ETHICS AND INTERSEX
INTERNATIONAL LIBRARY OF ETHICS, LAW, AND THE NEW MEDICINE

Founding Editors

DAVID C. THOMASMA†
DAVID N. WEISSTUB, Université de Montréal, Canada
THOMASINE KIMBROUGH KUSHNER, University of California, Berkeley, U.S.A.

Editor

DAVID N. WEISSTUB, Université de Montréal, Canada

Editorial Board

TERRY CARNEY, University of Sydney, Australia
MARCUS DÜWELL, Utrecht University, Utrecht, the Netherlands
SØREN HOLM, University of Cardiff, Wales, United Kingdom
GERRIT K. KIMSMA, Vrije Universiteit, Amsterdam, the Netherlands
DAVID NOVAK, University of Toronto, Canada
EDMUND D. PELLEGRINO, Georgetown University, Washington D.C., U.S.A.
DOM RENZO PEGORARO, Fondazione Lanza and University of Padua, Italy
DANIEL P. SULMASY, Saint Vincent Catholic Medical Centers, New York, U.S.A.
LAWRENCE TANCREDI, New York University, New York, U.S.A.

VOLUME 29

The titles published in this series are listed at the end of this volume.
Ethics and Intersex

Edited by

SHARON E. SYTSMA, PH.D.
Northern Illinois University,
DeKalb, U.S.A.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Author</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preface</td>
<td></td>
</tr>
<tr>
<td>Acknowledgements</td>
<td></td>
</tr>
<tr>
<td>Notes on Contributors</td>
<td></td>
</tr>
<tr>
<td>Introduction</td>
<td></td>
</tr>
<tr>
<td>Chapter 1: The Role of Genes and Hormones in Sexual Differentiation</td>
<td>Stephen F. Kemp</td>
</tr>
<tr>
<td>Chapter 2: Towards a More Inclusive Conception of Gender-Diversity for Intersex Advocacy and Ethics</td>
<td>David T. Ozar</td>
</tr>
<tr>
<td>Chapter 3: Intersex and the Rhetorics of Healing</td>
<td>J. David Hester</td>
</tr>
<tr>
<td>Chapter 4: Intersex and Human Rights: The Long View</td>
<td>Alice D. Dreger</td>
</tr>
<tr>
<td>Chapter 5: International Legal Developments Protecting the Autonomy Rights of Sexual Minorities: Who Should Determine the Appropriate Treatment for an Intersex Infant?</td>
<td>Julie A. Greenberg</td>
</tr>
<tr>
<td>Chapter 6: The Right to Be Wrong: Sex and Gender Decisions</td>
<td>Milton Diamond and Hazel Glenn Beh.</td>
</tr>
<tr>
<td>Chapter 7: Advances in Treating (Or Not Treating) Intersexed Persons: Understanding Resistance to Change</td>
<td>Edmund G. Howe</td>
</tr>
<tr>
<td>Chapter 8: Experiments in Gender: Ethics at the Boundaries of Clinical Practice and Research</td>
<td>Timothy F. Murphy</td>
</tr>
<tr>
<td>Chapter 9: Prenatal Gender Imprinting and Medical Decision-Making: Genetic Male Neonates with Severely Inadequate Penises</td>
<td>William G. Reiner</td>
</tr>
<tr>
<td>Chapter 10:</td>
<td>Gender Identity and Intersexuality</td>
</tr>
<tr>
<td>------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>Kenneth J. Zucker</td>
<td>165</td>
</tr>
<tr>
<td>Chapter 11:</td>
<td>Intersex, East and West</td>
</tr>
<tr>
<td>Garry Warne and Vijayalakshmi Bhatia</td>
<td>183</td>
</tr>
<tr>
<td>Chapter 12:</td>
<td>Adult Outcomes of Feminizing Surgery</td>
</tr>
<tr>
<td>Sarah M. Creighton</td>
<td>207</td>
</tr>
<tr>
<td>Chapter 13:</td>
<td>Clinical Management of Children and Adolescents with Intersex Conditions</td>
</tr>
<tr>
<td>Friedemann Pfäfflin and Peggy Cohen-Kettenis</td>
<td>215</td>
</tr>
<tr>
<td>Chapter 14:</td>
<td>Psychology and Clinical Management of Vaginal Hypoplasia</td>
</tr>
<tr>
<td>Lih-Mei Liao</td>
<td>225</td>
</tr>
<tr>
<td>Chapter 15:</td>
<td>The Ethics of Using Dexamethasone to Prevent Virilization of Female Fetuses</td>
</tr>
<tr>
<td>Sharon E. Sytsma</td>
<td>241</td>
</tr>
<tr>
<td>Chapter 16:</td>
<td>Intersexuality, Cultural Influences, and Cultural Relativism</td>
</tr>
<tr>
<td>Sharon E. Sytsma</td>
<td>259</td>
</tr>
<tr>
<td>Chapter 17:</td>
<td>Authenticity and Intersexuality</td>
</tr>
<tr>
<td>Herman E. Stark</td>
<td>271</td>
</tr>
<tr>
<td>Chapter 18:</td>
<td>Christianity and Human Sexual Polymorphism: Are They Compatible?</td>
</tr>
<tr>
<td>Patricia B. Jung</td>
<td>293</td>
</tr>
<tr>
<td>Chapter 19:</td>
<td>Ethics and Futuristic Scientific Developments Concerning Genitoplasty</td>
</tr>
<tr>
<td>Justine Schober</td>
<td>311</td>
</tr>
<tr>
<td>Chapter 20:</td>
<td>Postmodern Intersex</td>
</tr>
<tr>
<td>Iain Morland</td>
<td>319</td>
</tr>
<tr>
<td>Index</td>
<td>333</td>
</tr>
</tbody>
</table>
The chief goal of this book is to improve the quality of life for intersexual people. That goal requires not only the improvement of our medical practices, but also an increasing social awareness and understanding of intersexuality and its implications. To this end, I have sought contributions reflecting many different disciplines and contributors from many different countries. The book includes twenty chapters addressing controversial ethical and medical issues concerning infant genital surgery, neglected ethical issues, and the challenges intersexuality raises for both traditional medical practices and traditional cultural and religious views on human sexuality in general.

