NHGRI Planning Workshop
Bioethics and Humanities Research: Genetics and Worldviews

July 2, 2002, 8:30 to 5:00
Bethesda Marriott, Pooks Hill Road
Bethesda, Maryland

This one-day workshop will examine the role played by the National Human Genome Research Institute (NHGRI) in supporting research that explores how genetic knowledge influences the ways in which individuals and communities view themselves and the world around them. The primary focus of the workshop will be to explore how these studies–which use philosophical, theological, historical and other conceptual and analytical methodologies to examine changes in concepts of identity, human nature, responsibility and justice–can most effectively contribute to a broader discourse on these issues and to the development of sound health, social, and research policies and practices.

The goal of the workshop is to develop recommendations concerning: 1) emerging issues that will need to be addressed immediately and in the future; 2) how to gauge success for studies exploring these issues; and 3) how the findings of such research can be made more relevant and accessible to the genetic research, health and policy communities as well as the general public, and the role NHGRI can play in ensuring this relevance and accessibility. A brief report summarizing the discussions and recommendations made in these three areas will be developed to inform the ongoing planning process for the Ethical, Legal and Social Implications (ELSI) program at NHGRI.

Laurie Zoloth, Professor of Ethics and Director of the Program in Jewish Studies at San Francisco State University and recent past President of the American Society for Bioethics and Humanities, has agreed to moderate the meeting, which will bring together a relatively small group of philosophers, theologians, historians, social scientists, legal scholars, policy developers and genetic researchers, to discuss these issues. There will be no presentations at the meeting, just a series of focused discussions.

In preparation for the meeting, each participant will be invited to provide brief answers via email to four questions concerning their perceptions of this research. No names will be linked to the responses, which will be used to help focus the discussions at the meeting.

What is "Bioethics and Humanities Research on Genetics and Worldviews?"

> *"This research includes philosophical, theological and historical studies and certain types of legal and social sciences analyses that explore how genetic information and technologies influence how individuals and communities view themselves and the world around them. One of the ultimate goals of this research is to better understand how changing concepts of identity, human nature, responsibility and justice interact with health, social and research policies and practices."*
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> **–ELSI program and advisors**

Since 1990 the Ethical, Legal and Social Implications (ELSI) Research Program at the National Human Genome Research Institute (NHGRI) has funded a broad range of research to examine the issues surrounding the discovery, interpretation and use of genetic information. This research has included large studies, which use quantitative and qualitative social science methodologies to examine the psycho-social impact of this information in clinical and other settings, as well as smaller more analytical and conceptual studies looking at the ways this information affects how individuals and groups view themselves and the world around them. These latter studies, which examine so-called 'worldview' issues, have ranged from fairly applied projects–which combine philosophical analysis with legal and public policy analysis in the development of specific policy recommendations regarding such topics as fair access to genetic technologies and the use of genetic enhancement technologies–to more conceptually focused efforts aimed at exploring how these technologies interact with concepts of human nature, identity, responsibility and freedom. These studies have also included projects that combine qualitative and quantitative social sciences approaches with philosophical, historical and theological methodologies to develop data on how new genetic information and technologies interact with the worldviews of communities and population groups.

These projects have addressed questions such as: How will research into human genetic variation affect concepts of identity, kinship and community, and can these studies be designed in ways that minimize the potential for negative effects? How will the information generated by behavioral genetics research interact with traditional notions of personal, social and legal responsibility, and what are the implications for legal, health and social policy development? And What are the implications of genetic enhancement technologies for conceptions of humanity and human health, and how might this influence the development of health policies related to these technologies?

The approaches used in these studies have included large and small multi-disciplinary investigator teams, single investigator literature reviews and analyses, and expert and stakeholder conferences and workshops. The research findings from these projects have generally been published in peer-reviewed journals, in books or book chapters, or presented at meetings and published in proceedings or as special journal supplements.

To help get a sense of the types of issues that have been addressed in these studies over the years, a list has been compiled of selected projects funded by the ELSI program since 1990. If more detailed information is desired, a separate document with the abstracts and publications from each of these projects is also included.

