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THE ETHICS OF SCREENING IN HEALTH CARE AND MEDICINE: SERVING SOCIETY OR SERVING THE PATIENT?
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Arribas-Ayllon, Michael; Sarangi, Srikant; and Clarke, Angus
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Book  Document 4
Fraker, Mary and Mazza, Anne-Marie, rapporteurs
Institute of Medicine (United States) [and] National Research Council (United States). Committee on Science, Technology, and Law Policy and Global Affairs. Board on Life Sciences
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A DNA education. Taking personal genetic testing into the classroom brings ethical and legal sensitivities to the fore. [editorial]
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Wade, Christopher H.; Wilfond, Benjamin S.; McBride, Colleen M.
Effects of genetic risk information on children's psychosocial wellbeing: a systematic review of the literature.
Genetics in Medicine 2010 June; 12(6): 317-326

Abstract: PURPOSE: As advances in research have made a growing number of genetic tests available, clinicians will increasingly be faced with making decisions about when offering genetic testing services to children is appropriate. A key factor in such decisions involves determining whether knowledge of genetic health risks might have an impact on children's psychosocial wellbeing. METHODS: We conducted a systematic review of the literature using five online databases to identify studies that assessed the impact of communicating nondiagnostic carrier or presymptomatic genetic test results to children. RESULTS: A total of 17 articles met the inclusion criteria for this review. These studies used a wide range of methodologies to explore carrier and predictive testing. Although there was little quantitative evidence that receiving genetic test results led to a significant impact on children's psychosocial wellbeing, it was found that methodological inconsistencies, small samples, and reliance on assessments most appropriate for psychopathology make any firm conclusions about the impact of genetic testing on children premature. CONCLUSION: Currently, there is insufficient evidence to inform a nuanced understanding of how children respond to genetic testing. This suggests a strong need for further research that uses rigorous approaches to address children's emotional states, self-perception, and social wellbeing.

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Boenink, Marianne; van der Burg, Simone
Informed decision making about predictive DNA tests: arguments for more public visibility of personal deliberations about the good life.
Medicine, Health Care, and Philosophy 2010 May; 13(2): 127-138

Abstract: Since its advent, predictive DNA testing has been perceived as a technology that may have considerable impact on the quality of people's life. The decision whether or not to use this technology is up to the individual client. However, to enable well considered decision making both the negative as well as the positive freedom of the individual should be supported. In this paper, we argue that current professional and public discourse on predictive DNA-testing is lacking when it comes to supporting positive freedom, because it is usually framed in terms of risk and risk management. We show how this 'risk discourse' steers thinking on the good life in a particular way. We go
on to argue that empirical research into the actual deliberation and decision making processes of individuals and families may be used to enrich the environment of personal deliberation in three ways: (1) it points at a richer set of values that deliberators can take into account, (2) it acknowledges the shared nature of genes, and (3) it shows how one might frame decisions in a non-binary way. We argue that the public sharing and discussing of stories about personal deliberations offers valuable input for others who face similar choices: it fosters their positive freedom to shape their view of the good life in relation to DNA-diagnostics. We conclude by offering some suggestions as to how to realize such public sharing of personal stories.

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Kious, Brent M.
Genetic nondiscrimination and health care as an entitlement.
Journal of Medicine and Philosophy 2010 April; 35(2): 86-100
Abstract: The Genetic Information Nondiscrimination Act of 2008 prohibits most forms of discrimination on the basis of genetic information in health insurance and employment. The findings cited as justification for the act, the almost universal political support for it, and much of the scholarly literature about genetic discrimination, all betray a confusion about what is really at issue. They imply that genetic discrimination is wrong mainly because of genetic exceptionalism: because some special feature of genetic information makes discrimination on the basis thereof wrong. I suggest, to the contrary, that the best arguments against genetic discrimination assume that health care is an entitlement. I do this by examining two different exceptionalist arguments for genetic nondiscrimination, showing that they do not furnish good reasons for prohibiting genetic discrimination unless one supposes that health care is an entitlement.

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Exploring attitudes, beliefs, and communication preferences of Latino community members regarding BRCA1/2 mutation testing and preventive strategies
Genetics in Medicine 2010 February; 12(2): 105-115
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COMMUNITY GENETICS AND GENETIC ALLIANCES: EUGENICS, CARRIER TESTING AND NETWORKS OF RISK

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Public Health Genomics 2010 (2009 December); 13(2): 95-105
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Public Health Genomics 2010 (2009 December); 13(2): 106-115

Document 27
Factors influencing uptake of pharmacogenetic testing in a diverse patient population.
Public Health Genomics 2010; 13(1): 48-54

Abstract: Background: The successful integration of pharmacogenetic (PGx) testing into clinical care will require attention to patient attitudes. In this study, we aimed to identify the major reasons why patients would or would not consider PGx testing and whether these factors differed by race, socioeconomic and insurance status, and medical history. Methods: We developed and conducted a survey within the adult patient population of the Duke Family Medicine Center. Results: Of 75 completed surveys (65% African-American), 77% indicated they were 'very likely' or 'somewhat likely' to take a PGx test. Respondents who had experienced a side effect were significantly more likely to indicate they would take a PGx test and expressed greater interest in learning more about testing than those who had not. Drug safety and effectiveness were the major reasons to have PGx testing. Privacy concerns and lack of insurance coverage for testing were the major reasons to decline testing. Conclusions: We found no differences in interest in PGx tests by race or socioeconomic status, but found stronger interest from those with a history of side effects and private insurance. While the overall support of PGx testing is encouraging, greater reassurance of medical privacy and development of educational resources are needed.

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Jegede, Ayodele S.  
Culture and genetic screening in Africa  
Developing World Bioethics 2009 December; 9(3): 128-137  
Abstract: Africa is a continent in transition amidst a revival of cultural practices. Over previous years the continent was robbed of the benefits of medical advances by unfounded cultural practices surrounding its cultural heritage. In a fast moving field like genetic screening, discussions of social and policy aspects frequently need to take place at an early stage to avoid the dilemma encountered by Western medicine. This paper, examines the potential challenges to genetic screening in Africa. It discusses how cultural practices may affect genetic screening. It views genomics science as a culture which is trying to diffuse into another one. It argues that understanding the existing culture will
help the diffusion process. The paper emphasizes the importance of genetic screening for Africa, by assessing the current level of burden of diseases in the continent and shows its role in reducing disease prevalence. The paper identifies and discusses the cultural challenges that are likely to confront genetic screening on the continent, such as the worldview, rituals and taboos, polygyny, culture of son preference and so on. It also discusses cultural practices that may promote the science such as inheritance practices, spouse selection practices and naming patterns. Factors driving the cultural challenges are identified and discussed, such as socialization process, patriarchy, gender, belief system and so on. Finally, the paper discusses the way forward and highlights the ethical considerations of doing genetic screening on the continent. However, the paper also recognizes that African culture is not monolithic and therefore makes a case for exceptions.

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A ban on genetic discrimination [editorial]
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BMJ: British Medical Journal 2009 November 14; 339(7730): 1136-1140

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Raz, Aviad E.; Schicktanz, Silke
Diversity and uniformity in genetic responsibility: moral attitudes of patients, relatives and lay people in Germany and Israel.
Medicine, Health Care, and Philosophy 2009 November; 12(4): 433-442

Abstract: The professional and institutional responsibility for handling genetic knowledge is well discussed; less attention has been paid to how lay people and particularly people who are affected by genetic diseases perceive and frame such responsibilities. In this exploratory study we qualitatively examine the attitudes of lay people, patients and relatives of patients in Germany and Israel towards genetic testing. These attitudes are further examined in the national context of Germany and Israel, which represent opposite regulatory approaches and bioethical debates concerning genetic testing. Three major themes of responsibility emerged from the inter-group and cross-cultural comparison: self-responsibility, responsibility for kin, and responsibility of society towards its members. National contrast was apparent in the moral reasoning of lay respondents concerning, for example, the right not to know versus the duty to know (self-responsibility) and the moral conflict concerning informing kin versus the moral duty to inform (responsibility for kin). Attitudes of respondents affected by genetic diseases were, however, rather similar in both countries. We conclude by discussing how moral discourses of responsibility are embedded within cultural (national, religious) as well as phenomenological (being affected) narratives, and the role of public engagement in bioethical discourse.

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Clinical obligations and public health programmes: healthcare provider reasoning about managing the incidental results of newborn screening.

Journal of Medical Ethics 2009 October; 35(10): 626-634

Abstract: BACKGROUND: Expanded newborn screening generates incidental results, notably carrier results. Yet newborn screening programmes typically restrict parental choice regarding receipt of this non-health serving genetic information. Healthcare providers play a key role in educating families or caring for screened infants and have strong beliefs about the management of incidental results. METHODS: To inform policy on disclosure of infant sickle cell disorder (SCD) carrier results, a mixed-methods study of healthcare providers was conducted in Ontario, Canada, to understand attitudes regarding result management using a cross-sectional survey (N = 1615) and semistructured interviews (N = 42). RESULTS: Agreement to reasons favouring disclosure of SCD carrier results was high (65.1%-92.7%) and to reasons opposing disclosure was low (4.1%-18.1%). Genetics professionals expressed less support for arguments favouring disclosure (35.3%-78.8%), and more agreement with arguments opposing disclosure (15.7%-51.9%). A slim majority of genetics professionals (51.9%) agreed that a reason to avoid disclosure was the importance of allowing the child to decide to receive results. Qualitatively, there was a perceived "duty" to disclose, that if the clinician possessed the information, the clinician could not withhold it. DISCUSSION: While a majority of respondents perceived a duty to disclose the incidental results of newborn screening, the policy implications of these attitudes are not obvious. In particular, policy must balance descriptive ethics (ie, what providers believe) and normative ethics (ie, what duty-based principles oblige), address dissenting opinion and consider the relevance of moral principles grounded in clinical obligations for public health initiatives.