The book is meant to have an eclectic audience: intersexuals, their families, intersex advocates, urologists, endocrinologists, gynecologists, psychologists, psychiatrists, sexologists, biomedical ethicists, hospital ethics committee members, medical lawyers, medical ethicists, research ethicists, gender theorists, philosophers, theologians, sociologists, and anyone who wants to further their education on human sexuality. Chapters may be more technical than required by some people, and perhaps not as technical and others would want. I asked my authors to aim for clarity for a general readership without sacrificing the quality, accuracy, and creativity of their projects.

The chapters do not represent a single point of view, but instead include quite opposing views that reflect the contentious issues we face today. Readers should not assume that the chapters reflect the opinion of the editor, except of course, the chapters written by her.
ACKNOWLEDGEMENTS

With pleasure I take this opportunity to thank the many people who helped to make this book possible. Thanks to David Buller who first introduced me to the topic, to Cheryl Chase for sending me materials to begin my education on intersexuality, and to Ian Aaronson, for inviting me to serve as Ethics Consultant to the North American Task Force on Intersexuality. It was here that I was introduced to leading medical experts on intersexuality, who treated me with unexpected graciousness and impressed me with their sincerity and dedication to examining and improving the medical management of intersexuality, and some of whom generously agreed to contribute chapters in this book. Thanks also to Gilman Grave for inviting me to participate in the research-planning workshop on intersexuality sponsored by the National Institute of Child Health and Development, a very exciting and wonderful learning experience indeed. I am especially grateful to Heino Meyer-Bahlburg, from whom I learned so much, both from his published works and from some telephone and email conversations.

I also wish to express my thanks to Northern Illinois University for granting me a sabbatical enabling me to conduct my research and plan for this book, and also for helping to support my attendance at national and international bioethics conferences where I presented papers on intersexuality, which eventually worked their way into chapters in this book. Warm appreciation is especially owed to the participants of the annual David Thomasma International Bioethics Retreats, whose comments following my several presentations on intersexuality in 2001, 2003, and 2005, were a source of insight and inspiration. Deep thanks to Thomasine Kushner who pointed me in the right direction, and to David Weisstub for taking an interest in and realizing the urgency of this project.

Going further back, it is unlikely this book would have appeared without the wonderful education in philosophy I had at Loyola University after having been granted the Crown Humanities Fellowship. There I was able to pursue my already strong interest in biomedical ethics, largely under the direction of David Ozar, who
later became a fellow traveller in my investigations into intersexuality. Also, the audacity to offer my services as an ethics consultant to the task force was empowered by the fabulous experience of being a Teaching Scholar at the 2-year program on Research Ethics organized by Timothy Murphy, and funded by the National Institute of Health at the University of Illinois/Chicago. Thanks also to Tim for his many comments, constructive and destructive, which helped me to improve my chapter on the use of dexamethasone to reduce virilization of female infants at risk of Congenital Adrenal Hyperplasia. Any remaining flaws are my own responsibility.

Thanks to Peter Nichols and Emily Strom, and especially to Molly Gardner, for providing welcome professional assistance with the editing of several chapters, and to Fritz Schmuhl and Natalie Rieborn for their patience and helpfulness in helping me to properly prepare the manuscript for publication.
NOTES ON CONTRIBUTORS

Hazel G. Beh, MSW (1975), Ph.D. American Studies (1985), JD (1991) is a Professor of Law at the William S. Richardson School of Law, University of Hawaii at Manoa. She is the current chair of Education Law Section and past chair of the Contracts Section of the American Association of Law Schools. Her scholarship often considers legal issues related to higher education, insurance, health, sexuality, and medical research.

Vijayalakshmi Bhatia, M.D. is Additional professor of endocrinology at the Sanjay Gandhi Postgraduate Institute of Medical Sciences in Lucknow, India. Her work and publications are on aspects of pediatric endocrinology relevant to a tropical developing country, such as endemic iodine deficiency cretinism, calcium deficiency rickets, vitamin D deficiency in adolescence and pregnancy, diabetes mellitus, and disorders of sexual differentiation. She has co-edited a clinical handbook of pediatric and adolescent endocrinology.

Peggy T. Cohen-Kettenis is a clinical psychologist and psychotherapist. She is professor of medical psychology at the Department of Medical Psychology of the Vrije Universiteit Medical Center (VUmc), Amsterdam, The Netherlands, and director of the Gender Dysphoria Knowledge Center in this hospital. She has published on gender dysphoria, gender development and the relationship between gender-related behavior/psychopathology and sex hormones. In 2003 she published a book “Transgenderism and Intersexuality in Children and Adolescents: Making Choices” with professor Friedemann Pfäfflin.

