

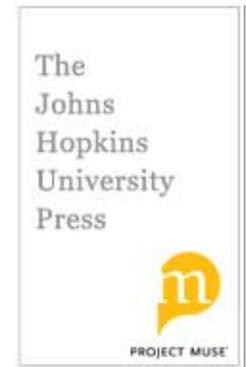


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Searching Across Boundaries: National Information Resource  
on Ethics and Human Genetics

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Kennedy Institute of Ethics Journal, Volume 12, Number 1, March 2002, pp.  
103-113 (Article)

Published by Johns Hopkins University Press  
DOI: <https://doi.org/10.1353/ken.2002.0006>

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## Searching Across Boundaries: National Information Resource on Ethics and Human Genetics

While indeed an historical moment, the announcement of the mapping of the human genome has been treated in the literature as a beginning—a new way to think about biology and the ways in which biological concepts are applied to medicine. Issues of both *Science* and *Nature* magazines celebrated the event by establishing interdisciplinary websites where readers can access essays on aspects of genome mapping and directly link to databases to search for more information on the topics (IV. Genome Gateway 2001; The Human Genome 2001). Since 1994, the National Information Resource on Ethics and Human Genetics (NIREHG), a special project of the National Reference Center for Bioethics Literature (NRC), has been providing such an integrated information service on ethics and genetics. Designed to enable a wide range of users to go from annotated bibliographies (Scope Notes) and brief essays (called “enotes”) to database searching, NIREHG fosters an interdisciplinary approach to research on ethics and genetics. Links are provided between and among Scope Notes and enotes to information maintained on the NIREHG site as well as to sources found throughout the Internet. In providing the following annotations added to NIREHG materials since 1997, the *Kennedy Institute of Ethics Journal* (in its online presence through Project Muse) becomes an additional forum for NIREHG links. “It is a rare and wonderful moment when success teaches us humility, and this, I argue, is precisely the moment at which we find ourselves at the end of the twentieth century” (IV. Keller 2000, p. 7). It is with both joy and humility that we celebrate the mapping of the human genome.

This publication was produced by staff members of the National Reference Center for Bioethics Literature (Martina Darragh, Harriet Gray, Pat Milmoie McCarrick, and Susan Cartier Poland), Kennedy Institute of Ethics, Georgetown University. The Center operates on Contract NO 1 LM73529 from the National Library of Medicine. Other support includes Contract NO 1 LM73514 (National Library of Medicine) for the BIOETHICSLINE database, and Grant P41 HG01115 (ELSI Branch, National Human Genome Research Institute) for the National Information Resource on Ethics and Human Genetics, both operated at the Kennedy Institute of Ethics.

I. GENETIC TESTING

Andrews, Lori B. *Future Perfect: Confronting Decisions About Genetics*. New York: Columbia University Press, 2001. 264 p.

Noting the wide impact of genetic testing, Andrews discusses patient self concept, reproduction decisions, confidentiality, discriminations in health insurance and employment, the need for competent counseling, and the legal, ethical, and social regulations she deems important to help solve dilemmas arising from the tests and their ensuing ramifications. She describes three models, pointing out both advantages and problems: a medical model with physician gatekeepers, a public health model that could provide education as well some testing for those unable to afford tests, and a fundamental rights model that could give greater weight to individuals decisions about the use of health care services. The book has 85 pages of footnotes.

American Society of Human Genetics. Social Issues Subcommittee on Familial Disclosure. Professional Disclosure of Familial Genetic Information. *American Journal of Human Genetics* 62 (2): 474–83, February 1998.

The ASHG statement outlines points to consider: the general rule of confidentiality, exceptional circumstances that permit disclosure, and the ethical duty to inform patients about familial implications. Background discussion includes: ethical frameworks for disclosure of otherwise confidential information, the duty to warn under law, and international trends and positions.

Boetzkes, Elisabeth. Genetic Knowledge and Third-Party Interests.

*Cambridge Quarterly of Healthcare Ethics* 8 (4): 386–92, Summer 1999.