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New York Times 2009 September 1; p. D6

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Barriers to the use of genetic testing: a study of racial and ethnic disparities.

Suther, Sandra; Kiros, Gebre-Egziabher

Genetics in Medicine 2009 September; 11(9): 655-662

Abstract: PURPOSE: Racial and ethnic disparities in health are evident among a range of diseases and health care services. New genetic technologies are likely to increase these disparities as access to expensive genetic tests further widens the gap. METHODS: Our analysis used data from a national representative sample collected in 2000. The total sample size for our analysis was 1724 men and women (consisting of 946 non-Hispanic whites, 392 Latinos, and 386 blacks) aged 18 to 91 years. Ordered logistic regression and binary logistic regression analysis were applied to investigate differences by race/ethnicity. RESULTS: Results showed significant differences by racial/ethnic groups in knowledge and concerns about the potential misuse of genetic testing. A significant difference was also found between the types of health insurance coverage by race/ethnicity as well as significantly higher levels of mistrust in a physician and the medical system. CONCLUSION: Our findings raise concern about several barriers among minorities and calls for a development of educational and communication strategies that facilitate in narrowing the gap between racial and ethnic groups.

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Grosse, Scott D.; McBride, Colleen M.; Evans, James P.; Khoury, Muin J.

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Mihaescu, Raluca; van Hoek, Mandy; Sijbrands, Eric J.G.; Uitterlinden, André G.; Witteman, Jacqueline C.M.; Hofman, Albert; van Duijn, Cornelia M.; Janssens, A Cecile J.W.

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**Technology assessment and resource allocation for predictive genetic testing: a study of the perspectives of Canadian genetic health care providers**

BMC Medical Ethics [electronic] 2009 June 18; 10: 6

**Abstract:** BACKGROUND: With a growing number of genetic tests becoming available to the health and consumer markets, genetic health care providers in Canada are faced with the challenge of developing robust decision rules or guidelines to allocate a finite number of public resources. The objective of this study was to gain Canadian genetic health providers’ perspectives on factors and criteria that influence and shape resource allocation decisions for publically funded predictive genetic testing in Canada. METHODS: The authors conducted semi-structured interviews with 16 senior lab directors and clinicians at publically funded Canadian predictive genetic testing facilities. Participants were drawn from British Columbia, Alberta, Manitoba, Ontario, Quebec and Nova Scotia. Given the community sampled was identified as being relatively small and challenging to access, purposive sampling coupled with snowball sampling methodologies were utilized. RESULTS: Surveyed lab directors and clinicians indicated that predictive genetic tests were funded provincially by one of two predominant funding models, but they themselves played a significant role in how these funds were allocated for specific tests and services. They also rated and identified several factors that influenced allocation decisions and patients' decisions regarding testing. Lastly, participants provided recommendations regarding changes to existing allocation models and showed support for a national evaluation process for predictive testing. CONCLUSION: Our findings suggest that largely local and relatively ad hoc decision making processes are being made in relation to resource allocations for predictive genetic tests and that a more coordinated and, potentially, national approach to allocation decisions in this context may be appropriate.

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**Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey**

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Malm, Heidi

**Genetic Privacy: Might There Be a Moral Duty to Share One's Genetic Information?**
American Journal of Bioethics 2009 June-July; 9(6-7): 52-54

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American Journal of Bioethics 2009 June-July; 9(6-7): 46-48

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**Direct-to-Consumer Genomics, Social Networking, and Confidentiality**
American Journal of Bioethics 2009 June-July; 9(6-7): 45-46

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Document 78

Lee, Sandra Soo-Jin; Crawley, LaVera

**Research 2.0: Social Networking and Direct-To-Consumer (DTC) Genomics**
American Journal of Bioethics 2009 June-July; 9(6-7): 35-44

**Abstract:** The convergence of increasingly efficient high throughput sequencing technology and ubiquitous Internet use by the public has fueled the proliferation of companies that provide personal genetic information (PGI) direct-to-consumers. Companies such as 23andme (Mountain View, CA) and Navigenics (Foster City, CA) are emblematic of a growing market for PGI that some argue represents a paradigm shift in how the public values this information and incorporates it into how they behave and plan for their futures. This new class of social networking business ventures that market the science of the personal genome illustrates the new trend in collaborative science. In addition to fostering a consumer empowerment movement, it promotes the trend of democratizing information-openly sharing of data with all interested parties, not just the biomedical researcher-for the purposes of pooling data (increasing statistical power) and escalating the innovation process. This target article discusses the need for new
approaches to studying DTC genomics using social network analysis to identify the impact of obtaining, sharing, and using PGI. As a locus of biosociality, DTC personal genomics forges social relationships based on beliefs of common genetic susceptibility that links risk, disease, and group identity. Ethical issues related to the reframing of DTC personal genomic consumers as advocates and research subjects and the creation of new social formations around health research may be identified through social network analysis.

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How Attitudes Research Contributes to Overoptimistic Expectations of Personal Genome Testing

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Are Social Networkers and Genome Testers One in the Same? The Limitations of Public Opinion Research for Guiding Clinical Practice
American Journal of Bioethics 2009 June-July; 9(6-7): 21-23
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American Journal of Bioethics 2009 June-July; 9(6-7): 19-21
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American Journal of Bioethics 2009 June-July; 9(6-7): 15-19
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Howard, Heidi; Borry, Pascal
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American Journal of Bioethics 2009 June-July; 9(6-7): 11-13
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McGuire, Amy; Diaz, Christina M.; Hilsenbeck, Susan G.; Wang, Tao
Social Networkers' Attitudes Toward Direct-to-Consumer Personal Genome Testing

American Journal of Bioethics 2009 June-July; 9(6-7): 3-10

Abstract: Purpose: This study explores social networkers' interest in and attitudes toward personal genome testing (PGT), focusing on expectations related to the clinical integration of PGT results. Methods: An online survey of 1,087 social networking users was conducted to assess 1) use and interest in PGT; 2) attitudes toward PGT companies and test results; and 3) expectations for the clinical integration of PGT. Descriptive statistics were calculated to summarize respondents' characteristics and responses. Results: Six percent of respondents have used PGT, 64% would consider using PGT, and 30% would not use PGT. Of those who would consider using PGT, 74% report they would use it to gain knowledge about disease in their family. 34% of all respondents consider the information obtained from PGT to be a medical diagnosis. 78% of those who would consider PGT would ask their physician for help interpreting test results, and 61% of all respondents believe physicians have a professional obligation to help individuals interpret PGT results. Conclusion: Respondents express interest in using PGT services, primarily for purposes related to their medical care and expect physicians to help interpret PGT results. Physicians should therefore be prepared for patient demands for information and counsel on the basis of PGT results.

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Lea, Dale Halsey

The Genetic Information Nondiscrimination Act (GINA): what it means for your patients and families


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Genetic discrimination: Australian experiences and policies

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Anderson, Sam

When science fiction became fact

GeneWatch 2009 April-May; 22(2): 11-14
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Supported by: NHGRI-funded publication; Grant 1 R13 HG004689-01

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Cowan, Ruth Schwartz
Moving up the slippery slope: mandated genetic screening on Cyprus.
Supported by: NHGRI-funded publication; 1 R13 HG004689-01

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Magnus, David; Cho, Mildred K.; Cook-Deegan, Robert M.
Direct-to-consumer genetic tests: beyond medical regulation?
Genome Medicine 2009 February 2; 1(2): 17
Abstract: ABSTRACT: The availability of personalized genomic tests, ordered directly by consumers, is rapidly growing. These tests are unlike other genetic or biochemical tests in the sheer amount of data they provide, but interpretation of these genome-wide analyses for health remains uncertain because of the lack of information about environmental and other factors, and because for the vast majority of genetic loci the associations with disease are weak. Although these tests could provide value to customers by offering tools for social networking or genealogy, there are questions about whether and how to regulate these tests and about the extent to which they provide medical information.

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Legislation on genetic testing and the practice of oncology.
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Nicolás, Pilar

*Ethical and juridical issues of genetic testing: a review of the international regulation.*

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Klein, Roger D.

*Analysis: Secretary's Advisory Committee on Genetics, Health, and Society report falls short.*

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Rommetveit, Kjetil; Porz, Rouven

*Tragedy and Grenzsituationen in genetic prediction*

Medicine, Health Care, and Philosophy 2009 February; 12(1): 9-16

*Abstract:* Philosophical anthropologies that emphasise the role of the emotions can be used to expand existing notions of moral agency and learning in situations of great moral complexity. In this article we tell the story of one patient facing the tough decision of whether to be tested for Huntington's disease or not. We then interpret her story from two different but compatible philosophical entry points: Aristotle's conception of Greek tragedy and Karl Jaspers' notion of Grenzsituationen (boundary situations). We continue by indicating some ways in which these two positions may be used for reflecting upon different perspectives involved in clinical decision-making, those of patients, clinicians and bioethicists. We conclude that the ideas we introduce can be used as hermeneutic tools for situating learning and dialogue within a broader cultural field in which literature and art may also play important roles.

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Document 112

Tabery, James

*From a genetic predisposition to an interactive predisposition: rethinking the ethical implications of screening for gene-environment interactions*


*Abstract:* In a widely acclaimed study from 2002, researchers found a case of gene-environment interaction for a gene controlling neuroenzymatic activity (low vs. high), exposure to childhood maltreatment, and antisocial personality disorder (ASPD). Cases of gene-environment interaction are generally characterized as evincing a genetic predisposition; for example, individuals with low neuroenzymatic activity are generally characterized as having a genetic predisposition to ASPD. I first argue that the concept of a genetic predisposition fundamentally misconstrues these cases of gene-environment interaction. This misconstrual will be diagnosed, and then a new concept--interactive predisposition--will be introduced. I then show how this conceptual shift reconfigures old questions and raises new questions for genetic screening. Attempts to screen embryos or fetuses for the gene associated with low neuroenzymatic activity with an eye toward selecting against the low-activity variant fall prey to the myth of pre-environmental prediction; attempts to screen newborns for the gene associated with low neuroenzymatic activity with an eye toward early intervention will have to face the interventionist's dilemma.

