Commentary on Spriggs: genetically selected baby free of inherited predisposition to early onset Alzheimer’s disease

I note with interest the controversy regarding a baby born free of an inherited predisposition to early onset Alzheimer’s disease through the use of preimplantation genetic diagnosis (PGD).

As the medical geneticist for the PGD programme for single gene disorders in Melbourne, Australia, I have seen many couples who have considered PGD for a wide range of genetic conditions. My observation is that many couples look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination of pregnancy.

An example of this is that in the last 11 years our unit has undertaken 13 prenatal diagnoses for Huntington’s disease from nine couples, whereas in the two years that we have been involved in PGD we have had six requests for PGD for Huntington’s disease and three couples have already had IVF cycles.

I have a number of concerns with the argument that the woman should not have a child utilising PGD because she is predisposed to Alzheimer’s disease. Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If so, in what case, what lengths should be gone to to prevent the woman becoming pregnant by natural means? If the commentators who make this argument agree that it is not appropriate to prevent couples where one is at risk of a genetic disorder from having children by natural means, then assisting them to have children not predisposed to a genetic disorder is in my view entirely ethically acceptable.

The concerns for the child of having a mother suffer from early onset Alzheimer’s disease are that they will not have a mother to bring them up and the impact this will have. While members of the woman’s family have developed disease in their 30s and 40s, this is by no means certain for the woman herself.

The only other report of people with this mutation also had early onset Alzheimer’s disease, but the numbers affected are very few, perhaps too few from which to draw a definitive conclusion about the exact age of onset for those with this mutation. For example the average of onset of the Val717Ile mutation is 57 years. This is a mutation involving the same amino acid (valine at position 717) and the substitution is for a chemically very similar amino acid (isoleucine compared to leucine). If the destiny of this particular woman is to develop Alzheimer’s disease in her mid 40s or beyond then her child will be an adult by the time she is severely affected. Even if we assume that onset of symptoms will be when the child is about 10 years old, the family are aware of this risk and can take steps to be prepared and put in place plans for this. Are couples with other sociological risk factors that put a child at risk of emotional deprivation prevented from utilising reproductive technology? In Australia at least, those who are from low income brackets or who use illicit drugs are not precluded from assisted reproductive technology, yet both these factors are associated with a number of poorer outcome measures for children.

Finally, PGD is a major undertaking for families. It is a protracted, expensive, and very stressful process and ultimately there is no guarantee that a child will be born through using it. Many couples who consider utilising PGD do not go through with the process for these reasons and choose other reproductive options, including traditional prenatal diagnosis, and natural pregnancy with no intervention, or they decide against having children. Therefore families who undertake this process are generally highly motivated and, one intuitively feels that the resultant child is less likely to suffer social deprivation. This issue will only be resolved by long term follow up studies.

In conclusion, I believe that PGD is ideally suited to situations where families wish to avoid their child developing a genetic disease, but where they feel uncomfortable about terminating pregnancies. This includes late onset conditions such as neurodegenerative diseases and familial cancer syndromes, as well as early onset diseases that are considered relatively mild, such as deafness.

M B Delatycki

Preimplantation Genetic Diagnosis Team, Genetic Health Services Victoria, Royal Children’s Hospital, Flemington Road, Parkville, Victoria 3052, Australia; delatym@cryptic.rch.unimelb.edu.au

References


Electronic submissions to the Journal of Medical Ethics

At the time of writing there appear to have been no electronic submissions to the Journal of Medical Ethics. It seems appropriate, therefore, to begin electronic correspondence with a consideration of some of the ethical implications of this new form of ethical dialogue.

I have posted this response to Kenneth Boyd’s editorial on Mrs Pretty and Ms B as this article may provoke debate far beyond the medical and ethical establishment. This issue may be of tremendous concern to patients or their carers who are presently suffering in circumstances similar to those described.