Protection from the interests of insurers or prospective employers are discussed from the point of view of the ethical basis of the professional obligation to confidentiality as well as the right to privacy of those tested. However, the author supports family members, saying that “first-party resistance to disclosure may be overcome by weighty third-party claims.”

Chadwick, Ruth; Shickle, Darren; ten Have, Henk; and Wiesing, Urban, eds. *The Ethics of Genetic Screening*. Dordrecht, The Netherlands: Kluwer Academic Publishers, 1999. 255 p.

Twenty-one chapters and 23 authors provide views of genetic testing/screening in different European countries and offer brief discussions of sociological perspectives, moral and philosophical issues, privacy, reconciling liberty and the common good, and questions raised in genetic testing of children.

Clayton, Ellen Wright. Genetic Testing in Children. *Journal of Medicine and Philosophy* 22 (3): 233–51, June 1997.

Clayton argues that there is room for substantial disagreement between parents and physicians about the appropriateness of genetic testing for children. She provides a series of cases and concludes that one should “give increasing deference to the views of the child as the child grows older.”

Cohen, Cynthia B. Wrestling With the Future: Should We Test Children for Adult-Onset Genetic Conditions?

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*Kennedy Institute of Ethics Journal* 8 (2): 111–30, June 1998.

In this special issue about genetic testing and counseling, guest editor Cohen points out the reluctance to test children since genetics professionals often think the psychosocial harm is greater than any benefits and the child's autonomy is violated in adulthood. The author concludes that decisions regarding testing should utilize many factors relevant to the particular child with the final decision made by the parents and the mature child.

The Future of Medicine: How Genetic Engineering Will Change Us In the Next Century. *Time* [Special Issue] 153 (1), 11 January 1999.

This issue devoted to a broad view of the entire field of genetics offers several specific essays about the ramifications of genetic testing/screening: "Good Eggs, Bad Eggs: The Growing Power of Prenatal Genetic Tests Is Raising Thorny New Questions About Ethics, Fairness and Privacy" by Frederic Golden, David Bjerklie, and Alice Park, pp. 56–59; "Playing the Odds: Health Insurers Want to Know What's in Your DNA" by Christopher Hallowell, p. 59; and "The DNA Detectives" by Jeffrey Kluger, pp. 62–63.

Glannon, Walter. Genes, Embryos, and Future People. *Bioethics* 12 (3): 187–211, July 1998.

Glannon writes that "the testing and selective termination of genetically defective embryos is the only medically and morally defensible way to prevent the existence of people with severe disability, pain and suffering that make their lives not worth living for them on the whole."

Goldworth, Amnon. Informed Consent in the Genetic Age. *Cambridge Quarterly of Healthcare Ethics* 8 (3): 393–400, Summer 1999.

Goldworth stresses the importance of autonomy and the need to give informed consent by anyone who undergoes genetic testing. He thinks that "it should be difficult to trump autonomy by consequential claims," and wonders "how much individual self-governance the citizens of a democratic society will be willing to forgo in order to achieve a collective good."

Grody, Wayne W., and Pyeritz, Reed E. Report Card on Molecular Genetic Testing: Room for Improvement? [Editorial.] *Journal of the American Medical Association* 281 (9): 845–47, 3 March 1999.

The authors emphasize that the scope of molecular genetic testing is increasing so rapidly that professional medical societies must work to ensure high quality in the process and physicians must prepare to be involved both before and after testing "to a high degree." They think that molecular testing will be the predominant way that physicians of all specialties will diagnose and manage patients well into the twenty-first century.

Hiller, Elaine H.; Landenburger, Gretchen; and Natowicz, Marvin R. Public Participation in Medical Policy-Making and the Status of Consumer Autonomy: The Example of Newborn-Screening Programs in the United States. *American Journal of Public Health* 87 (8): 1280–88, August 1997.

Saying that state newborn-screening programs are the largest group of genetic tests in the country, the authors surveyed them to look at public and

parental participation. They conclude that increased public participation would “result in more representative policy-making and could enhance the quality of services provided by newborn-screening programs.”

