur. It is therefore very praiseworthy that its authors undertook the effort to dedicate a book to the issue of genetic counseling in chromosome aberrations. Indeed, *Genetic Counseling in Chromosome Aberrations* might have been a better title.

The first section of the book ("Basic Concepts) offers an introduction to the principles of human cytogenetics. The following sections are entitled "The Parent with a Chromosome Aberration," "The Normal Parent with the Chromosomally Abnormal Child," "Reproductive Failure" (due to chromosomal aberrations), "Prenatal Diagnosis," and, at the end, appendices that mainly include