The electronic response forum of the BMJ has been in operation for over four years. An editorial in the BMJ on physician assisted suicide has attracted 125 responses at the time of writing. An important feature of electronic debate is that submissions clearly generate a lot of debate, is that the contributions often refer to each other. These responses range from the scholarly and meticulously argued to distressing and distressing. As both an avid reader of rapid responses to the BMJ, and a physician, I consider both sorts of contributions to be valuable, but increasingly feel uncertain about what my written response to them will be. When I wish to enter into dialogue with the author, I feel on secure ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms at drawing up a response to point out its weaknesses. Equally, as a family doctor, I hope that I am able to approach distressing accounts of suffering with a degree of empathy. It is sometimes the case, however, that submissions clearly showing distress also contain dubious argument that any peer review process would deal with severely. Where accounts of suffering alongside dubious arguments are posted from patients I personally feel qualms about responding, finding myself caught between the roles of vituperative reviewer and empathic listener. As an editorial in the BMJ on the subject of electronic responses has noted: “We’ve begun to capture the opinions and experience of patients... and publish just about anything that isn’t libellous or doesn’t breach patient confidentiality”. Inevitably, such a broad range of responses will produce many that deserve to be challenged. Merely to ignore dubious argument implies that such opinions are correct. Furthermore, it is astonishingly easy to post an electronic response, and the process contains no warning that opinions expressed may be severely challenged. We should consider what the rules of debate on this Journal of Medical Ethics web site should be.

To prevent any misunderstanding, I wish to state that this response does not issue out of intense personal suffering, and that I am prepared for the most stringent peer review of its contents. Say anything in response, but please don’t ignore me.

References

**Editor’s response**

Dr Lewis raises the important issue of what the rules of debate should be in electronic correspondence. As an editor, I feel as if I am caught in the maelstrom of evolution. The web has radically changed the nature of debate and the presentation of information and knowledge. It is not clear to me how and whether it should be controlled. My general approach has been to let the experiment run in a free way and look at the results. Then it will be clearer what rules are required.

Electronic correspondence, for me, is different from scholarly debate. It takes advantage of the web’s accessibility to give people the opportunity to express their own views and to see the range of views on a particular issue. At present, the JME operates on the principle that it will publish electronically any response which is not libellous or harmful in other ways. Electronic letters which contribute significantly to the debate (such as Dr Lewis’s letter) may be selected for publication in the paper version of the journal.

The core business of a journal such as the JME should be the publication of scholarly articles which contribute to knowledge. But as a medical ethics journal, it should also be engaging and relevant to professionals and non-professionals. We have introduced a current controversy section which reports an issue of contemporary interest and we solicit off-the-cuff comment from people who may have relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is then rounded off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal concepts.

The book is extraordinarily innovative in many respects. Not only is the case history and analysis format interesting and methodologically robust, but the case material is so challenging and the ethical analyses so wide ranging and diverse that it is difficult to put this book down! One discovers how different analytical strategies lead to progressively deeper levels of understanding of the ethical issues, thus exposing “the limits of the matter”; along the way one is referred to books, chapters, and articles for further reading. As might be expected, Fulford’s notion that an explicit analysis of values is helpful in defining diagnostic concepts, and in medicine is a recurring theme. Dickenson’s interest in informed consent (also in children), “moral luck”, and her feminist reconstruction of the rules of debate should be in electronic correspondence.

In Two Minds: A Casebook of Psychiatric Ethics

D Dickenson, Bill (KWM) Fulford. Oxford Centre for Applied Ethics, University of Oxford, Suite 7, Littlegate House, St Ebbes Street, Oxford OX1 1PT

Although the title describes this as a “casebook”, it is far more than that. The casebook format entices the reader into a series of readily accessible discussions of increasing complexity and erudition until a vast landscape of medical ethics is evoked and in many instances the very bedrock of moral diversity exposed. The authors seem effortless to introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The central piece of the book is undoubtedly a series of well-chosen cases (thematical progressing from diagnosis to management and prognosis), each followed by an extensive analysis of the ethical issues, including contrasting arguments from different vantage points. There then follows a commentary by a practitioner with relevant experience—in some cases this reflects a practical, no-nonsense approach, while other commentators develop points or themes made by the authors. Each section is then rounded off with an extensively annotated bibliography. Considerable space is also devoted to legal issues: an appendix provides a four page glossary of key legal concepts.