Holtzman, Neil A. Genetic Screening and Public Health. [Editorial.] *American Journal of Public Health* 87 (8): 1275–76, August 1997.

Holtzman thinks that mandatory screening of newborns should include the opportunity for parents to decide on the merits of such genetic testing. Noting that parents rarely refuse testing when parental consent is required (Maryland), the author says that public health agencies have “a major responsibility to ensure the validity and utility of testing through adequate regulations.”

Holtzman, Neil A. The UK’s Policy on Genetic Testing Services Supplied Direct to the Public—Two Spheres and Two Tiers. *Community Genetics* 1 (1): 49–52, 1998.

The “Code of Practice on Human Genetic Testing Services Supplied Direct to the Public,” prepared by the United Kingdom’s Advisory Committee on Genetic Testing, permits the public to obtain testing for inherited recessive disorders direct from suppliers or commercial laboratories. For other types of genetic testing a physician must be involved. Thus some tests are available to those who can pay for them; others must obtain testing through the National Health Service, which at present covers the testing of relatives for cystic fibrosis, but not the general public. The short, seven point code is included.

Khoury, Muin J.; Burke, Wylie; and Thomson, Elizabeth J., eds. *Genetics*

*and Public Health in the 21st Century: Using Genetic Information to Improve Health and Prevent Disease*. Oxford/New York: Oxford University Press, 2000. 639 p.

This six-part volume reflects the array of roles genetics, genetic testing, and evaluation might play in the fundamental mission of public health: to assure an environment where all people can be healthy. The authors address the overarching principles of human genetics in public health, the use of assessment in genetics, and public health evaluation of genetic testing combined with population interventions.

McGee, Glenn. *The Perfect Baby: Parenthood in the New World of Cloning and Genetics*. 2d ed. Oxford: Rowan & Littlefield Publishers, Inc., 2000. 186 p.

McGee characterizes the idea of a perfect baby as “subtle commercialization” similar to such ideals as the perfect bride or perfect wine and says it is reminiscent of early eugenic theories. The book provides a background for genetic technology; discusses genetic testing, gene therapy, and possible cures; and touches upon cloning. The book is easily understood by prospective parents who wish to know of possible parenting choices in the new century.

McGovern, Margaret M.; Benach, Marta O.; Wallenstein, Sylvan; et al. Quality Assurance in Molecular Genetic Testing Laboratories. *Journal of the American Medical Association* 281 (9): 835–40, 3 March 1999.

Based on a survey of 245 molecular genetic testing laboratories, the authors conclude that many were operating suboptimally and in need of improvement in personnel qualification and

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practice standards. Particular attention focused on the need to guard patient rights to confidentiality and informed consent.

National Institutes of Health (NIH), United States. Consensus Development Conference. Genetic Testing for Cystic Fibrosis. *Archives of Internal Medicine* 159 (14): 1529–39, 26 July 1999.

The Consensus Development Conference concluded that genetic testing for cystic fibrosis (CF) should be offered those with a family history of CF, partners of CF persons, couples planning a pregnancy, and couples seeking prenatal care, but not to the general adult population or to newborns. It urged further research and education, noting the need to protect privacy and to prevent discrimination or stigmatization.

Post, Stephen G., and Whitehouse, Peter J., eds. *Genetic Testing for Alzheimer Disease: Ethical and Clinical Issues*. Johns Hopkins University Press, 1998. 284 p.

Divided into four parts, this collection provides an overview of genetic research on Alzheimer disease (AD), describes the difficulties involved in genetic counseling for AD based on APOE alleles instead of single-gene mutations, examines social issues such as genetic test patenting and actuarial policies for confidential data, and explores the public's perceptions and misperceptions about the nature and use of genetic testing.

Rhodes, Rosamond. Genetic Links, Family Ties, and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge. *Journal of Medicine and Philosophy* 23 (1): 10–30, February 1998.

Rhodes looks at individuals' responsibilities to one another in light of genetic testing, using three cases to illustrate her views. She concludes that no one has a moral right to genetic ignorance and that moral responsibility "depends on a variety of factors including blood ties, social relationships, the history of interaction, and particular features of the situation and the individuals involved."

