

# PostScript

## 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).<sup>1,2</sup> 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 offering 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.<sup>3</sup> Firstly, do the commentators believe that the couple should not have a child by natural means because of this fact? If this were the 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,<sup>4</sup> 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.<sup>5</sup> 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 Aus-

tralia 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.<sup>6,7</sup>

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 having 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.

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#### References

- 1 Spriggs M. Genetically selected baby free of inherited predisposition to early onset Alzheimer's disease. *J Med Ethics* 2002;28:290.
- 2 Verlinsky Y, Rechitsky S, Verlinsky O, et al. Preimplantation diagnosis for early onset Alzheimer disease caused by V717L mutation. *JAMA* 2002;287:1018-21.
- 3 Towner D, Loewy R. Ethics of preimplantation diagnosis for a woman destined to develop early onset Alzheimer disease. *JAMA* 2002;287:1038-40.
- 4 Murrell JR, Hake AM, Quaid KA, et al. Early onset Alzheimer disease caused by a new mutation (V717L) in the amyloid precursor protein gene. *Arch Neurol* 2000;57:885-7.
- 5 Goate A, Chartier-Harlin M-C, Mullan M, et al. Segregation of a missense mutation in the amyloid precursor protein gene with familial Alzheimer's disease. *Nature* 1991;349:704-6.
- 6 Bor W, Najman JM, Andersen MJ, et al. The relationship between low family income and psychological disturbance in young children: an Australian longitudinal study. *Aust N Z J Psychiatry* 1997;31:664-75.
- 7 Kirisci L, Dunn MG, Mezzich AC, et al. Impact of parental substance use disorder and child neglect severity on substance use involvement in male offspring. *Prev Sci* 2001;2:241-55.

### 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<sup>1</sup> 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.<sup>2</sup> An editorial in the BMJ on physician assisted suicide<sup>3</sup> has attracted 125 responses at the time of writing. An important feature of electronic responses, particularly on items that 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 personal accounts of suffering. 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 sure 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.<sup>4</sup> Where accounts of suffering alongside dubious arguments are posted from patients I personally feel squeamish 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".<sup>2</sup> 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

- 1 Boyd KM. Mrs Pretty and Ms B [editorial]. *J Med Ethics* 2002;28:211-12.
- 2 Delamothe T, Smith R. Twenty thousand conversations. *BMJ* 2002;324:1171-2.
- 3 Doyal L, Doyal L. Why active euthanasia and physician assisted suicide should be legalised. *BMJ* 2001;323:1079-80.

4 **McCracken L.** It is time to learn the Hippocratic Oath indeed. Electronic response to: Roddy E, Jones E, Yeager E, *et al.* On Hippocrates. *BMJ* 2002;**325**:496a. <http://bmj.com/cgi/eletters/325/7362/496/a#25093> accessed 3 Aug 2002.

### Editor's response

Dr Lewis raises the important issue of what the rules of debate should be in electronic correspondence.<sup>1</sup>

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 an interesting view on that topic. Electronic correspondence should serve a similar function: to increase people's interaction with the journal and with others.

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## BOOK REVIEWS



### In Two Minds: A Casebook of Psychiatric Ethics

D Dickenson, Bill (KWM) Fulford. Oxford University Press, 2000, £27.50, pp 382. ISBN 0-19-26-28-58-5

Although the title describes this as a "casebook", it is much 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 morality exposed. The authors seem effortlessly to

introduce complex philosophical ideas, including sections on the philosophy of science and the philosophy of mind (rationality, meaning, agency, identity etc). The centre-piece of the book is undoubtedly a series of well-chosen cases (thematically 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 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 cases.

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 scholarly 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 heart 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 in all areas of medicine is a recurring theme. Dickenson's interest in informed consent (also in children), "moral luck", and her feminist reconstruction of rationality, are drawn upon in several sections.

