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Document 1
Lafferrière, Jorge Nicolás
LAS IMPLICACIONES JURÍDICAS DEL DIAGNÓSTICO: PRENANTAL: EL CONCEBIDO COMO HIJO Y PACIENTE
Call number: KHA2047 .L34 2011

Document 2
Alsulaiman, Ayman; Al-Odaib, Ali; Rijjal, A.I.; Hewison, Jenny
Preimplantation genetic diagnosis in Saudi Arabia: parents’ experience and attitudes
Georgetown users check Georgetown Journal Finder for access to full text
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Handyside, Alan
Let parents decide. Twenty years on from the first pregnancies after preimplantation genetic diagnosis, Alan Handyside argues that informed prospective parents are largely good guides to the use of the thriving technology.
Nature 2010 April 15; 463(7291): 978-979
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Document 4
Denier, Yvonne
From brute luck to option luck? On genetics, justice, and moral responsibility in reproduction.
Journal of Medicine and Philosophy 2010 April; 35(2): 101-129
Abstract: The structure of our ethical experience depends, crucially, on a fundamental distinction between what we are responsible for doing or deciding and what is given to us. As such, the boundary between chance and choice is the spine of our conventional morality, and any serious shift in that boundary is thoroughly dislocating. Against this background, I analyze the way in which techniques of prenatal genetic diagnosis (PGD) pose such a fundamental challenge to our conventional ideas of justice and moral responsibility. After a short description of the situation, I first examine the influential luck egalitarian theory of justice, which is based on the distinction between choice and luck
or, more specifically, between option luck and brute luck, and the way in which it would approach PGD (section II), followed by an analysis of the conceptual incoherencies (in section III) and moral problems (in section IV) that come with such an approach. Put shortly, the case of PGD shows that the luck egalitarian approach fails to express equal respect for the individual choices of people. The paradox of the matter is that by overemphasizing the fact of choice as such, without regard for the social framework in which they are being made, or for the fundamental and existential nature of particular choices-like choosing to have children and not to undergo PGD or not to abort a handicapped fetus-such choices actually become impossible.

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AUSWÄHLN ODER ANNEHMEN? PRÄNATAL- UND PRÄIMPLANTATIONSDIAGNOSTIK: TESTVERFAHREN AN WERDENDEM LEBEN

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INHERITED CANCER SYNDROMES: CURRENT CLINICAL MANAGEMENT
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Hall, Alison; Bostanci, A.; Wright, C.F.
Non-invasive prenatal diagnosis using cell-free fetal DNA technology: applications and implications.
Public Health Genomics 2010; 13(4): 246-255
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Monaco, Laura C.; conway, Laura; Valverde, Kathleen; Austin, Jehannine C.
Exploring genetic counselors' perceptions of and attitudes towards schizophrenia.
Public Health Genomics 2010; 13(1): 21-26
Abstract: Schizophrenia is a common complex condition, for which no genetic testing is yet clinically available. Genetic counseling for psychiatric disorders is viewed by genetic counselors as a growth area, and to meet any increase in demand it is important to understand existing context. Thus, we surveyed general practice members of the National Society of Genetic Counselors, to examine perceptions and attitudes relating to schizophrenia. A total of 136 genetic counselors completed the survey, of whom 50% were engaged in general practice roles and therefore eligible to participate. Of these, 40% reported 'rarely' or 'never' asking about psychiatric illness when taking a family history. Some respondents expressed concern that discussing genetics of schizophrenia and providing risk assessment with families may be more confusing or worrisome than helpful. Many counselors reported that patients feel frustrated with the inability of genetic counselors to provide individual risk calculations. It appears that genetic
counselors are reluctant to ask patients about psychiatric illness, and are concerned that their services might not be helpful in the context of schizophrenia.

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**Document 15**

Rantanen, Elina; Pöntinen, Seppo; Nippert, Irmgard; Sequeiros, Jorge; Kääriäinen, Helena

*Expertise, empathy and ethical awareness: ideals of genetic counseling based on framing of genetic information in international guidelines*


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Mand, C.; Duncan, R.E.; Gillam, L.; Collins, V.; Delatycki, M.B.

*Genetic selection for deafness: the views of hearing children of deaf adults.*

Journal of Medical Ethics 2009 December; 35(12): 722-8

**Abstract:** The concept of selecting for a disability, and deafness in particular, has triggered a controversial and sometimes acrimonious debate between key stakeholders. Previous studies have concentrated on the views of the deaf and hard of hearing, health professionals and ethicists towards reproductive selection for deafness. This study, however, is the first of its kind examining the views of hearing children of deaf adults towards preimplantation genetic diagnosis and prenatal diagnosis to select for or against deafness. Hearing children of deaf adults (or CODAs, as they call themselves, and are widely known in the deaf community) straddle both the deaf and hearing worlds, and this dual perspective makes them ideally placed to add to the academic discourse concerning the use of genetic selection for or against deafness. The study incorporated two complementary stages, using initial, semistructured interviews with key informants (CODAs and health professionals) as a means to guide the subsequent development of an electronic survey, completed anonymously by 66 individuals. The participants shared many of the same views as deaf individuals in the D/deaf (or "culturally deaf") community. The similarities extended to their opinions regarding deafness not being a disability (45.5% believed deafness was a distinct culture rather than a disability), their ambivalence towards having hearing or deaf children (72.3% indicated no preference) and their general disapproval of the use of genetic technologies to select either for or against deafness (60% believed that reproductive technologies, when used to select for or against deafness, should not be available to the community).

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Vadaparampil, Susan T.; Quinn, Gwendolyn P.; Knapp, Caprice; Malo, Teri L.; Friedman, Susan

*Factors associated with preimplantation genetic diagnosis acceptance among women concerned about hereditary breast and ovarian cancer*

Genetics in Medicine 2009 October; 11(10): 757-765

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McGowan, Michelle L.; Burant, Christopher J.; Moran, Rocio; Farrell, Ruth

*Patient education and informed consent for preimplantation genetic diagnosis: health literacy for genetics and assisted reproductive technology.*

Genetics in Medicine 2009 September; 11(9): 640-645

Supported by: NHGRI-funded publication; Grant NHGRI-ELSI P50-HG003390
Abstract: PURPOSE: Innovative applications of genetic testing have emerged within the field of assisted reproductive technology through preimplantation genetic diagnosis. As in all forms of genetic testing, adequate genetic counseling and informed consent are critical. Despite the growing recognition of the role of informed consent in genetic testing, there is little data available about how this process occurs in the setting of preimplantation genetic diagnosis. METHODS: A cross-sectional study of in vitro fertilization clinics offering preimplantation genetic diagnosis in the United States was conducted to assess patient education and informed consent practices. Descriptive data were collected with a self-administered survey instrument. RESULTS: More than half of the clinics offering preimplantation genetic diagnosis required genetic counseling before preimplantation genetic diagnosis (56%). Genetic counseling was typically performed by certified genetic counselors (84%). Less than half (37%) of the clinics required a separate informed consent process for genetic testing of embryonic cells. At a majority of those clinics requiring a separate informed consent for genetic testing (54%), informed consent for preimplantation genetic diagnosis and genetic testing took place as a single event before beginning in vitro fertilization procedures. CONCLUSIONS: The results suggest that patient education and informed consent practices for preimplantation genetic diagnosis have yet to be standardized. These findings warrant the establishment of professional guidelines for patient education and informed consent specific to embryonic genetic testing.
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From Iran to Latin America: must prenatal diagnosis necessarily be provided with abortion for congenital abnormalities?
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American Journal of Bioethics 2009 August; 9(8): 63-65
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Does prenatal diagnosis morally require provision of selective abortion?
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Providing preimplantation genetic diagnosis in the United Kingdom, The Netherlands and Germany: a comparative in-depth analysis of health-care access.
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García, E.; Timmermans, D.R.M.; van Leeuwen, E.
Reconsidering prenatal screening: an empirical-ethical approach to understand moral dilemmas as a question of personal preferences
Journal of Medical Ethics 2009 July; 35(7): 410-414
Abstract: In contrast to most Western countries, routine offer of prenatal screening is considered problematic in the Netherlands. The main argument against offering it to every pregnant woman is that women would be brought into a moral dilemma when deciding whether to use screening or not. This paper explores whether the active offer of a prenatal screening test indeed confronts women with a moral dilemma. A qualitative study was developed, based on a randomised controlled trial that aimed to assess the decision-making process of women when confronted with a test offer. A sample of 59 women was interviewed about the different factors balanced in decision-making. Participants felt themselves caught between a need for knowledge and their unwillingness to take on responsibility.
Conflict was reported between wishes, preferences and ethical views regarding parenthood; however, women did not seem to be caught in a choice between two or more ethical principles. Participants balanced the interests of the family against that of the fetus in line with their values and their personal circumstances. Therefore, we conclude that they are not so much faced with an ethical dilemma as conflicting interests. We propose that caregivers should provide the opportunity for the woman to discuss her wishes and doubts to facilitate her decision. This approach would help women to assess the meaning of testing within their parental duties towards their unborn child and their current offspring.

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Loike, John D.; Tendler, Moshe
**Behavioral genetics: the quest for an ethical genome**
ASSIA: Jewish Medical Ethics 2009 June; 7(1): 14-23

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**Is non-selection of disabled and diseased embryos using PGD ethically acceptable, legally permissable and halachic?**
ASSIA: Jewish Medical Ethics 2009 June; 7(1): 4-13

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Ostojic, Sasa; Pedri, M. Louisa
**Current view on ethics and genetics: the importance of progressive evolution of medical genetics and genetic counselling**

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Attitudes of high-risk women toward preimplantation genetic diagnosis.
Fertility and Sterility 2009 June; 91(6): 2361-2368
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Burton, Adrian
Controversy surrounds the selection of embryos to avoid cancer.
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Genetic counseling for thalassemia in the Islamic Republic of Iran
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Practical and ethical considerations of noninvasive prenatal diagnosis.
JAMA: The Journal of the American Medical Association 2009 May 27; 301(20): 2154-2156
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Tuffs, Annette
New German law bans tests of fetuses for adult onset illnesses [news]
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Georgetown users check Georgetown Journal Finder for access to full text
Preimplantation genetic diagnosis: does age of onset matter (anymore)?

**Abstract:** The identification and avoidance of disease susceptibility in embryos is the most common goal of preimplantation genetic diagnosis (PGD). Most jurisdictions that accept but regulate the availability of PGD restrict it to what are characterized as 'serious' conditions. Line-drawing around seriousness is not determined solely by the identification of a genetic mutation. Other factors seen to be relevant include: impact on health or severity of symptoms; degree of penetrance (probability of genotype being expressed as a genetic disorder); potential for therapy; rate of progression; heritability; and age of onset. In the original applications of PGD, most, if not all of these factors were seen as necessary but none was seen as sufficient for determining whether a genetic condition was labelled 'serious'. This, however, is changing as impact on health or severity of symptoms is coming to eclipse the other considerations. This paper investigates how age of onset (primarily in the context of the United Kingdom (UK)) has become considerably less significant as a criterion for determining ethically acceptable applications of PGD. Having moved off the threshold of permitting PGD testing for only fatal (or seriously debilitating), early-onset diseases, I will investigate reasons for why age of onset will not do any work to discriminate between which adult-onset diseases should be considered serious or not. First I will explain the rationale underpinning age of onset as a factor to be weighed in making determinations of seriousness. Next I will challenge the view that later-onset conditions are less serious for being later than earlier-onset conditions. The final section of the paper will discuss some of the broader disability concerns at stake in limiting access to PGD based upon determinations of the 'seriousness' of genetic conditions. Instead of advocating a return to limiting PGD to only early-onset conditions, I conclude that the whole enterprise of trying to draw lines of what is to count as a 'serious' condition is itself problematic and in certain ways morally misleading.

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Establishing the role of pre-implantation genetic diagnosis with human leucocyte antigen typing: what place do "saviour siblings" have in paediatric transplantation?
Archives of Disease in Childhood 2009 April; 94(4): 317-320
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Journal of Genetic Counseling 2009 April; 18(2): 137-146
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Farrelly, Colin

Preimplantation genetic diagnosis, reproductive freedom, and deliberative democracy.
Journal of Medicine and Philosophy 2009 April; 34(2): 135-154

Abstract: In this paper I argue that the account of deliberative democracy advanced by Amy Gutmann and Dennis Thompson (1996, 2004) is a useful normative theory that can help enhance our deliberations about public policy in morally pluralistic societies. More specifically, I illustrate how the prescriptions of deliberative democracy can be applied to the issue of regulating non-medical uses of pre-implantation genetic diagnosis (PGD), such as gender selection. Deliberative democracy does not aim to win a philosophical debate among rival first-order theories, such as libertarianism, egalitarianism or feminism. Rather, it advances a second-order analysis that strives to help us determine what would constitute a reasonable balance between the conflicting fundamental values that arise in the context of regulating PGD. I outline a theoretical model (called the Reasonable Genetic Intervention Model) that brings these issues to the fore. Such a model incorporates the concern for both procedural and substantive principles; and it does so in a way that takes provisionality seriously.

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The role and impact of personal faith and religion among genetic service providers.
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**Prenatal choices: genetic counseling for variable genetic diseases**


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**The responsibility of the truth-teller**

In: Rehmann-Sutter, Christoph; Müller, Hansjakob, eds. Disclosure Dilemmas: Ethics of Genetic Prognosis after the 'Right to Know/Not to Know' Debate. Farnham, England; Burlington, VT: Ashgate Pub., 2009: 183-190

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**How legal frameworks construct patterns of liability in genetic counselling: an international perspective**

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**The symbolic fallout of gene talk: replacing the person with manageable constructs**

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Karimi, Mehran; Bonyadi, Mohammadmehdi; Galehdari, Mohhamad reza; Zareifar, Soheila
**Termination of pregnancy due to Thalassemia major, Hemophilia, and Down's syndrome: the views of Iranian physicians.**

**Abstract:** BACKGROUND: Genetic disorders due to kindred marriages are common medical conditions in Iran; however, the legal aspects of abortion remain controversial. This study was undertaken to determine physicians' opinions regarding the termination of pregnancy for three genetic diseases: thalassemia major, hemophilia, and Down's syndrome. METHODS: A questionnaire was administered to selected physicians by stratified random sampling to determine the following: age, gender, knowledge about prenatal diagnosis of diseases in high risk pregnancies, agreement with abortion, recommended gestational age for abortion, and, if opposed to abortion, the reason. RESULTS: Of 323 physicians, who participated in the study, 91.3(295), 40.6(131), and 78.6%(254) were in agreement and 8.7(28), 59.4(192), and 21.4%(69) were opposed to abortion for thalassemia major, hemophilia, and Down's syndrome, respectively. Among 289 physicians opposed to abortion in respect of each of all three conditions, the following reasons were cited: religion, 18; emotional, 10; quality of care, 23; hope to find a new treatment option in the future, 103; miscellaneous reasons, 6; and a combination of these reasons, 129. Among 680 physicians in agreement with abortion in relation to all of the diseases, 4.6%(31) were agreed with abortion in less than 12 weeks gestation, 79.2%(538) in less than 16 weeks gestation, 5.6%(38) in less than 20 weeks gestation, 2.2%(15) in less than 24 weeks gestation, and 8.4%(58) were agreed with beyond the 24 weeks of gestational age. CONCLUSION: The majority of physicians were in agreement with abortion for thalassemia major and Down's syndrome because of the overall prognosis, but opposed to abortion for hemophilia.