Sommerville, Ann, and English, Veronica. Genetic Privacy: Orthodoxy or Oxymoron? *Journal of Medical Ethics* 25 (2): 144–50, April 1999.

While noting that all patient decisions should take into account responsibilities to family members and to the community, the authors discuss the ways in which genetic testing highlights issues of autonomy and patient choice. They conclude with the question "Can genetic information be exclusively owned?"

Takala, Tuija. The Right to Genetic Ignorance Confirmed. *Bioethics* 13 (3–4): 288–93, July 1999.

The author rebuts the argument that ". . . genetic information about oneself is also information about one's relatives" and asserts that individuals have the right to refuse to know the results of genetic testing even when the request for testing is made for a pedigree study.

Thompson, Alison K., and Chadwick, Ruth F., eds. *Genetic Information: Acquisition, Access and Control*. New York: Kluwer Academic/Plenum, 1999. 335 p.

The editors have assembled the proceedings of a 1997 international conference as a framework for thoughtful

research and reflection related to the three named aspects of genetic information: acquisition, access, and control. A particularly strong discussion of the issues that genetic screening poses for those who live with disabilities and the disability rights movement is included. The use of genetic information by the insurance industry is also addressed, particularly as a grave concern to those societies that, unlike the UK, do not have universal health insurance.

Wachbroit, Robert. The Question Not Asked: The Challenge of Pleiotropic Genetic Tests. *Kennedy Institute of Ethics Journal* 8 (2): 131–44, June 1998.

Moving on from single-gene disorders, the author is concerned with com-

plex genetic mutations where testing may indicate that more than one disease could develop. He asks whether patients being tested for one condition should be informed if another possible condition is found and concludes that all information should be disclosed.

Zimmern, R. L. Genetic Testing: A Conceptual Exploration. *Journal of Medical Ethics* 25 (2): 151–56, April 1999.

Positing that there is nothing essentially different about genetic information that requires special regulation, Zimmern acknowledges that “. . . fear and mistrust of DNA technology by the public requires that society act to regulate the technology itself.”

## II. EUGENICS

American Society of Human Genetics. Board of Directors. ASHG Statement: Eugenics and the Misuse of Genetic Information to Restrict Reproductive Freedom. *American Journal of Human Genetics* 64 (2): 335–38, February 1999.

Educating the public is the best way “to prevent genetic information from being used to restrict reproductive freedom . . . .” The ASHG deplors any laws, regulations, or other means that would restrain or constrain reproductive freedom on the basis of genetic characteristics of either the parents or potential offspring and urges international cooperation to meet this goal.

Broberg, Gunnar, and Roll-Hansen, Nils, eds. *Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway, and Finland*.

East Lansing: Michigan State University Press, 1996. 294 p.

The authors present “case studies of what happened when Denmark, Finland, Norway and Sweden set in place sterilization and eugenics programs as part of large-scale social welfare experiments based on assumptions that they would contribute to economic prosperity and social progress.” They point out that such programs continued after World War II.

Dikotter, Frank. *Imperfect Conceptions: Medical Knowledge, Birth Defects, and Eugenics in China*. New York: Columbia University Press, 1998. 226 p.

Dikotter shows how cultural currents in China have promoted the “Eugenics Law,” passed in 1995 and now known as the “Maternal and Infant

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Health Law.” Prospective newlyweds diagnosed with hereditary, venereal, reproductive, or mental diseases are considered “unsuitable for reproduction” and encouraged to undergo sterilization, abortion, or remain celibate. The author looks at the history of eugenics in Communist China and Taiwan.

Dowbiggin, Ian Robert. *Keeping America Sane: Psychiatry and Eugenics in the United States and Canada 1880–1940*. Ithaca, NY: Cornell University Press, 1997. 245 p. Psychiatrist Dowbiggin explores “why and to what extent did psychiatrists actually endorse eugenics? How responsible were they for eugenic laws?” He analyzes the careers and works of prominent psychiatrists practicing and teaching in the early years of psychiatry and concludes that they meant well in embracing popular eugenic ideas in an age of “progressivism.” He notes that virtually all psychiatrists of this era expressed “an opinion favorable toward eugenics.”