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**Ethical Issues in Palliative Care—Reflections and Considerations**


This book is a collection of essays by a variety of specialists with a particular interest in palliative care. It contains seven chapters by six different authors.

The first chapter Why is the study of ethics important? is by Patricia Webb, a lecturer in medical ethics at the University of Oxford. She tells us that studying ethics encourages logical reasoning thinking in the face of difficult decisions such as allocation of resources, access to services, best care, clinical research, and rights to life. Webb reminds us that clinical guidelines may not be much help in the face of an ethical dilemma with no clear right or wrong answer.

The chapter called Care versus cure by David Lipsen, a palliative care physician, explores the difference between care with and without intention to cure. He emphasises that by sharing the reality of uncertainty (with patient, family, and colleagues) we can make more realistic decisions, and that information is a mechanism for sharing the power of doctors and patients.

Giving it straight—the limits of honesty and deception by Heather Draper, a lecturer in biomedical ethics, explores the difference between honest and dishonest selective truth-telling. Spencer Webb reminds us of the importance of patients’ right to, by Calliope Farsides, a senior lecturer in medical ethics, reminds us of the importance of patients’ right to know.

The next chapter, How informed can consent be?, by Calliope Farsides, a senior lecturer in medical ethics, explores the difference between honest and dishonest selective truth-telling. Spencer Webb reminds us of the importance of patients’ right to know.

The chapter on Advocacy by Patricia Webb defines advocacy as “the role of one with expertise who is invited to negotiate on behalf of another”, and is an interesting analysis of the power differences between patients and professionals. She makes the point that “patients have little power to influence the nature of care provision unless a determined effort is made to reduce their actual and perceived vulnerability”. She also emphasises, however, that skilful communication allows the patient to feel involved in decision making. With good team care few patients need an advocate, except those few who prefer to be very passive, or who are unable to make decisions, such as those with severe learning difficulties.

The next chapter, How informed can consent be?, by Calliope Farsides, a senior lecturer in medical ethics, explores the difference between honest and dishonest selective truth-telling. Spencer Webb reminds us of the importance of patients’ right to know.

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tact and express consent and the problems of coercion and "sufficient information". In Euthanasia—slippery slope or mercy killing, Marny Prouse, a sociologist, director of nursing at a hospice, with a BA in law and now a risk and litigation manager, has written and edited a book on the euthanasia debate, and finally urges us to "to research and practise our arguments and beliefs so that we can be comfortable and credible when moral ques-
tions about the end of life are discussed". The final chapter on "Teaching ethics in the practice setting by Rachel Burman, a consultant in palliative medicine, emphasises that medical ethics involves many disciplines, including social sciences, law, theology, and philosophy, as well as medicine. The teaching of medical ethics is ideally done, she says, in multidisciplinary groups with sensitive and detailed discussion of real life ethical dilemmas, with both philosophers and clini-
cians facilitating. In the USA ethical commit-
tees are commonplace in hospitals, where there is often a resident ethicist on the staff to handle ethical cases, develop policies, and education. In the UK ethical committees have been largely restricted to looking at research protocols, but the development of clinical ethical committees to act as a forum and resource for managing difficult clinical dilemmas is accelerating.

Several of these chapters contain helpful clinical case histories, but the next edition of the book should contain a chapter, written by a clinical ethicist, with a collection of clinical cases and scenarios based on those discussed by ethical committees, together with a discussion of some of the key and debated that they raised. This would demonstrate this powerful teaching method and would also provide some relevant practical material for teams and trusts that are try-
ing to set up their own ethical committees.