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Nyrhinen, Tarja; Hietala, Marja; Puukka, Pauli; Leino-Kilpi, Helena

Are patient rights to information and self-determination in diagnostic genetic testing upheld? A comparison of patients' and providers' perceptions.

Journal of Genetic Counseling 2009 February; 18(1): 72-81

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Document 114

Genetics and Public Policy Center


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Document 115

Genetics and Public Policy Center

State laws pertaining to surreptitious DNA testing


Document 116

McGuire, Amy L.; Majumder, Mary Anderlik

Two cheers for GINA?

Genome Medicine 2009 January 20; 1(1): 6

Abstract: ABSTRACT: The Genetic Information Nondiscrimination Act of 2008 (GINA) was recently enacted in the United States. Its supporters have applauded the passage of GINA, and they hope that it will alleviate public fear about genetic discrimination and facilitate genetic testing and participation in genetic research. Critics worry that GINA does not provide adequate protection because it fails to address discrimination on the basis of non-genetic health-related information, and it only regulates the use of genetic information in health insurance and employment. Despite these limitations, GINA represents a major step forward in US policy. Additional research is needed to assess the impact of GINA on industry practice and public opinion. In the mean time, education about GINA and its limitations can help individuals make more informed decisions about genetic testing and participation in genetic research.

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Document 117

Holohan, M.K.

GINA: The Genetic Information Nondiscrimination Act of 2008

Medical Ethics Newsletter [Lahey Clinic] 2009 Winter; 16(1): 4, 7
Document 118
Tan, Morse Hyun-Myung
Advancing civil rights, the next generation: the Genetic Information Nondiscrimination Act of 2008 and beyond.
Health Matrix 2009 Winter; 19(1): 63-119
Abstract: On the leading edge of civil rights law and bioethics/healthcare law, this Article provides the first law review analysis of the recently passed Genetic Information Nondiscrimination Act (GINA) of 2008, which extends important protection against discrimination in health insurance and employment. GINA also bolsters genetic research by freeing research subjects from the threat of genetic discrimination. This Article demonstrates how GINA further protects this society against the rising dangers of genetic discrimination beyond previously existing federal and state law.

Document 119
Borry, Pascal; Howard, Heidi C.; Sénécal, Karine; Avard, Denise
Direct-to-consumer genome scanning services. Also for children?

Document 120
Bale, Mark
Key principles relating to genetic testing and insurance

Document 121
Schneider, Carl E.
Thou good and faithful servant.

Document 122
Katsanis, Sara; Javitt, Gail
Genetics and Public Policy Center
Surreptitious DNA Testing
Challenging the rhetoric of choice in prenatal screening
Bioethics 2009 January; 23(1): 68-77

Abstract: Prenatal screening, consisting of maternal serum screening and nuchal translucency screening, is on the verge of expansion, both by being offered to more pregnant women and by screening for more conditions. The Society of Obstetricians and Gynaecologists of Canada and the American College of Obstetricians and Gynecologists have each recently recommended that screening be extended to all pregnant women regardless of age, disease history, or risk status. This screening is commonly justified by appeal to the value of autonomy, or women's choice. In this paper, I critically examine the value of autonomy in the context of prenatal screening to determine whether it justifies the routine offer of screening and the expansion of screening services. I argue that in the vast majority of cases the option of prenatal screening does not promote or protect women's autonomy. Both a narrow conception of choice as informed consent and a broad conception of choice as relational reveal difficulties in achieving adequate standards of free informed choice. While there are reasons to worry that women's autonomy is not being protected or promoted within the limited scope of current practice, we should hesitate before normalizing it as part of standard prenatal care for all.

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McNamee, Michael John; Müller, Amo; van Hilvoorde, Ivo; Holm, Søren
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**Ethical issues in genomic medicine**
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Mooney, Carla
**Genetic testing and engineering**
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**Ethical and policy implications of conducting carrier testing and newborn screening for the same condition**
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Botkin, Jeffrey R.
**Research for newborn screening: developing a national framework**
Supported by: NHGRI-funded publication; grant 1 R01 HG02579
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**Lessons to be learned from the move toward expanded newborn screening**


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**Newborn screening for conditions that do not meet the Wilson and Jungner criteria: the case of Duchenne muscular dystrophy**


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**Cystic fibrosis: screening, testing, ethics**
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Porz, Rouven

The need for an ethics of kinship: decision stories and patients' context

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Hallowell, Nina

Consent to genetic testing: a family affair?


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Reviewing the recommendations of the Committee for the Study of Inborn Errors of Metabolism (SIEM).
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**An unwelcome side effect of direct-to-consumer personal genome testing: raiding the medical commons**
JAMA: The Journal of the American Medical Association 2008 December 10; 300(22): 2669-2671
Supported by: NHGRI-funded publication; Grants R01HG004333 and P50HG003374

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The impact of direct-to-consumer marketing of cancer genetic testing on women according to their genetic risk
Genetics in Medicine 2008 December; 10(12): 888-894

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Erwin, Cheryl

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Genetics in Medicine 2008 December; 10(12): 869-873

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Boddington, Paula; Gregory, Maggie
**Adolescent carrier testing in practice: the impact of legal rulings and problems with "Gillick competence"**
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**Direct-to-consumer genetic tests: flawed and unethical**
Lancet Oncology 2008 December; 9(12): 1113

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Wahlberg, Ayo
**Reproductive medicine and the concept of ‘quality’**
Clinical Ethics 2008 December; 3(4): 189-193

**Abstract:** Selection in reproductive medicine today relies on normative assessments of what ‘good life’ consists of. This paper explores the terms under which such assessments are made by focusing on three particular concepts of ‘quality’: quality of life, biological quality and population quality. It is suggested that the apparently conflicting hypes, hopes and fears that surround reproductive medicine can co-circulate because of the different forms of normative assessment that these concepts allow. To ensure clarity in bioethical deliberations about selection, it is necessary to highlight how these differing forms of assessment are mobilized and invoked in practices of and debates about reproductive medicine.

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Macur, Juliet
**Born to run? Little ones get test for sports gene**
New York Times 2008 November 30; p. A1, A34

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Is genetic information relevantly different from other kinds of non-genetic information in the life insurance context?
Journal of Medical Ethics 2008 July; 34(7): 548-551

Abstract: Within the medical, legal and bioethical literature, there has been an increasing concern that the information derived from genetic tests may be used to unfairly discriminate against individuals seeking various kinds of insurance; particularly health and life insurance. Consumer groups, the general public and those with genetic conditions have also expressed these concerns, specifically in the context of life insurance. While it is true that all insurance companies may have an interest in the information obtained from genetic tests, life insurers potentially have a very strong incentive to (want to) use genetic information to rate applicants, as individuals generally purchase their own cover and may want to take out very large policies. This paper critically focuses on genetic information in the context of life insurance. We consider whether genetic information differs in any relevant way from other kinds of non-genetic information required by and disclosed to life insurance companies by potential clients. We will argue that genetic information should not be treated any differently from other types of health information already collected from those wishing to purchase life insurance cover.

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Abstract: Persons exhibiting mutations in two tumor suppressor genes, BRCA1 and BRCA2, have a greatly increased risk of developing breast and/or ovarian cancer. The incidence of BRCA gene mutation is very high in Ashkenazi Jewish women of European descent, and many issues can arise, particularly for observant Orthodox women, because of their genetic status. Their obligations under the Jewish code of ethics, referred to as Jewish law, with respect to the acceptability of various risk-reducing strategies, may be poorly understood. In this article the moral direction that Jewish law gives to women regarding testing, confidentiality, and other issues is explored. The intent is to broaden nurses' knowledge of how a particular religious tradition could impact on decision making around genetics testing, with the aim of enhancing their understanding of culturally sensitive ethical care.

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Selecting potential children and unconditional parental love.

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Abstract: For now, the best way to select a child's genes is to select a potential child who has those genes, using genetic testing and either selective abortion, sperm and egg donors, or selecting embryos for implantation. Some people even wish to select against genes that are only mildly undesirable, or to select for superior genes. I call this selection drift--the standard for acceptable children is creeping upwards. The President's Council on Bioethics and others have raised the parental love objection: Just as we should love existing children unconditionally, so we should unconditionally accept whatever child we get in the natural course of things. If we set conditions on which child we get, we are setting conditions on our love for whatever child we get. Although this objection was prompted by selection drift, it also seems to cover selecting against genes for severe impairments. I argue that selection drift is not inconsistent with the ideal of unconditional parental love and, moreover, that the latter actually implies that we should practise selection drift--in other words, we should try to select potential children with the best genetic endowments. My endowment argument for the second claim works from an analogy between arranging an endowment prior to conception to fund a future child's education, and arranging a genetic endowment by selecting a potential child who already has it, where in both cases the child would not have existed without the endowment. I conclude with some programmatic remarks about the nonidentity problem.

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**Abstract:** Myriad Genetics holds a patent on testing for the hereditary breast and ovarian cancer genes, BRCA1 and BRCA2, and therefore has a forced monopoly on this critical genetic test. Myriad launched a Direct-to-Consumer (DTC) marketing campaign in the Northeast United States in September 2007 and plans to expand that campaign to Florida and Texas in 2008. The ethics of Myriad's patent, forced monopoly and DTC campaign will be reviewed, as well as the impact of this situation on patient access and care, physician liability, and the future of DTC campaigns for genetic testing.

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**Expanding newborn screening: process, policy, and priorities.**
**Abstract:** In the 1960s, newborn screening programs tested for a single very rare but serious disorder. In recent years, thanks to the development of new screening technology, they have expanded into panels of tests; a federally sponsored expert group has recommended that states test for twenty-nine core disorders and twenty-five secondary disorders. By the standards used to decide whether to introduce new preventive health services into clinical use, the
decision-making in newborn screening policy has been lax.