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Attitudes and perceptions about prenatal diagnosis and induced abortion among adults of Pakistani population.
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Informed choice in prenatal testing: a survey among obstetricians and gynaecologists in Europe and Asia.
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Ahmed, Shenaz; Hewison, Jenny; Green, Josephine M.; Cuckle, Howard S.; Hirst, Janet; Thornton, Jim G.
Decisions about testing and termination of pregnancy for different fetal conditions: a qualitative study of European white and Pakistani mothers and affected children
Journal of Genetic Counseling 2008 December; 17(6): 560-572
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Asscher, Eva C.A.
The regulation of preimplantation genetic diagnosis (PGD) in the Netherlands and the UK: a comparative study of the regulatory frameworks and outcomes for PGD
Clinical Ethics 2008 December; 3(4): 176-179
Abstract: Developments in biotechnology present difficult social and ethical challenges that need to be resolved by regulators among others. One crucial problem for regulators of new technologies is to ensure that regulation is both clear and sufficiently flexible to respond to new developments. This is particularly difficult to achieve in contentious fields such as medical biotechnology. In the European Union there is a divergence in the solutions to this problem which has lead to different regulatory frameworks for medical biotechnology. This paper compares and contrasts the British and Dutch regulatory frameworks for the selection of embryos by preimplantation genetic diagnosis as an example of the regulation of medical biotechnology. Some of the outcomes of the regulatory choices and possible reasons behind the divergent frameworks are discussed, such as the ethical outlooks and political systems in these countries.
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Kalokairinou, E.M.
The experience of beta-thalassaemia and its prevention in Cyprus
Abstract: Haemoglobinopathies are a series of hereditary genetic diseases which, if left untreated, usually prove fatal. The present paper discusses how one of the most important of these, beta-thalassaemia, afflicted the island of Cyprus in the last century and almost threatened to eliminate the whole population. In narrating the medical facts of the disease we point out the moral dilemmas which medical personnel, the state and the church had to deal with before they embarked on a program for the treatment and prevention of beta-thalassaemia. After careful study of the program we conclude that, although in the given case it proved a successful model for the management of beta-thalassaemia, it bears no resemblance whatsoever to eugenics.
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**Changing interpretations, stable genes: responsibilities of patients, professionals, and policy makers in the clinical interpretation of complex genetic information.**
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Rantanen, Elina; Hietala, Marja; Kristoffersson, Ulf; Nippert, Irmgard; Schmidtke, Jörg; Sequeiros, Jorge; Kääriäinen, Helena
**Regulations and practices of genetic counselling in 38 European countries: the perspective of national representatives.**
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Buckley, Frank; Buckley, Sue
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Social and ethical controversies in thrombophilia testing and update on genetic risk factors for venous thromboembolism.
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Byk, Christian
Preimplantation genetic diagnosis: an ambiguous legal status for an ambiguous medical and social practice
Abstract: The controversy about to which extend PGD may be applies is particularly interesting because it stresses on a paradoxical point concerning PGD. Although this technique is strictly regulated in most European countries where it is regularly practised, the legal status of PGD may appear to some as unethical because it may be viewed as a facilitator for those who would like to select children for reason other than medical. The need to test human embryos before birth and the consequences that may occur to those detected with some abnormalities also revives the issue of the respect due to the human embryo.

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**Document 117**

Landau, R.

*Sex selection for social purposes in Israel: quest for the "perfect child" of a particular gender or centuries old prejudice against women?*


**Abstract:** On 9 May 2005, the Israeli Ministry of Health issued guidelines spelling out the conditions under which sex selection by preimplantation genetic diagnosis (PGD) for social purposes is to be permitted in Israel. This article first reviews the available medical methods for sex selection, the preference for children of a specific gender in various societies and the ethical controversies surrounding PGD for medical and social purposes in different countries. It focuses then on the question of whether procreative liberty or parental responsibility should be the centre of attention in this context. Finally, the article critically examines the new Israeli guidelines and their implications for the women undergoing the necessary medical treatments, for the children born as a result, for other members of the family and for society in general.

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Stoller, Sarah E.

*Why we are not morally required to select the best children: a response to Savulescu*

Bioethics 2008 September; 22(7): 364-369

**Abstract:** The purpose of this paper is to review critically Julian Savulescu's principle of 'Procreative Beneficence,' which holds that prospective parents are morally obligated to select, of the possible children they could have, those with the greatest chance of leading the best life. According to this principle, prospective parents are obliged to use the technique of pre-implantation genetic diagnosis (PGD) to select for the 'best' embryos, a decision that ought to be made based on the presence or absence of both disease traits and non-disease traits such as intelligence. While several articles have been written in response to Savulescu's principle, none has systematically explored its philosophical underpinnings to demonstrate where it breaks down. In this paper I argue that the examples that Savulescu employs to support his theory in fact fail to justify it. He presents these examples as analogous to PGD, when in fact they differ from it in subtle but morally relevant ways. Specifically, Savulescu fails to acknowledge the fact that his examples evoke deontological and virtue ethics concerns that are absent in the context of PGD. These differences turn out to be crucial, so that, in the end, the analogies bear little support for his theory. Finally, I lay out the implications of this analysis for reproductive ethics.

**Document 119**

Boddington, Paula; Parker, Michael

*Preimplantation genetic diagnosis for familial hypercholesterolaemia: a commentary on the recent HFEA decision*

Clinical Ethics 2008 September; 3(3): 145-148

**Abstract:** The Human Fertilisation and Embryology Authority have recently granted a licence to perform preimplantation genetic diagnosis (PGD) for the homozygous form of familial hypercholesterolaemia (FH), explicitly excluding its use for the heterozygous form. The grounds for such decisions centre on how serious a condition is thought to be as well as on the availability of effective treatment, and decisions are made on a case-by-case basis.
The case for licensing homozygous FH is discussed and compared with other cases, and the case for making a distinction between PGD for homozygous and heterozygous FH is also examined. Testing for homozygous FH raises difficult issues of non-disclosure of results for heterozygous FH. Fears that this decision may represent a 'slippery slope' to more widespread testing are argued to be overstated.

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Merhi, Z.O.; Pal, L.
Gender "tailored" conceptions: should the option of embryo gender selection be available to infertile couples undergoing assisted reproductive technology?
Journal of Medical Ethics 2008 August; 34(8): 590-593
Abstract: The purpose of this article is to ascertain and appraise the ethical issues inherent to the utilisation of preimplantation genetic diagnosis for gender selection in infertile patients anticipating undergoing a medically indicated assisted reproductive technique procedure. Performance of preimplantation genetic diagnosis per request specifically for gender selection by an infertile couple undergoing medically indicated assisted reproductive technique may not breach the principles of ethics, and is unlikely to alter the population balance of sexes.

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Impact of genetic diagnosis of a mitochondrial disorder 5-17 years after the death of an affected child

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"Tell them it's not so bad": prenatal screening for Down syndrome and the bias toward abortion
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Sex selection by preimplantation genetic diagnosis (PGD) for nonmedical reasons in contemporary Israeli regulations
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Slowther, Anne

Selection of embryos
Clinical Ethics 2008 June; 3(2): 60-62

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Hofmann, Bjørn

The inference from a single case: moral versus scientific inferences in implementing new biotechnologies
Medical Humanities 2008 June; 34(1): 19-24

Abstract: Are there similarities between scientific and moral inference? This is the key question in this article. It takes as its point of departure an instance of one person’s story in the media changing both Norwegian public opinion and a brand-new Norwegian law prohibiting the use of saviour siblings. The case appears to falsify existing norms and to establish new ones. The analysis of this case reveals similarities in the modes of inference in science and morals, inasmuch as (a) a single case functions as a counter-example to an existing rule; (b) there is a common presupposition of stability, similarity and order, which makes it possible to reason from a few cases to a general rule; and (c) this makes it possible to hold things together and retain order. In science, these modes of inference are referred to as falsification, induction and consistency. In morals, they have a variety of other names. Hence, even without abandoning the fact–value divide, there appear to be similarities between inference in science and inference in morals, which may encourage communication across the boundaries between "the two cultures" and which are relevant to medical humanities.

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Women's motives for not participating in preconception counseling: qualitative study.
Community Genetics 2008 March; 11(3): 166-170

Abstract: AIMS: Information about risk factors and preventive measures given before conception is estimated to prevent 15-35% of adverse pregnancy outcomes. We aimed to identify women's motives for not responding to an invitation for preconception counseling (PCC) from their general practitioner. METHODS: A purposive sample of 11 women who did not respond to an invitation for PCC and who became pregnant within 1 year was interviewed. RESULTS: Three key themes influencing nonresponse emerged from the data: perceived knowledge, perceived lack of risk and a misunderstanding of the aim of PCC. CONCLUSION: For successful future implementation of PCC, a more tailored approach may be necessary for certain (groups of) women, addressing the reasons why women do not consider themselves part of the target group for PCC.

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Perry, Ronen
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Holm, Søren
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Ethical considerations regarding parental decisions for termination following prenatal diagnosis of sex chromosome abnormalities.
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**Constructing 'health', defining 'choice': legal and policy perspectives on the post-PGD embryo in four jurisdictions**
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Anticipating issues related to increasing preimplantation genetic diagnosis use: a research agenda.
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Faust, Halley S.
Should we select for genetic moral enhancement? A thought experiment using the MoralKinder (MK+) haplotype.
Theoretical Medicine and Bioethics 2008; 29(6): 397-416
Abstract: By using preimplantation haplotype diagnosis, prospective parents are able to select embryos to implant through in vitro fertilization. If we knew that the naturally-occurring (but theoretical) MoralKinder (MK+) haplotype would predispose individuals to a higher level of morality than average, is it permissible or obligatory to select for the MK+ haplotype? I.e., is it moral to select for morality? This paper explores the various potential issues that could arise from genetic moral enhancement.
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Excursus on genetic testing, selective abortion, and the new eugenics
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Gunning, Jennifer
The broadening impact of preimplantation genetic diagnosis: a slide down the slippery slope or meeting market demand?

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Wolbert, H.C. Werner
Is there a duty to create saviour siblings?

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Suthers, Graeme
Privacy and property issues for a familial cancer service
Abstract: Approximately 1 in 30 people develop cancer due to an underlying familial predisposition. Genetic counselling and testing for people with (and at risk of) familial cancer are becoming more widely available, but service providers need to address challenging issues in relation to privacy and property. As in any counselling situation, a genetic counsellor seeks to ensure that the principles of autonomy, confidentiality, beneficence, and equity operate in favour of the client. But in dealing with a familial disorder, the application of these principles to the individual must be balanced with the potential for these principles to apply to other family members. This paper summarises the recent experience of a familial cancer service in seeking to avoid situations in which these principles, operating for both individual clients and their relatives, can come into conflict.

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Newell, Christopher; Peterson, Madelyn M.; Bridle, Lisa
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Prenatal screening and counseling in Iran and ethical dilemmas
Community Genetics 2008; 11(5): 267-272

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**Public perception of prenatal genetic testing: arguments put forward by the public during a participatory policy project in the Netherlands**
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Steinbock, Bonnie

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Reproductive Biomedicine Online 2007 December; 15 (Suppl 2): 38-42

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**Silence between patients and doctors: the issue of self-determination and amniocentesis in Japan**

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Ehrich, Kathryn; Farsides, Bobbie; Williams, Clare; Scott, Rosamund

**Testing the embryo, testing the fetus**
Clinical Ethics 2007 December; 2(4): 181-186

**Abstract:** This paper stems from an ethnographic, multidisciplinary study that explored the views and experiences of practitioners and scientists on social, ethical and clinical dilemmas encountered when working in the area of pre-implantation genetic diagnosis for serious genetic disorders. We focus here on staff perceptions and experiences of working with embryos and helping women/couples to make choices that will result in selecting embryos for transfer and disposal of 'affected' embryos, compared to the termination of affected pregnancies following prenatal diagnosis. Analysis and discussion of our data led us to consider the possible advantages of pre-implantation genetic diagnosis and whether a gradualist account of the embryo's and fetus's moral status can account for all of these, particularly since a gradualist account concentrates on the significance of time (developmental stage) and makes no comment as to the significance of place (in vitro, in utero).

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Kaimal, Girija; Steinberg, Annie G.; Ennis, Sara; Harasink, Sue Moyer; Ewing, Rachel; Li, Yuelin

Parental narratives about genetic testing for hearing loss: a one year follow up study
Journal of Genetic Counseling 2007 December; 16(6): 775-787

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A national survey of genetic counselors' personal values
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Genetic counselors' experiences of moral value conflicts with clients [abstract]
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Alliman, S.; McCarthy Veach, P.; Bartels, D.; Bower, M.; James, C.; LeRoy, B.

Ethical and professional challenges in clinical practice: a comparative analysis of Australian and U.S. genetic counselors [abstract]
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Views on religion and abortion: a comparison of genetic counselors and the general population [abstract]
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Recontacting former patients regarding BRCA1/2 rearrangement testing: opinions and practices of genetics professionals [abstract]
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"Eugenics" by another name? [commentary]

Canadian Journal of Neurological Sciences = Le Journal Canadien des Sciences Neurologiques 2007 November; 34(4): 494-495

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Hashiloni-Dolev, Yael; Shkedi, Shiri

On new reproductive technologies and family ethics: pre-implantation genetic diagnosis for sibling donor in Israel and Germany.

Social Science and Medicine 2007 November; 65(10): 2081-2092

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Ehrich, Kathryn; Williams, Clare; Farsides, Bobbie; Sandall, Jane; Scott, Rosamund

Choosing embryos: ethical complexity and relational autonomy in staff accounts of PGD

Sociology of Health and Illness 2007 November; 29(7): 1091-1106

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MacKenzie, Catriona

Feminist bioethics and genetic termination

Bioethics 2007 November; 21(9): 515-516

Abstract: A brief discussion of how relational autonomy, phenomenological theories of embodiment and narrative approaches to clinical ethics can open up the space for more subtle feminist ethical reflection about genetic termination.