P Kaye

Life and Death in Healthcare Ethics: A Short Introduction


This is a compact, nicely written book that provides a refreshing alternative to the utilitarian orthodoxy that dominates contem-
porary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medi-
cine and health care. This contribution is a short and useful introduction to such an approach.

The book announces itself as being written with "both the general reader and students and professionals in medicine, nursing, law, philosophy and related areas in mind". Accordingly, it assumes no prior knowledge of ethics. It gives a neat introductory overview of some ethical issues raised by reproduction, death, and dying. The issues considered include euthanasia and withdrawal of treat-
ment, the persistent vegetative state, abortion, cloning, and in vitro fertilisation.

By the early chapters with a real-life case, Watt captures the interest of the reader. The case is introduced and discussed dispassionately. It is then employed as a springboard for a general discussion of princi-
pies often thought dry and difficult. Newcom-
ers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Ar-
thur case is introduced as a context for dis-
cussing putative distinctions between killing and letting die, and intending and foreseeing; approaches to homicide suggested by compet-
ing ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of "person-
hood" are discussed. Watt considers the notion of quality of life as good in itself and raises ques-
tions about the social significance of tube feeding. The Cox case, in chapter 3, elicits a discussion of concepts such as that of a worthless life, the oft-misunderstood princi-
ples of double effect, and questions of au-
tonomy. In this chapter, Watt introduces a concept she calls "lethal bodily invasion". Even if a Nazi doctor did not care whether his victims survived his experimentation on them, the doctor's intention to invade their bodies in a way he knew would do them no good, but only lethal harm, would be enough to identify his course of action as grossly immoral. This is plausible enough in the con-
text Watt suggests. In order to test her princi-
ple as outlined, however, Watt needs to exam-
ine other situations where the principle of double effect is involved. The principle of double effect is often raised in the context of self defence, defence of a third party, and war. Clearly, the book is an analysis of war. A broad discus-
sion of defensive action is well beyond its scope; however, it is profitable to analyse like cases where the principle of double effect is often summoned as a justification for deaths that are not intended. It is quite another to say that it is entirely impermissible to perform life-saving treat-
ment on one twin (even where the parents want it), in the same way as it is impermissible for the Nazi doctor to use a patient as fodder. Watt considers medical ethics as the "four principles" (chs 1 and 2). I have rarely read such a seamless introduction to the underlying principles of medical ethics and medical law. Watt would do well to read this.Later chap-
ters in this section deal with diverse cultures (ch 3) and the human body (ch 4). Of particu-
lar note here is the excellent treatment given to inform-
ance, consent, confidentiality, and truthfulness. There is much to be gained here by the book's intended audience. The chapter on the human body seems unusual in a book of this type, but is a well argued discussion of how the human body, both alive and dead, should be treated. This chapter also covers the ethics of postmortem examinations and biopsies both of which are in the public mind at present; this discussion is clear and full of "common sense". Watt's ethical discussion of retained organs and biopsies. The discussion of the ethical problems of mixed cultures is an unexpected inclusion and there is reliance on more contemporary philosophy rather than the traditional arguments. The New Zealand back-
ground of the original edition shows through most obviously in this chapter but this does not detract from the arguments put forward.

The "meat" of the book, however, is in the secon-
d chapter (142 pages out of a total of 297). The "standard" topics of genetics, prenatal problems, birth, organ transplantation, AIDS, euthanasia, and brain death are all dealt with well and clearly, especially transplantation. The general format of the chapters is to briefly dis-
cuss the medical problems and then to intro-
duce the ethical dimension. This ensures that a reader not familiar with a certain topic is reminded of the problems before entering into the ethical discussion. The chapters on genetics and ending human lives are particularly good in this respect. Two topics not commonly found in introductory texts are covered: the section, namely, psychiatry and the problems with aging and dementia. Both are discussed sensitively and with compassion and are welcome inclusions in a text of this type.