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Minors and informed consent in carrier testing: a survey of European clinical geneticists
Journal of Medical Ethics 2008 May; 34(5): 370-374

Abstract: PURPOSE: A study was made of attitudes of clinical geneticists regarding the age at which minors should be allowed to undergo a carrier test and the reasons they provide to explain their answer. METHODS: European clinical institutions where genetic counselling is offered to patients were contacted. 177 (63%) of the 287 eligible respondents answered a questionnaire. RESULTS: Clinical geneticists were significantly more in favour of providing a carrier test to a younger person if the request was made together with the parents than if the adolescent requested the test personally. Although a large fraction of respondents (16%-30%) were "neither unwilling nor willing" to provide a carrier test to a 16-year-old adolescent who requested the test personally, for most disorders slightly more clinical geneticists were "very willing" or "willing". CONCLUSION: Age is not the only decisive element when considering the participation of adolescents in decisions affecting their health. The clinical geneticists referred to cognitive, emotional and sexual maturity and the support of parents as crucial elements in their comments regarding when to tell children about their genetic risk or to allow adolescents to request a carrier test.

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*Predictive genetic testing of children for adult-onset diseases and psychological harm*
Journal of Medical Ethics 2008 April; 34(4): 275-278

*Abstract:* One of the central arguments given to resist testing currently healthy, asymptomatic children for adult-onset diseases is that they may be psychologically harmed by the knowledge gained from such tests. In this discussion I examine two of the most serious arguments: children who are tested may face limited futures, and that testing may result in damage to the child's self esteem (where the test result returns a positive diagnosis). I claim that these arguments do not stand up to critical evaluation. In conclusion, whilst I do not suggest that all at-risk children should be tested for adult-onset diseases we ought to listen carefully to some parental requests for such testing because the putative psychological harms may not be as significant or likely as initially thought. This is because parents generally have the best interests of their children at heart and if they are properly supported and educated about predictive genetic testing and the possible consequences, then the risk of psychological harms occurring may be ameliorated.

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Abstract: Clinicians, as well as other health-care professionals in genetics clinics, may find themselves in the position where they must consider whether it would be appropriate to offer a diagnostic genetic test to an adolescent. While a clinician's decision to offer a diagnostic genetic test may be straightforward in clinical terms, the dynamics of family interaction and circumstances may make the decision-making process more complicated. Disagreement between parent and child place clinicians in a difficult position and they must be clear about the scope of their professional responsibility and obligations, to both parents and the adolescent. The purpose of this paper is to discuss the Gillick principles and statutory requirements regarding the genetic testing of adolescents. While I will discuss the clinician's obligations, these legal requirements also have applicability to other health-care professionals, such as genetic counsellors, working in genetics clinics.
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U.S. SYSTEM OF OVERSIGHT OF GENETIC TESTING: A RESPONSE TO THE CHARGE OF THE SECRETARY OF HHS. DRAFT REPORT OF THE SECRETARY'S ADVISORY COMMITTEE ON GENETICS, HEALTH, AND SOCIETY
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**Carrier screening for Gaucher disease: lessons for low-penetrance, treatable diseases**

Abstract: CONTEXT: The aim of carrier screening is to prevent severe, untreatable genetic disease by identifying couples at risk before the birth of an affected child, and providing such couples with options for reproductive outcomes for affected pregnancies. Gaucher disease (GD) is an autosomal recessive storage disorder, relatively
frequent in Ashkenazi Jews. Carrier screening for GD is controversial because common type 1 GD is often asymptomatic and effective treatment exists. However, screening is offered to Ashkenazi Jews worldwide and has been offered in Israel since 1995. OBJECTIVE: To examine the scope and outcomes of nationwide GD screening. DESIGN, SETTING, AND PARTICIPANTS: All Israeli genetic centers provided data on the number of individuals screened for GD, the number of carriers identified, the number of carrier couples identified, and the mutations identified in these couples between January 1, 1995, and March 31, 2003. Carrier couples were interviewed via telephone between January 21, 2003, and August 31, 2004, using a structured questionnaire for relevant outcome measures. MAIN OUTCOME MEASURES: Screening scope (number of testing centers, tested individuals, and carrier couples), screening process (type of pretest and posttest consultations), and screening outcomes (utilization of prenatal diagnosis and pregnancy terminations). RESULTS: Between January 1, 1995, and March 31, 2003, 10 of 12 Israeli genetic centers (83.3%) offered carrier screening. Carrier frequency was 5.7%, and 83 carrier couples were identified among an estimated 28,893 individuals screened. There were 82 couples at risk for offspring with type 1 GD. Seventy of 82 couples (85%) were at risk for asymptomatic or mildly affected offspring and 12 of 82 couples (15%) were at risk for moderately affected offspring. At postscreening, 65 interviewed couples had 90 pregnancies, and prenatal diagnosis was performed in 68 pregnancies (76%), detecting 16 fetuses with GD (24%). Pregnancies were terminated in 2 of 13 fetuses (15%) predicted to be asymptomatic or mildly affected and 2 of 3 fetuses (67%) with predicted moderate disease. There were significantly fewer pregnancy terminations in couples who in addition to genetic counseling had medical counseling with a GD expert (1 of 13 [8%] vs 3 of 3 with no medical counseling [100%], P = .007). CONCLUSIONS: In this study of GD screening among Ashkenazi Jewish couples in Israel, most couples did not terminate affected pregnancies, although screening was associated with a few pregnancy terminations. The main possible benefit was providing couples with knowledge and control. The divergence of these outcomes from stated goals of screening programs is likely to confront carrier screening programs for low-penetrance diseases.
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International Journal of Technology Assessment in Health Care 2007 Fall; 23(4): 495-504

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Gagen, Wendy Jane; Bishop, Jeffrey P.

**Ethics, justification and the prevention of spina bifida**

Journal of Medical Ethics 2007 September; 33(9): 501-507

*Abstract:* During the 1970s, prenatal screening technologies were in their infancy, but were being swiftly harnessed to uncover and prevent spina bifida. The historical rise of this screening process and prevention programme is analysed in this paper, and the role of ethical debates in key studies, editorials and letters reported in the Lancet, and other related texts and government documents between 1972 and 1983, is considered. The silence that surrounded rigorous ethical debate served to highlight where discussion lay—namely, within the justifications offered for the prevention of spina bifida, and the efficacy and benefits of screening. In other words, the ethical justification for screening and prevention of spina bifida, when the authors are not explicitly interested in ethics, is considered. These justifications held certain notions of disability as costly to society, with an imperative to screen and prevent spina bifida for the good of the society.

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Van Hoyweghen, Ine; Horstman, Klasien; Schepers, Rita

**Genetic 'risk carriers' and lifestyle 'risk takers'. Which risks deserve our legal protection in insurance?**


*Abstract:* Over the past years, one of the most contentious topics in policy debates on genetics has been the use of genetic testing in insurance. In the rush to confront concerns about potential abuses of genetic information, most countries throughout Europe and the US have enacted genetics-specific legislation for insurance. Drawing on current debates on the pros and cons of a genetics-specific legislative approach, this article offers empirical insight into how such legislation works out in insurance practice. To this end, ethnographic fieldwork was done in the underwriting departments of Belgian insurance companies. Belgium was one of the first European countries introducing genetics-specific legislation in insurance. Although this approach does not allow us to speak in terms of 'the causal effects of the law', it enables us to point to some developments in insurance practice that are quite different than the law's original intentions. It will not only become clear that the Belgian genetics-specific legislation does not offer adequate solutions to the underlying issues it was intended for. We will also show that, while the legislation's focus has been on the inadmissibility of genetic discrimination, at the same time differences are made in the insurance appraisal within the group of the asymptomatic ill. In other words, by giving exclusive legal protection to the group of genetic risks, other non-genetic risk groups are unintendely being under-protected. From a policy point of view, studying genetics-specific legislation is especially valuable because it forces us to return to first principles: Which risks
deserve our legal protection in insurance? Who do we declare our solidarity with?

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**Pulling rank: why should US military personnel be singled out for genetic discrimination? [editorial]**

Nature 2007 August 30; 448(7157): 969

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**For the first time, FDA recommends gene testing**

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Lessick, Mira

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Phelps, Ceri; Wood, F.; Bennett, P.; Brain, K.; Gray, J.

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New England Journal of Medicine 2007 July 5; 357(1); 61-63

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Indian Journal of Medical Ethics 2007 July-September; 4(3): 133-134

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Factors affecting decisions to accept or decline cystic fibrosis carrier testing/screening: a theory-guided systematic review
Genetics in Medicine 2007 July; 9(7): 442-450
Kopelman, Loretta M.

**Using the best interests standard to decide whether to test children for untreatable, late-onset genetic diseases**


**Abstract:** A new analysis of the Best Interests Standard is given and applied to the controversy about testing children for untreatable, severe late-onset genetic diseases, such as Huntington's disease or Alzheimer's disease. A professional consensus recommends against such predictive testing, because it is not in children's best interest. Critics disagree. The Best Interests Standard can be a powerful way to resolve such disputes. This paper begins by analyzing its meaning into three necessary and jointly sufficient conditions showing it: 1. is an "umbrella" standard, used differently in different contexts, 2. has objective and subjective features, 3. is more than people's intuitions about how to rank potential benefits and risks in deciding for others but also includes evidence, established rights, duties and thresholds of acceptable care, and 4. can have different professional, medical, moral and legal uses, as in this dispute. Using this standard, support is given for the professional consensus based on concerns about discrimination, analogies to adult choices, consistency with clinical judgments for adults, and desires to preserve of an open future for children. Support is also given for parents' legal authority to decide what genetic tests to do.

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Bennett, Paul; Smith, Susan J.