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Thachuk, Angela

The space in between: narratives of silence and genetic terminations

Bioethics 2007 November; 21(9): 511-514

Abstract: In North America, prenatal testing and genetic terminations are becoming clinically normalized. Yet despite this implied social acceptance, open discussions surrounding genetic terminations remain taboo and silenced. Women are socially isolated, their experiences kept secret, and their grief disenfranchised. The lack of social consensus regarding genetic terminations, the valorization of scientific knowledge, and the bioethical framing of the issue as a matter of personal choice and autonomy collectively serve to reify this silence. In many respects genetic screening offers a form of technological surveillance procuring security from the unwanted kind of child. Yet the manner in which ‘the unwanted kind of child’ is understood varies from context to context. While we carry with us the consequences of decisions made elsewhere, the institutionalized discourses upon which these decisions are made are not always so readily transportable. One must somehow reconcile ‘the unwanted kind of child’ of the biomedical model with ‘the unwanted kind of child’ who was to be a member of one's family. In this paper, my intention is not to
engage in the broader debate surrounding prenatal testing and genetic terminations. Rather, I employ my clinical encounters with these practices to illustrate the absence of an ethical language that might do justice to the experiences such practices construct. The limitations of a bioethical discourse that remains abstracted from lived experience are discussed.

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Braude, Peter; Flinter, Frances

*Use and misuse of preimplantation genetic testing*

BMJ: British Medical Journal 2007 October 13; 335(7623): 752-754

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*Experiencing the genetic body: parents' encounters with pediatric clinical genetics*

Medical Anthropology 2007 October-December; 26(4): 355-391

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Case, Amy P.; Ramadhani, Tunu A.; Canfield, Mark A.; Wicklund, Catherine A.

*Awareness and attitudes regarding prenatal testing among Texas women of childbearing age*

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Hoffman, Jan

Where risk and choice and hope converge, a guiding voice

New York Times 2007 September 18; p. F5, F10

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Why parents have no duty to select 'the best' children
Clinical Ethics 2007 September; 2(3): 149-154
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Living in the shadow of BRCA1 [editorial]
Clinical Ethics 2007 September; 2(3): 110-112
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The appropriate extent of pre-implantation genetic diagnosis: health professionals' and scientists' views on the requirements for a 'significant risk of a serious genetic condition'
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Information and informed consent for neonatal screening: opinions and preferences of parents.
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Complexities in reproductive choice: medical professionals' attitudes to and experiences of pre-implantation genetic diagnosis.
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CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 478-482

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CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 475-478

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Asch, Adrienne; Wasserman, Davis
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CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 468-475

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Testing, terminating, and discriminating
CQ: Cambridge Quarterly of Healthcare Ethics 2007 Fall; 16(4): 462-468

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Mahowald, Mary B.
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Screening for fetal abnormalities: from a health technology assessment report to a national statute
International Journal of Technology Assessment in Health Care 2007 Fall; 23(4): 436-442

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Merkel, Reinhard
Arbeitsgruppe Pränataldiagnostik


Ethik in der Medizin 2007 September; 19(3): 221-225

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Zeiler, Kristin

Shared decision-making, gender and new technologies

Medicine, Health Care and Philosophy 2007 September; 10(3): 279-287

Abstract: Much discussion of decision-making processes in medicine has been patient-centred. It has been assumed that there is, most often, one patient. Less attention has been given to shared decision-making processes where two or more patients are involved. This article aims to contribute to this special area. What conditions need to be met if decision-making can be said to be shared? What is a shared decision-making process and what is a shared autonomous decision-making process? Why make the distinction? Examples are drawn from the area of new reproductive medicine and clinical genetics. Possible gender-differences in shared decision-making are discussed.

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Himmel, Wolfgang; Michelmann, Hans Wilhelm

Access to genetic material: reproductive technologies and bioethical issues

Reproductive Biomedicine Online 2007 September; 15(Supplement 1): 18-24

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Controversies and challenges of array comparative genomic hybridization in prenatal genetic diagnosis

Genetics in Medicine 2007 September; 9(9): 596-599

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The future (r)evolution of preimplantation genetic diagnosis/human leukocyte antigen testing: ethical reflections


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Doerflinger, Richard M.

**Washington insider:** House passes amended Genetic Nondiscrimination Bill; continued impasse on stem cell legislation, new executive order; defeat of deceptive human cloning bill; Supreme Court decision on partial-birth abortion

National Catholic Bioethics Quarterly 2007 Autumn; 7(3): 455-463

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**Preimplantation genetic diagnosis: current and future perspectives**


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**Choosing disability: preimplantation genetic diagnosis and negative enhancement**


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**Utilization of prenatal diagnosis and termination of pregnancies for the prevention of Down syndrome in Israel.**

Israel Medical Association Journal 2007 August; 9(8): 600-602

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Guilam, Maria Cristina R.; Corrêa, Marilena C.D.V.

**Risk, medicine and women: a case study on prenatal genetic counselling in Brazil**

Developing World Bioethics 2007 August; 7(2): 78-85

**Abstract:** Genetic counselling is an important aspect of prenatal care in many developed countries. This tendency has also begun to emerge in Brazil, although few medical centres offer this service. Genetic counselling provides prenatal risk control through a process of individual decision-making based on medical information, in a context where diagnostic and therapeutic possibilities overlap. Detection of severe foetal anomalies can lead to a decision involving possible termination of pregnancy. This paper focuses on medical and legal consequences of the detection of severe foetal anomalies, mainly anencephaly and Down syndrome, and in light of the fact that abortion is illegal in Brazil. The discussion is based on the literature and empirical research at a high-complexity public hospital in Rio de Janeiro.

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Attitudes of German infertile couples towards preimplantation genetic diagnosis for different uses: a comparison to international studies
Human Reproduction 2007 July; 22(7): 2051-2057
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Gilbar, Roy
Communicating genetic information in the family: the familial relationship as the forgotten factor
Journal of Medical Ethics 2007 July; 33(7): 390-393
Abstract: Communicating genetic information to family members has been the subject of an extensive debate recently in bioethics and law. In this context, the extent of the relatives' right to know and not to know is examined. The mainstream in the bioethical literature adopts a liberal perception of patient autonomy and offers a utilitarian mechanism for solving familial tensions over genetic information. This reflects a patient-centred approach in which disclosure without consent is justified only to prevent serious harm or death to others. Based on a legal and bioethical analysis on the one hand, and an examination of empirical studies on the other, this paper advocates the adoption of a relational perception of autonomy, which, in the context of genetics, takes into account the effect that any decision—whether to disclose or not to disclose—will have on the familial relationship and the dynamics of the particular family. Adding this factor to the criteria usually advocated by lawyers and ethicists will facilitate reaching a sensitive decision, which recognises the various interests of family members beyond the risk to physical health. Taking this factor into account will require a process of deliberation both between doctors and patients, and in the family. It will also require a relaxation of medical confidentiality, as the family rather than the patient is gradually perceived as the unit of care. Moreover, adopting such a relational approach will accord with current views of doctors and patients who base their decision primarily on the nature of the familial relationship.
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Fetal conditions and fatal decisions: ethical dilemmas in ultrasound screening in Vietnam.
Social Science and Medicine 2007 June; 64(11): 2248-2259
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Communicating genetic information in families—a review of guidelines and position papers.
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Soini, S.
Preimplantation genetic diagnosis (PGD) in Europe: diversity of legislation a challenge to the community and its citizens
Abstract: Preimplantation genetic diagnosis (PGD) aims to safeguard the reproductive confidence of couples who have an increased risk of having a child with a serious hereditary disease. Non-directive genetic counselling is an essential part of PGD. Lately, performance of PGD for some new and non-medical indications, such as selecting for a tissue-matching embryo for a saviour sibling, or sex-selection for family-balancing, has raised ethical concerns. Who decides when to perform PGD, and for which conditions? The European member states have very diverse regulation on PGD. Some countries totally ban PGD, while the others keep close track of the new applications. The people in need of PGD seek it in the other member states. These cross-border treatments cause psychological stress and pose many so far unresolved legal questions. The individuals need more information about all the aspects of PGD. This article analyses contemporary indications for PGD in Europe and relevant ethical discussion, and second, shows the diversity in regulation and reflects the consequences thereof.
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CMAJ/JAMC: Canadian Medical Association Journal 2007 May 8; 176(10): 1445-1446
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Abandoning the common law: medical negligence, genetic tests and wrongful life in the Australian High Court.
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Selecting "saviour siblings": reconsidering the regulation in Australia of pre-implantation genetic diagnosis in conjunction with tissue typing.

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Providers' knowledge of genetics: a survey of 5915 individuals and families with genetic conditions
Genetics in Medicine 2007 May; 9(5): 259-267

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Mohler would favor altering 'gay' fetus [news]
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Attitudes towards preimplantation genetic diagnosis—a German and Japanese comparison

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How important is consent in maternal serum screening for Down syndrome in France? Information and consent evaluation in maternal serum screening for Down syndrome: a French study [review]
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Patient decision-making for clinical genetics
Nursing Inquiry 2007 March; 14(1): 13-22
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Health Care Ethics USA 2007 Spring; 15(2): 4-8
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Latimer, Joanna
 Becoming in-formed: genetic counselling, ambiguity and choice
 Abstract: The paper presents findings from an ethnography of dysmorphology, a specialism in genetic medicine, to explore genetic counselling as a process through which parents ‘become informed.’ Current professional and policy debate over the use of genetic technology in medicine emphasises the need for informed choice making, and for genetic services that provide parents with what is referred to as ‘non-directive genetic counselling.’ In the paper the process of becoming informed is shown to be very specific and to have its own effects. Specifically, genetics is performed in dysmorphology as a space of ambiguity and uncertainty. In addition, parents are engaged by the clinic as participants in the very processes through which their child, and perhaps their family, are clinically classified. The paper examines the effects of parents’ immersion in this clinical space of deferral to suggest how the need for reproductive choice, and calculation, is predicated upon clinical processes that shift parents between the experience of definition and uncertainty. The paper thus troubles simple stories about autonomous and informed choice, particularly reproductive choice, as icons of contemporary versions of what it is to be fully human.
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**Ethical considerations of early (first vs. second trimester) risk assessment disclosure for trisomy 21 and patient choice in screening versus diagnostic testing.**

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Shuster, Evelyne
**Microarray genetic screening: a prenatal roadblock for life?**
Lancet 2007 February 10-16; 369(9560): 526-529

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**One for the album**
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**The first cut**
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Korenromp, Marijke J.; Page-Christiaens, Godelieve C.M.L.; van den Bout, Jan; Mulder, Eduard J.H.; Visser, Gerard H.A.
**Maternal decision to terminate pregnancy in case of Down syndrome**
American Journal of Obstetrics and Gynecology 2007 February; 196(2): 149
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Baggot, Paddy Jim; Baggot, M.G.
**Obstetric genetic counseling for lethal anomalies**
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**The genomic era and serious mental illness: a potential application for psychiatric genetic counseling**
Psychiatric Services 2007 February; 58(2): 254-261

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**Spiritual assessment in genetic counseling**
Journal of Genetic Counseling 2007 February; 16(1): 41-52

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Human Reproduction 2007 February; 22(2): 323-326

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Silversides, Ann
**The wide gap between genetic research and clinical needs [news]**

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Bauer, Patricia E.
**What's lost in prenatal testing [op-ed]**
Lucast, Erica K.  
**Informed consent and the misattributed paternity problem in genetic counseling**  
Bioethics 2007 January; 21(1): 41-50  
**Abstract:** When misattributed paternity is discovered in the course of genetic testing, a genetic counselor is presented with a dilemma concerning whether to reveal this information to the clients. She is committed to treating the clients equally and enabling informed decision making, but disclosing the information may carry consequences for the woman that the counselor cannot judge in advance. A frequent suggestion aimed at avoiding this problem is to include the risk of discovering nonpaternity in the informed consent process for counseling. In this paper I argue that such a move does not resolve the problem, because the conflict hinges on the interpretation of equality on which the counselor operates. Given the principles of genetic counseling, neither construal of equality yields a satisfactory solution to the conflict. In fact, I conclude that including nonpaternity in informed consent is not endorsed by either view, and we are still left with the question of what to do should nonpaternity be discovered. I suggest a compromise position concerning disclosure, involving revealing relevant genetic information but withholding nonpaternity when possible.

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Gunning, Jennifer
**A gain for autonomy and reproductive choice: the issue of 'saviour siblings' resolved**
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**The human condition and the pursuit of perfection in human reproduction**
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Featherstone, Katie; Gregory, Maggie; Atkinson, Paul
**The moral and sentimental work of the clinic: the case of genetic syndromes**
Call number: **QH438.7 .N49 2007**

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Simpson, Bob
**Negotiating the therapeutic gap: prenatal diagnostics and termination of pregnancy in Sri Lanka**
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Knoepffler, Nikolaus
**Tolerance and respect in bioethical conflicts**
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Buxton, Jess
**Unforeseen uses of preimplantation genetic diagnosis -- ethical and legal issues**
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Gynaecologists and geneticists as storytellers: disease, choice and normality as the fabric of narratives on preimplantation genetic diagnosis


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Deech, Ruth; Smajdor, Anna

Saviour siblings, designer babies, and sex selection


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Genetic counselling


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Browner, C.H.

Can gender "equity" in prenatal genetic services unintentionally reinforce male authority?


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Different perceptions and attitudes regarding prenatal testing among service providers and consumers in Israel

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Association of ultrasound findings with decision to continue Down syndrome pregnancies

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*Straightening your heir: on the constitutionality of regulating the use of preimplantation technologies to select preembryos or modify the genetic profile thereof based on expected sexual orientation [note]*

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*The conflicts between individuals, families and society, as well as between different family members, embodied in reproductive genetics*
In her: *A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany.* Dordrecht: Springer, 2007: 131-146
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"Wrongful life", in the eyes of the law, the counselors and the disabled
In her: *A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany.* Dordrecht: Springer, 2007: 119-130
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*Genetic counselors' moral practices*
In her: *A Life (Un)Worthy of Living: Reproductive Genetics in Israel and Germany.* Dordrecht: Springer, 2007: 63-81
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**What choices should we be able to make about designer babies? A Citizens' Jury of young people in South Wales**
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**Are the present day "designer babies" a threat to humankind?**
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Modra, Lucy
**Prenatal genetic testing kits sold at your local pharmacy: promoting autonomy or promoting confusion?**
Bioethics 2006 September; 20(5): 254-263

**Abstract:** Research groups around the world are developing non-invasive methods of prenatal genetic diagnosis, in which foetal cells are obtained by maternal blood test. Meanwhile, an increasing number of genetic tests are sold directly to the public. I extrapolate from these developments to consider a scenario in which PNGD self-testing kits are sold directly to the public. Given the opposition to over-the-counter genetic tests and the continuing controversy surrounding PNGD, it is reasonable to expect objections to PNGD self-testing kits. I focus on one potential objection, that PNGD self-testing kits would undermine the autonomy of potential test subjects. More specifically, that 'direct to the public' PNGD would fail to ensure that consumers exercise authority in the following PNGD-related choices: Should I use PNGD? Based on the results of the PNGD test, should I continue or terminate my pregnancy? Under the current system, PNGD is provided by health care practitioners, who are required to counsel women both before and after the test. In contrast, 'direct to the public' PNGD would allow women to make their PNGD-related decisions outside the context of the health care system. I compare these two decision-making contexts, arguing that the health care system is not unequivocally better at promoting the autonomy of potential test subjects. Therefore the promotion of autonomy does not constitute a strong argument against such test kits. Other objections may be more persuasive, so I do not offer an overall assessment of the acceptability of 'direct to the public' PNGD.