The final section covering research ethics, jus-
tice, law and "trying new things". This rather broad area is dealt with excellently and the readeroddly named chapter on "Trying new and unusual things" is highly recommended reading for anyone wishing to introduce new treatments (medical or surgical).

Overall, the book is well organised and, while it is an introductory text, there are ample references to sustain the authors' argu-
ments and for further reading. Case studies

www.jmedethics.com
are used extensively throughout the text to illustrate the discussions. In my opinion, the authors have succeeded in producing a text that is a practical introduction to medical ethics. I would warmly recommend this book to all medical and nursing students and a copy should be in all medical libraries.

**Russell Encyclopedia of Ethical, Legal and Policy Issues in Biotechnology**


This encyclopaedia is an important and comprehensive resource that is likely to be of value to a wide range of academic users for many years to come. It is particularly useful as a starting point for background research by bioethicists writing about topics in genetics and biotechnology. The collection takes a broad view of the topics, ranging from core topics such as genetic enhancement and the ethics of genetics research, to a series of sections that take the form of national reports on the political, ethical, and regulatory contexts covering genetically modified organisms. One potential problem for any reference work of this kind is getting out of date, given the changing nature of biotechnological research. The articles in the encyclopaedia that we read were well written and accessible, and in the main looked likely to be relevant for a while to come.

The first thing that strikes you about the two volumes of this encyclopaedia is that they are very well made, attractive, solidly bound books. The sections are reinforced by first use of the encyclopaedia. A great deal of care has gone into making this reference work accessible and a pleasure to use. Two very minor additions that would have increased this ease of use would have been to add page numbers to the list of headings and a contents page to the second volume. Nevertheless as a whole the collection was extremely easy to navigate.

The editors have reviewed all start with a summary of the points to be discussed and then proceed to a general overview of the technology or history of the topic. For those topcis on very contentious issue there is a discussion of the major arguments for and against. The headings generally have good references to other sources that will be useful for those wanting to know more. These are very large volumes so we have based this review on a selection of its headings. Some of them are very good indeed. Dan Brock's heading, “Cloning, ethics” is also a fascinating essay. The discussion of research into the XXY karyotype and the MAO mutation provide an excellent background to the section. Again, this section would have been a valuable addition for people wanting to do further work on his topic.

Overall, the editors have assembled an impressive cast, with many of the American names that you would expect to be involved in such a project. This does bring us to our first minor grumble: there are about a hundred contributors to this volume but only three are from the United Kingdom. This absence cannot be due to a lack of UK expertise and it is slightly disappointing that there is no contribution from writers based in the UK such as Ruth Chadwick, John Harris, or Soren Holm. This does raise the question of how attractive this volume is likely to be to the readers who are not in North America. In addition to the majority of authors, being from the USA much of the public policy and legal discussion in the volumes is US centred. It is hard to see how this could have been avoided, given the authors, however, it does mean that the researcher using this text will need to be careful to ensure that the chapters quoted have supplementary texts covering the rest of the world.

Given that these two volumes cost £370 it's unlikely that any but the most enthusiastic and wealthy individual will be able to buy the encyclopaedia. This is primarily a collection for libraries.