Sarah M Creighton, M.D., FRCOG, is Consultant Gynecologist at University College Hospital, London, UK and at Great Ormond Street Hospital, London, UK. She works as part of a multidisciplinary intersex team offering gynecological input for children, adolescents and adults. I have a major research interest in the adult outcomes of intersex and related conditions. I have focused
NOTES ON CONTRIBUTORS

particularly on the gynecological and psychosexual consequences of reconstructive genital surgery and have published widely in peer review journals.

Milton Diamond, Ph.D., Professor in the Department of Anatomy, Biochemistry, Physiology, and Reproductive Biology, and Director of the Pacific Center for Sex and Society at the John A. Burns School of Medicine, University of Hawaii. He has published two books, *Sexual Decisions* and *Sexwatching: Looking into the World of Sexual Behavior*, both reprinted in other languages, edited several others, and has published over 150 articles on scientific, medical and ethical issues related to both animal and human sexuality, several of which are on intersexuality. He is the recipient of the Magnus Hirshfeld Medal for Outstanding Contributions to Sex Research and has earned international recognition in his field. He is one of the key figures to have brought problems with our traditional medical treatment of intersexuality to light, as well with the scientific hypotheses about human sexuality underlying it.

Alice Domurat Dreger, Ph.D., is Visiting Associate Professor of Medical Humanities and Bioethics in the Program in Medical Humanities and Bioethics at the Feinberg School of Medicine, Northwestern University, and Director of Medical Education for the Intersex Society of North America. Her books include *Hermaphrodites and the Medical Invention of Sex* (Harvard University Press, 1998), *Intersex in the Age of Ethics* (University Publishing Group, 1999), and *One of Us: Conjoined Twins and the Future of Normal* (Harvard University Press, 2004).

Julie Greenberg, B.A., J.D., Professor of Law, Thomas Jefferson School of Law. Professor Greenberg is an internationally recognized expert on the legal issues relating to gender, sex, sexual identity and sexual orientation. Her path-breaking work on the legal aspects of gender identity has been cited by a number of state and federal courts, as well as courts in other countries, and has been quoted in more than 100 books and articles.

J. David Hester, Ph.D. is co-founder of the Centre for Rhetorics and Hermeneutics, co-Senior Editor of “Queen: a journal of rhetoric and power”. He is a member of the Zentrum für Ethik in den Wissenschaften of the University of Tübingen, and a research fellow of the Alexander von Humboldt Foundation. His doctorate is in rhetorical theory and criticism of the New Testament, from out of which his current research focus has turned upon the questions of the origins of rhetorical strategies of sex, sexuality and sexed identity in the public sphere, including the biblical origins of the heterosexist paradigm and its impact upon culture, law, and medicine.

Edmund Howe, M.D., J.D., is a medical ethicist and Professor in the Department of Psychiatry at the Uniformed Services University of the Health Sciences in
Bethesda, Maryland. He has authored over a hundred articles on biomedical ethics and is Editor-in-Chief of the Journal of Clinical Ethics.

Patricia Beattie Jung, Ph.D., is a Professor of Moral Theology at Loyola University Chicago. Her research focuses on a variety of issues in Christian sexual ethics. Recently she edited with Joseph A. Coray Sexual Diversity and Catholicism: Toward the Development of Moral Theology (The Liturgical Press, 2001) and co-edited with Mary E. Hunt and Radhika Balakrishna, Good Sex: Feminist Wisdom from the World Religions (Rutgers University Press, 2001).

Stephen F. Kemp, M.D., Ph.D. is Professor of Pediatrics and Medical Humanities at the University of Arkansas for Medical Sciences. He has been at the University of Arkansas for Medical Sciences and Arkansas Children’s Hospital since 1984, and was Chief of the Section of Pediatric Endocrinology from 1987-2001. His research interests have been in the field of growth and growth hormone therapy, and he is the author of a number of publications related to this topic. Dr. Kemp is currently President of the Human Growth Foundation.

Lih-Mei Liao, BSc, MSc, PhD is a Consultant Clinical Psychologist & Honorary Senior Lecturer at the Sub-Department of Clinical Health Psychology of the University College in London. She works with women presenting psychological difficulties associated with reproductive and sexuality issues. She has published over 40 papers and chapters in women's health. Her current interests are broadly concerned with female sexuality. She leads a group of clinical psychologists also providing services to obstetrics and gynecology in several hospitals in London.

Iain Morland, MA, Mphil, is a Doctoral Candidate in English Literature at the Royal Holloway, University of London. Author of articles on intersex in publications such as The Psychologist, Continuum, and Studies in Law, Politics and Society, Iain Morland proposes a multidisciplinary approach to intersex that includes the humanities as well as health sciences. His doctoral dissertation examines the ethics of narrative-based intersex treatment. He is also co-editor, with Annabelle Willox, of Queer Theory (Palgrave Macmillan, 2005).

Timothy F. Murphy, Ph.D., is Professor of Philosophy in the Biomedical Sciences at the University of Illinois College of Medicine at Chicago. He is the author or editor of eight books, including Justice and the Human Genome Project (University of California Press), Gay Science: The Ethics of Sexual Orientation Research (Columbia University Press), and Case Studies in Biomedical Research Ethics (MIT Press). He has also written extensively on ethical issues in genetic research, human sexuality, transplantation, and assisted reproductive technologies. With grant support from the Department of Defense, he convened one of the first national conferences dealing with the Human Genome Project. He has also had grant support from the National Institutes of Health and has sponsored two national conferences dealing with the ethics of
research with human beings. He has also been a Visiting Scholar at the Institute for Ethics of the American Medical Association.