Selected Bioethics and Humanities Research Projects Funded by ELSI Program

(project abstracts and publications are provided in a separate document)

Philosophical and Theological Studies

Buchanan, Allen E. Human genome initiative and limits of ethical theory.
Caskey, C. Thomas. National study conference on genetics, religion, and ethics.
Callahan, Daniel J. Genetic prism--understanding health and responsibility.
Elliot, Bruce C. Jr. Ethnicity, Citizenship, Family: Identity after the HGP
Gert, Bernard. Ethical issues arising from the human genome project.
Peters, Theodore F. Theological questions raised by the human genome initiative.
Rothschild, Joan. Science, technology and the perfect child: an ethics and values critique.
Sagoff, Mark. Concepts of nature, biotechnology, and the human genome.
Sarkar, Sahotra. Genetic reductionism--its sources and implications.

Clinical Ethical Issues

Parens, Erik. Prenatal testing for genetic disability.
Wasserman, David T. Genetic testing, disabilities, and the quality of life.
Botkin, Jeffrey. Prenatal diagnosis and the selection of children.
Callahan, Daniel J. Ethical priorities for clinical uses of genome research.
Teich, Albert H. Ethical and legal implications of genetic testing.

Ethics, Law and Social Policy

Juengst, Eric T. Anticipating enhancement: ethical, legal and social issues.
Juengst, Eric T. Managing enhancement: ethical and public policy issues.
Juengst, Eric T. Enhancement ethics and the molecular genetics of aging.
Holmes, Helen B. Impact of the HGI on society: a women's studies approach.
Kahn, Jeffrey P. Genetics & disability insurance: ethics, law & policy.
Kay, Lily E. Information and the transformation of molecular biology.
Mahowald, Mary. The human genome project and women.
Mehlman, Maxwell J. Access to the genome--justice at the frontier of science.
Murray, Thomas H. Human genome initiative and access to health care.
Rothman, David J. The genome project and technologies of enhancement.
Rothstein, Mark. Legal and ethical issues raised by the human genome project.
Wachbroit, Robert. Reassessing health, normality, and confidentiality.
Wasserman, David T. Genetic factors in crime--findings, uses and implications.
Wikler, Daniel I. Human genome research in an interdependent world.

Historical Studies

Aronowitz, Robert. History of breast cancer risk, 1900-present.
Cowan, Ruth. History of prenatal diagnosis.
Markel, Howard. The stigma of disease: implications of genetic testing.
Proctor, Robert. Cancer and the human genome: ethical implications.
Schneider, William. Research and application of genetics blood group: 1900-1950.

Social Sciences Studies

Condit, Celeste M. An empirical study of change in public genetic discourse.
Condit, Celeste M. Race and public communication about human variation.
Conrad, Peter. Genetics and behavior in the news media 1945-1995.
Hilgartner, Stephen. Organizing the HGI-social impact and technology design.
Nelkin, Dorothy. Human heredity in American popular culture.

ELSI Research in the Humanities–Project Abstracts & Publications
(Alpha by Investigator)

ARONOWITZ, Robert
Cooper Hospital/University Medical Center, Camden, New Jersey
"History of Breast Cancer Risk, 1900-Present"
Grant # 1 R01 HG01837 Grant Period: 08/01/98-01/31/2001

This project is focused on the ways in which two diagnostic technologies--screening mammography and genetic testing--emerged, diffused, interacted with medical and social thought and values, and provoked controversy. The central research questions are: What are the factors that have led to the dramatic shift in beliefs about, and practices surrounding, breast cancer risk over the past fifty years? What have been the consequences? The investigators will focus on key comparisons, transitions, and developments in the history of breast cancer risk which have produced visible, significant, and stable social responses. They will collect and examine a broad range of primary and secondary material that might yield clues to the changing perception of breast risk and its consequences. This project's underlying hypothesis is that the contemporary controversies over the proper ways to incorporate genetic testing in clinical practice, establish the meaning of genetic information, conduct research with human subjects, and protect the privacy of individuals undergoing or contemplating genetic testing are largely the result of unresolved conflicts among competing values and interests (in addition to the more evident problem of scientific uncertainty). One goal of this historical project is to make these conflicting values and interests explicit, and thus allow them to be debated and resolved and thus contribute to better integration of genetic knowledge in clinical and public health practices.