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The unleashing of genetic terminology: how genetic counselling mobilizes for risk management
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New Genetics and Society 2006 August; 25(2): 159-170
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Belgian loophole allows Swiss parents a "saviour" baby

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The obstetrician's view: ethical and societal implications of non-invasive prenatal diagnosis.
Prenatal Diagnosis 2006 July; 26(7): 631-634

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The issue of constitutional law legitimacy on "human assisted reproduction" between reasonableness of the choices and effectiveness of the protection of all involved subjects
Preimplantation genetic diagnosis: development and regulation

**Abstract:** Pre-implantation genetic diagnosis (PGD) is used to biopsy and analyse embryos created through in vitro fertilisation (IVF) to avoid implanting an embryo affected by a mutation or chromosomal abnormality associated with serious illness. It reduces the chance that the parents will be faced with a difficult decision of whether to terminate the pregnancy, if the disorder is detected during the course of gestation. PGD is widely accepted for this purpose although there have been suggestions that such procedures have the effect of de-valuing persons in the community with disabilities. PGD potentially has other more controversial purposes, including the selection of the sex of the baby for personal preferences such as balancing the family, rather than to avoid a sex-linked disorder. Recently PGD has become available to create a donor child who is Human Leukocyte Antigen (HLA) matched with a sibling in need of stem cell transplant. In most cases the intention is to utilise the cord blood. However, an HLA-matched child could potentially be required to be a donor of tissues and organs throughout life. This may arise should the initial cord blood donation fail for any one of several reasons, such as inadequate cord blood cell dose, graft failure after cord blood transplant, or the recipient child experiencing a recurrence of the original illness after transplant. However, such on-going demands could also arise if a HLA-matched child was fortuitously conceived by natural means. As such, the issue is not PGD, but rather whether to harvest bone marrow or a solid organ from a child. This raises the question of whether there should be limits and procedures to protect such children from exploitation until they achieve sufficient competence to be able to make mature and autonomous decisions about whether to donate, even if the consequence may in some cases be that it is too late to save the sibling. Additionally, the parents may not be able to make a dispassionate decision, when they have a conflict of interests between their children. As such, parents may not be the best proxy decision-makers in this area and the decision might be better made by an
independent authority or court. This paper considers ethical and legal issues arising from PGD. It will compare the willingness of the HFEA in the United Kingdom to allow this process to be used even in cases where the condition suffered by the sibling is non-heritable, with the more restrictive guidelines in New Zealand and questions the constitutional basis on which ethics committees develop policy in the absence of a legislative framework.

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Bromage, D.I.
Prenatal diagnosis and selective abortion: a result of the cultural turn?
Medical Humanities 2006 June; 32(1): 38-42
Abstract: There is a growing trend in obstetric medicine of prenatal diagnosis and the selective abortion of foetuses that are likely to be born with a disability. Reasons commonly given to explain this trend include the financial implications of screening and testing policies, the disruption to families caused by the birth of a child with a disability, and the potential quality of life of the unborn child. This paper reflects upon another possible reason for this. It is argued that it is, in part, a consequence of our attitudes towards disability and a pursuit of aesthetic perfection. These attitudes arise from a social context that may be explained by considering the effect on the disabled community of the transition from modernity to postmodernity. This shift is demonstrated by inspecting some of the synonymous developments in art history. It is suggested that this "cultural turn" may have both helped and hindered people with disabilities, but the hypothesis requires further testing. This could best be achieved with a qualitative study of what motivates parental decision making in the obstetric unit.

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No easy answers [editorial]
Nature 2006 May 18; 441(7091): 255

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Prenatal panel screening considerations for non-neuronopathic Gaucher disease in the Ashkenazi-Jewish population
Israel Medical Association Journal 2006 May; 8(5): 347-350

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Social Science & Medicine 2006 May; 62(10): 2360-2372

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Beyond race or ethnicity and socioeconomic status: predictors of prenatal testing for Down syndrome

Kuppermann, Miriam; Learman, Lee A.; Gates, Elena; Gregorich, Steven E.; Nease, Robert F., Jr.; Lewis, James; Washington, A. Eugene


Abstract: BACKGROUND: Although maternal serum screening (MSS) for Down's syndrome has become routinely available in most obstetric clinics in many countries, few studies have addressed the reasons why women agree to undergo the MSS test. OBJECTIVES: The aims of this study were to describe the circumstances in which MSS was offered to pregnant women and their reasons for undertaking it. METHODS: Participant observation and in depth interviews were used in this study; specifically, the experiences of women who had a positive result for MSS and who then followed this up with amniocentesis were examined. The interviewees were twenty six mothers aged between 22 and 35 years. The interviews were audio taped and transcribed for analysis. The results were analysed by the constant comparative method. RESULTS: This study identified the reasons on which pregnant women appeared to base their decisions when undergoing MSS. The reasons were first, the recognition that the procedure was a prenatal routine procedure; second, the need to avoid the risk of giving birth to a baby with Down's syndrome, and third, a trust in modern technology and in the professional authorities. CONCLUSIONS: This study offers insights into the informed choice made by women with a positive MSS result. The reasons for undergoing MSS might help health professionals and policy makers to reflect on their practice and this may, in turn, improve the quality of prenatal care during MSS.

How many human embryonic stem cell lines are sufficient? A. U.S. perspective [editorial]

Civin, Curt I.; Rao, Mahendra S.


Abstract: There has been substantial debate over the number of human embryonic stem cell (hESC) lines that are sufficient for research. In this editorial, the U.S. perspective will be reviewed.

How many human embryonic stem cell lines are sufficient? A. U.S. perspective [editorial]

Civin, Curt I.; Rao, Mahendra S.


Abstract: There has been substantial debate over the number of human embryonic stem cell (hESC) lines that are sufficient for research. In this editorial, the U.S. perspective will be reviewed.
Hull, Richard J.
Cheap listening? -- Reflections on the concept of wrongful disability
Bioethics 2006 April; 20(2): 55-63

Abstract: This paper investigates the concept of wrongful disability. That concept suggests that parents are morally obligated to prevent the genetic transmission of certain conditions and so, if they do not, any resulting disability is 'wrongful'. In their book From Chance to Choice, Buchanan, Brock, Daniels and Wikler defend the concept of wrongful disability using the principle of avoidability via substitution. That principle is scrutinised here. It is argued...
that the idea of avoidability via substitution is both conceptually problematic and rather insensitive. Instead, it is suggested that the question of whether or not bringing a particular disability about is wrongful does not simply hinge on whether or not substitution takes place. Rather, it involves an evaluation of parental aspirations and responsibilities. It is argued that the desire need not be responsible for creating challenges for others that lie outside what is perceived to be an acceptable range provides a justification for termination of pregnancy on the grounds of projected disability that neither commits one to wrongful life claim, nor requires that one substitute a non-disabled child instead. The ramifications of such an approach are explored. The paper concludes by suggesting that the question of what is considered to be an acceptable range of human capability is an increasingly important one. It is argued that, when addressing that question, we should be acutely aware of the social context that may go some way to define what we consider to be an acceptable range.
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Newson, Ainsley

*Should parental refusals of newborn screening be respected?*

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McMahon, William M.; Baty, Bonnie Jeanne; Botkin, Jeffrey

*Genetic counseling and ethical issues for autism*

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Mayor, Susan

*Babies born after preimplantation genetic diagnosis need follow-up [news]*
BMJ: British Medical Journal 2006 February 4; 332(7536): 254

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Fanos, Joanna H.; Spangner, Kerstin A.; Musci, Thomas J.

*Attitudes toward prenatal screening and testing for Fragile X*
Genetics in Medicine 2006 February; 8(2): 129-133

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Burke, Wylie; Press, Nancy

*Ethical obligations and counseling challenges in cancer genetics*

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Kapterian, Gisele

*Harriton, Waller and Australian negligence law: is there a place for wrongful life?*
Journal of Law and Medicine 2006 February; 13(3): 336-351

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Grob, Rachel N.
TESTING BABY: PARENTS' PERSPECTIVES ON GENETIC DIAGNOSIS
Call number: RB155.65 .G76 2006a

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Franklin, Sarah and Roberts, Celia
BORN AND MADE: AN ETHNOGRAPHY OF PREIMPLANTATION GENETIC DIAGNOSIS
Call number: RG628.3 .P74 F73 2006

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Zahraa, Mahdi; Shafie, Shaniza
An Islamic perspective on IVF and PGD, with particular reference to Zain Hashmi, and other similar cases
Arab Law Quarterly 2006; 20: 152-180
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Lehmann, Karl
The prevention of genetic illnesses from the point of view of pastoral care
Dolentium Hominum 2006; 21(1): 88-96
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Milunsky, Aubrey
Judgement, error and negligence in genetic aspects of maternal fetal medicine
Dolentium Hominum 2006; 21(1): 46-49
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Preimplantation genetic diagnosis: an overview of socio-ethical and legal considerations.
Annual Review of Genomics and Human Genetics 2006; 7: 201-221
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Haker, Hille
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In: Hilpert, Konrad; Mieth, Dietmar , eds. Kriterien biomedizinischer Ethik: Theologische Beiträge zum
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Communication of genetic information within families: the case for familial comity
Journal of Bioethical Inquiry 2006; 3(3): 161-166
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McDaniel, Susan H.; Peters, June; Acheson, Louise
Professional collaboration to assess and care for genetic disorders
Call number: RB155.I525 2006

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Ethical issues in reproductive genetics
Call number: RB155.I525 2006

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Polansky, Samara
Overcoming the obstacles: a collaborative approach to informed consent in prenatal genetic screening
Health Law Journal 2006; 14: 21-43
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Reilly, Philip
Preimplantation genetic diagnosis
Call number: QH431.R383 2006

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Resnik, David B.; Vorhaus, Daniel B.

**Genetic modification and genetic determinism**


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Mahowald, Mary Briody

**Preconception and prenatal decisions**


Call number: R725.5 .M34 2006

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Holm, Søren

**Wrongful life, the welfare principle and the non-identity problem: some further complications**


Call number: K3601 .F57 2006

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Freeman, Michael

**Saviour siblings**


Call number: K3601 .F57 2006

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Carlson, Elof Axel

**Prenatal diagnosis and an alleged eugenics through the back door**


Call number: Q175.35 .C37 2006

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Baldwin, Thomas

**Choosing who: what is wrong with making better children?**


Call number: K3611 .A77 F73 2006

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Deane-Drummond, Celia

**Genetic counselling**

In her: Genetics and Christian Ethics. Cambridge: Cambridge University Press, 2006: 101-123
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Tonti-Filippini, Nicholas
Reproductive discrimination
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Skene, Loane
Should the law limit genetic tests on embryos and foetuses?
University of New South Wales Law Journal 2006; 29(2): 250-253
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de Wert, Guido; Geraedts, Joep P.M.
Preimplantation genetic diagnosis for hereditary disorders that do not show a simple Mendelian pattern: an ethical exploration
Call number: RG133.5.C6685 2006

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Sharpe, Neil F.; Carter, Ronald F.
Prenatal screening and diagnosis
Call number: RB155.6.S74 2006

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Reiner, William G.
Prenatal gender imprinting and medical decision-making: genetic male neonates with severely inadequate penises
Call number: RC883.E84 2006

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Cirion, Aitziber Emaldi
Preimplantation diagnosis: problems and future perspectives
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Spar, Debora L.
**Designing babies: fixing flaws and pursuing perfection**
Call number: **RG133.5 .S666 2006**

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Siddiqui, Faraz
**Assessing the ethicality of pre-implantation genetic diagnosis beyond the discourse of eugenics**

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Chipman, Peter
**The moral implications of prenatal genetic testing**
Penn Bioethics Journal 2006; 2(2): 13-16

**Abstract:** The advance of medical technology now permits many genetic tests to be administered to a fetus in the womb. The goal of this testing is to determine the potential for genetically based disorders and disabilities. The use of these tests has major implications on the decision of a parent to abort a child based on what information they find in the prospective child's genes. Advocates of prenatal testing argue that it enables the families of these prospective children to make an informed decision when faced with the possibility of disability. I argue that this choice is drastically limited by social coercion through a discriminatory and stereotyped perception of the disabled community. Permitting an uncontrolled barrage of prenatal genetic tests will further promote the stereotype of a disabled life, and thus hinders our societal goal to recognise and promote equality and individuality. Which disabilities to test for, or what genes to search for, is a judgement that should be made only through extensive consultation with members of the disabled community, including individuals who have suffered from or who have been directly associated with the disability which is said to be tested.

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Check, Erika
**Screen test [news]**
Nature 2005 December 8; 438(7069): 733-734

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**Unapproved tests on a chip [editorial]**
Nature 2005 December 8; 438(7069): 711

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Nationale Ethikkommission im Bereich Humanmedizin (Schweiz) / National Advisory Commission on Biomedical Ethics (Switzerland)
Präimplantationsdiagnostik

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Alonso Bedate, Carlos
Ethical and legal implications of the use of molecular biology in the clinic
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Preimplantation Genetic Diagnosis:
Bern, Switzerland: Swiss National Advisory Commission on Biomedical Ethics; 2005 December, 19 p.