David T. Ozar, Ph.D., is Professor and Co-Director of Graduate Studies in Health Care Ethics in the Department of Philosophy at Loyola University Chicago, and Director of Loyola’s Center for Ethics and Social Justice. He has taught at Loyola since 1972 and has been Director of the Center for Ethics and Social Justice since 1994. He has published two books and more than a hundred articles and book chapters on ethical issues in health care, the professions, and other social systems.

Friedemann Pfäfflin, M.D., is Professor of Forensic Psychotherapy and Head of the Forensic Psychotherapy Unit at the University of Ulm, Germany. He is editor of the International Journal of Transgenderism (IJT), President of the International Association for the Treatment of Sexual Offenders (IATSO), past president of the Harry Benjamin International Gender Dysphoria Association (HBIGDA), past president of the International Association for Forensic Psychotherapy (IAFP).

William G. Reiner, M.D. is Director, Psychosexual Development Clinic, Associate Professor, Section of Pediatric Urology, Adjunct Professor, Division of Child and Adolescent Psychiatry, University of Oklahoma Health Sciences Center (Oklahoma, USA). With his training and professional experience in Urology, Psychiatry, and Child and Adolescent Psychiatry, Dr. Reiner conducts research on psychosocial development in children, adolescents, and young adults with major genito-urinary birth anomalies. He has published and spoken internationally on topics of sexual identity and psychosexual development in children with intersex conditions and other disorders of sexual differentiation, children with myelomeningocele, and on children with classical bladder exstrophy.

Justine Schober, M.D., from Erie, Pennsylvania has published dozens of articles on intersexuality in national and international journals since the late 1980’s and has lectured on the topic even more extensively in the United States and throughout the world. She was a member of the North American Task Force on Intersexuality, and is a consultant to the Intersex Society of North America.

Herman Stark, Ph.D. He is currently head of the philosophy program and the international honors society at South Suburban College in South Holland, IL. He has received numerous teaching awards. His philosophical novel, A Fierce Little Tragedy (2003, 2005), has been nominated for the Society for Phenomenological and Existential Philosophy and American Philosophical Association book awards. He has published articles on Heidegger, Philosophy of Mind, Epistemology, Philosophy of Science, and Logic.
Sharon Sytsma, Ph.D, is an Associate Professor of Philosophy at Northern Illinois University. She has served as Chair of the Ethics Subcommittee of the North American Task Force on Intersexuality and an ethics consultant at a workshop sponsored by the National Institute of Child Health and Human Development. She has published articles on ethical issues pertaining to intersexuality in Cambridge Quarterly of Health Care Ethics and Dialogues in Pediatric Urology, and a case study and commentary in the Hastings Center Report. She has also published articles on other biomedical ethical issues, and in ethical theory.

Garry Warne, MBBS, FRACP, is Senior Endocrinologist and Director, RCH International (RCHI) at the Royal Children’s Hospital, Melbourne. His basic and clinical research on aspects of sex differentiation spans 30 years. He has received a Golden Orchid award from the AIS Support Group (UK) and Honorary Life Membership of the AIS Support Group Australia Inc. He has written two widely-used parent and patient information booklets, “Your Child with Congenital Adrenal Hyperplasia” and “Complete Androgen Insensitivity.” He visits Asia frequently for the purposes of teaching, research, and project administration.

Kenneth Zucker, Ph.D., C.Psych., is Professor of Psychology and Psychiatry at the University of Toronto and Head of the Gender Identity Service, Child, Youth, and Family Program Centre for Addiction and Mental Health. His clinical and research interests pertain to psychosexual differentiation and its disorders. He is the current President of the International Academy of Sex Research, and Editor of the Archives of Sexual Behavior.
SHARON E. SYTSMA

INTRODUCTION

The term “intersexuality,” while increasingly more common, is still unfamiliar to most people, and is often misunderstood, so I begin with a simple definition: Intersexuality is the biological condition of being “in between” male and female. There are many different kinds of intersexuality, and many different degrees of each. Sometimes intersexuality can be recognized by a mere visual inspection, such as when it is manifest in ambiguous genitalia. In other cases, genitalia will appear to be typically male or typically female, but will be discordant with the “sex” of the chromosomes, the gonads, or both. Intersex conditions are somewhat rare, though not nearly as rare as one might think. While the percentage of the population affected is difficult to determine, suffice it to say at this point that about 3500 infant genital surgeries take place each year for cosmetic and/or for sex assignment purposes in the United States alone.

To some extent, it is an accident of historical influences that we have been kept in the dark about intersexuality, as Alice Dreger explains in her book *Hermaphrodites and the Medical Invention of Sex* (Harvard University Press, 1998). But it is important to realize that intersexuality is a natural phenomenon occurring in animals as well as in human beings. Some societies have recognized the existence of intersexual individuals and have “made room” for them in their social structure. Others have rejected them, leaving such infants to be exposed to the elements and perish. Yet others have raised them to a status higher than ordinary males and female, or have attributed to them superior qualities or gifts, or have simply thought them to be economically desirable members of a family.