BOTKIN, Jeffrey R.
University of Utah Salt Lake City, Utah
"Prenatal Diagnosis and the Selection of Children"
Grant # R01 HG0966 Grant period: 09/30/99 - 08/31/01

Given the current and anticipated capabilities to perform prenatal diagnosis, the medical profession, and society more broadly, must decide how these technologies should be used. Specifically, what prenatal diagnostic tests should professionals offer prospective parents or provide on request? Should there be limits on the tests made available to prospective parents or should choices be unlimited, restricted only by the individual values of informed couples? This project will analyze the literature relevant to the development of professional standards for the application of this technology. Particular attention will be paid to literature from the disability community as well as the broad range of medical and bioethics literature. The principal product of this two year project will be a book titled "The Transparent Womb: Prenatal Diagnosis and the Biologic Selection of Children." The book will be written for the educated lay community, as well as for the medical profession and bioethics communities. This project will develop a clear proposal on the appropriate uses of prenatal diagnosis and will foster a broad debate on these important issues.

BUCHANAN, Allen E.
University of Wisconsin Madison, Wisconsin
"The Human Genome Initiative and Limits of Ethical Theory"
Grant # R01 HG01023 Grant period: 08/18/93 - 07/31/96

This project will investigate many general and far-reaching moral issues raised by the Human Genome Initiative, from distributive and intergenerational justice to concepts of personal identity, eugenics, and the implications of moral theories for policy development in genetics. The research will build upon sources in contemporary ethical work on the moral status of future generations, distributive justice including Rawls, equality of opportunity, and personal identity. The specific objectives of the research include examination of the implications of the possibilities for genetic intervention for equality of opportunity, investigation of the implications of anticipated advances in genetic knowledge and genetic intervention for conceptions of the nature of the self, comparison between modern genetic research and eugenics, and determination of the extent to which ethical theorizing can provide guidance for private individuals and public policy makers. Aided by outstanding scientists, the investigators will attempt to remedy the failure of contemporary ethical literature to engage with concrete problems of individual decision making or public policy. The methodology of this project is that of a historically contextualized, rigorous conceptual and normative analysis of the moral foundations of the pursuit of genetic knowledge and of capacities for genetic intervention.

Buchanan, AE, DW Brock, N Daniels, and D Wickler. From Chance to Choice: Genetics & Justice. Cambridge, UK: Cambridge University Press, 2000. 398p.

CALLAHAN, Daniel
The Hastings Center Briarcliff Manor, New York
"Ethical Priorities in for Clinical Uses of Genome Research"
Grant # R01 HG00418 Grant period: 04/01/91 - 03/31/95

This study will focus on setting priorities in the screening, testing, counseling, and treatment of pre-symptomatic and contingent genetic conditions. Under the assumption that unlimited resources will not be immediately available for smoothly introducing genome research into the clinical arena, this project will develop an ethically sound set of priorities to guide this process. In order to structure the introduction of novel technologies in ways appropriate to individual and societal notions of health and well-being, The Hastings Center will develop, analyze, and assess strategies for responding to these practical concerns. We are asking: What clinical priorities, if any should be established from information arising out of genetic research? Should there be any relative priority among disease groups and population served? and What should be the relative priority of clinical resources directed toward genetics compared to other clinical endeavors? To provide a context for these efforts, the Center will also formulate a theory of the goals of medicine designed to accommodate changing understandings of genetic health and simultaneously point to priorities that can direct rational implementation of clinical services.

Wilfond, B.S. and K. Nolan. "National Policy Development for the Clinical Application of Genetic Diagnostic Technologies: Lessons from Cystic Fibrosis." JAMA. December 1993; 270(24): 2948-2954.

Boyle, P.J. et al. "Public Priorities for Genetic Services." Hastings Center Report. May-June 1995; 25(3, Special Supplement).

CALLAHAN, Daniel
The Hastings Center Briarcliff Manor, New York
"The Genetic Prism: Understanding Health and Responsibility"
Grant # R13 HG00432 Grant period: 09/30/90 - 06/30/92 Conf dat:April 8-9, 1991 Berkeley, CA

This project is designed to support a conference on the implications for our understanding of health and moral responsibility of the Genome Project. The purpose of the conference will be to better anticipate the cultural impact that knowledge generated by the Genome Project will have on society. The conference will be held on the campus of the University of California, Berkeley in March or April of 1991. It will draw together speakers from the fields of medicine and genetics, philosophy, history, and the social sciences. The four major themes of the conference will encompass: cultural understandings of diseases and illness, moral responsibility, the political implications of genetic classifications, and the moral imperative to seek a cure for disease in general and genetic disease in particular. The program will be open to the public but will particularly be aimed at the researchers and others involved in the Genome Project in Northern California and the Bay Area. A conference report designed for wide circulation will help to assure wide distribution of the conference results.