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de Wert, Guido
Preimplantation genetic diagnosis: the ethics of intermediate cases [opinion]
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Choices and Boundaries. Should people be able to select embryos free from an inherited susceptibility to cancer?

http://www.hfea.gov.uk/AboutHFEA/HFEAPolicy/Choicesandboundaries/Choices_Boundaries.pdf (link may be outdated)

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Motluk, Alison
**Which IVF test is best for baby? [news]**
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**Preimplantation HLA typing: having children to save our loved ones**
Journal of Medical Ethics 2005 October; 31(10): 582-586

Abstract: Preimplantation tissue typing has been proposed as a method for creating a tissue matched child that can serve as a haematopoietic stem cell donor to save its sick sibling in need of a stem cell transplant. Despite recent promising results, many people have expressed their disapproval of this method. This paper addresses the main concerns of these critics: the risk of preimplantation genetic diagnosis (PGD) for the child to be born; the intention to have a donor child; the limits that should be placed on what may be done to the donor child, and whether the intended recipient can be someone other than a sibling. The author will show that these concerns do not constitute a sufficient ground to forbid people to use this technique to save not only a sibling, but also any other loved one's life. Finally, the author briefly deals with two alternative scenarios: the creation of a human leukocyte antigen (HLA) matched child as an insurance policy, and the banking of HLA matched embryos.

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Is conceiving a child to benefit another against the interests of the new child?
Journal of Medical Ethics 2005 June; 31(6): 341-342

Abstract: Conceiving a child by way of embryo selection and tissue matching to benefit a sick sibling is generally justified on the grounds that as well as the potential to save the sick child, there is a benefit for the new baby. The new baby is selected so he or she will not have the disease suffered by the first child. It is not possible, however, to select against conditions for which there is no test and Jamie Whitaker's birth is a case where the process of in vitro fertilisation with tissue matching is viewed as being of benefit only to a third party—the sick child. Some people object to using the technology for this purpose. There are also good reasons to argue that the technology should be used to save a sick child, and that it would be morally remiss for Jamie's parents not to consent to the use of his cord blood.

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The unwitting sacrifice problem
Journal of Medical Ethics 2005 June; 31(6): 327-332

Abstract: The diagnosis of bipolar disorder has been linked to giftedness of various sorts and this raises a special problem in that it is likely that the condition has a genetic basis. Therefore it seems possible that in the near future we will be able to detect and eliminate the gene predisposing to the disorder. This may mean, however, that, as a society, we lose the associated gifts. We might then face a difficult decision either way in that it is unclear that we are preventing an unalloyed bad when we diagnose and eliminate bipolar disorder through prenatal genetic testing and yet if we allow the individual to be born we are condemning that person to being an unwitting sacrifice in that they might well suffer considerable net distress as a result of our need to keep our gene pool enriched in the relevant way.

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*Patients' resistance to risk information in genetic counseling for BRCA1/2*

Archives of Internal Medicine 2005 March 14; 165(5): 523-529

**Abstract:** BACKGROUND: Risk information from health care providers is relevant to and used in nearly all medical decisions. Patients often misunderstand their risks, yet little is known about the risk perception that patients derive from risk communications with health care providers. This study examines patients' risk perceptions following communication with health care providers during genetic counseling about the risks of breast cancer and BRCA1/2 mutations. METHODS: A prospective, longitudinal study was conducted from October 2002 to February 2004 of women who received genetic counseling. The women completed a survey before their counseling and a telephone interview in the week after the counseling. Main outcome measures included change from precounseling in risk perception and accuracy of postcounseling risk perception (relative to actual risk information communicated). RESULTS: A total of 108 women agreed to participate in the study. The women's postcounseling risk perceptions were significantly lower than their precounseling risk perceptions (breast cancer: 17%, P<.001; mutation: 13%, P<.001) but were significantly higher than the actual risk information communicated (breast cancer: 19%, P<.001; mutation: 24%, P<.001). Accuracy of breast cancer risk perception but not mutation risk perception was associated with precounseling worry (P = .04), even after adjusting for trait anxiety (P = .01). CONCLUSIONS: This research demonstrates patients' resistance to risk information. Inappropriately high risk perception derived from a risk communication with a health care provider can lead patients to make different, and potentially worse, medical decisions than they would with an accurate risk perception and to be unnecessarily distressed about their risk.

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**Should selecting saviour siblings be banned?**
Journal of Medical Ethics 2004 December; 30(6): 533-537

**Abstract:** By using tissue typing in conjunction with preimplantation genetic diagnosis doctors are able to pick a human embryo for implantation which, if all goes well, will become a "saviour sibling", a brother or sister capable of donating life-saving tissue to an existing child. This paper addresses the question of whether this form of selection should be banned and concludes that it should not. Three main prohibitionist arguments are considered and found wanting: (a) the claim that saviour siblings would be treated as commodities; (b) a slippery slope argument, which suggests that this practice will lead to the creation of so-called "designer babies"; and (c) a child welfare argument, according to which saviour siblings will be physically and/or psychologically harmed.

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Godard, Beatrice; Cardinal, Genevieve
**Ethical implications in genetic counseling and family studies of the epilepsies**
Epilepsy and Behavior 2004 October; 5(5): 621-626

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Krones, Tanja; Richter, Gerd
**Preimplantation Genetic Diagnosis (PGD): European perspectives and the German situation**

**Abstract:** This article gives an overview about the ethical dispute on preimplantation genetic diagnosis (PGD), its legal status and its practical usage in Europe. We provide a detailed description of the situation in Germany wherein prenatal diagnosis is routinely applied, but PGD is prohibited on the basis of the internationally unique embryo protection act (EPA) that was put into force in 1991. Both PGD and stem cell research were vigorously debated in Germany during the last four years. As regards the PGD debate specifically, the voices of the ones directly affected were not adequately taken into consideration. We describe the predominant lines of argumentation in this debate and some essential results of our "bioethical field study" of opinions on and usage of PGD in Germany and their implications for the German legislation and ethical theory.

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Hayry, Matti
**There is a difference between selecting a deaf embryo and deafening a hearing child**
Journal of Medical Ethics 2004 October; 30(5): 510-512

**Abstract:** If genetic diagnosis and preimplantation selection could be employed to produce deaf children, would it be acceptable for deaf parents to do so? Some say no, because there is no moral difference between selecting a deaf embryo and deafening a hearing child, and because it would be wrong to deafen infants. It is argued in this paper, however, that this view is untenable. There are differences between the two activities, and it is perfectly possible to condone genetic selection for deafness while condemning attempts to deafen infants at birth.
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Farsides, B.; Williams, C.; Alderson, P.

**Aiming towards "moral equilibrium": health care professionals' views on working within the morally contested field of antenatal screening**

Journal of Medical Ethics 2004 October; 30(5): 505-509

**Abstract:**

**OBJECTIVE:** To explore the ways in which health care practitioners working within the morally contested area of prenatal screening balance their professional and private moral values.

**DESIGN:** Qualitative study incorporating semistructured interviews with health practitioners followed by multidisciplinary discussion groups led by a health care ethicist.

**SETTING:** Inner city teaching hospital and district general hospital situated in South East England.

**PARTICIPANTS:** Seventy practitioners whose work relates directly or indirectly to perinatal care.

**RESULTS:** Practitioners managed the interface between their professional and private moral values in a variety of ways. Two key categories emerged: "tolerators", and "facilitators". The majority of practitioners fell into the "facilitator" category. Many "facilitators" felt comfortable with the prevailing ethos within their unit, and appeared unlikely to feel challenged unless the ethos was radically challenged. For others, the separation of personal and professional moral values was a daily struggle. In the "tolerator" group, some practitioners sought to influence the service offered directly, whereas others placed limits on how they themselves would contribute to practices they considered immoral.

**CONCLUSIONS:** The "official" commitment to non-directiveness does not encourage open debate between professionals working in morally contested fields. It is important that practical means can be found to support practitioners and encourage debate. Otherwise, it is argued, these fields may come to be staffed by people with homogeneous moral views. This lack of diversity could lead to a lack of critical analysis and debate among staff about the ethos and standards of care within their unit.

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Offit, Kenneth; Groeger, Elizabeth; Turner, Sam; Wadsworth, Eve A.; Weiser, Mary A.

**The "duty to warn" a patient's family members about hereditary disease risks**


**Abstract:**

Genetic tests for adult-onset disorders, including common forms of cancer, are now commercially available, and tests for genetic polymorphisms that predict drug effects or toxicity after treatment are under development. For each of these circumstances, testing of 1 individual may imply an increased risk to his/her relative. The obligation, if any, to warn family members of the identification of a genetic mutation has generated concerns regarding the conflict between the physician's ethical obligations to respect the privacy of genetic information vs the potential liabilities resulting from the physician's failure to notify at-risk relatives. A duty to warn relatives about risks due to some infectious agents has been assumed by state and local health agencies, and the duty to breach confidentiality to warn of imminent harm has been the subject of case law. In general, the special nature of genetic tests has been viewed as a barrier to physicians' breaching the confidentiality of personal genetic information. However, the failure to warn family members about hereditary disease risks has already resulted in 3 lawsuits against physicians in the United States. While the findings of case law and the state and federal statutes that bear on the issue of "duty to warn" of inherited health risk are still being defined, we believe that health care professionals have a responsibility to encourage but not to coerce the sharing of genetic information in families, while respecting the boundaries imposed by the law and by the ethical practice of medicine.
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Repeal of embryo law urged after child's cure [news]
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Fertility and Sterility 2004 September; 82(Supplement 1): S245-S248
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The status of preimplantation genetic diagnosis in Japan: a criticism [opinion]
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Abstract: Genetic counseling is viewed as a therapeutic interrelationship between genetic counselors and their clients. In a previous relational ethics research project, various themes were identified as key components of relational ethics practice grounded in everyday health situations. In this article the relational ethics approach is further explored in the context of genetic counseling to enhance our understanding of how the counselor-client relationship is contextually developed and maintained. Qualitative interviews were conducted with six adult clients undergoing genetic counseling for predictive testing. Engagement, dialogue and presence were revealed as relevant to genetic counselor-client relationships. A relational ethics approach in genetic counseling challenges the concept of nondirectiveness and may enhance the outcome of counseling for both counselor and client.

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Upright generations of the future: tradition and medicalization in community genetics
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Preimplantation genetic diagnosis (PGD) was introduced at the beginning of the 1990s as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease. At that time, embryos obtained in vitro were tested to ascertain their sex, and only female embryos were transferred. Since then, techniques for genetic analysis at the single-cell level, involving assessment of first and second polar bodies from oocytes or blastomeres from cleavage-stage embryos, have evolved. Fluorescence in-situ hybridisation (FISH) has been introduced for the analysis of chromosomes and PCR for the analysis of genes in cases of monogenic diseases. In-vitro culture of embryos has also improved through the use of sequential media. Here, we provide an overview of indications for, and techniques used in, PGD, and discuss results obtained with the technique and outcomes of pregnancies. A brief review of new technologies is also included.
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Socioeconomic barriers to informed decisionmaking regarding maternal serum screening for Down syndrome: results of the French National Perinatal Survey of 1998
American Journal of Public Health 2004 March; 94(3): 484-491

Abstract: OBJECTIVES: We sought to evaluate socioeconomic disparities in serum screening for Down syndrome and assess whether such disparities are more likely to reflect limits in access or information or, rather, informed decisionmaking. METHODS: A nationally representative sample of 12,869 French women completed interviews after giving birth. RESULTS: We found substantial disparities in the likelihood of (1) women not being offered screening, (2) screening not being offered as a result of late prenatal care, and (3) women not knowing whether or not they had undergone screening. Except in the case of nationality, there was essentially no evidence of differences in refusal of testing. CONCLUSIONS: Rather than representing informed decisionmaking, socioeconomic disparities in screening for Down syndrome are mostly due to limits in access or to information.

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Creating a stem cell donor: a case study in reproductive genetics
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Abstract: During the nearly 10 years since its introduction, preimplantation genetic diagnosis (PGD) has been used predominantly to avoid giving birth to a child with identified genetic disease. Recently, PGD was used by a couple not only to test IVF-created embryos for genetic disease, but also to test for a nondisease trait related to immune compatibility with a child in the family in need of an hematopoetic stem cell transplant. This article describes the case, raises some ethical and policy issues, highlights gaps in U.S. policy, and finally makes some recommendations for addressing advancing genetic and reproductive technologies.
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**Preimplantation genetic diagnosis: choosing the "good enough" child**


**Abstract:** Preimplantation genetic diagnosis (PGD) raises serious moral questions concerning the parent-child relationship. Good parents accept their children unconditionally: they do not reject/attack them because they do not have the features they want. There is nothing wrong with treating a child as someone who can help promote some other worthwhile end, providing the child is also respected as an end in him or herself. However, if the child's presence is not valued in itself, regardless of any further benefits it brings, the child is not being treated as an end in the full sense of the term. In this paper, I argue that these principles apply to human embryos, as well as to born human offspring: the human moral subject is a bodily being, whose interests and rights begin with the onset of his or her bodily life. The rights of the living, bodily human individual include a right not to be attacked/abandoned because of his or her genetic profile. PGD is harmful to the parent-child relationship, and we give mixed messages to parents by expecting them to show unconditional commitment to offspring after birth, while inviting them to take a very different approach at the prenatal stage.

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Abstract: Enhancement of autonomous choice may be considered as an important reason for facilitating the use of genetic tests such as preimplantation genetic diagnosis. The principle of respect for autonomy is a crucial component not only of Western liberal traditions but also of Western bioethics. This is especially so in bioethical discussions and analyses of clinical encounters within medicine. On the basis of an analysis of qualitative research interviews performed with British, Italian and Swedish geneticists and gynaecologists on ethical aspects of preimplantation genetic diagnosis, the plausibility of the notion of autonomy within reproductive medicine is discussed. The analysis of interviews indicates not only that there is a gap between theoretical discussions and concrete practice, but also that an increase in choice--paradoxically--can hamper couples' choice.

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**Molloy v. Meier [Date of Decision: 6 May 2003]**

West's North Western Reporter, 2d Series, 2003; 660: 444-458

**Abstract:** Court Decision: 660 North Western Reporter, 2d Series 444; 6 May 2003 (date of decision). The Minnesota Court of Appeals held that physicians consulted by a biological parent regarding the genetic condition of her child must advise the parent with a duty of care pursuant to the appropriate standard of care. Kimberly Molloy consulted with defendant physicians about her biological daughter's developmental and behavioral problems. Defendant Meier suspected the child had Fragile X Syndrome, but did not order a genetic test for the disease and did not follow up on this suspected diagnosis. Molloy consulted with other physicians about her daughter and they too failed to diagnose or test the child. Molloy subsequently gave birth to another child, with her second husband, and this child also had Fragile X Syndrome. The court also held that, even if Molloy did not consult with the physician directly, a physician must notify a minor child's biological parent of a genetic abnormality. Molloy's suit was considered a wrongful conception suit, not a wrongful birth claim, because the alleged damage occurred at conception and the plaintiff did not claim she would have aborted the child had a proper diagnosis been made. [KIE/INW]

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Document 608

McLaughlin, Janice

**Screening networks: shared agendas in feminist and disability movement challenges to antenatal screening and abortion**

Disability and Society 2003 May; 18(3): 297-310

Georgetown users check [Georgetown Journal Finder](#) for access to full text
**Document 609**

Erikson, Susan L.