Several of the clinical cases are "grey area" cases—cases that do not easily fit into clear diagnostic slots, where clinicians disagree about the precise diagnosis and may start doubting their own judgment. For example, the question of the differential diagnosis of a man who appears to have a religious delusion, yet leads a very successful professional life turns "not on the facts about his experiences and behaviour, but on a series of value judgements". The authors point out that the diagnosis of schizophrenia in the DSM-IV (a widely used diagnostic classification system) requires the criterion of "social/occupational dysfunction . . . below the level achieved prior to the onset". Here a paradox is demonstrated: the evaluation of "social dysfunction" depends on values, yet the authors of the DSM-IV claim that the system was "grounded in empirical evidence"! The reader is challenged to come to terms with the value related elements of the diagnosis of schizophrenia and related diagnoses. As with several other cases, the importance of a team approach is emphasised, bringing to bear, as it should, a variety of perspectives that may include elements of cultural formulation and the patient's values.

Other chapters address teamwork and service organisation, and research ethics; a section on wider perspectives gives an international view; in an interesting chapter Fulford describes the basis for his belief that psychiatry can take the lead in bioethics, "providing lessons for medicine as a whole". There is also a useful sample teaching seminar, showing how theory is put into practice.

This book will appeal to any reader who wishes to escape from the well-worn path of "four principles plus". It is likely to be enriching to psychiatrists who feel that the DSM-IV and ICD-10 are constrained not so much by limitations of their science, but of their humanities. It provides thoughtful material

for those interested in finding a way of resolving the tensions between physical medicine, psychiatry, and ethics. The book is a treasure trove of annotated bibliographies and very enjoyable to read.

**S Louw**

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

Edited by P Webb. Hochland and Hochland, 2000, £15.95, Pp 138. ISBN 1-898507-27-9

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 palliative care with a background in nursing. She tells us that studying ethics encourages logical reasoned 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 Jeffrey, a consultant in palliative medicine and writer on medical ethics, reminds us that care is concerned as much with the subjective feelings of the patient as with the physical disease, and aims to relieve suffering and improve quality of life. He emphasises that by sharing the reality of uncertainty (with patient, family, and colleagues) we can make more realistic decisions, and that informed consent 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 truth-telling and honesty, and between honest and dishonest selective truthfulness. "There is a sense in which we are always selective with the truth", she writes and reminds me of the saying so useful in palliative care that: "Truth like medicine can be skilfully used, respecting its potential to help and to harm".

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 most patients to be directly 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, makes the point that it is often useful to consider consent not primarily as a legal concept but a moral one, and one that depends on the relationship between patient and carer being a relationship of trust, reciprocity, and beneficence, with mutual recognition of their duties and obligations. She goes on to look at the differences between

tacit 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 an excellent essay on the euthanasia debate, and finally urges us “to research and practise our arguments and beliefs so that we can be comfortable and credible when moral questions 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 behavioural 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 clinicians facilitating. In the USA ethical committees are commonplace in hospitals, where there is often a resident ethicist on the staff to help with difficult clinical cases, developing 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 this useful book should contain 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 areas of debate that they raised. This 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.

P Kaye

### Life and Death in Healthcare Ethics: A Short Introduction

H Watt. Routledge, 2000, £7.99, vii + 97pp. ISBN 0-415-21574-9

This is a compact, nicely written book that provides a rejuvenating 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 some ethical concerns 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 beginning 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 principles often thought dry and difficult. Newcomers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the *Arthur* case is introduced as a context for discussing putative distinctions between killing

and letting die, and intending and foreseeing; approaches to homicide suggested by competing ethical theories are also covered. In the second chapter, the *Bland* case is analysed and philosophical concepts such as that of “personhood” are discussed. Watt considers the notion of life as good in itself and raises questions 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 principle of double effect, and questions of autonomy. 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 context Watt suggests. In order to test her principle as outlined, however, Watt needs to examine other situations where the principle of double effect is often employed.

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 health care ethics. A broad discussion 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 not intended but foreseen. If a mentally disordered man, or child for that matter, runs amok with a shotgun in a school, is a marksman not justified in shooting to maim? If the aggressor dies, is this lethal bodily invasion impermissible? Would the marksman not be regarded as remiss if he failed to act to prevent the death of the schoolchildren?