The awareness of human intersexuality has emerged largely as a result of the trauma and harm some intersexuels attribute to its medicalization—that is—to the fact that it has been treated as a kind of pathology in need of medical intervention. The internet has also played a role in bringing intersexuality into the public consciousness, because it has facilitated communication between intersexed people, allowing them to share their experiences (which has been life-saving for some), develop advocacy groups, and gather the confidence, energy, and strength to challenge long-standing, but ultimately unexamined and unsupported medical practices dealing with them. In fairness, these medical practices were grounded in larger unexamined historical and cultural presuppositions. The challenges have raised profound and urgent ethical issues for medicine. Even while motivated by
sincere benevolence, there is no doubt that certain aspects of common practices indeed have been unethical, some more forgivable than others.

Already there has been significant progress in the medical management of intersexuality. Physicians treating intersexed children have been sensitized to the psychological damage that has resulted from the use of intersexed children as teaching tools or as curiosities. There have been huge advances in the area of informed consent. In the past, doctors have often made decisions regarding infant genital surgery for normalizing or sex assignment purposes without informing the parents about the child’s intersexual condition. They were convinced that it would be too traumatic for parents to know the whole truth, and that withholding information was necessary to ensure both parental bonding with the infant and unambiguous gender-rearing. It was unthinkable that children could grow up with ambiguous genitalia and be well adjusted and stable. Even when some information was provided to parents, the parents were often advised not to inform their children of their intersexed condition or medical history, but to raise them unambiguously in the sex assigned at birth. Intersexed children and others have written extensively about the damage that secrecy has done in compounding the already difficult situation. The importance of full disclosure is a lesson apparently in need of repetition. We have previously made the same mistake regarding the disclosure of terminal diseases to adults and children. We tend to exaggerate the harms of disclosure and underestimate its benefits. If physicians have not been convinced of the beneficence of extending complete disclosure to the parents, at least they now know, or ought to know, that informed consent is a legal obligation. Progress has also been made in helping physicians learn to convey information to parents and to intersexed children in ways that will cause the least amount of pain and trauma. Books and videos are available for these purposes.

Further progress has been made in detailing the information needed in order for parental decisions to be based on informed consent. Specifically, it has been stipulated that parents should be informed that traditional surgical practices have not been based on evidence—that follow-up studies have not been conducted to ensure that medical protocols were really working to increase the quality of life of intersexed, or that those practices would be better than simply providing psychological counseling to help parents and children deal with the ignorance and prejudices of people under the influence of the “sexual dimorphic” assumption. Physicians now realize that parents should know that not performing surgery is an alternative in most cases.

Other changes in our practices include the reduction of surgeries performed in certain cases. Female sex assignment surgery is not as often performed in cases of XY infants with micropenis due to growing evidence of prenatal hormonal imprinting and the realization that men with micropenises can have satisfactory sexual relations and even father children. Clitorectomy is rarely performed in the United States, although it still is standard procedure in some European and other countries. It has also been reported that parents and physicians are less likely to opt for clitoral recession or reduction in cases of mild virilization of female infants, due to the growing awareness that in these cases, the enlargement of the clitoris becomes
INTRODUCTION

less noticeable as the child grows, and also because of concerns about damaging sexual responsiveness.

Still, many difficult and urgent ethical issues raised by intersexuality and by traditional practices are still facing us today: Is it morally permissible to conduct infant genital surgery when we don’t know whether allowing children to grow up with ambiguous genitalia is really necessarily damaging, or whether counseling could help them survive the teasing and taunting from their children? Is it morally permissible to perform vaginoplasty when we don’t know whether vaginoplasty is more successful if done shortly after birth or when the child is older and able to express a desire for it? When we don’t know whether people who complain about surgery do so because of the harms from some other aspect of the treatment, such as by the humiliation of being examined regularly in front of many people, or by secrecy? When we don’t know if those who do not complain about effects of their surgery are really satisfied or whether they could have been happier having been raised with ambiguous genitalia with the assistance of psychological counseling? We cannot reliably predict gender identity or sexual orientation. In light of the dearth of long-term studies, what should physicians now recommend? Should they proceed with “business as usual”? Should a moratorium be called? Or should parents have the right to make decisions regarding genital surgery for their children? Is it likely that society can change and be more accepting of intersexuality? Can we judge what will be more important to the intersexed person—genital sensitivity and capacity for pleasure or reproductive capacity?

Clearly, the most urgent issues have to do with whether or not genital surgery should continue to be performed on infants for either sex-assignment or for cosmetic purposes. These issues are addressed by many of the contributors to this book, though not with any unanimous consensus about what is best. These surgical and ethical issues have dominated our attention because intersexuality has been regarded as primarily a surgical issue. Intersexuality has been the province of urology, with input from endocrinology, but those focuses need to be informed by other disciplines as well—both medical and non-medical. Only fairly recently has the idea that psychology and psychiatry could have an important role in the clinical management of intersexuality been gaining recognition, yet we are far from the point where psychologists are routinely incorporated into the clinical management team.

Sexuality is a pervasive and important dimension of existence, and intersexuality raises questions that go beyond the surgical, medical, and psychological domains. For this reason, in addition to urologists, endocrinologist, psychiatrists, and psychologists, I have invited members of many other professions to contribute chapters to this book in the hopes of increasing the depth and breadth of our understanding of intersexuality in order to better inform the discussion of our surgical practices. These professions include gynecology, theology, law, history of medicine, medical ethics, and philosophy. I have also sought contributions from experts on intersexuality from many different countries, including Canada, Germany, The Netherlands, England, Australia and India. Indeed, the chief mark of the uniqueness of this book is its attempt to provide a multi-disciplinary and multi-cultural approach to intersexuality. This global approach is extremely important. International collaboration provides a larger pool of cases, helping to broaden our
knowledge of techniques and practices as well. An international focus also would help in developing retrospective and prospective studies needed to fill in for the dearth of evidence supporting surgical practices. Also, noting cultural differences in approach and attitudes will encourage reflection on our own and speed the development of our knowledge and understanding.