**Post-diagnostic abortion in Germany: reproduction gone awry, again?**

Social Science and Medicine 2003 May; 56(9): 1987-2001

Georgetown users check [Georgetown Journal Finder](#) for access to full text

**Document 610**

Browner, C.H.; Preloran, H. Mabel; Casado, Maria Christina; Bass, Harold N.; Walker, Ann P.

**Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients**

Social Science and Medicine 2003 May; 56(9): 1933-1946

Georgetown users check [Georgetown Journal Finder](#) for access to full text

**Document 611**

Getz, Linn; Kirkengen, Anne Luise

**Ultrasound screening in pregnancy: advancing technology, soft markers for fetal chromosomal aberrations, and unacknowledged ethical dilemmas**

Social Science and Medicine 2003 May; 56(10): 2045-2057

Georgetown users check [Georgetown Journal Finder](#) for access to full text

**Document 612**

Ashraf, Haroon

**UK appeal court upholds embryo selection ruling**

Lancet 2003 April 19; 361(9366): 1354

Georgetown users check [Georgetown Journal Finder](#) for access to full text

[http://www.thelancet.com/journal](http://www.thelancet.com/journal) (link may be outdated)

**Document 613**

Stormer, Nathan

**Seeing the fetus: the role of technology and image in the maternal-fetal relationship**

JAMA: The Journal of the American Medical Association 2003 April 2; 289(13): 1700

Georgetown users check [Georgetown Journal Finder](#) for access to full text

[http://jama.ama-assn.org](http://jama.ama-assn.org) (link may be outdated)

**Document 614**

Wustner, Kerstin

**Ethics and practice: two worlds? The example of genetic counselling**

New Genetics and Society 2003 April; 22(1): 61-87
Is there an ethical difference between preimplantation genetic diagnosis and abortion?

**Abstract:** When a person at risk of having a child with a genetic illness or disease wishes to have an unaffected child, this can involve difficult choices. If the pregnancy is established by sexual intercourse, the fetus can be tested early in pregnancy, and if affected a decision can be made to abort in the hope that a future pregnancy with an unaffected fetus ensures. Alternatively, preimplantation genetic diagnosis (PGD) can be used after in vitro fertilisation (IVF) to select and implant an unaffected embryo that hopefully will proceed to term and produce a healthy baby. We are aware that many individuals at risk regard the latter as ethically more acceptable than the former, and examine whether there is an ethical difference between these options. We conclude that PGD and implantation of an unaffected embryo is a more acceptable choice ethically than prenatal diagnosis (PND) followed by abortion for the following reasons: Choice after PGD is seen as ethically neutral because a positive result ("a healthy pregnancy") balances a negative result ("the destruction of the affected embryo") simultaneously (assuming the pregnancy proceeds to full term and a healthy baby is born). While there is usually the intention to establish a healthy pregnancy after an abortion, this is not simultaneous; A woman sees abortion as a personal physical violation of her integrity, and as the pregnancy proceeds she increasingly identifies with and gives ethical status to the embryo/fetus as it develops in utero and not in the laboratory; Many people see aborting a fetus as "killing", whereas in the case of PGD the spare embryos are "allowed to die". We argue that this difference of opinion gives further weight to our conclusion, but note that this has been addressed and debated at length by others.

Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information -- commentary and author's reply

Using data obtained during a retrospective interview study of 30 women who had undergone genetic testing-BRCA1/2 mutation searching- this paper describes how women, previously diagnosed with breast/ovarian cancer, perceive their role in generating genetic information about themselves and their families. It observes that when describing their motivations for undergoing DNA testing and their experiences of disclosing genetic information within the family these women provide care based ethical justifications for their actions. Finally, it argues that generating genetic information and disclosing this information to kin raise different types of ethical issues. The implications of these findings for ethical debates about informed choice in the context of genetic testing are discussed.

Balancing autonomy and responsibility: the ethics of generating and disclosing genetic information

Using data obtained during a retrospective interview study of 30 women who had undergone genetic testing-BRCA1/2 mutation searching- this paper describes how women, previously diagnosed with breast/ovarian cancer, perceive their role in generating genetic information about themselves and their families. It observes that when describing their motivations for undergoing DNA testing and their experiences of disclosing genetic information within the family these women provide care based ethical justifications for their actions. Finally, it argues that generating genetic information and disclosing this information to kin raise different types of ethical issues. The implications of these findings for ethical debates about informed choice in the context of genetic testing are discussed.
Concern for families and individuals in clinical genetics

Journal of Medical Ethics 2003 April; 29(2): 70-73

Abstract: Clinical geneticists are increasingly confronted with ethical tensions between their responsibilities to individual patients and to other family members. This paper considers the ethical implications of a "familial" conception of the clinical genetics role. It argues that dogmatic adherence to either the familial or to the individualistic conception of clinical genetics has the potential to lead to significant harms and to fail to take important obligations seriously. Geneticists are likely to continue to be required to make moral judgments in the resolution of such tensions and may find it useful to have access to ethics training and support.

http://www.jmedethics.com (link may be outdated)

The mystery of my eggs [PGD]

New York Times Magazine 2003 March 16; p. 44-46

http://www.nytimes.com (link may be outdated)

Marie Wood and Terry Borman v. University of Utah Medical Center


Preimplantation diagnosis


Ethical dimensions of genetic counseling

Clinics in Perinatology 2003 March; 30(1): 81-93

European Society of Human Reproduction and Embryology [ESHRE]. Ethics Task Force

Georgetown users check Georgetown Journal Finder for access to full text
Taskforce 5: preimplantation genetic diagnosis
Human Reproduction 2003 March; 18(3): 649-651

Moutou, Celine; Rongieres, Catherine; Bettahar-Lebugle, Karima; Gardes, Nathalie; Philippe, Christophe; Viville, Stephane
Preimplantation genetic diagnosis for achondroplasia: genetics and gynaecological limits and difficulties

Robertson, John A.
Extending preimplantation genetic diagnosis: the ethical debate

Tassicker, Ros; Savulescu, Julian; Skene, Loane; Marshall, Pam; Fitzgerald, Lara; Delatycki, Martin B.
Prenatal diagnosis requests for Huntington's disease when the father is at risk and does not want to know his genetic status: clinical, legal, and ethical viewpoints
BMJ: British Medical Journal 2003 February 8; 326(7384): 331-333

Boyle, Robert J.; Savulescu, Julian
Prenatal diagnosis for "minor" genetic abnormalities is ethical

http://www.bmj.com (link may be outdated)
Robertson, John A.

PGD: new ethical challenges

Georgetown users check Georgetown Journal Finder for access to full text

Hazimi, Muhsin ibn 'Ali Faris

Akhlaqiyat al-istirshad al-wirathi fi al-mujtam'at al-Islamiyah = Ethics of genetic counseling in Muslim societies

Nationaler Ethikrat (Germany) = German National Ethics Council

GENETIC DIAGNOSIS BEFORE AND DURING PREGNANCY: OPINION

Veach, Patricia McCarthy; LeRoy, Bonnie S.; and Bartels, Dianne M.

FACILITATING THE GENETIC COUNSELING PROCESS: A PRACTICAL MANUAL

Sass, Hans-Martin and Schröder, Peter, eds.

PATIENTENAUFKLÄRUNG BEI GENETISCHEM RISIKO

Marsico, Gaia

The need to correct the offer of prenatal diagnosis in the light of a women's voice

Marsico, Gaia

The need to correct the offer of prenatal diagnosis in the light of a women's voice

Call number: RA778 .W73 2003
Noia, Giuseppe
The ethics of prenatal diagnosis
Call number: RA778 .W73 2003

Sutton, Agneta
Prenatal diagnosis: fears and expectations
Call number: RA778 .W73 2003

Ulrich, Hans G.
Ethische Konflikte bei der Präimplantationsdiagnostik (Preimplantation-Genetic-Diagnosis) [Ethical conflicts in preimplantation diagnosis]
Call number: R724 .M327 2003

Veach, Patricia McCarthy; LeRoy, Bonnie S.; Bartels, Dianne M.
National Society of Genetic Counselors Code of Ethics
Call number: RB155.7 .V434 2003

Veach, Patricia McCarthy; LeRoy, Bonnie S.; Bartels, Dianne M.
Behaving ethically
Call number: RB155.7 .V434 2003

Chasen, S.T.; Skupski, D.W.; McCullough, L.B.; Chervenak, F.A.
Ethical dimensions of nuchal translucency screening.
Call number: RG626 .C66 2003

Carrera, J.M.
Bioethical aspects of ultrasonographic and invasive prenatal diagnosis.
Call number: RG626 .C66 2003
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Csaba, A.; Papp, Z.

**Decision-making in prenatal diagnosis.**


Call number: RG626 .C66 2003

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* **Article**  Document 642

Patrawala, Zeenat

**The Down syndrome abortion dilemma**

Ivy Journal of Ethics; 3(1): 24-27

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http://www.rso.cornell.edu/bsc/ (link may be outdated)

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* **Article**  Document 643

Haker, Hille

**Harm as the price of liberty? Preimplantation diagnosis and reproductive freedom**

Ethical Perspectives 2003; 10(3-4): 215-223

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* **Article**  Document 644

Lohmann, Georg

**On the relation between moral, legal and evaluative justifications of pre-implantation genetic diagnosis (PGD)**

Ethical Perspectives 2003; 10(3-4): 196-203

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* **Chapter**  Document 645

Al-Jader, Layla

**Reproductive genetic screening: a public health perspective from the United Kingdom.**


Call number: QH447 .E53 2003 v.5

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* **Chapter**  Document 646

Munthe, Christian

**Preimplantation genetic diagnosis: ethical aspects.**


Call number: QH447 .E53 2003 v.4
LeRoy, Bonnie S.

**Nondirectiveness.**
Call number: QH447 .E53 2003 v.4

Wertz, Dorothy C.

**Clinical genetics and genetic counseling professionals: attitudes to contentious issues.**
Call number: QH447 .E53 2003 v.1

Hellsten, Sirkku K.

**Autonomy and responsibility in reproductive genetics.**
Call number: QH447 .E53 2003 v.1

Gosden, Christine M.

**Genetics and the control of human reproduction.**
Call number: QH447 .E53 2003 v.2
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Davis, Dena S.
Genetic disability and legal action: wrongful birth, wrongful life.
Call number: QH447.E53 2003 v.2

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Genetic counseling: nondirectiveness.
Call number: QH447.E53 2003 v.2

* Chapter Document 653
Zoloth, Laurie
Uncountable as the stars: inheritable genetic intervention and the human future--a Jewish perspective.
Call number: QH442.D475 2003

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Ethical differences between inheritable genetic modification and embryo selection.
Call number: QH442.D475 2003

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Bennett, Belinda
Choosing a child's future? Reproductive decision-making and preimplantation genetic diagnosis.
Call number: K3611.A77 R444 2003
Nelson, James Lindemann
The meaning of the act: relationship, meaning, and identity in prenatal genetic screening.
Call number: R724 .N463 2003

Dimopoulos, Penny; Bagaric, Mirko
The moral status of wrongful life claims
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Knox, Rebecca
Preimplantation genetic diagnosis: disease control or child objectification?
Georgetown users check Georgetown Journal Finder for access to full text

Human Fertilisation and Embryology Authority [HFEA] (Great Britain)
Court of Appeal allows tissue typing for human embryos under strict conditions
Georgetown users check Georgetown Journal Finder for access to full text

Adams, Karen E.
Ethical considerations of applications of preimplantation genetic diagnosis in the United States
Medicine and Law 2003; 22(3): 489-494
Abstract: Preimplantation genetic diagnosis (PGD) was developed to offer diagnosis of genetic disorders prior to initiation of a pregnancy, whereas previously such disorders would be diagnosed at amniocentesis or chorionic villus sampling after a pregnancy had already been undertaken. Such application of this technology is not controversial. But PGD has been used to not only diagnose genetic disorders but also to select for certain other characteristics, and this use of the technique is much more controversial. A case is presented in which PGD was used not only to select against a genetic disorder, but to select for a certain HLA type which matched an affected sibling. The new child's cord blood was transplanted into his affected sister, who subsequently was found to be free of disease. The ethics of "having a child to save a child" are explored, and possible other uses of PGD that lead to eugenic outcomes are considered. The lack of regulation of this technology in the US is contrasted with existing legislation in other countries, and the need for national and international consensus regarding appropriate uses of PGD is emphasized.
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Pilnick, Alison

**What "most people" do: exploring the ethical implications of genetic counselling**

New Genetics and Society 2002 December; 21(3): 339-350

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* Document 662

English, Veronica; Romano-Critchley, Gillian; Sheather, Julian; Sommerville, Ann

**Ethics briefings**

Journal of Medical Ethics 2002 December; 28(6): 384-385

**Abstract:** Born to be a donor?; Review of the law on organ donation and retention; New UN [United Nations] rapporteur on right to health; and Euthanasia in Belgium

Georgetown users check [Georgetown Journal Finder](http://www.jmedethics.com) for access to full text

*Document 663*

Raphael, T.

**Disclosing the sex of the fetus: a view from the UK [editorial]**

Ultrasound in Obstetrics and Gynecology 2002 November; 20(5): 421-424

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International Society of Nurses of Genetics [ISON]

**Genetic Counseling for Vulnerable Populations: The Role of Nursing: Position Statement**


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Rakowski, Eric

**Who should pay for bad genes?**

California Law Review 2002 October; 90(5): 1345-1414

Georgetown users check [Georgetown Journal Finder](http://www.jmedethics.com) for access to full text

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Zahed, L.; Nabulsi, M.; Tamim, H.

**Attitudes towards prenatal diagnosis and termination of pregnancy among health professionals in Lebanon**

Prenatal Diagnosis 2002 October; 22(10): 880-886

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*Document 667*
Spriggs, M.  
**Genetically selected baby free of inherited predisposition to early-onset Alzheimer’s disease**  
Journal of Medical Ethics 2002 October; 28(5): 290 

**Abstract:** The application of preimplantation genetic diagnosis to select against early-onset Alzheimer’s has been criticised on several grounds. Some critics think it is wrong to reject an embryo because it may develop a disease later on in middle age and some question whether a woman who will soon become incapacitated and unable to provide for her child should be a candidate for assisted reproductive technology. 