**Genetics, insurance and participation: how a Citizens' Jury reached its verdict**

Social Science and Medicine 2007 June; 64(12): 2487-2498

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Klitzman, Robert; Thorne, Deborah; Williamson, Jennifer; Marder, Karen

**The roles of family members, health care workers, and others in decision-making processes about genetic testing among individuals at risk for Huntington disease**


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Blase, Terri; Martinez, Ariadna; Grody, Wayne W.; Schimmenti, Lisa; Palmer, Christina G.S.

**Sharing GJB2/GJB6 genetic test information with family members**

Journal of Genetic Counseling 2007 June; 16(3): 313-324

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Schmidt; Eric B.
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Bioethics 2007, May; 21(4): 191-197
Abstract: As parents become increasingly able to make genetic trait selections on behalf of their children, they will need ethical guidance in deciding what genetic traits to select. Dena Davis has argued that parents act unethically if they make selections that constrain their child's range of futures. But some selections may expand the child's range of futures. And other selections may shift the child's range of futures, without either constraining or expanding that range. I contend that not only would parents act unethically if they make selections that constrain the range of their child's futures, they would act unethetically if they make selections that shift the range of their child's futures, because selections that shift the range of the child's futures would allow parents to over-determine their child's futures. Thus, I contend that parents would act ethically only if they make selections that expand their child's range of futures.
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Gustafson, Shanna L.; Gettig, Elizabeth A.; Watt-Morse, Margaret; Krishnamurti, Lakshmanan
**Health beliefs among African American women regarding genetic testing and counseling for sickle cell disease**
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Nyhrinen, Tarja; Hietala, Marja; Puukka, Pauli; Leino-Kilpi, Helena
**Privacy and equality in diagnostic genetic testing**
Nursing Ethics 2007 May; 14(3): 295-308

**Abstract:** This study aimed to determine the extent to which the principles of privacy and equality were observed during diagnostic genetic testing according to views held by patients or child patients' parents (n = 106) and by staff (n = 162) from three Finnish university hospitals. The data were collected through a structured questionnaire and analysed using the SAS 8.1 statistical software. In general, the two principles were observed relatively satisfactorily in clinical practice. According to patients/parents, equality in the post-analytic phase and, according to staff, privacy in the pre-analytic phase, involved the greatest ethical problems. The two groups differed in their views concerning pre-analytic privacy. Although there were no major problems regarding the two principles, the differences between the testing phases require further clarification. To enhance privacy protection and equality, professionals need to be given more genetics/ethics training, and patients individual counselling by genetics units staff, giving more consideration to patients' world-view, the purpose of the test and the test result.

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Scully, Jackie Leach; Porz, Rouven; Rehmann-Sutter, Christoph
'These days don't make genetic test decisions from one day to the next' -- using time to preserve moral space
Bioethics 2007 May; 21(4):208-217

**Abstract:** The part played by time in ethics is often taken for granted, yet time is essential to moral decision making. This paper looks at time in ethical decisions about having a genetic test. We use a patient-centred approach, combining empirical research methods with normative ethical analysis to investigate the patients' experience of time in (i) prenatal testing of a foetus for a genetic condition, (ii) predictive or diagnostic testing for breast and colon cancer, or (iii) testing for Huntington's disease (HD). We found that participants often manipulated their experience of time, either using a stepwise process of microdecisions to extend it or, under the time pressure of pregnancy, changing their temporal 'depth of field'. We discuss the implications of these strategies for normative concepts of moral agency, and for clinical ethics.

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Sims, Erika J.; Mugford, Miranda; Clark, Allan; Aitken, David; McCormick, Jonathan; Mehta, Gita; Mehta, Anil
UK Cystic Fibrosis Database Steering Committee

**Economic implications of newborn screening for cystic fibrosis: a cost of illness retrospective cohort study**

Lancet 2007 April 7-13; 369(9568): 1187-1195

**Abstract:** BACKGROUND: Newborn screening for cystic fibrosis might not be introduced if implementation and running costs are perceived as prohibitive. Compared with clinical diagnosis, newborn screening is associated with clinical benefit and reduced treatment needs. We estimate the potential savings in treatment costs attributable to newborn screening. METHODS: Using the UK Cystic Fibrosis Database, we used a prevalence strategy to undertake a cost of illness retrospective snapshot cohort study. We estimated yearly costs of long-term therapies and intravenous antibiotics for 184 patients who were diagnosed as a result of screening as newborn babies, and 950 patients who were clinically diagnosed aged 1-9 years in 2002. Costs of adding cystic fibrosis screening to an established newborn screening service in Scotland were adjusted to 2002 prices and applied to the UK as a whole. Costs were recalculated in US$. FINDINGS: Cost of therapy for patients diagnosed by newborn screening was significantly lower than equivalent therapies for clinically diagnosed patients: mean ($7228 vs $12 008, 95% CI of difference -6736 to -2028, p<0.0001) and median ($352 vs $2442, -1916 to -180, p<0.0001). When we limited the clinically diagnosed group to only those diagnosable with a 31 cystic fibrosis transmembrane regulator mutation assay and assumed similar disease progression in the clinically diagnosed group as in the newborn screening group, we showed that mean ($3,397,344) or median ($947,032) drug cost savings could have offset the estimated cost of adding cystic fibrosis to a UK national newborn screening service ($2,971,551). INTERPRETATION: Including indirect costs savings, newborn screening for cystic fibrosis might have even greater financial benefits to society than our estimate shows. Clinical, social, and now economic evidence suggests that universal newborn screening programmes for cystic fibrosis should be adopted internationally.

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Nyrhinen, Tarja; Hietala, Marja; Puukka, Pauli; Leino-Kilpi, Helena

**Consequences as ethical issues in diagnostic genetic testing—a comparison of the perceptions of patients/parents and personnel**

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**Ethical and legal implications of genetic testing in androgen insensitivity syndrome**


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The disabled Jesus: a parent looks at the logic behind prenatal testing and stem cell research
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Gruber, Jeremy
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A bill to prohibit discrimination on the basis of genetic information with respect to health insurance and employment

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Mada mashru'iyyat al-ilzam bil-fahs al-tibbi qabl al-zawaj, dirasah muqaranah = Legality of enforcing premarital screening, a comparative study

Abstract: The book consists of four main chapters: importance of medical screening and its risks; sharia-based jurisprudential foundations for investigating the question of premarital screening; sharia-based ruling regarding premarital screening; nature of premarital screening and its impact on one's marriage decision.

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**Peering into the future. Genetic testing is transforming medicine -- and the way families think about their health. As science unlocks the intricate secrets of DNA, we face difficult choices and new challenges**


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Ross, Lainie Friedman

**Heterozygote carrier testing in high schools abroad: what are the lessons for the U.S.?**

**Abstract:** The main value of carrier detection in the general population is to determine reproductive risks. In this manuscript I examine the practice of providing carrier screening programs in the school setting. While the data show that high school screening programs can achieve high uptake, I argue that this may reflect a lack of full understanding about risks, benefits, and alternatives, and the right not to know. It may also reflect the inherent coercion in group testing, particularly for adolescents who are prone to peer pressure. The problem of carrier screening in the schools is compounded when the condition has a predilection for certain groups based on race, ethnicity or religion. I examine programs around the world that seek to test high school students for Tay Sachs and Cystic Fibrosis carrier status. I argue that carrier programs should be designed so as to minimize stigma and to allow individuals to refuse. The mandatory school environment cannot achieve this. Rather, I conclude that screening programs should be designed to attract young adults and not adolescents to participate in a more voluntary venue.

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**Genetic testing and counseling: selected ethical issues**
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Maturity of judgement in decision making for predictive testing for nontreatable adult-onset neurogenetic conditions: a case against predictive testing of minors
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Green, Nancy S.; Dolan, Siobhan, M.; Murray, Thomas H.
Newborn screening: complexities in universal genetic testing

Abstract: Newborn screening (NBS)--in which each newborn infant is screened for up to 50 specific metabolic disorders for early detection and intervention--is the first program of populationwide genetic testing. As a public health intervention, NBS has greatly improved the lives of thousands of affected children. New technologies and new economic and social forces pose significant ethical and clinical challenges to NBS. Two primary challenges concern (1) accommodating clinical and ethical standards to rapid technological developments in NBS and (2) preparing public health systems to respond to the medical advances and social forces driving expansion of NBS programs. We describe and analyze these challenges through consideration of 3 disorders: phenylketonuria, medium-chain acyl-CoA dehydrogenase deficiency, and cystic fibrosis.

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Malpas, P.J.

**Why tell asymptomatic children of the risk of an adult-onset disease in the family but not test them for it?**

Journal of Medical Ethics 2006 November; 32(11): 639-642

**Abstract:** This paper first considers why it is important to give children genetic information about hereditary conditions in the family, which will go on to affect their lives in a salient way. If it is important to inform children that they are at risk for an adult-onset disease that exists in the family, why should they not also grow up knowing whether they actually carry the genetic mutation? Central to this discussion is the importance of the process of disclosure and the environment in which genetic information is divulged. It is concluded that the reasons given for defending disclosure of genetic conditions in the family to children are also important reasons to cautiously defend predictive genetic testing of children for adult-onset diseases.

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law students or between students from different courses concerning the adolescent son. Three quarters of students thought that he should be told about his mother's disease, and 91% thought the adolescent son should have the opportunity of genetic testing for HD himself. However, significant differences were found concerning the 10-year old son, with 44% of law students and 30% of medical students in favour of testing the child for HD. Students raised some important ethical issues in their elective comments. In conclusion, we found highly positive attitudes towards informing a 16-year old of his mother's HD and offering to test him. These attitudes were not in tune with guidelines. Students did not consider several practical and ethical issues of genetic testing of children and adolescents. Specific education should ensure that attitudes are based on sufficiently detailed knowledge about all aspects of genetic testing of children to discourage pressures on persons at risk of HD.

