Ethical Problems and Genetics Practice

Ethical Problems and Genetics Practice provides a rich, case-based account of the ethical issues arising in the genetics clinic and laboratory. By analysing a wide range of evocative and often arresting cases from practice, Michael Parker provides a compelling insight into the complex moral world of the contemporary genetics professional and the challenges they face in the care of patients and their families. This book is essential reading for anyone interested in the ethical issues arising in everyday genetics practice. *Ethical Problems and Genetics Practice* is also a sustained engagement with the relationships between bioethics and social science. In proposing and exemplifying a new approach to bioethics, it makes a significant contribution to debates on methods and interdisciplinarity and will therefore also appeal to all those concerned with theoretical and methodological approaches to bioethics and social science.

MICHAEL PARKER is Professor of Bioethics and Director of the Ethox Centre at the University of Oxford, where his research focuses on the ethical implications of the clinical use of genetics and on the ethical aspects of collaborative global health research.

Cambridge Bioethics and Law

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician-assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

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Ruth Macklin
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Donna Dickenson
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Matti Häyry, Ruth Chadwick, Vilhjálmur Árnason, Gardar Árnason
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Michael Parker
The Ethox Centre, University of Oxford

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Contents

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For the past ten years or so, since our first monthly case discussion, which I describe in Chapter 1, the team at the Oxford Regional Genetics Service at the Churchill Hospital have generously welcomed me as a member of their group. I would like to thank all of the clinical geneticists, genetic counsellors and laboratory staff who have worked at the Churchill over this period including those of you who have since gone on to work elsewhere. Without your warmth, openness, generosity and spirit of critical reflection I would never have written this book. For obvious reasons, I have been very careful not to use any cases presented or discussed in Oxford. Nevertheless, this book owes a lot to the discussions we have had and to all the things I have learnt in my time with you.

Without doubt, the biggest single influence on the content of this book has been the Genethics Club. It is not really necessary or appropriate for me to say anything very much about it here because the book as a whole is itself my attempt to make sense of why and how the Genethics Club works and why it has had such enduring appeal. Nevertheless, one of the main reasons for this has clearly been the enthusiasm and commitment of everyone who has attended and in particular the willingness of those who have presented cases to open up their work to discussion and critical reflection with others in this forum. I would like to take this opportunity to thank everyone who has ever attended the Genethics Club. Never has it been truer for an author to say that his book would not have been possible without you.

The Genethics Club was not my idea alone. Building on the work I was doing at the Oxford Regional Genetics Service with Anneke Lucassen, the idea for the club was initially conceived by Angus Clarke, Tara Clancy, Anneke and myself and further developed by a group of

genetics professionals from around the United Kingdom who we invited to attend a symposium on ethical issues in clinical genetics in Oxford in 2000. In practice, the success of the Genethics Club has been largely due to the enthusiasm and enduring commitment of Angus, Tara and Anneke. Working with them on this continues to be a real pleasure and I'm hoping we've got a few more years in us yet.

Over the years, I have also discussed the topics explored in this book with many academic friends and colleagues outside of the world of genetics. Of particular value to me have been conversations with social scientists including Mary Boulton, Mary Dixon-Woods, Mikey Dunn, Ray Fitzpatrick, Nina Hallowell, Cate Heeney, Annemarie Mol, Bob Simpson, Margaret Sleeboom-Faulkner, Mariam Fraser, Marilyn Strathern and Steve Woolgar. These conversations have been of special importance because one of my aims in this book and in the work leading up to it has been to try to find a way of doing bioethics which takes the methodological and theoretical concerns of both philosophy and the social sciences seriously. To the extent that this has been successful it is due in large measure to the encouragement of and discussion with the people above. The book's failings in this regard are as in all others of course my own.

I have also benefitted hugely from discussion of the ideas in this book with colleagues at the Ethox Centre over a number of years. Ethox is a really stimulating place to work. The collegiate atmosphere and supportive critical research culture at the Centre have been key to the writing of this book and important sources of inspiration for me in my other work. There isn't space to mention everyone in the centre individually by name here but I am truly grateful to everyone in the Ethox team for their support with this book and with the development of the Centre and its work.

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Finally, my partner Mariam Fraser has discussed all of the ideas in this book with me and the whole way I see things is different because of our time together.