Intersexuality isn’t just about individuals and conditions that have nothing to do with those who are not intersexed. Rather, becoming educated about intersex is to become educated about important dimensions of what it means to be a human being. Thus, learning about intersexuality leads not only to the understanding of others, but to self-understanding. The fact of intersexuality has implications that have the effect of shaking up our worlds, and demanding a reorientation to our understanding of ourselves as sexual beings. Intersexuality has important implications that impose the need to rethink strongly ingrained beliefs. To borrow from Rawls, the fact of intersexuality upsets the harmony between our set of beliefs, provoking the need to reestablish a “reflective equilibrium” between them. Some will experience this as a daunting task demanding the sacrifice of tenacious beliefs central to their own identity. For others, the experience can be liberating and even life saving.

Let us take as our starting point that intersexuality is natural. If intersexuality is natural, then the assumption that all human beings are either wholly male or female, the theory of sexual dimorphism, is false, or at least it is not the whole truth. Because there are so many causes of intersexuality, and because all these causes admit of degrees, the idea of a continuum between male and female emerges as a substitute for the “either/or” model of human sexuality. Given the range we find of femininity in females and masculinity in males, this idea of a continuum between sexes appears to be plausible.

Another implication of the facts and etiologies of intersexuality is that neither chromosomes, nor gene sequences, nor gonads, nor hormones, nor rearing, nor genital appearance alone determine sexuality. Talk about being able to determine the “true sex” of a person by attending to just one of these physical elements is not only arbitrary, but greatly misleading, and even harmful. The truth is: some people are intersexed.

These revelations regarding the complexity of sexuality parallel those regarding sexual orientation. Some people are attracted exclusively to the opposite sex and some exclusively to their same sex, and some to both, in varying degrees. While there is higher incidence of homosexual orientation among intersexed people, sexual orientation cannot be predicted with any kind of certainty either for them or for non-intersexed individuals. Sexual orientation also has been known to shift throughout the course of a lifetime, sometimes as a result of traumatic experiences, and sometimes for no apparent reason at all.

Yet another continuum characterizes gender identity. While most of us, intersexed or not, think of ourselves as having either a masculine or feminine gender identity, some of us feel in between these largely socially-constructed gender categories, or capable of identifying with either in varying degrees. Further, gender identity is even more complicated, as is evidenced by the fact that in some individuals it changes throughout the course of their lives. Children with gender dysphoria (a loaded term) often grow out of it. Tomboys become debutantes.
Most intersexed persons receiving sex assignment surgery at birth do not report feelings of gender dysphoria and do not seek reversals of those surgical procedures. But while most intersexuals “accept” their assigned gender in the sense that they don’t seek surgical sex reassignment, we ought not to conclude that they come really to “identify” as members of their assigned sex, or even if they do, that surgical sex assignment is the best response to ambiguous genitalia. It may be that rejecting one’s sex assignment received at birth and choosing to live as a member of the opposite gender is associated with too many emotional, social, financial, or physical costs. Or it may be that gender identity is just very flexible, or at least very flexible in some people, just as sexual orientation is more flexible in bisexuals than in people who are strictly heterosexuals. Studies indicating the higher incidence of male sex assignment of intersexed infants in cultures that confer more rights and freedom to males than to females support this hypothesis.

The implications of intersexuality are far-reaching indeed. This is why education about intersexuality is so important today. It is likely that intersexuality can shed light on the variations in the continua of sexual orientation, and gender identity, and gender expression.

For instance, these complexities are relevant to the distinction espoused by some feminist philosophers between the “masculine” and the “feminine” voices in ethics. The attitude towards this distinction is far from univocal—some feminists urging the superiority of the feminine over the masculine voice (care ethics vs. rights approaches to ethics), some urging women to celebrate and hold on to the feminine voice rather than relinquishing it and adopting the masculine voice, and some who urge that both voices can be informed and enlightened through the other, so that each are natural starting points, but can be open to the balancing influence and insights of the other. Intersexuality implies that there are voices other than the merely masculine or the merely feminine, and that intersexuals may have uniquely gifted moral voices because of their interim position. If some men seem to be from Mars, and some women seem to be from Venus, some men and women must come from somewhere in between—in fact from any number of places in between. This observation calls to mind Coleridge’s claim that all great minds are androgynous. Virginia Woolf also shared this insight. For the creative mind, she claimed: “It is fatal to be a man or woman pure and simple: one must be a woman manly, or a man womanly.”

Intersexuality also has implications for our understanding of homosexuality. While we don’t understand all the factors that contribute to the development of homosexuality, it is no surprise that a person with XX chromosomes, but who is born with perfectly normal male genitalia and is raised as a male, would be attracted to women. Note how cumbersome the term “homosexual” is when applied to such people. Furthermore, sometimes a person is born with male chromosomes, but because of the inadequate size of the penis, or because of congenital malformations of the genital area, is surgically assigned to the female sex, but nevertheless develops an orientation to females. This shows that not only are some homosexuals born that way, but some are made that way as a result of human intervention. Surely this should cause those condemning homosexuality to pause and reconsider. In light of these reflections, no longer does the French phrase “Viva la difference!” retain
its light-hearted charming quality. A modification, however, is easily substituted: “Mais, vivent toutes les différences!”