Gray, Paul. Cursed by Eugenics. *Time* 153 (1): 84–85, 11 January 1999. [In Special Issue: *The Future of Medicine: How Genetic Engineering Will Change Us in the Next Century*.]

Gray thinks that when “science promises such dazzling advances” it is a good time to look at the rise and fall of eugenics, which he describes as a “cautionary tale.” Eugenics flaws may seem obvious now, but the errors caused “unintended consequences for millions of people.” He urges the public to think of these scientists the next time one hears of “promoting the scientific improvement of the human race.”

Hunt, John. Perfecting Humankind: A Comparison of Progressive and Nazi Views on Eugenics, Sterilization and Abortion. *Linacre Quarterly* 66 (1): 129–41, February 1999.

An overall picture of the international eugenics movement is outlined with emphasis on the roles that the United States and Germany played in fostering eugenic thinking. Although eugenics is a “discredited science today,” Hunt fears that current abortion and sterilization rates along with managed care economics could be a source of concern regarding a return of eugenics in America.

Larson, Edward J. Confronting Scientific Authority With Religious Values: Eugenics in American History. In *Genetic Engineering: A Christian Response Crucial Considerations for Shaping Life*, ed. Timothy J. Demy and Gary P. Steward, pp. 104–24. Grand Rapids, MI: Kregel Publications, 1999.

Larson discusses the role that religion in Louisiana and Alabama played in preventing “sterilization of the feeble-minded, the mentally ill, and the deviant.” He says that while “genetic research offers great medical potential, our religious heritage must be represented in the political arena as a moral ‘check and balance.’”

The New Genetics. *Journal of Medical Ethics* [Special Issue] 25 (2): 75–214, April 1999.

Eugenics is discussed in 7 of the 23 genetics articles in this issue. Daniel Wikler’s “Can We Learn from Eugenics” provides a brief historical summary, looking at four “eugenic doctrines” that are not seen as current problems. He argues that the moral

challenge now is to “achieve social justice.” Other works are: “Preimplantation Genetic Diagnosis and the ‘New’ Eugenics” by David S. King; “The Social Nature of Disability, Disease and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick” by Christopher Newell; “Prenatal Diagnosis and Discrimination Against the Disabled” by Lynn Gillam; “Equality and Selection for Existence” by Ingmar Persson; “Should Doctors Intentionally Do Less Than the Best” by Julian Savulescu; and “Doctors’ Orders, Rationality and the Good Life: Commentary on Savulescu.”

Paul, Diane B. *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*. Albany: State University of New York Press, 1998. 219 p.

Paul looks at “shifts in the meaning of ‘eugenics’ and the struggles to

demarcate it from genetics,” including “motivation (where eugenics is equated with social goals, whereas medical genetics is identified with individual aims) and means (where eugenics is equated with coercion, whereas medical genetics is associated with freedom of choice).”

Rifkin, Jeremy. A Eugenic Civilization. In his *The Biotech Century: Harnessing the Gene and Remaking the World*, pp. 116–47. New York: Jeremy P. Tarcher/Putnam, 1998.

Rifkin says that current genetic technologies establish the “foundation for a commercial eugenics civilization.” “Genetic engineering technologies are, by their very nature, eugenics tools.” He provides a history of the eugenics movement in the United States, indicating that the “new eugenics is coming to us not as a sinister plot, but rather as a social and economic boon.”

### III. GENE THERAPY

Demy, Timothy J., and Stewart, Gary P., eds. *Genetic Engineering: A Christian Response*. The Christian Response Series. Grand Rapids, MI: Kregel Publications, 1999. 320 p.

The editors divide the work into three parts: “Genetic Engineering and Society” with eight essays concerned with gene therapy and its relation to religion, justice, and human rights; “Genetic Engineering the Family” containing six essays including discussions of genetic testing and counseling, neonatal intensive care, and reproductive issues; and “Genetic Engineering and the Individual” with six essays, among them two on cloning. The introduction notes that the essays point out the need for responsibility and opportunity ap-

plied to genetics in the “light of the Christian faith.”