Georgetown users check [Georgetown Journal Finder](http://www.jmedethics.com) for access to full text

http://www.jmedethics.com (link may be outdated)

* Document 668  
Spriggs, M.; Savulescu, J.  
"Saviour siblings"  
Journal of Medical Ethics 2002 October; 28(5): 289 

**Abstract:** The Victorian Infertility Treatment Authority has given permission to allow tissue typing in combination with preimplantation genetic diagnosis. This is a new application of IVF. Not only will it allow parents to select an embryo free from serious genetic disease it will allow them to simultaneously select for a match so that the umbilical cord blood of the resulting baby can provide stem cells to treat an existing sibling who has a disease. 

Georgetown users check [Georgetown Journal Finder](http://www.jmedethics.com) for access to full text

http://www.jmedethics.com (link may be outdated)

* Document 669  
Andrews, Lori B.  
**People as products: the conflict between technology and social values**  
Hedgehog Review 2002 Fall; 4(3): 45-65 [Online].  

Georgetown users check [Georgetown Journal Finder](http://www.virginia.edu/iasc/publications_hedgehog_review.php) for access to full text

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* Document 670  
De Crespigny, L.; Savulescu, J.  
**Is paternalism alive and well in obstetric ultrasound? Helping couples choose their children [editorial]**  
Ultrasound in Obstetrics and Gynecology 2002 September; 20(3): 213-216

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Garel, M.; Gosme-Seguret, S.; Kaminski, M.; Cuttini, M.  
**Ethical decision-making in prenatal diagnosis and termination of pregnancy: a qualitative survey among physicians and midwives**  
Prenatal Diagnosis 2002 September; 22(9): 811-817

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Document 672
Lavery, S.A.; Aurell, R.; Turner, C.; Castellu, C.; Veiga, A.; Barri, P.N.; Winston, R.M.
**Preimplantation genetic diagnosis: patients' experiences and attitudes**
Human Reproduction 2002 September; 17(9): 2464-2467

Document 673
Kohut, Ruth J.; Dewey, Deborah; Love, Edgar J.
**Women's knowledge of prenatal ultrasound and informed choice**
Journal of Genetic Counseling 2002 August; 11(4): 265-276

Document 674
Dyer, Clare
**UK [United Kingdom] regulatory authority challenged over embryo screening [news]**
BMJ: British Medical Journal 2002 July 20; 325(7356): 119

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Ziker, Dana
**Appropriate aims: setting boundaries for reprodgenetic technology**

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Rothenberg, Karen H.; Terry, Sharon F.
**Before it's too late -- addressing fear of genetic information**
Science 2002 July 12; 297(5579): 196-197

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Jansen, Brigitte
**Modern medicine and biotechnology: an ethical conflict of interest?**
Science and Engineering Ethics 2002 July; 8(3): 319-325
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Orellana, Claudia
Controversy over compensation for disabled child in Germany [news]
Lancet 2002 June 29; 359(9325): 2259

* Document 679
Orellana, Claudia
German ethics group advises against pre-implantation genetic diagnosis [news]
Lancet 2002 June 1; 359(9321): 1926

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Hui, Pui Wah; Lam, Yung Hang; Chen, Min; Tang, Mary Hoi Yin; Yeung, William Shu Biu; Ng, Ernest Hung Yu; Ho, Pak Chung
Attitude of at-risk subjects towards preimplantation genetic diagnosis of (alpha)- and (beta)-thalassaemias in Hong Kong
Prenatal Diagnosis 2002 June; 22(6): 508-511

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Stern, Harvey J.; Harton, Gary L.; Sisson, Micahel E.; Jones, Shirley L.; Fallon, Lee A.; Thorsell, Lilli P.; Getlinger, Michael E.; Black, Susan H.; Schulman, Joseph D.
Non-disclosing preimplantation genetic diagnosis for Huntington disease
Prenatal Diagnosis 2002 June; 22(6): 503-507

* Document 682
Mitchell, C. Ben
Hurtling toward eugenics . . . again [editorial]
Ethics and Medicine 2002 Summer; 18(2): 3-5

* Document 683
Patterson, Annette; Satz, Martha
Genetic counseling and the disabled: feminism examines the stance of those who stand at the gate
Hypatia: A Journal of Feminist Philosophy 2002 Summer; 17(3): 118-142
* Article Document 684

Stern, S.J.; Amos, K.S.; Murrelle, L.; Welch, K. Oelrich; Nance, W.E.; Pandya, A.

**Attitudes of deaf and hard of hearing subjects towards genetic testing and prenatal diagnosis of hearing loss**

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* Article Document 685

Lewis, Linwood J.

**Models of genetic counseling and their effects on multicultural genetic counseling**

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* Article Document 686

Bower, Matthew A.; Veach, Patricia McCarthy; Bartels, Dianne M.; LeRoy, Bonnie S.

**A survey of genetic counselors' strategies for addressing ethical and professional challenges in practice**

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* Article Document 687

Loewy, Roberta Springer; Towner, Dena

**Societal involvement in prenatal diagnosis [reply]**

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* Article Document 688

Dolbear, Gail L.; Newell, Linda T.

**Consent for prenatal testing: a preliminary examination of the effects of named HIV reporting and mandatory partner notification**

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Kopaczynski, Germain

**Preimplantation genetic diagnosis**
Ethics and Medics 2002 May; 27(5): 1-3

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Document 690

Kabra, S.G.

**Gender disparity: need to look beyond 'female foeticide'**

Issues in Medical Ethics 2002 April-June; 10(2): 24

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Bennett, Robin L.; Hart, Kimberly A.; O'Rourke, Erin; Barranger, John A.; Johnson, Jack; MacDermot, Kay D.; Pastores, Gregory M.; Steiner, Robert D.; Thadhani, Ravi

**Fabry disease in genetic counseling practice: recommendations of the National Society of Genetic Counselors**

Journal of Genetic Counseling 2002 April; 11(2): 121-146

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Document 692

Savulescu, J.

**Is there a "right not to be born"? Reproductive decision making, options and the right to information**

[editorial]

Journal of Medical Ethics 2002 April; 28(2): 65-67

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Document 693

Spriggs, M.; Savulescu, J.

**The Perruche judgment and the "right not to be born"**

Journal of Medical Ethics 2002 April; 28(2): 63-64

**Abstract:** The French government has given in to public pressure and overturned a controversial legal ruling which recognised the right of a disabled child to seek damages. Most notably, the ruling, widely described as establishing a child's right "not to be born", had provoked "outrage" amongst groups defending the rights of the disabled and led to a ban on prenatal scans by French gynaecologists. Once again, only parents will be able to seek damages but some people think the ruling has been misinterpreted.

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Document 694

Liu, Shiliang; Joseph, K. S.; Kramer, Michael S.; Allen, Alexander C.; Sauve, Reg; Rusen, I. D.; Wen, Shi Wu

**Relationship of prenatal diagnosis and pregnancy termination to overall infant mortality in Canada**

JAMA: The Journal of the American Medical Association 2002 March 27; 287(12): 1561-1567

**Abstract:** CONTEXT: Prenatal diagnosis and termination of affected pregnancies can prevent infant deaths due to congenital anomalies, but an effect at the population level has not been shown. OBJECTIVE: To examine the impact of recent changes in congenital anomaly-related fetal and infant deaths on overall population-based infant mortality. DESIGN, SETTING, AND SUBJECTS: Birth cohort-based study of all live births, stillbirths, and infant deaths in Canada (excluding Ontario) for 1991-1998. MAIN OUTCOME MEASURES: Cause-specific infant mortality rates and gestational age-specific fetal death rates. RESULTS: The birth cohort-based infant mortality rate fluctuated between 6.4 and 6.1 per 1000 live births between 1991 and 1995, then dropped to 5.4 per 1000 in 1996 and 5.5 per 1000 in
The rate of infant death from congenital anomalies was stable between 1991 and 1995 but declined by 21% (95% confidence interval, 19%-32%) from 1.86 per 1000 in 1995 to 1.47 per 1000 in 1996 and 1997. Fetal deaths due to pregnancy termination at 20 to 23 weeks' gestation increased dramatically in 1994, while fetal deaths due to congenital anomalies at 20 to 21 weeks increased in 1995 and subsequently. Provinces/territories with high rates of fetal death due to pregnancy termination/congenital anomalies at 20 to 23 weeks had fewer infant deaths due to congenital anomalies. CONCLUSION: A large decrease in infant deaths due to congenital anomalies was associated with the most recent decline in infant mortality in Canada, suggesting that increases in prenatal diagnosis and pregnancy termination for congenital anomalies are related to decreases in overall infant mortality at the population level.

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**Document 695**

Gibbs, Nancy

*Dying to have a family: Genetic screening guaranteed a healthy baby. Did Mom make the right choice?*

*Time* 2002 March 11; 159(10): 78

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**Document 696**

Williams, Clare; Alderson, Priscilla; Farsides, Bobbie

*Drawing the line' in prenatal screening and testing: health practioners' discussions*

*Health Risk and Society* 2002 March; 4(1): 61-75

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**Document 697**

Roberts, Christy D.; Stough, Laura M.; Parrish, Linda H.

*The role of genetic counseling in the elective termination of pregnancies involving fetuses with disabilities*

*Journal of Special Education* 2002 Spring; 36(1): 48-55

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**Document 698**

Gooding, Holly C.; Wilfond, Benjamin; Boehm, Karina; Biesecker, Barbara Bowles

*Unintended messages: the ethics of teaching genetic dilemmas*


*Abstract:* Bioethicists teaching and writing about the uses of prenatal genetic testing sometimes use “difficult cases” in which people with a disability want to test and select for the presence of their disability. Such cases challenge our stereotypes but also play into them.

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**Document 699**

Towner, Dena; Loewy, Roberta Springer

*Ethics of preimplantation diagnosis for a woman destined to develop early-onset Alzheimer disease*

*JAMA: The Journal of the American Medical Association* 2002 February 27; 287(8): 1038-1040

Georgetown users check [Georgetown Journal Finder](#) for access to full text
Preimplantation diagnosis for early-onset Alzheimer disease caused by V717L mutation

CONTEXT: Indications for preimplantation genetic diagnosis (PGD) have recently been expanded to include disorders with genetic predisposition to allow only embryos free of predisposing genes to be preselected for transfer back to patients, with no potential for pregnancy termination. OBJECTIVE: To perform PGD for early-onset Alzheimer disease (AD), determined by nearly completely penetrant autosomal dominant mutation in the amyloid precursor protein (APP) gene. DESIGN: Analysis undertaken in 1999-2000 of DNA for the V717L mutation (valine to leucine substitution at codon 717) in the APP gene in the first and second polar bodies, obtained by sequential sampling of oocytes following in vitro fertilization, to preselect and transfer back to the patient only the embryos that resulted from mutation-free oocytes. SETTING: An in vitro fertilization center in Chicago, Ill. PATIENTS: A 30-year-old AD-asymptomatic woman with a V717L mutation that was identified by predictive testing of a family with a history of early-onset AD. MAIN OUTCOME MEASURES: Results of mutation analysis; pregnancy outcome. RESULTS: Four of 15 embryos tested for maternal mutation in 2 PGD cycles, originating from V717L mutation--free oocytes, were preselected for embryo transfer, yielding a clinical pregnancy and birth of a healthy child free of predisposing gene mutation according to chorionic villus sampling and testing of the neonate's blood. CONCLUSION: This is the first known PGD procedure for inherited early-onset AD resulting in a clinical pregnancy and birth of a child free of inherited predisposition to early-onset AD.
* **Document 704**
de Decker, H.P.  
**Mother-to-fetus HIV transmission during amniocentesis -- ethical concerns**  
SAMJ South African Medical Journal 2002 February; 92(2): 124- 125  
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* **Document 705**  
Eaton, Lynn  
**France outlaws the right to sue for being born [news]**  
BMJ: British Medical Journal 2002 January 19; 324(7330): 129

* **Document 706**  
de Bousingen, Denis Durand  
**France tightens disabled patients' rights to sue doctors [wrongful life] [news]**  
Lancet 2002 January 19; 359(9302): 233

* **Document 707**  
Steinbock, Bonnie  
**Sex selection: Not obviously wrong**  
**Abstract:** Although sex selection calls for careful thought, it seems in many cases to be neither intrinsically objectionable nor likely to have bad consequences.

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**Abstract:** "How far should people be allowed to go in trying to have better babies? And whose definition of "better" should prevail? This Fred Friendly Seminar moderated by Dateline NBC correspondent John Hockenberry considers the ethical dilemmas facing individuals and society that grow out of prenatal testing and genetic options that may be available in the future – such as cloning. Panelists include Francis Collins, director of the National Human Genome Research Institute; ABC journalist Meredith Vieira; Princeton University's Lee Silver, author of Remaking Eden: How Genetic Engineering and Cloning Will Transform the American Family; [description from the FHS website] An 18 page viewer's guide to the television series developed by the American Museum of Natural History is available. The guide includes preparation suggestions; a synopsis of the scenarios in each program; discussion questions for pre- and post-viewing; and strategies, real-life case studies, and extension projects to develop and continue the dialogue. More resources are online at [http://www.pbs.org/fredfriendly/ourgenes](http://www.pbs.org/fredfriendly/ourgenes).
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Nippert, Irmgard

**International perspectives on abortion and genetic counselling. A European perspective.**


Call number: R724 .S5526 1999

* **Chapter** Document 717

Lam, Stephen T.S.

**Informed consent in genetic counseling and pediatric genetics. A View from Hong Kong.**


Call number: R724 .S5526 1999

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**Prenatal testing and disability: the need for a participatory approach to research**


Call number: QH332 .A85 2002

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**Fetal quality control.**


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Jallinoja, Piia T.

**Ethics of clinical genetics: the spirit of the profession and trials of suitability from 1970 to 2000**


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**Serious genetic disorders: can or should they be defined?**

American Journal of Medical Genetics 2002; 108: 29-35

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Dormandy, E.; Hooper, R.; Michie, S.; Marteau, T.M.

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Call number: TP248.6 .W675 2001

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Call number: RG133.5 .E838 2002
Fetal assessment: a feminist approach to a bioethical case study using Hutchinson's method of ethical clarification.


Call number: BJ401.D65 2002

Just caring: do future possible children have a just claim to a sufficiently healthy genome?


Call number: RA418.M444 2002

Legal responses to some of the new developments in reproductive technologies: part.3: the future of reproductive technologies and the law


Abstract: Primary care physicians are unprepared for the increase in demands for prenatal genetic testing. Often, they do not possess the necessary knowledge, skills or attitudes to provide genetic counselling. Yet, since the demand for prenatal genetic services is growing faster than the number of genetic professionals, the responsibility of genetic counselling will fall to these physicians. Physicians who lack genetic literacy may find themselves the targets of lawsuits for wrongful birth and wrongful life. Wrongful birth and wrongful life claims (in the context of genetics) both assert that but for the physician's negligence, the handicapped child would not have been born. Such medical malpractice suits against physicians exist in the United States, the United Kingdom, Canada and Australia. This paper discusses the case law on wrongful birth/life cases in these four countries. The authors conclude that as the number and availability of prenatal genetic tests increases, so too will the number of genetic malpractice claims, unless the education of physicians and medical students in genetics is promoted, possibly with the Internet as the new educational paradigm.