Rethinking the naturalness and the morality of homosexuality necessitates the rethinking of religious views and biblical interpretation, and the adoption of a more humble stance with regard to them. Yet openness to this rethinking might very well lead to social changes more in keeping with the most profound aspects of religious outlooks. The ideas of radical bifurcations between males and females, the masculine and the feminine, between homosexuals and heterosexuals fall away as the implications of intersexuality are appreciated. Would that the barriers, social prejudices, and condemnation that have arisen out of these bifurcations fall away as easily!

The twenty chapters included in the volume are independent of each other and can be read in any order according to the readers’ preferences and needs. There is, however, an underlying logical flow. The first three chapters provide background information on intersexuality. Rather than offering a mere overview, however, they give fresh perspectives on the issues and should be of interest even to those who are well-read on extant literature on intersexuality. Stephen Kemp provides the biological background by identifying and explaining the genetic and hormonal causes of the major forms of intersexuality. He includes summaries of the newest scientific discoveries and theories concerning both sexual differentiation and gender identity. Next, David Ozar develops a conceptual scheme that not only aims to uncover presuppositions in and expand the general public’s notions of gender differences, but also to do the same for the intersex advocacy movement. That is, he provides a language that contains enough distinctions to capture not only the experience of intersexuals, but also that of transgendered and bigendered individuals. David Hester compares narrative reports from intersexuals with different conditions, and also the narrative responses of those who have had surgery as infants and those who didn’t have it. His essay highlights the current controversy between our traditional practices, which have not been subjected to retrospective studies, and those that intersexuals would consider dramatic improvements over them. These narratives have the effect of allowing non-intersexed people insight into the effects of medical practices and social attitudes concerning intersexuality by giving them the “inside view.” They are important in that they sensitize non-intersexed people to the plight of intersexuals. Too long have the voices of intersexed people remained unheard.

The three following chapters focus on rights and the law relative to the issue of intersex. Alice Dreger, veteran intersex advocate, calls for immediate reform in our medical practices. She reflects on the reasons why intersex reform has taken so long, and argues that it is because the problems that led to ethical lapses in the treatment of intersexuals are actually endemic to the medical profession generally. She claims that a distinctive feature of the intersex advocacy movement only recently explicitly articulated is that infant genital surgery is a human rights issue. She goes so far as to claim that such surgery is a violation of human rights analogous to those perpetrated in the infamous Tuskegee Syphilis Study.

Julie Greenberg then reviews recent legal developments around the world to address the issue of whether there ought to be a moratorium on infant genital
NOT BELIEVING That an absolute moratorium would be in the best interest of intersex children, she proposes a protocol that would likely have the effect of greatly reducing the number of such surgeries performed. The protocol respects parental autonomy, but requires that a committee of experts on intersexuality, ideally including adult intersexuals, oversee the process of obtaining their informed consent. Milton Diamond and Hazel Beh appeal to John Stuart Mill’s Principle of Liberty to defend the right of individuals to make their own decisions about sex and gender, whether in cases of intersex or of transgender. They argue that infant genital surgery would involve a violation of the right to autonomy, and should be deferred until the intersexed person can make judgments about their own gender identity and participate in the decisions about which medical procedures they desire.

Next, Edmund Howe explains some of the psychological and practical causes of the resistance to change among medical professionals. After identifying questions relevant to the issue about whether infant genital surgery ought to be our response to the birth of an intersexed child, and also identifying the reasons (usually, the lack of empirical knowledge) why these questions are difficult to answer, Howe advances a Rawlsian argument for delaying surgery until the child can participate in the decision. His argument proceeds on the basis of the “maximin principle” that we ought to choose from alternative policies the one that has the least worst consequences for those who are least well off. Timothy Murphy then examines the question of whether developments in research ethics standards since the 1960’s might have prevented some of the ethical lapses of John Money’s handling of the David Reimer case (perhaps better known as the John/Joan case), in which a twin boy whose penis was accidentally destroyed in an accident during circumcision was surgically assigned and raised as a female. Drawing on the distinction between clinical practice and medical research and pointing out the importance of the freedom of physicians to engage in non-validated treatments, he argues that it is likely that even given contemporary mechanisms such as Institutional Review Boards, it is very likely that experiments in gender sex assignment like that of John Money’s John/Joan case could still occur. However, the existence of responsible Institutional Review Boards might have prevented other ethical failings, such as the continuation of such surgeries without informed consent or without follow-up studies on the long-term sequelae of such surgeries.