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**Community involvement in developing policies for genetic testing: assessing the interests and experiences of individuals affected by genetic conditions**

**Abstract:** Because the introduction of genetic testing into clinical medicine and public health creates concerns for the welfare of individuals affected with genetic conditions, those individuals should have a role in policy decisions about testing. Mechanisms for promoting participation range from membership on advisory committees to community dialogues to surveys that provide evidence for supporting practice guidelines. Surveys can assess the attitudes and the experiences of members of an affected group and thus inform discussions about that community's concerns regarding the appropriate use of a genetic test. Results of a survey of individuals affected with inherited dwarfism show how data can be used in policy and clinical-practice contexts. Future research of affected communities' interests should be pursued so that underrepresented voices can be heard.

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Hogarth, Stuart; Melzer, David; Zimmern, Ron

**The regulation of commercial genetic testing services in the UK: a briefing for the Human Genetics Commission**

**Abstract:** "This briefing has been prepared for the Genetic Services sub-group of the Human Genetics Commission (HGC). Its main purpose is to assist members of the Sub-group as they reconvene after a period in which the group has been in abeyance. Its focus is the regulation of commercial genetic testing services, an area the Sub-group is expected to address as it reconvenes. It sets out the history of such activity from the formation of the ACGT [Advisory Committee on Genetic Testing] in 1996 and outlines the complications which arose when this body was absorbed within the newly established HGC in 1999. It briefly outlines the recommendations of Genes Direct, the HGC's report on the regulation of direct-to-public testing and highlights some of the main developments in the period since the report was issued, both in the regulatory arena and in the development of commercial testing services."
Annex I analyses the recommendations made in the Genes Direct report pertaining to the IVD [In Vitro Diagnostics] Directive and identifies areas which may be worthy of further investigation. The briefing also encourages the HGC to clarify its use of the term 'predictive' in the Genes Direct report and Annex 2 seeks to assist in this by listing all the uses of the term in the report." [reprinted from Foreword]

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**The ethics of predictive genetic testing in prevention trials involving adolescents.**


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**The medical examination in United States immigration applications: the potential use of genetic testing leads to heightened privacy concerns**


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**Ethical issues in genetic testing**


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**Genetic discrimination and the need for federal legislation**


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**Informing one's family about genetic testing for hereditary non-polyposis colorectal cancer (HNPCC): a retrospective exploratory study**

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Hamilton, Rebekah J.; Bowers, Barbara J.; Williams, Janet K.

**Disclosing genetic test results to family members**


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Beckman, Ludvig

**Democracy and genetic privacy: the value of bodily integrity**

Medicine, Health Care and Philosophy: A European Journal 2005; 8(1): 97-103

**Abstract:** The right to genetic privacy is presently being incorporated in legal systems all over the world. It remains largely unclear however what interests and values this right serves to protect. There are many different arguments made in the literature, yet none takes into account the problem of how particular values can be justified given the plurality of moral and religious doctrines in our societies. In this article theories of public reason are used in order to explore how genetic privacy could be justified in a way that is sensitive to the "fact of pluralism". The idea of public reason is specified as the idea that governments should appeal only to values and beliefs that are acceptable to all reasonable citizens in the justification of rights. In examining prevalent arguments for genetic privacy—based on the value of autonomy or on the value of intimacy—it is concluded that they do not meet this requirement. In dealing with this deficiency in the literature, an argument is developed that genetic privacy is fundamental to the democratic participation of all citizens. By referring to the preconditions of democratic citizenship, genetic privacy can be justified in a way that respects the plurality of comprehensive doctrines of morality and religion in contemporary societies.

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Mallia, Pierre; ten Have, Henk

**Pragmatic approaches to genetic screening**

Medicine, Health Care and Philosophy: A European Journal 2005; 8(1): 69-77

**Abstract:** Pragmatic approaches to genetic testing are discussed and appraised. Whilst there are various schools of pragmatism, the Deweyan approach seems to be the most appreciated in bioethics as it allows a historical approach indebted to Hegel. This in turn allows the pragmatist to specify and balance principles in various contexts. There are problems with where to draw a line between what is referred to here as the micro- and macro-level of doing bioethics, unless one is simply to be classified as a principlist. Whilst most discussions on genetics occur at a macro level, most specifying must be done also at a micro level—the clinical encounter. Whilst pragmatism encourages us to understand better social and scientific factors and puts into perspective statements like 'playing God', doubts are raised about the 'consensus' process and how one can put aside fundamental values such as the moral status of the embryo on which there is general disagreement. If those doing pragmatism do not endorse these values, there seems to be little ground for process and compromise with those who do. It seems therefore that pragmatism cannot ignore values, even those which are not endorsed by everyone.

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Heinrichs, Bert

**What should we want to know about our future? A Kantian view on predictive genetic testing**


**Abstract:** Recent advances in genomic research have led to the development of new diagnostic tools, including tests which make it possible to predict the future occurrence of monogenetic diseases (e.g. Chorea Huntington) or to determine increased susceptibilities to the future development of more complex diseases (e.g. breast cancer). The use of such tests raises a number of ethical, legal and social issues which are usually discussed in terms of rights. However, in the context of predictive genetic tests a key question arises which lies beyond the concept of rights, namely, What should we want to know about our future? In the following I shall discuss this question against the background of Kant's Doctrine of Virtue. It will be demonstrated that the system of duties of virtue that Kant elaborates in the second part of his Metaphysics of Morals offers a theoretical framework for addressing the question of a proper scope of future knowledge as provided by genetic tests. This approach can serve as a source of moral guidance complementary to a justice perspective. It does, however, not rest on the rather problematic—claim to be able to define what the "good life" is.
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Attitudes of healthcare professionals and parents regarding genetic testing for violent traits in childhood

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Are genetic self-tests dangerous? Assessing the commercialization of genetic testing in terms of personal autonomy

Theoretical Medicine and Bioethics 2004; 25(5-6): 387-398

Abstract: Should a growing market for genetic self-tests be welcomed or feared? From the point of view of personal autonomy the increasing availability of predictive health information seems promising. Yet it is frequently pointed out that genetic information about future health may cause anxiety, distress and even loss of "life-hopes." In this article the argument that genetic self-tests undermine personal autonomy is assessed and criticized. I contend that opportunities for autonomous choice are not reduced by genetic information but by misperceptions and misunderstandings of the results of genetic tests. Since the interpretation of genetic information is sometimes distorted by the information provided about the genetic products, more attention should be given to deceitful marketing that overblows the utility of genetic products. Yet personal autonomy is reduced neither by genetic tests nor by genetic information and there is consequently no compelling case for the conclusion that genetic self-tests
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**Abstract:** Women (N=21) who had had breast cancer and had been enrolled in a large genetic breast cancer epidemiological study were interviewed about their experience of participation in the study, their attitudes to the confidentiality of data, and the feedback of personal and general research results. Collection of family history information seemed more salient in indicating the genetic nature of the study than the enrolment information sheet. There were no concerns about confidentiality. While participants would have welcomed general feedback about the results of the study and were critical that this had not been provided, the feedback of personal information proved complicated and, sometimes, difficult. It is suggested that individual feedback of genetic test information in epidemiological studies should be undertaken only when there are specific reasons.

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Archives of Internal Medicine 2003 March 10; 163(5): 573-582

**Abstract:** USA. dhadley@nhgri.nih.gov BACKGROUND: Genetic testing to refine cancer risk is available. However, little is known about factors affecting the uptake of testing for the most common hereditary colon cancer, hereditary nonpolyposis colorectal cancer. This study investigated attitudes, intentions, and uptake of genetic testing within newly identified families with hereditary nonpolyposis colorectal cancer. METHODS: Cohort study conducted at the National Institutes of Health between April 15, 1996, and November 20, 1999. Data were collected through questionnaires before semistructured education sessions, individual counseling sessions, and the offer of genetic testing. RESULTS: Of the 111 eligible first-degree relatives, 51% chose to participate in education and individual counseling sessions. Participation was associated with greater numbers of first-degree relatives with cancer; no association was found between participation and personal history of cancer. Before education and individual counseling sessions, 64% of participants had heard little about genetic testing for cancers; however, most (97%) stated intentions to pursue testing. Fifty-one percent identified learning about their children's risks as the most important reason to consider testing. Thirty-nine percent identified the potential effect on their health insurance as the most important reason to not undergo testing. Of the 111 eligible first-degree relatives, 51% chose to undergo genetic testing. Participants' intentions to pursue genetic testing were significantly affected by concerns regarding the ability to handle the emotional aspects of testing and the psychosocial effect on family members. CONCLUSIONS: Genetic counseling and testing offers the potential to focus cancer screening resources in individuals truly at increased risk, thereby reducing mortality and morbidity. Fears of discrimination and concerns about psychological and psychosocial issues may present barriers to the use of current cancer prevention strategies, including genetic counseling and testing.

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2=1 : "
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**Reports on the potential dangers of genetic tests sold direct to the public**

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

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Abbing, H.R.

**Some legal aspects of genetic screening**
Medicine and Law 2003; 22(3): 401-409

**Abstract:** Screening activities in health care are not always useful and sometimes harmful. The mere offer of a screening test puts the individual's autonomy under constraint. With genetic (predictive and risk assessment) tests, the right to free, informed consent and to protection of privacy and medical confidentiality is even more warranted. Screening evokes many questions from the perspective of the right to health care as well as (in particular with genetic screening) from the perspective of respect for individual human rights. Fear of liability puts pressure on professional restraint not to offer every screening test available. States have to take legislative measures for guaranteeing that only those screening activities become available that can significantly contribute to individual and public health. They also should consider additional rules for protecting individual rights where those that are generally accepted in the "ordinary" medical setting (the individual patient-doctor relationship), offer insufficient protection.

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Gustafsson Stolt, U.; Ludvigsson, J.; Liss, P.E.; Svensson, T.