Goering, Sara. Gene Therapies and the Pursuit of a Better Human. *Cambridge Quarterly of Healthcare Ethics* 9 (3): 330–41, Summer 2000.

Goering explores the “treatment vs. enhancement” distinction in genetic medicine and suggests using a decision-making model based on Rawls’s “veil of ignorance” as a first step in determining what would constitute a justifiable genetic improvement. Speculating that the designation of a trait as a “disability” may in fact devalue the lives of those currently living with that trait, the author points out that any discussion of what constitutes treat-

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ment or enhancement is based primarily on how society defines disease.

Gura, Trisha. After a Setback, Gene Therapy Progresses . . . Gingerly. *Science* 291 (5509): 1692–95, 1697, 2 March 2001.

After noting that gene therapy research is “. . . a field in which hype has far outstripped payoffs,” Gura provides a history of genetic research in hemophilia and describes the current climate of clinical trials using human subjects after the field’s first death [Jesse Gelsinger].

Peterson, James C. *Genetic Turning Points: The Ethics of Human Genetic Intervention*. Critical Issues in Bioethics Series. Grand Rapids, MI: William B. Eerdmans Publishing Company, 2001. 364 p.

Written to meet the need of thinking through the “ethical challenges of human genetic intervention,” the work is presented from the perspective of the Christian tradition and provides a framework for a semester course. The

author moves from genetic research to “genetic testing, genetically created pharmaceuticals, and finally genetic surgery that directly alters a person’s genes.” Peterson describes the need in genetic engineering for clarity, especially in terminology, the need for careful reflection, and the need to think and plan ahead.

Shickle, Darren. Are “Genetic Enhancements” Really Enhancements? *Cambridge Quarterly of Healthcare Ethics* 9 (3): 342–52, Summer 2000.

Shickle discusses genetic enhancements in the context of cosmetic and pharmacological ones and notes that the high percentage of side effects in the latter calls into question the “progressive” nature of enhancements. Noting that all decisions about biotechnology are based on some concept of the “good,” the author describes “enhancement” as a normative concept rather than as a cost-benefit ratio to be analyzed.

#### IV. GENOME MAPPING

Chapman, Audrey R., ed. *Unprecedented Choices: Religious Ethics at the Frontiers of Genetic Science*. Theology and the Sciences Series. Minneapolis: Fortress Press, 1999. 260 p.

Chapman opens with a general background of genetic developments and then discusses cloning, patenting life, human personhood, sociobiology, and other topics from a religious and theological perspective. “The genetic revolution offers both a challenge and an opportunity to the religious community: a challenge to apply religious

values and frameworks to new and unprecedented issues and an opportunity to help interpret and illuminate significant ethical choices before their members and the broader society” (p. 16).

Davies, Kevin. *Cracking the Genome: Inside the Race to Unlock Human DNA*. New York: Free Press, 2001. 310 p.

Davies, the editor of *Nature Genetics*, closely followed the ongoing Human Genome Project for 10 years. In this work, he details the finances, the scientific steps, and the characters in-

volved in mapping the human genome. The author has a Ph.D. in genetics and brings his expertise to the work, including interviews with Francis Collins and Craig Venter.

Genome Gateway. [Online at <http://www.nature.com/genomics/>.]

*Nature* magazine augments the online version of its issue dedicated to the mapping of the human genome (*Nature* 409 (6822), 15 February 2001) with an archive of research papers on all aspects of genome mapping, a section of news items on developments in the field, and a module devoted to post-genomics (technical discussions of techniques used in genetic research).

The Human Genome. *Science* [Special Issue] 291 (5507), 16 February 2001. [Online at <http://www.sciencemag.org/content/vol291/issue5507/>.]

To celebrate the announcement of the mapping of the human genome, *Science* magazine dedicated an issue to the various aspects of the project and makes a portion of it available online at no charge. Sections provide a time line for the mapping of various genomes, an overview of the process, and instructions on how to use the human genome sequence data maintained in the public domain.