A series of chapters on scientific studies follow that make clear how deficient our current knowledge is and how far we have to go in our ability to enable sound judgments regarding infant genital surgery. William Reiner presents data from studies of genetic males who because of developmental defects or aberrations were raised as females according to the theory that men without adequate penises would be better off as female. Based on his own studies and the studies of others, Reiner subscribes to the theory of prenatal hormonal imprinting. He concludes with implications for the Standard of Care for certain conditions, and with some ethical prescriptions based on lessons learned from our past errors. Kenneth Zucker, on the other hand, argues that the evidence for prenatal hormonal imprinting is far from conclusive. Not only are there studies that provide conflicting evidence, but even when the sex of rearing does not yield a concordant sexual identity, there are other factors that can explain this discordance, such as the failure of the parents to raise
the child unambiguously as male or female. He proposes that we ought not to abandon the hypothesis that sex of rearing determines gender identity on the data available to us at this point. Garry Warne and Vijayalakshmi Bahia present outcomes of studies conducted in their respective countries, Australia and India, and also in Vietnam, along with interesting descriptions of the cultural influences influencing decision-making for medical treatment. Sarah Creighton discusses the various techniques and their respective problems involved in feminizing surgery, whether clitoral surgery or vaginoplasty. She reviews data regarding outcomes from her own studies and those of other researchers. The news is not good. Clitoral surgery, even when involving techniques less drastic that clitorectomy, compromises adult sexual functions. She reports that vaginoplasty, particularly when performed in early childhood, leads to poor outcomes: it often needs to be repeated later in life, and it is fraught with complications.

Traditionally, psychological care for parents of intersexuals and for intersexuals themselves has been woefully lacking. Of late, there has been more awareness of the need for on-going psychological assistance, both for children receiving genital surgery and for those who don’t. The next two chapters address the important need for psychological counseling, and the many ways it can improve outcomes. Friedemann Pfäfflin and Peggy Cohen-Kettenis detail their recommendations for the many ways psychologists can help parents adjust to their children’s condition, make responsible decisions regarding treatment based on full disclosure, inform their children in age-appropriate ways, and prepare for dealing with relatives, neighbors and day-care centers. They also show how counseling can help children develop self-esteem, a healthy lifestyle, and later, maneuver the rough roads of puberty, sexual awakening, and intimate relationships. Lih-Mei Liao, focuses her attention on the ways psychological counseling can help bring about more positive quality of life outcomes for women undergoing either vaginoplasty or dilation to increase the size of their vagina. Counseling can help with compliance issues, overcoming psychological barriers to intimacy and the unnecessary preoccupation with vaginal sex. She also discusses the ways that psychologists can help physicians design more accurate and thorough outcome studies, develop better communication skills, and advise their patients more effectively.

Sharon Sytsma introduces two ethical issues that have not received much attention due to the spotlight on infant genital surgery. The first of her articles examines the prevalent use of dexamethasone to treat pregnant women at risk for giving birth to children with Congenital Adrenal Hyperplasia in order to avoid virilization of the genitals, a practice that has been shown to be successful. However, the drug has never been tested for this purpose, and there are an increasing number of studies that suggest that prenatal use of DEX may have negative long-term effects. She argues that prenatal DEX use for this purpose should not be considered the standard of care, should not be recommended or prescribed by physicians outside of clinical studies, and that even continued research with it might not be justified. The second issue is addressed through a very troubling, even haunting, case study. How should we handle cases in which parents from other countries come to ours to have their adolescents receive genital surgery for their intersexed conditions, yet because of cultural norms, insist that their children do not play a
deliberative role in choosing surgery, but that the surgery be performed based solely on the parents’ (usually the father’s) decision? Sytsma addresses the question of the limits of our duty to respect other cultures when requests are made that violate our own ethical norms.

The next two chapters include articles from theological and philosophical viewpoints. Patricia Jung examines the presupposition of sexual dimorphism in Christian thought and shows that an examination of biblical texts does not rule out sexual polymorphism. She points out the important implications of intersexuality not only for Christian ethics, but also for Christian teaching on marriage and parenting, and even for how we think about God. She urges that reasonable biblical interpretation should cohere with sound science and that therefore Christians should come to see intersexuality as “made in the image and likeness of God.” Herman Stark illustrates how Heidegger’s notion of authenticity provides a way of thinking about existential aspects of the lives of intersexed persons. Like David Hester, he draws from autobiographical experiences of intersexed persons, and points to both what is universal and what is particular in their experience. He shows how the notion of authenticity can help to illuminate various aspects of the plight of intersexed persons who have been sex-assigned at birth or in early childhood—the plight that arises in large part because of the artificial enforcement of a sexually dimorphic paradigm on them. He also argues that intersexuality raises interesting questions about the limits of Heidegger’s own construal of authenticity.

In the penultimate chapter, Justine Schober describes new possibilities for the treatment of intersex deriving from stem cell research and tissue engineering. Using autologous totipotent stem cells in vaginoplasty and phallicplasty could avoid problems of rejection, desensitization, and other complications of current treatment modes. Furthermore, these developments may make it easier to delay certain aspects of genitoplasty until the intersexed person can participate in the decisions about the surgery. Further promising research likely to improve genitoplasty concerns the role certain hormones can play in the healing process, suggesting timing considerations for surgery, or the modification of naturally occurring hormonal factors. Finally, Iain Morland undertakes an examination of whether, as Alice Dreger had argued in her epilogue in Hermafrodites and the Medical Invention of Sex, postmodern approaches ensure the optimal treatment of intersexuality. His claim is that all the features of postmodernism identified by Dreger do not unequivocally support the ethical views shared by intersex advocates, but rather, that they provide only ambiguous guidelines, which could actually work against those views. The issue is an abstract philosophical one that essentially advocates an appeal to the Doctrine of Socratic Ignorance: it is better to know that you don’t know, than to think you know and be mistaken. Thus, Morland urges taking up a posture of epistemic humility in order to allow the truth regarding the best medical practices to emerge most effectively. As a philosopher, I find this recommendation to be a most suitable note on which to conclude this volume.

Sharon Sytsma, Associate Professor, Department of Philosophy, Northern Illinois University, DeKalb, Illinois, U.S.A.