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). 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 in operation 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 utilizing 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 the woman were the case, then 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 our view entirely ethically acceptable.

The chances 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 onset of the Val171Ile 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 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 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 further in 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 debates is that they may generate a lot of debate, is that the contributions often refer to each other. These responses range from the scholarly and meticulous to the polemical and vituperative. 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 discussing 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 squeamish about responding, finding myself caught between the roles of vituperative reviewer and empathetic 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 arguments 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.

W Lewis

References

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similar function: to increase people’s interac-
issue of contemporary interest and we solicit
engaging and relevant to professionals and
as a medical ethics journal, it should also be
should be the publication of scholarly
paper version of the journal.

significantly to the debate (such as Dr Lewis’s

vast landscape of medical ethics is evoked and
series of readily accessible discussions of
book", it is much more than that. The

Electronic correspondence, for me, is differ-
correspondence. It provides thoughtful material
operates on the principle
rules are required.
Electronic correspondence, for me, is differ-

introduce complex philosophical ideas, in-
cluding 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 methodologi-
cally 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 back of the matter”
along the way one or 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 categories and that the web is a
recurring theme. Dickenson’s interest in in-
formed consent (also in children), “moral
luck”, and her feminist reconstruction of
rationality, are drawn upon in several sections.

Several of the diagnostic categories are
“grey areas”—cases—that do not easily fit into
clear diagnostic slots, where clinicians disagree
about the precise diagnosis and may start
doubting their criteria. 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
judgments”. 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 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 biosocial 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 enrich-
ing 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 resolv-
ing the tensions between physical medicine,
psychiatry, and ethics. The book is a treasure
trove of annotated bibliographies and very
enjoyable to read.

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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.

Although the title describes this as a “case-
book”, 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 presenta-
tion of information and knowledge. It is not
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 differ-
ent 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

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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 argued that 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 behavioral sciences, law, theology, and philosophy, as well. 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 help with clinical cases, developing policies, and education. In the UK ethical committees have been largely restricted to looking at research protocols, but the develop-
ment 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 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 and unusual things it is important to bring to the attention of the reading public. This would demonstrate this powerful teaching method and would also provide some relevant practi-
cial 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

ISBN 0 415 2157 4 9

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 biotechnical 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 of the 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 being 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-
ples often thought dry and difficult. Newcom-
ers to the study of ethics will be pleasantly surprised.

In the first chapter—for example, the Arth
case is introduced as a context for dis-
ussing putative distinctions between killing and letting die, and intending and foreseeing. approaches to homicide suggested by compet-
ting ethical theories are also covered. In the second chapter, the Bland case is analysed and philosophical concepts such as that of "per-
sistence" are discussed. Watt considers the notion of life as good in itself and raises ques-
tions about the social significance of tube feeding. The Cax case, in chapter 3, elicits a discussion of concepts such as that of a worthless life and the misused principle 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 or not, on presentation 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 would apply. 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 how the principle of double effect is not intended for lethal bodily invasion.

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 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 "theorising about the right of life" and "emotions of doctors and nurses in a 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, jus-
tice, law and "trying new things". This rather broad area is dealt with excellently and the rather oddly named chapter on "Tying 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

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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 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 discussions that revolve around 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 informative, 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 authors have been reinforced by first use of this dictionary. 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 (given that these cases of use have not 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 fact that we 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 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 Swindells, "Genetic and molecular technologies, pediatrics and technology" 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 allow the reader to see that the issues of 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 discussions of the point of view text 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.usu.se/biobanks-report.html) documents a workshop 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 the interests of people and society in general in the case of conflict, and, at 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 other countries 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 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 such scientific strategies; business interests; ethical and policy issues; and ethical and legal dilemmas. The chapters are quite long, and some of the headings are quite foreboding, which could have served to tie together the various considerations. 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 the use of their body and the other about the 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 choose to delegate some such decision to someone else.

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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” (xiv). 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)'s 1994 Committee on Human Embryo Research (CHER), Green portrays both the “intellectual” discourse 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 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 6 deals with the relation of ER to reproductive cloning. Green formulates a comprehensive criticism of the National Bioethics Advisory Commission’s (NBAC) 1999 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 complexity of the interests of scientists, patient groups, the medical industry, policy makers, politicians, legal professionals, ethicists, theologians, and religious pressure groups concerning 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 advocate arguments by analogy 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 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 “(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