The principle suggested by Watt also appears to necessitate the conclusion that even where two patients will die and one is threatening the life of the other unless a doctor intervenes to save one, the doctor is required to do nothing and allow both to die. Such were the circumstances of the recent UK case of the conjoined twins, “Jodie” and “Mary”. It is one thing to say that the doctor *may* decide not to intervene—for example, on the grounds that he wants to respect the parents’ wishes: it is quite another to say that it is entirely impermissible to perform life-saving treatment on one twin (even where the parents wish it), in the same way as it is impermissible for the Nazi doctor to use a patient as fodder for experimentation. In the conjoined twins’ case, there are relevant moral differences. The immediate aim, not merely the further end, of the doctor in performing the operation is to save the life of one of the children. The Nazi doctor, by contrast, has the saving of lives as, at best, his further end. It is worth remembering too that by Watt’s own account, sometimes omissions to act to save a patient can be wrongful. And one begins to wonder whether the requirement that a doctor refrain, on moral grounds, from treating either of the patients destined for certain imminent death is not moral reasoning gone awry.

Chapter 3 is followed by brief explorations of the controversial topics of abortion and embryo destruction. The final chapter looks at the question of moral disagreement and conscientious objection. It is a reminder, if any be needed, of the practical nature of moral theory.

It is the book’s simplicity that leads me to believe that it will be read eagerly by students from a range of different disciplines. The layout and typographical style make the book particu-

larly accessible. There is a comprehensive index and bibliography. If I have a criticism, it is that the book could have been longer. However, for those who want a basic text to introduce them to life and death issues in bioethics, this is a most welcome contribution.

J Laing

### Medical Ethics, 3rd edn.

A Campbell, G Gillett, G Jones. Oxford University Press, 2001, £19.95, pp 297. ISBN 0 19 558445 7

*Medical Ethics*, to quote the authors, is intended as a practical introduction to the ethical questions doctors and other health professionals meet. The book is divided into three main sections, Foundations, Clinical ethics and Medicine and society; each section is further subdivided into topics dealt with in a single chapter.

The first section deals very well with the basic background and theories of ethics and does not lay too much stress on the well established “four principles” (chs 1 and 2). I have rarely read such a seamless introduction to the underlying principles of medical ethics and teachers would do well to read this. Later chapters in this section deal with diverse cultures (ch 3) and the human body (ch 4). Of particular note here is the excellent treatment given to information, 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 encompasses the topics of postmortem examinations and biopsies both of which are in the public mind at present; this discussion is clear and full of “common sense” and if taken to heart would, hopefully, avoid further public outcries on the matter 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 on traditional arguments. The New Zealand background 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 second section (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 discuss the medical problems and then to introduce 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 included in this 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 covers research ethics, justice, law and “trying new things”. This rather broad area is dealt with excellently and the rather oddly 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’ arguments and for further reading. Case studies



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

Edited by T Murray, M Mehlman. John Wiley and Sons, 2000, £370, pp 1132. ISBN 0-471-17612-5

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 biotechnology, 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 informed, 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. This impression is 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 sections that we 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 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 the ideal introduction to the topic and one that would be useful as a required reading. Similarly positive things can be said about Robert Nelson's heading "Gene therapy, ethics, germ cell gene transfer". The section by Georgia Wiesner, Susan Lewis, and Jennifer Scott on "Human subjects research, ethics and pedigree studies" was also excellent and well informed—both from a clinical point of view and also from a bioethics perspective. David Wasserman's heading on "Behavioural genetics" is also a fascinating essay. The discussion of research into the XYY karyotype and the MAO mutation provide an excellent background to the section. Again, this section would be the ideal introduction 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 Søren 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 they have also used 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.

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

Edited by M G Hansson. Uppsala University, 2001, free, pp 93. ISBN 91-506-1472-X

This booklet (freely accessible online at <http://www.bioethics.uu.se/biobanks-report.html>) documents a public hearing 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 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 between 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 scientific strategies; business interests; overarching 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".

Those chapters of most interest 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 underlying 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 many 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, 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 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 one)—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 his 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 very well mean that I choose to delegate some such decisions to someone else.

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

R M Green. Oxford University press, 2001, £22.50, \$US29.95, pp 231. ISBN 0195109473

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) 1994 human embryo research panel, Green portrays both the functioning 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

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 6 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 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 complex interplay 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 attempt to settle the arguments by siding 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 (page 61, page 155, 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" (page 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

## NOTICES

### 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 Zealand (tel: +64 3 477 1377; fax: +64 3 477 2720; email: [pat@dcms.co.nz](mailto: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.

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