**The Use of Human Biobanks. Ethical, Social, Economical, and Legal Aspects**


This booklet (freely accessible online at http://www.biobioths.uu.se/biobanks-report.html) documents a conference organised by a Swedish research project on the various social and ethical issues raised by the use of so-called biobanks—that is, large collections of human tissue samples. There is considerable interest among researchers, the biotech industry, and society at large in using biobanks for the continued investigation of genetic health factors that is now following the completed mapping of the human genome. Central issues are: the responsibility of biobanks or users of these to protect tissue donors in various ways; how these responsibilities should be balanced against business and research interests, as well as against the interests of people and society in general in case of conflict and, not least, what procedures of informed consent (including the hard question of the scope of the consent) should be deemed as appropriate in the biobank setting. Although formulating these issues against the background of the actual scientific, legal, and business situation in this area, the booklet provides few answers, but outlines various studies that are to be undertaken. Because the contributions focus almost exclusively on the Swedish context (an addition of “in Sweden” to the title would not have been misplaced), this makes the relevance of this publication to a broader international audience somewhat limited. In some cases, this focus becomes so overwhelming that Swedish research ethical practice and legislation is taken for granted, without any attention being paid to different considerations. Arguments and conclusions may be more or less applicable depending on what use of biobanks is being considered. Another example is Eriksson’s somewhat longwinded account of various “models” of informed consent, which does not serve to clarify any of the underlining normative issues, such as the question of what ultimate value such a model should be taken to serve or what is more precisely meant by the notion of an “autonomous” consent. In spite of this, however, Eriksson makes several bold normative statements in the form of three principles (of which two seem to be mere logical consequences of the first one)—although, unfortunately, without any hint of supporting arguments. Hansson’s idea of two principles of integrity (one about the individual’s right to control his or her own body and his or her right to influence the policy making process) is equally lacking in underlying reflection, since he fails to note that controlling what happens to me or parts of my body may well mean that I cannot delegate some such decision to someone else.

**The Human Embryo Research Debates: Bioethics in the Vortex of Controversy**


United States ethicist Ronald M Green approaches the issue of embryo research (ER) in the very accessible form of a “philosophical memoir” (xvi). Reporting in detail from his experience of serving on several high level ethics advisory boards, focusing mostly on his membership of the National Institutes of Health (NIH) ER Working Group, Green portrays himself as a member of this panel, Green portrays both the problems and the increasingly more influential form of institutionalised ethics, as well as the social and political dynamics governing its (in)effectiveness. The author also covers extensive ground regarding the subject matter of ER...
itself and familiarises the reader with the technical issues and conceptual conundrums (potentiality, moral status, harming future persons) involved.

Green states in the title of The Human Embryo Research Debates: Bioethics in the Vortex of Controversy that he is concerned with a plurality of debates. Examining the discourse in the US, he first deals with the different areas in which ER is debated: of the book's eight chapters, chapters one and four stress the relevance of ER for the fields of in vitro fertilisation (IVF) research, the study of birth defects, and the development of contraceptive methods. Chapter six deals with the relation of ER to reproductive cloning, Green formulates a comprehensive criticism of the National Bioethics Advisory Commission's (NBAC) 1997 report on cloning, claiming that it contributed significantly to the neglect of ER in US public policy. Chapter seven covers NBAC's 1999 report on stem cell research, stresses the importance of ER on the form of so-called "therapeutic cloning", and again takes a critical stance towards NBAC's shap- ing of the discourse. As the above issues are of relevance to groups with radically differing interests, throughout the book Green also deals with a second level of ER debates. This concerns the complex web of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups with regard to the different forms of ER. In light of the fact that the author is chair of Dartmouth College's department of religion and former president of the Society of Christian Ethics, one might expect that he would argue strenuously for the rights of the embryo with the restrictive conservative party in discourse. This, however, is not the case. Rather, he points out with frustration that a powerful conservative minority has effectively managed to obstruct and stall ER since the mid 90s. Emphasising the negative consequences resulting from ER being forced to take place almost exclusively in the private sector he argues fiercely and outspokenly in favour of a comprehensive federally funded exploration of the potential medical benefits at hand. Given the dramatic clash of interests of the involved parties, the author is centrally interested in isolating an ideal procedure suitable for governing negotiations between the conflicting parties. Here, Green draws strongly on the Rawlsian concept of overlapping consensus and urges discourse participants to be willing to abide by public reason and to set aside their individual special concerns out of respect for other individuals and the common good (pages 61, 153, page 169 and following pages).