Boyle, P.J. et al. "Genetic Grammar: Health, Illness, and the Human Genome Project." Hastings Center Report. 1992; Special Supplement 22(4): S1.

CASKEY, C. Thomas
Baylor College of Medicine Houston, Texas
"National Study Conference on Genetics, Religion, and Ethics" Agreement # Y01 HG20003 (Co-funded with DOE) Agreement period: 10/01/91 - 09/30/92

This project will assemble persons of diverse religious commitments to study the religious and ethical implications of genome research. Four regional inter-disciplinary study groups will produce preparatory papers for an international, ecumenical conference, in March 1992. The papers will be supplemented by several addresses with respondents, interpretations of case studies on recent genetic research, and by presentations on diverse religious points of view. Topics addressed include: the impact of prevailing theologies of human life and new knowledge of molecular biology; modifying human nature by genetic manipulation; defining the limits of scientific inquiry and technology; religious organizations as educators on genetics; the role of women in science and the impact of the genome project on reproductive decisions; and concerns about screening, confidentiality, and factors affecting genetic counseling. The corpus of addresses, reports, case studies and discussions will be published in book form.

Genetics, Religion and Ethics Project, The Institute of Religion and Baylor College of Medicine, the Texas Medical Center, Houston, Texas, June 1, 1992, "Summary Reflection Statement" Human Gene Therapy. October 1992; 3(5): 525-527.

Nelson, J.R. On the New Frontiers of Genetics and Religion. Grand Rapids, MI: William B. Eerdmans, 1994. 212p.

CONDIT, Celeste M.
University of Georgia Athens, Georgia
"An Empirical Study of Change in Public Genetic Discourse"
Grant # R01 HG01362 Grant period: 01/02/96 - 12/31/97

This study employs a critical content analytic approach to ascertain the degree of perfectionist, essentialist and discriminatory social norms associated with the rise in public discourse about genetic medicine. It employs a coding protocol with demonstrated intercoder reliability. Using this protocol, coders will be able to produce a quantitative survey of a structured random sample of congressional discourse, newspapers, popular magazines, and television coverage from 1950 to 1995. The resulting comparative and proportional description of changes in public norms regarding human reproduction, health, and identity will enable more accurate forecasting of future uptake of genetic medicine and will help to highlight appropriate precautions and opportunities.

Condit, C.M., N. Ofulue and K. Sheedy. "Determinism and Mass Media Portrayals of Genetics." American Journal of Human Genetics. April 1998; 62: 979-84.

Condit, C.M. "Reply to Nelkin and Lindee." American Journal of Human Genetics. August 1998; 63: 663-4.

Condit, C.M. The Meanings of the Gene: Heredity in 20th Century American Public Discourse. University of Wisconsin Press (In press)

CONDIT, Celeste M.
University of Georgia, Athens, Georgia
Race and Public Communication about Human Variation
Grant # R01 HG002191 Grant period: 06/01/01 - 05/31/04

This project explores the feasibility of producing messages about human genetic variation that are non-discriminatory in their impact on public attitudes. Toward this end it pursues three research objectives. First, the project employs focus groups to describe existing lay understandings of the relationships among genetics, race, and human characteristics (including disease). Second, building on the results of the focus groups, it will use a representative population survey and a message impact study to identify vocabularies and to generate sample messages for communicating about human variation in nondiscriminatory ways. Third, it will develop a reliable and appropriate measurement scale for assessing the discriminatory impact of messages about human genetic variation. The project will focus on the concerns of African Americans about discrimination and genetics and on attitudes about African Americans and genetics held by European Americans and the general population.