**Bioethical theory and practice in genetic screening for type 1 diabetes**
Medicine, Health Care and Philosophy: A European Journal 2003; 6(1): 45-50

**Abstract:** Due to the potential ethical and psychological implications of screening, and especially in regard of screening on children without available and acceptable therapeutic measures, there is a common view that such procedures are not advisable. As part of an independent research- and bioethical case study, our aim was therefore to explore and describe bioethical issues among a representative sample of participant families (n = 17,055 children) in the ABIS (All Babies In South-east Sweden) research screening for Type 1 diabetes (IDDM). The primary aim is the identification of risk factors important for the development of diabetes and other multifactorial immune-mediated diseases. Four hundred, randomly chosen, participant mothers were asked to complete a questionnaire exploring issues of information, informed consent, bio-material, confidentiality and autonomy, and of prevention/intervention. 293 completed the questionnaire, resulting in a response rate of 73.3%. The majority of questions had the form of 6-point Likert-type response scales (1-6). We found that the majority of respondents felt calm in regard of samples and written material, and also concerning the possibility of their child in the future being identified as having high risk of developing Type 1 diabetes. An important finding concerning access and control of mainly biological data was indicated, with the respondents expressing concern for potential future use. We believe our findings indicate that this kind of empirical studies can substantially contribute to our understanding of bioethical issues of medical research involving genetics. Issues, such as safeguards ensuring the ethical criteria of autonomy and respect, were emphasised by our respondents. We believe the issues brought up may promote further discussion, and do suggest issues for consideration by, among others, researchers, bioethicists and Institutional Review Boards.
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Hellman, Deborah

**What makes genetic discrimination exceptional?**


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Kinkead, Gwen

**To study disease, Britain plans a genetic census**

New York Times 2002 December 31; p. F5, F8

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**Who's looking at your DNA [direct-to-consumer genetic testing] [news]**

Lancet 2002 December 7; 360(9348): 1850

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**Fundamental problems and solutions concerning genetic testing (2nd part)**

Alpha Omega 2002 December; 5(3): 473-497

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**Ethical considerations of genetic testing**
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**Genetic discrimination: why Congress must ban genetic testing in the workplace**
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**What's brewing in genetic testing [editorial]**
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**Genetic testing for lung cancer risk: if physicians can do it, should they?**
JGIM: Journal of General Internal Medicine 2002 December; 17(12): 946-951
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Working towards ethical management of genetic testing
Lancet 2002 November 23; 360(9346): 1685-1688

Abstract: Developments in genetic testing and increased public awareness of inherited disease have led to increasing interest in and concern about the ethical issues raised by clinical genetics. We looked at methods for ethical management of genetic testing, and investigated the advantages and limitations of use of ethical guidelines in clinical genetics. We believe that a key element in successful management of genetic testing in addition to guidelines will be availability of ethics training and support for geneticists, nurses, and counsellors. Clinical ethics committees and clinical ethicists can act as a useful focus for such training and advice if their role is seen to be genuinely supportive by health professionals and patients. We also argue that increased public involvement at the national level in policy debate about control of genetic testing is needed.

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Hastings Center Report 2002 November-December; 32(6): 6

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Key roles of government in genomics and proteomics: a public health perspective
Genetics in Medicine 2002 November-December; 4(6 Supplement): 72S-76S

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Guidelines for genetic testing of healthy children [policy statement]

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Gollust, Sarah E.; Hull, Sara Chandros; Wilfond, Benjamin S.
Limitation of direct-to-consumer advertising for clinical genetic testing

Abstract: Although direct-to-consumer (DTC) advertisements for pharmaceuticals have been appearing in the mass media for 20 years, DTC advertisements for genetic testing have only recently appeared. Advertisements for genetic testing can provide both consumers and physicians with information about test availability in an expanding market. However, 3 factors limit the value and appropriateness of advertisements: complex information, a complicated social context surrounding genetics, and a lack of consensus about the clinical utility of some tests. Consideration of several advertisements suggests that they overstate the value of genetic testing for consumers' clinical care. Furthermore, advertisements may provide misinformation about genetics, exaggerate consumers' risks, endorse a
A deterministic relationship between genes and disease, and reinforce associations between diseases and ethnic groups. Advertising motivated by factors other than evidence of the clinical value of genetic tests can manipulate consumers' behavior by exploiting their fears and worries. At this time, DTC advertisements are inappropriate, given the public's limited sophistication regarding genetics and the lack of comprehensive premarket review of tests or oversight of advertisement content. Existing Federal Trade Commission and Food and Drug Administration regulations for other types of health-related advertising should be applied to advertisements for genetic tests.

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**The genetic revolution: new ethical issues for obstetrics and gynaecology**
Best Practice and Research in Clinical Obstetrics and Gynaecology 2002 October; 16(5): 745-756

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**An equality paradigm for preventing genetic discrimination**

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**General practitioners and predictive genetic testing for late-onset diseases in Flanders: what are their opinions and do they want to be involved?**
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A population-based study of Ashkenazi Jewish women's attitudes toward genetic discrimination and BRCA1/2 testing
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**Motivations and concerns of women considering genetic testing for breast cancer: a comparison between affected and at-risk probands**

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Henneman, L.; Bramsen, I.; van der Ploeg, H.M.; ten Kate, L.P.

**Preconception cystic fibrosis carrier couple screening: impact, understanding, and satisfaction**

Genetic Testing 2002 Fall; 6(3): 195-202

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Baird, Patricia A.

**Identification of genetic susceptibility to common diseases: the case for regulation**

Perspectives in Biology and Medicine 2002 Fall; 45(4): 516-528

**Abstract:** There is, and will continue to be, pressure to disseminate and market population-wide availability of genetic susceptibility tests for common, complexly determined diseases. Many of the claims for such genetic screening tests are made by parties who stand to gain: laboratories, service providers, biotechnology firms, scientists working in genetics. Despite the fact that there is little or no evidence to support the claims of benefit, the current lack of appropriate regulation means there is a danger that promotion and advertising will nevertheless be successful in marketing such testing. Some suggestions as to the content of possible regulation are made, and some impediments to the implementation of regulation are discussed.

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Ross, Lainie Friedman

**Predictive genetic testing for conditions that present in childhood**

Kennedy Institute of Ethics Journal 2002 September; 12(3): 225-244

**Abstract:** There is a general consensus in the medical and medical ethics communities against predictive genetic testing of children for late onset conditions, but minimal consideration is given to predictive testing of asymptomatic children for disorders that present later in childhood when presymptomatic treatment cannot influence the course of the disease. In this paper, I examine the question of whether it is ethical to perform predictive testing and screening of newborns and young children for conditions that present later in childhood. I consider the risks and benefits of (1) predictive testing of children from high-risk families; (2) predictive population screening for conditions that are untreatable; and (3) predictive population screening for conditions in which the efficacy of presymptomatic treatment is equivocal. I conclude in favor of parental discretion for predictive genetic testing, but against state-sponsored predictive screening for conditions that do not fulfill public health screening criteria.

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Preserving privacy, preventing discrimination becomes the province of genetics experts


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Commentary: epidemiology and the continuum from genetic research to genetic testing

American Journal of Epidemiology 2002 August 15; 156(4): 297-299

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Diagnostic testing in neurogenetics. Principles, limitations, and ethical considerations

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Attitudes of pediatric residents toward ethical issues associated with genetic testing in children

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A consumer charter for genomic services [commentary]

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A rational view of insurance and genetic discrimination

Science 2002 July 12; 297(5579): 195-196

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**The supply of genetic tests direct to the public: a consultation document.**


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**Genetic testing for breast and ovarian cancer predisposition: cancer burden and responsibility**

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**An act concerning genetic privacy [Approved: 1 June 2002]**


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**Professional and personal attitudes about access and confidentiality in the genetic testing of children: a pilot study**

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Ethical, social and legal implications of pharmacogenomics: a critical review
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Freedom and responsibility in genetic testing

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**Genetic testing and discrimination in employment: recommending a uniform statutory approach**
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Who Gets to Know? Genetics and Privacy (2002)
Films for the Humanities & Sciences

**Abstract:** When it comes to genetic testing, how much should a patient be told? If the news is bad, who else should the patient inform? And could - or should - such privileged information be made available to employers, insurance companies, and others? [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.primedia.com/divisions/educationandtraining/filmsforhumanities (link may be outdated)

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Genes on Trial: Genetics, Behavior, and the Law (2002)
Films for the Humanities & Sciences

**Abstract:** "Could genetic research stigmatize people who carry a "bad" gene? Could their behavior actually be determined by that gene? If so, then just how free is free will? Moderated by Harvard Law School's Charles Ogletree, this Fred Friendly Seminar scrutinizes social, ethical, and legal issues involving genetic research into undesirable traits such as addiction to alcohol by exploring the relationship between the genetic basis for addiction and the limits of personal responsibility. [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.

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**The ethics of prenatal screening and the search for global bioethics.**


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American Society of Human Genetics [ASHG]

**Statement from the American Society of Human Genetics (ASHG): The Board of Directors of the American Society of Human Genetics has endorsed Senate Bill 318, the Genetic Nondiscrimination and Health Insurance and Employment Act**


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**Marshall, Eliot**

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**Genetic discrimination in the workplace and the need for federal legislation**

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Abstract: OBJECTIVES: The development of predictive genetic tests provides a new area where consumers can gain knowledge of their health status and commercial opportunities. "Over-the-counter" or mail order genetic tests are most likely to provide information on carrier status or the risk of developing a multifactorial disease. The paper considers the social and ethical implications of individuals purchasing genetic tests and whether genetic information is different from other types of health information which individuals can obtain for themselves. DESIGN: The discussion is illustrated by findings from a questionnaire survey of university students as potential consumers. Topics covered included what health tests they had already used, expectations of genetic tests, willingness to pay, who should have access to the results and whether there need to be restrictions on such tests. SAMPLE: Six hundred and fifteen first-year students in the universities of Leuven, Cardiff, Central Lancashire, Vienna and Nijmegen studying either medicine or a non-science subject. RESULTS: Students were enthusiastic about genetic tests and had high expectations of their accuracy and usefulness but most thought they should be available through the health service and a minority thought that some tests, for example for sex selection, should not be available at all. There were few differences in responses by sex or subject of study but some by country. The paper also considers ethical and social issues outside the scope of a questionnaire survey of this type. CONCLUSION: To address some of these issues the sale of genetic tests to individuals can be made subject to ethical guidelines or codes of practice, for example to protect vulnerable groups, but there are fundamental social and ethical questions which such guidelines cannot address.