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Wisdom, casuistry, and the goal of reproductive counseling

Medicine, Health Care and Philosophy: A European Journal 2002; 5(3): 281-289

Abstract: Reproductive counseling includes counseling of prospective parents by obstetricians, clinical geneticists, and genetic counselors regarding, for example, the use of assisted reproductive technologies, prenatal testing, and preimplantation genetic diagnosis. Two different views on wisdom and the goal of reproductive counseling are
analyzed. According to the first view, the goal of reproductive counseling is to help prospective parents reach a wise decision. A specific course of action is recommended by the counselor in contrast to other possible alternatives. According to the second view, the goal of reproductive counseling is not to help prospective parents reach a wise decision but to help them reach their own decision wisely. It is the prospective parents who should make the decision, and it is their value commitments that should be decisive. It is argued that the second approach is to be preferred to the first. It combines respect for autonomy with a recognition of the need for assistance in decision-making. Both the first and second views relate the goal of reproductive counseling to wisdom. A problem is, however, what wisdom more precisely means - there are many different views. A casuistic view of wisdom is investigated. This view roughly defines wisdom as practical prudence in dealing with particular cases. What characterizes a casuistic decision-making method is elaborated in more detail. Applied to the second view, a casuistic view of wisdom implies that the counselor should encourage prospective parents to take into consideration the nature of the particular problem at hand, the context of the problem, their own individual identities, their personal value commitments, and various alternative perspectives, values and arguments.

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Suter, Sonia Mateu
The routinization of prenatal testing

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* Article Document 735
Hildt, Elisabeth
Autonomy and freedom of choice in prenatal genetic diagnosis
Medicine, Health Care and Philosophy: A European Journal 2002; 5(1): 65-71
Abstract: An increase in autonomy and freedom is often considered one of the main arguments in favour of a broad use of genetic testing. Starting from Gerald Dworkin's reflections on autonomy and choice this article examines some of the implications which accompany the increase in choices offered by prenatal genetic diagnosis. Although personal autonomy and individual choice are important aspects in the legitimation of prenatal genetic diagnosis, it seems clear that an increase in choice offered by prenatal genetic diagnosis also leads to various implications that may negatively influence the freedom of the persons involved.

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Oduncu, Fuat S.
The role of non-directiveness in genetic counseling
Medicine, Health Care and Philosophy: A European Journal 2002; 5(1): 53-63
Abstract: When the complete human genome has been sequenced, everyone of us will become a potential candidate for genetic counseling and testing. Within a short period of time everyone will obtain his personal genetic passport identifying deleterious and susceptibility genes. With the availability of presymptomatic tests for late-onset disorders and the possibilities of prevention and treatment, the conflict between directiveness and nondirectiveness will dominate the counseling setting. Despite general consent on providing genetic information in a nondirective fashion to preserve value neutrality and enhance client's autonomy, there is no accepted common definition of what non-directiveness really is or ought to be. The article tries to elaborate some aspects which might be fruitful and clarifying in the complex issues involved in the black box of genetic counseling.

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Commercialisation of Genetic Services: the role of genetic counsellors
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Goals of genetic counseling
Clinical Genetics 2001 November; 60(5): 323-330
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**Prenatal diagnosis, genetics and reproductive decision-making**
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Ferriman, Annabel
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**Favorable attitudes toward testing for chromosomal abnormalities via analysis of fetal cells in maternal blood**
Genetics in Medicine 2001 July-August; 3(4): 301-309
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Nursing Ethics 2001 July; 8(4): 360-374
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**Attitudes towards prenatal HIV testing and treatment among pregnant women in southern India**


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**Prenatal diagnoses of sex chromosome conditions**


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Middleton, Anna; Hewison, Jenny; Mueller, Robert

**Prenatal Diagnosis for Inherited Deafness -- What is the Potential Demand?**

Journal of Genetic Counseling 2001 April; 10(2): 121-131

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**Ethical and Professional Challenges Posed by Patients With Genetic Concerns: A Report of Focus Group Discussions With Genetic Counselors, Physicians, and Nurses**

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**Prenatal genetic testing**

Health Progress 2001 March-April; 82(2): 33-35

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Harris, Ryan A.; Washington, A. Eugene; Feeny, David; Kuppermann, Miriam

**Decision analysis of prenatal testing for chromosomal disorders: What do the preferences of pregnant women tell us?**


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Maryland. Court of Special Appeals

Kassama v. Magat [Date of Decision: 2001 February 28]

Abstract: Court Decision: 767 Atlantic Reporter, 2d Series 348; 28 Feb 2001 (date of decision). The Court of Special Appeals of Maryland held that wrongful life is not a recognized cause of action in Maryland. Millicent Kassama sought medical care from Dr. Magat for her pregnancy. During her first visit with Dr. Magat, an ultrasound showed that Kassama was pregnant with a 17-week-old fetus. Magat referred her for alpha fetoprotein (AFP) testing, and Kassama's results showed an increased risk for Down's syndrome. Because the AFP test was not performed until the fetus was approximately 22 weeks old, and abortions on fetuses older than 24 weeks are not performed in Maryland, Magat informed Kassama that she would likely have to travel out-of-state should she choose to abort. Kassama claimed Magat did not inform her of either the test results or her options. Subsequently, Kassama gave birth to a baby with Down's syndrome. Kassama asserted that the infant would have been aborted but for the physician's negligence, and sought damages on behalf of the child for living in a defective state. The Maryland Court of Special Appeals held that there is no cause of action for wrongful life "because it is an impossible task to calculate damages based on a comparison between life in an impaired state and no life at all." The court affirmed the trial court's judgment for Magat. [KIE/INW]
Measuring Up: The Eugenics Debate (2001)
Canadian Broadcasting Corporation (CBC) Learning
Abstract: "It is an awful choice: knowing that your unborn child may have a major physical problem, do you decide to abort? The advances of science have thrown society into a moral quandary. Genetic testing for diseases is pushing the boundaries of parental expectations. This program investigates the science and the conscience: as a society, can we decide who lives among us? Ethicists, scientists, parents, and those born with disabilities and disease weigh in on the issue." [description from CBCLearning website]

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Les Personnes Handicapées Face au Diagnostic Prénatal: Éliminer Avant la Naissance ou Accompagner?
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Call number: RG133.5 .D38 2001

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**Antenatal screening and its possible meaning from unborn baby’s perspective**


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**Prenatal genetic testing and wrongful birth lawsuits**

DuBois, James M.


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**Medicine, technology, and gender in the history of prenatal diagnosis.**

Cowan, Ruth Schwartz


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Viville, Stephane; Pergament, Deborah; Fiddler, Morris


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**“Wrongful life” a la francaise**

Callus, Therese

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Kielstein, Rita; Sass, Hans-Martin


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Call number: R724 .B4826 2001

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Elliott, Deni
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Women's voices: Prenatal diagnosis and care for the disabled
Health Care Analysis 2001; 9(2): 133-150
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*Disease prevention and the genetic revolution: defining a parental right to protect the bodily integrity of future children*
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*Solidarity in perinatal medicine*
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*Case Report: Resolution of an Ethical Dilemma [abstract]*
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*Consumerism in Prenatal Diagnosis: A Challenge for Ethical Guidelines*
Journal of Medical Ethics 2000 December; 26(6): 444-446
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Turnbull, David

**Genetic Counselling: Ethical Mediation of Eugenic Futures?**

*Futures* 2000 November-December; 32(9-10): 853-865

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**General Practitioners' Attitudes and Beliefs on Antenatal Testing for HIV: Postal Questionnaire Survey**

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*Journal of Medical Ethics* 2000 October; 26(5): 400-403

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**Prenatal and neonatal testing and screening: a double-edged sword**

*Nursing Clinics of North America* 2000 September; 35(3): 627-642

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Johnson, Karen A.; Brensinger, Jill D.

**Genetic counseling and testing: implications for clinical practice**

*Nursing Clinics of North America* 2000 September; 35(3): 615-626

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Hall, Mark A.; Rich, Stephen S.

**Genetic Privacy Laws and Patients' Fear of Discrimination by Health Insurers: The View from Genetic Counselors**
Abstract: A fascinating criticism of abortion occasioned by prenatal diagnosis of potentially disabling traits is that the complex of test-and-abortion sends a morally disparaging message to people living with disabilities. I have argued that available versions of this "expressivist" argument are inadequate on two grounds. The most fundamental is that, considered as a practice, abortions prompted by prenatal testing are not semantically well-behaved enough to send any particular message; they do not function as signs in a rule-governed symbol system. Further, even granting, for the sake of argument, the expressive power of testing and aborting, it would not be possible, contra the argument's proponents, to distinguish between abortions undertaken because of beliefs about the disabling conditions the fetus might face as a child and abortions undertaken for many other possible reasons - e.g., because of the poverty the fetus would face or the increase in family size that the birth of a new child would occasion. Here, I respond to criticisms of those arguments, and propose and defend another: the expressivist argument cannot, in general, distinguish successfully between abortion and therapy as modalities for responding to disabilities.
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Wertz, Dorothy C.; Gregg, Robin

**Genetics Services in a Social, Ethical and Policy Context: A Collaboration Between Consumers and Providers**

Journal of Medical Ethics 2000 August; 26(4): 261-265

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Kennedy Institute of Ethics Journal 2000 June; 10(2): 129-146

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Journal of Genetic Counseling 2000 April; 9(2): 153-159

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Attitudes Toward Genetic Counseling and Prenatal Diagnosis Among a Group of Individuals with Physical Disabilities
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Quality Management in Health Care 2000 Spring; 8(3): 19-26

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Gavaghan, Colin
Deregulating the Genetic Supermarket: Preimplantation Screening, Future People, and the Harm Principle

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Human Genetics Committee; Council for Responsible Genetics
Predictive testing [position paper, 1999 October]
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Schmidtke, Jörg, ed.
GUTER RAT IST TEUER: WAS KOSTET DIE HUMANGENETIK, WAS NUTZT SIE?
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PRENATAL TESTING AND DISABILITY RIGHTS
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Mayman, Nasir B. 'Abd Allah
Al-irshad al-jini: Ahammiyatuh- atharuh- mahadhiruh [Genetic counseling: Its importance, effects and precautions]
Abstract: This paper was submitted to the symposium held by the Islamic Organization for Medical Sciences (IOMS) in Kuwait during the period 13-15 October 1998 on genetics. The author argues that no decisive scriptural texts in Islam can give clear answers for the juristic questions raised by the techniques of genetic counseling. The paper showed that an Islamic juristic vision about the different types of genetic counseling should be based on specific Islamic legal maxims.

Document 843
Zuhayli, Muhammad
Al-irshad al-jini [Genetic counseling]
Abstract: What are the acceptable and unacceptable aspects of genetic counseling from an Islamic ethical perspective? This is the main question of this paper which was submitted to the symposium held by the Islamic Organization for Medical Sciences (IOMS) in Kuwait during the period 13-15 October 1998 on genetics. The author argues that genetic counseling has considerable benefits that Islam recognizes. However, some precautious procedures should be taken in order to avoid committing any unlawful practices.

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The right to know and not to know.
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**Genetics: ethical challenges in the Baltic countries.**  
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**Medical technique and our coping with suffering: prenatal diagnosis as an example.**  
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Dekker, Cornelis  
**Medical ethics and reproductive genetics in Swedish public discourse**  
Biomedical Ethics: Newsletter of the European Network for Biomedical Ethics 2000; 5(3): 100-105

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**Reproduction, ethics, the ethics of reproductive genetic counseling: nondirectiveness.**  
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Smith, Jonathan A.; Michie, Susan; Allanson, Abi; Elwy, Rani
**Certainty and Uncertainty in Genetic Counselling: A Qualitative Case Study**
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**Should Genetic Health Care Providers Attempt to Influence Reproductive Outcome Using Directive Counseling Techniques? A Public Health Prospective**
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**Communicating Genetic Risk: Pros, Cons, and Counsel**
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**A Professional Code of Ethics Provides Guidance for Genetic Nursing Practice**
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Um, Young-Rhan

A Critique of a "Wrongful Life" Lawsuit in Korea
Nursing Ethics 2000; 7(3): 250-261

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The Ethical Question: Medical Genetics - Fragile X Syndrome (1996)
Division of Continuing Medical Education, American Medical Association [AMA]

Abstract: Contents according to WorldCat: "Welcome; Fragile X Syndrome; DNA testing for inherited disease; the issue of look back; when to test and how to counsel; the disclosure of reproductive options; the duty to warn; the insurance problem; access to genetic testing; concluding remarks." A 48 p. study guide written by R. Mark Evans, Ph.D. accompanies the video program. Sections in the written material focus on the role of the physician with regard to counseling re genetic testing, a duty to warn, discussion of reproductive options, and confidentiality and access to testing. The welcome and conclusion were written by James S. Todd and Thomas J. Loftus; video narration by Beverly Feldt and it was written and produced by David Finney [WorldCat record]. This tape is segment five in a series called "The Ethical Question" produced by the American Medical Association. The series was supported by an educational grant from the United States Air Force Reserve.

Twilight of the Golds (1996)
Barnes & Noble online

Abstract: "A seemingly perfect family boasting a handsome son, a pregnant daughter married to a doctor, and caring parents is rocked by the perceived likelihood--determined by the daughter's geneticist husband--that the anticipated addition to their family may be genetically predisposed to being homosexual. An issue-oriented drama adapted for Showtime from the play by Jonathan Tolins (description from Yahoo). This film was an Official Selection of the 1997 Sundance Film Festival." The Golds are ecstatic with the news that their daughter and her doctor-geneticist husband are expecting their first child. Their son looks forward to being an uncle, but an unexpected revelation of the genetic predisposition of the unborn child brings about difficult conversations and unexpected and unfortunate challenges to family love and acceptance.

"Perfect Baby": An ABC Nightline Special with Barbara Walters on July 19, 1990 (1990)

Abstract: This program includes interviews with Dr. Lander and Dr. Arthur Caplan.

Prenatal Diagnosis: To Be or Not to Be? (1981)
Filmakers Library

Abstract: David Suzuki hosts this documentary program about prenatal diagnosis and counseling in Canada. Several Toronto hospitals participated and various health professionals talk about amniocentesis, fetoscopy, and ultrasound studies to discover abnormalities in the fetus. Down's syndrome, Tay Sachs disease, and spina bifida are discussed, as well as other questions concerning use of testing to determine sex or minor disabilities and differences.