LETTERS

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 look to PGD for “milder” conditions and adult onset conditions for which they are not comfortable to have traditional prenatal diagnosis and termination.

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 offered it 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 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 our view entirely ethically acceptable.

The concern 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 age of onset of the Val177Ile 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 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 serious 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.

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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 submissions is the ability to draw up a response that can be developed into a debate. These responses range from the scholarly and meticulous to a discussion of the legal and medical ethics of physician assisted suicide. 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 should be when I wish to enter into dialogue with the author. I feel on solid ground when considering the scholarly submission that is clearly intended as a contribution to a peer reviewed journal, and have no qualms about 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 arguments that any peer review process would deal with severely. Where accounts of suffering alongside dubious arguments are posted from patients I personally feel sorry 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.

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References

Electronic correspondence should serve a valuable function by providing a platform to express views and engage in debate. The ease of electronic communication allows for a wide range of perspectives to be shared, whether from experts or laypeople. It is time to embrace this medium as a tool for intellectual exchange, to foster dialogue, and to advance understanding.

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In Two Minds: A Casebook of Psychiatric Ethics

Although the title describes this as a “casebook,” the book is more than that. It is a comprehensive and accessible guide to psychiatric ethics. The casebook format engages the reader in a series of readable discussions of complex ethical issues, using real-world examples to illustrate points. The authors present their arguments in a clear and logical manner, making the material accessible to a wide audience.

The book is divided into several parts, each focusing on a different aspect of psychiatric ethics. It covers topics such as decision-making, informed consent, and end-of-life care. Each chapter is well-structured, with a clear introduction, main body, and conclusion. The authors provide a wealth of information, including legal, ethical, and practical considerations.

One of the strengths of this book is its use of case studies to illustrate ethical dilemmas. The authors carefully select cases that are both challenging and relevant, providing readers with a nuanced understanding of the complexities involved in psychiatric ethics. The cases are followed by expert commentary and analysis, offering insights from a range of perspectives.

Overall, In Two Minds is an invaluable resource for anyone interested in psychiatric ethics. It is an excellent introduction for students and professionals alike, and an ideal reference for those already working in the field. The book’s clear and engaging style makes it accessible to a broad audience, while its depth of coverage ensures that it is a valuable addition to any professional’s library.
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 contemporary bioethics. There is currently a dearth of bioethical literature presenting what might be called a more traditional approach to medicine 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 several ethical positions raised by reproduction, death, and dying. The issues considered include euthanasia and withdrawal of treatment, 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 the utilitarian and deontological positions. The case is introduced and discussed dispassionately. It is then employed as a forum and resource for managing difficult clinical dilemmas, with both philosophers and clinicians facilitating. In the USA ethical committees are commonplace in hospitals, where there is often a resident ethicist on the staff to handle clinical cases, developing policies, and education. In the UK ethical committees have been largely restricted to looking at research protocols, but the development of 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 this book should contain at least another 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 controversial issues that raised. Watt would demonstrate this powerful teaching method and would also provide some relevant practical material for teams and trusts that are trying to set up their own ethical committees.

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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.

**T 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 questions that are raised 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 engineered 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 the scope of the main work 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 format is reinforced by first use of the colour 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 be useful would be 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 second volume all started 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 topics 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 of great interest to people wanting to do further work on this 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 he has used independently and thoroughly referenced 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.

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


This booklet (freely accessible online at http://www.bioethics.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, 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 differences that exist in Sweden and other parts of the West. For example, Mats G Hansson states, as a basic feature of the ethical background to biobank issues, that it would be disrespectful of researchers’ integrity if their control over collected research materials, data, and results were limited by regulation; and he claims that this can be inferred from the traditional legal right of Swedish individual researchers to have such control. This presupposes, however, that this tradition (which is hardly a given from an international perspective, where universities and funding parties are often granted much more control) should be taken as universal—a presupposition that clearly begs relevant ethical questions. The value of the booklet is further impeded by the lack of a substantial overview chapter (either at the beginning or at the end) which could have served to tie together the rather heterogeneously written pieces on different aspects of the research, addressing ethical conflicts; empirical as well as normative studies of informed consent, and issues of civil as well as public law into a coherent picture of “the biobank issue.”

These chapters are most interesting from an ethical point of view deal with the basic conflict between individual integrity and social utility (Mats G Hansson); what model of informed consent is most appropriate in a biobank setting (Stefan Eriksson), and uncovering cultural conceptions of the body and its parts (Jacob Dahl Rendtorff). The treatment of these areas is rather shallow, however, in several respects. For example, although the fact that a biobank may be used for different purposes (apart from basic research, diagnosis, treatment, and securing quality of care) is noted by Hansson and Eriksson, no attempt is made to investigate to what extent different considerations argumentations and conclusions may be more or less applicable depending on what use of biobanks is being considered. Another example is Eriksson’s somewhat long-winded account of various “models” of informed consent, which does not serve to clarify any of the underlying 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)—though, unfortunately, without any hint of supporting arguments. Hansson’s idea of two principles of integrity (one about the individual’s right to control and the other about the individual’s right to control 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 very well mean that I choose to delegate some such decisions to someone else.

**C Munthe**

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*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” (xv). 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’s (NIH’s) 1994 embryo research panel, Green portrays both the strengths and weaknesses of this 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

www.jmedethics.com
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 Complexity_ 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; that report, according to Green, is arguable and outspokenly in favour of a so-called "therapeutic cloning", and again takes a critical stance towards NBAC's shaping 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 complexity of the interests of the involved parties, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups. The advantage of the comprehensive view of Green's book is that it presents a transparent and valuable case study of this approach to determine the status of the embryo and health-related research as well as 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" (page 63 and pages following).

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 feminization syndrome or testicular feminisation syndrome)—and similar conditions, for example, XY gonadal dysgenesis (Swyer'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 Zea- land (tel: +64 3 477 1377; fax: +64 3 477 2720; email: pat@dcms.co.nz).

European Integration:
Philosophy and Ethics of Health Care

The XVIIth 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 ESPM8, 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@efg.kun.nl).