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Abstract: This note summarises the main points that were made by the speakers and during the discussion. Report: The European Parliament Temporary Committee on Human Genetics and Other New Technologies in Human Medicine by Mr. T. Grunert, head of the secretariat of the temporary committee; Genetic Testing: State of the Art by Dr. K. Lindpaintner, head of Roche Genetics; Ethical Aspects of Population Screening by Prof. Dr. J.J. Cassiman, Center for Human Genetics, Leuven, Belgium; Public Attitudes and Debate on Genetic Testing by Dr. K. van der
Bruggen, Rathenau Institute, the Netherlands; Genetic Tests and Insurance by Mr. R. Walsh, Association of British Insurers; Panel Discussion, Presentation by Ms. H. Tybkjaer, Danish Cystic Fibrosis Association; Presentation by Dr. J. Cream, Alzheimer's Society, United Kingdom; and Presentation by Ms. L. Cordier, European Commission DG Research. [KIE]

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**Beyond consent: ethical and social issues in genetic testing**

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**Genetic testing: technology that is changing the adoption process**

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Pancreatology 2001; 1(6): 576-580
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Genetic testing policy issues for the new millennium: abstract of remarks
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Restoring public trust in gene therapy [editorial]
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Methods in Molecular Biology 2001; 170: 53-69
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Cancer genetics: a model for multifactorial conditions?

Abstract: Research in the area of genetic susceptibility and cancer is beginning to challenge traditional socio-ethical and legal norms. In particular, increased personal data protection legislation is severely constraining the ability to maintain or initiate new cancer registries for proper epidemiological purposes. Likewise, the principle and obligation of the confidentiality of genetic information cannot remain sacrosanct in the face of the immediate health needs of biological relatives. Finally, participation in research and even the willingness to be tested and treated is constantly threatened by the uncertainty surrounding insurability. What are the new ethical parameters emerging in research in cancer genetics?

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Schotsmans, Paul T.
Prenatal testing for Huntington's disease
Call number: R724.B48256 2001

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Ellis, Ian; Lerch, Markus M.; Whitcomb, David C.; (for the Consensus Committees of the European Registry of Hereditary Pancreatic Diseases; Midwest Multi-Center Pancreatic Study Group; International Association of Pancreatology)
Genetic testing for hereditary pancreatitis: guidelines for indications, counselling, consent and privacy issues
Pancreatology 2001; 1(5): 405-415

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Murray, Robert F.
Social and medical implications of new genetic techniques.
Call number: QH445.2.H88 2001

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Research in medical ethics: genetic diagnosis.
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Genetic services for children: who should consent?
In: Mahowald, Mary B.; McKusick, Victor A.; Scheurle, Angela S.; Aspinwall, Timothy J., eds. Genetics in the Clinic: Clinical, Ethical, and Social Implications for Primary Care. St. Louis, MO: Mosby; 2001: 167-179.
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Beeson, Diane; Doksum, Teresa

Family values and resistance to genetic testing.
Call number: R724 .B4826 2001

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Genetic predisposition and the politics of prediction.
Call number: QH332 .N49 2001

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Human Genetics Commission

Human genetics commission launches consultation on the future of genetic information

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Winickoff, David E.

Biosamples, Genomics, and Human Rights: Context and Content of Iceland's Biobanks Act
Document 1248
ABC News
Abstract: "Genetic Testing for Alzheimer's Nightline takes a closer look at genetic testing for Alzheimer's and the ethical dilemma over marketing such a test when no cure is available" (from ABC web description)

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

Document 1249
Genetic Testing: The Scientific, Social, Ethical and Legal Applications and Implications in the Criminal Justice System (2000)
North Carolina Association for Biomedical Research [NCABR]
Abstract: One video in the North Carolina Association for Biomedical Research [NCABR]'s annual series. A discussion guide accompanies the video.

Document 1250
A Question of Genes: Inherited Risks (1997 - air date of September 16, 1997) / If You Could Know Your LifeStory, Would You Want to Know How it Ends?
Oregon Public Broadcasting
Abstract: Program includes teacher's guide and covers seven vignettes regarding genetic testing and genetic information. During the program, Barbara Biesecker, Genetics Counsellor at NIH, is interviewed. Case Study 1 "New Choices, New Dilemmas" and concerns prenatal testing and parental decisions making. The test considered in this vignette is cystic fibrosis. Case Study 2 "Unexpected Consequences" discusses a physician trying to decide what to do with additional information discovered about his patient in the course of a genetic test. With his patient's consent, Dr. Rader tested her for the gene marker for heart disease. The same gene also serves as a marker for Alzheimer's Disease. He doesn't know whether to share that information with her or not. Case 3 "A Daughter's Tale" focuses on the multi-generational effect of genetic disease, in this case, Alzheimer's Disease. Case 4 "A Balancing Act" considers both scientific goals and business interests involved when a company is involved in genetic research. The program considers the "ethical side of genetic research." Case 5 "The Disenfranchised" explores access issues to genetic testing and screening. This segment focuses on women and points out that some women may lack the economic resources to access diagnosis and treatment for breast cancer, much less to seek genetic testing for a predisposition to the disease. Other groups may not trust medical research and so choose not to access resources. The case of African-American women and the lack of trust in the community stemming from decades-long studies done on African-American men and untreated syphilis decades ago. Case 6 "Testing Family Bonds" explores intrafamilial effects of genetic testing. Two sisters participate in an NIH study that tests for predisposition to breast cancer and ovarian cancer. One sister has a gene that predisposes her to the disease while the other sister does not. Case 7 "Extreme Measures" looks at the benefits and burdens of genetic testing. Again breast cancer is the disease focus. Long ago Polly had her breast removed as a preventive measure after all three of her sisters died from breast cancer. Now genetic testing is available but Polly's daughter does not want the test because she fears her health insurance will be lost. Program resources and website available through http://www.backbonemedia.org/genes.html.

Document 1251
Deadly Inheritance (1997)
Fanlight Productions
Abstract: "For twenty years, 38-year-old Christie Kilgore has lived with the knowledge that she may be carrying the gene that causes Huntington's disease, the fatal neurological disorder which has afflicted her mother and others in her family. Thanks to recent advances in genetics, she has been given a new and frightening opportunity--the
chance to discover if she is going to live or die. This extraordinary documentary follows Christie and her family over the months between her initial blood test and the unforgettable moment when she is told her results. More than just a gripping medical suspense story, this film is a powerful real-life drama of love, family, and compassion." [Description from cassette box] This film was selected as the "Best Social Issue Documentary Hot Docs '98, Toronto, Ontario, Canada" and received the "Canadian Nurses Association National Media Award," "1999 Best Documentary, Bar Harbor Film Festival," "1999 Freddie Award Winner, International Health & medical Film Competition," and the "1999 Columbus International Film Festival, Bronze Plaque."

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

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Document 1252


Bullfrog Films

Abstract: "The discovery of the structure of DNA may have the most far-reaching consequences of any of this century's amazing scientific advances. As geneticists unlock the DNA code, they learn how differences in the DNA that makes of particular genes are linked to variations in physical traits, from an organism's size to its resistance or susceptibility to disease. While there’s no doubt that genetic engineering holds tremendous promise for alleviating human suffering, what are the risks? This program looks at some problem areas: loss of privacy unless access to personal genetic information is protected; discrimination in employment and insurance based on genetic tests; and loss of respect for people with disabilities as the public comes to view certain inherited conditions as 'avoidable' and some call for restricting the reproductive rights of those who are genetically 'flawed'. Some problems require public debate. How much money should be devoted to genetic research when we know that money spent on nutrition and environmental clean-up can produce immediate tangible results? To what extent should human beings intervene in the basic workings of nature? GENE BLUES sets the stage for a national debate on the ramifications of gene technology." (Description from cassette box)

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

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Document 1253

Winding Your Way Through DNA: Promise & Perils of Biotechnology: Genetic Testing

Pyramid Media

Abstract: This videotape is intended for high school and college biology classes and public education programs. The program was developed by a team of high school and college teachers, ethicists, historians, and scientists following a public symposium, "Winding Your Way Through DNA" on September 25 and 26, 1992, sponsored by the University of California, San Francisco and the San Francisco Exploratorium. A teacher's guide accompanies the video (33p.) and includes objectives, milestones in biotechnology, handouts, a list of resources (genetic disorder profiles and genetic organizations), a glossary, and a list of references.

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Document 1254


Fanlight Productions

Abstract: "This provocative documentary explores the difficult ethical issues arising from advances in biotechnology that now make it possible to identify genetic defects during pregnancy. It features interview with seven couples who speak openly and honestly about how they made their individual decisions about prenatal testing -- as well as about how they have dealt with the positive and negative consequences of those decisions. Also included are the comments of geneticists, genetic counselors, physicians, mid-wives, disability activists and scholars; central to their discussion is a recognition of our society's changing perspectives on disability, which raise new questions about the option of selective abortion. While offering no easy answers the film stresses the importance of acknowledging the ways in which the weight of responsibility for making these decisions has shifted from "experts" to expectant couples. The Burden of Knowledge raises crucial questions about personal responsibility and about the changing roles of science, medicine, and technology in an increasingly complex world." [Description from video cassette]
**Confronting the Killer Gene (1989)**
PBS Video

**Abstract:** Arlo Guthrie comments on his father Woody Guthrie's Huntington's Disease. The work also includes scenes from Venezuela where Dr. Nancy Wexler studied a large extended family where one in five members have Huntington's Disease.