Because of the significant impact of religious pressure groups in ER debates in the US, Green dedicates considerable attention to religiously motivated arguments and in particular to the frequently encountered claim that human life (and tacitly implied: full moral status) begins "at the moment of conception". In chapter two he cites detailed current biological evidence, forcefully showing that even on the biological level this claim is difficult to uphold. Setting forth "a Copernican Revolution in our thinking about ethical issues related to the life sciences" (page 26, without mention of the Kantian origin of this metaphor) Green argues (a) that it is difficult to talk of "one objective point of conception and that biological occurrences are best understood as processes rather than events. Hence, as nature does not provide us with clear cut boundary markers, he suggests analogously to the current practice of brain death that (b) the determination of threshold points involves deliberate choice and decision on our part in such a way that a reasonable compromise is achieved between the benefits and harms associated with the choice of a specific boundary marker, both for the wider public and health related research as well as for the entity under consideration. Arguing further against any kind of "single criterion approach" to determine the status of the embryo, Green champions a "pluralistic and pragmatic approach" characterised by the belief that "a variety of criteria interact and work together to lead to a mounting sense of concern and ultimately to judgments of protectability about entities" (pages 63 and pages following). Therefore, in Green's view, the issue of the embryo's moral status is essentially a political question and "translates into the question of just how much protection it is reasonable and fair to give it at each point in its development" (page 39). Less detailed is an argument in chapter six attempting to establish that the concept of harm is, contrary to Parfit's "non-identity argument"; meaningfully applicable in the context of wrongful life cases (pages 126-128).

In the age of the "globalisation of ethics" (John Harris) in which ethics commissions and advisory boards are more and more setting the agenda in bioethical policy making, the strength of Green's book is that it presents a transparent and valuable case study of this practice. Questions regarding, for example, the criteria for selecting a competent and representative panel; how much power these institutions should be granted; what kind of standards and methodology for published reports is necessary; what degree of public participation is desirable, and how to deal with minority views, have obviously not been settled once and for all with Green's book, but it is a stimulating and clear account which shows that these issues are just as important, difficult, and necessary as thorough academic debates on—for example, the relation of facts to values. The book will be of interest to anyone who is interested in the mechanics determining the interaction of bioethics and the political sphere: it requires no previous familiarity with the topic and can thus also be recommended to the general reader.

H Schmidt

The Androgen Insensitivity Syndrome Support Group (AISSG)
The Androgen Insensitivity Syndrome Support Group (AISSG) http://www.medhelp.org/ www/ais is a consortium of worldwide support groups, originating in the UK, providing information and support to adults and families affected by some conditions affecting the development of the reproductive system. These are conditions that have been subject to considerable secrecy and paternalism in the past, and AISSG promotes full disclosure of diagnostic information with accompanying psychological support. It also encourages recent moves to evaluate the efficacy of genital reconstruction surgery and supports the notion of autonomy and informed consent. The conditions supported included AIS— androgen insensitivity syndrome (old name testicular feminisation syndrome or testicular feminisation syndrome)—and similar conditions, for example, XY gonadal dysgenesis (Swer's syndrome), 5-alpha reductase deficiency, leydig cell hypoplasia, Mayer Rokitansky Kuster Hauser (MRKH) syndrome, Mullerian dysgenesis/aplasia, and vaginal atresia.

9th Conference of the ABA: "Virtue and Vice in Bioethics"
You are invited to the 9th Conference of the ABA: "Virtue and Vice in Bioethics" on the 3–6 July 2003. The venue is Queenstown, New Zealand. Confirmed invited speakers: Art Frank, Carl Elliot, and Annette Baier. Further information: Pat Johnston, Dunedin Conference Management Services, New Zealand (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcms.co.nz).

European Integration: Philosophy and Ethics of Health Care
The XVIIIth international congress of the European Society for Philosophy of Medicine and Healthcare will be held from August 21–23 2003 in Vilnius, Lithuania. Its theme is European Integration—Philosophy and Ethics of Health Care. Further information: Professor Dr Henk ten Have, secretariat ESPHM, Department of Ethics, Philosophy and History of Medicine, University Medical Center, PO Box 9101, 6500 HB Nijmegen, the Netherlands (fax: +31 (0)24 340254; email: h.tenhave@cfg.kun.nl).