Keller, Evelyn Fox. *The Century of the Gene*. Cambridge, MA: Harvard University Press, 2000. 186 p.

Keller, professor of History and Philosophy of Science at MIT, describes the relation of genetics and molecular biology to the building of a biological organism and urges the necessity of trying to understand the interactions of all components involved. She says

that the completion of the Human Genome Project is only the beginning of the ways that we must adapt biological thinking, and she is concerned that the meanings of words used in discussing genetics should be scientific and exact in usage.

Mahowald, Mary Briody. *Genes, Women, Equality*. New York: Oxford University Press, 2000. 314 p.

The author writes that she gives ethical importance in reverse order of the title with equality first, then women, and then her recent study, genetics. She questions both the benefits and burdens to women offered by current genetic understanding. The 16 chapters in the work discuss genetics combined with topics such as: a feminist view, women in research and clinical genetics, allocation of services, testing for diseases, behavioral genetics, privacy, health insurance, cloning, parenthood, and cultural differences.

Watson, James D. *A Passion for DNA: Genes, Genomes, and Society*. Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 2000. 250 p.

This collection of 26 essays by Nobel prize winner Watson were written over a period of 30 years and include many of the introductory essays included in the Cold Spring Harbor Laboratory's Annual Report. The book is divided into five sections: Autobiographical Flights, Recombinant DNA Controversies, Ethos of Science, War on Cancer, and Societal Implications of the Human Genome Project.

Zilinskas, Raymond A., and Balint, Peter J., eds. *The Human Genome Project and Minority Communities: Ethical, Social and Political Dilem-*

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mas. Westport, CT: Praeger Publishers, 2001. 144 p.

The editors' preface notes that the book "addresses the divisions between minority groups and the scientific community, particularly in the area of medical and genetic research." The book grew from a conference "The Human Genome Project: Reaching the Minority Communities in Maryland"

held at the University of Maryland, Baltimore, in June 1997. The editors think that the Human Genome Project, "conducted in accordance with the highest ethical standards," can be particularly helpful to minority communities who could "have much to gain from innovative medical therapies that may result from the study of human genetics."

#### V. GENE PATENTING

Bruce, Donald. Ethical Concerns About Patenting in Relation to Living Organisms. *Human Reproduction and Genetic Ethics* 6 (1): 10–14, 2000.

Dr. Bruce, Director of the Society, Religion and Technology Project of the Church of Scotland, wrote for the Bioethics working group of the European Ecumenical Commission for Church and Society, this submission to the European Commission and the European Parliament of 13 detailed concerns on proposed harmonized legislation on the patenting of transgenic animals, plants, micro-organisms, and sections of the human genome.

Chapman, Audrey R. *Perspectives on Genetic Patenting: Religion, Science, and Industry in Dialogue*. Washington, DC: American Association for the Advancement of Science, 1999. 300 p.

This compilation presents views about gene patenting by members of professional associations; university science, medical, and philosophy departments; the government's bioethics commission; several ethics centers; a law firm; and three different religious groups. The dialogue group met three

times to discuss whether it is appropriate to patent nature, what is being patented, whether patents imply ownership, whether patents contribute to human welfare, the nature of DNA, and whether patenting is undignified to humans. The book presents views expressed by individuals in the dialogue group.

Stolberg, Sheryl Gay. Patent on Stem Cell Studies Puts U.S. Officials in Bind; Talks to Begin Next Week on a University's Claim of Sole Control Over Research. *New York Times* (17 August): A1, A16, August 2001.

U.S. Patent 6,200,806 [online at <http://patft.uspto.gov/netahtml/srchnum.htm>] is apparently the only one in the world to claim intellectual property ownership of human embryonic stem cells themselves and the method of isolating such cells. The patent owner, the [University of] Wisconsin Alumni Research Foundation or WARF has granted rights to a private, commercial entity, the Geron Corporation from Menlo Park, California, and is expected to negotiate public access with officials from the National Institutes of Health.