CONRAD, Peter
Brandeis University Waltham, Massachusetts
"Genetics and Behavior in the News Media--1945-1995"
Grant # R55 HG00849 Grant period: 09/30/94 - 09/29/96

This sociological and historical study examines how the news media have presented information, findings and theories about genetics and behavior from 1945 to 1995. Specifically, it examines news reporting of findings related to "behavioral genetics", focusing on the most frequently-reported genetic-behavior studies, alcoholism and mental illness. Other genetic-behavioral issues in the news, such as achievement (e.g., I.Q. and gender and math), hyperactivity, homosexuality, and criminal behavior, will also be investigated as a comparative case. By using a sociological framework, the study investigates how the news is selected, shaped and presented, and what frameworks, emphases, and "biases" appear in the news stories. By examining these presentations over time and by comparing the various cases, key assumptions and factors used in presenting genetic findings in the news can be identified. Data for this study will come from a systematic examination of major newspapers and news magazines, televised national evening news, and wire service reports, supplemented by interviews with science and medicine journalists and editors of key scientific journals.

COWAN, Ruth
State University of New York Stonybrook, New York
"History of Prenatal Diagnosis" Agreement # Y01 HG10005 Agreement period: 10/01/90 - 09/30/91 (Co funded with NEH)

This project involves the research and writing of a history of modern prenatal diagnosis. Recent scholarly work in the history of science, technology, and medicine will provide the conceptual perspectives for the work. Resources to be used include the professional literatures of medicine, genetic counseling, bioethics, genetics, and medical administration; the popular literature of medical advice to the general public; the literature of the women's health movement; published legal records; archival records; and the secondary literature on the abortion controversy and on the women's movement since 1950. The book which will result from this research will be intended for a general audience of intelligent readers -- and will, hopefully, demonstrate the way in which historical research and analysis can be fruitfully brought to bear in making social and moral decisions.

Cowan, R. "Aspects of the History of Prenatal Diagnosis." In: "Reproductive Genetic Testing: Impact upon Women." Fetal Diagnosis and Therapy, eds. Evans, Rothenberg and Thomson. 1993; 8(supplement): 10-17.

Cowan, R. "Genetic Technology and Reproductive Choice: An Ethics for Autonomy." In: The Code of Codes: Scientific and Social Issues in the Human Genome Project, eds. D.J. Kevles and L. Hood. Cambridge, MA; Harvard University Press, 1992. 244-264.

ELLIOT, Bruce C. Jr.
University of Minnesota Minneapolis, Minnesota
"Ethnicity, Citizenship, Family: Identity after the HGP"
Grant # 1 R01 HG02196-01 Grant period: 05/01/2000 04/30/2002

This project will bring together an interdisciplinary working group of scholars to explore these questions. During a three year period, it will meet to develop the language, criteria, and conceptual framework for exploring issues related to genetic variation research and social identity. Specifically the project will address ways in which the information emerging from research into human genetic variation may affect three overlapping domains: concepts of identity and authenticity; concepts of identity and community; and concepts of identity, family, and kinship. The multidisciplinary working group that will explore these complex and novel issues includes scholars from genetics, philosophy, religious studies, sociology, cultural anthropology, and history, as well as scholars whose work is intimately tied to questions of race and ethnicity, such as those working in African-American studies, Jewish Studies, and Native American Studies. At the end of the project, we will be prepared to both publish the scholarly discourse to the academic community and disseminate the results of our reflections to a wider audience via the Internet.

Paul Brodwin: "Genetics, identity, and the anthropology of essentialism." Anthropological Quarterly, March 2002.

GERT, Bernard
Dartmouth College Hanover, New Hampshire
"Ethical and Legal Studies Relating to the Program to Map and Sequence The Human Genome"
Grant # R01 HG00130 Grant period: 08/01/90 - 04/30/94

This project will first identify and analyze a series of specific ethical concerns or questions that have, or will arise as a consequence of the HGP, including genetic screening and diagnosing genetic disorders or predispositions, privacy, ownership, and security of HGP data, and genetic variations within and between groups. These concerns will be analyzed in the context of morally relevant variables that emerge from the application of a formal moral theory. Analyses based on the application of other moral theories will be done to control for unintentional biases. The research team will apply a formal set of moral rules in order to establish relevant variables that permit a distinction between morally acceptable and unacceptable policy alternatives, in order to address the ethical concerns and questions that are likely to arise in considering policy alternatives relating to the knowledge and information acquired by the HGP. Finally, a series of mechanisms for informing and involving the various constituencies in a discussion of issues and policy options will be examined. These include research articles, a book, and summer workshops.

Berger, E.M. and B. Gert. "Genetic Disorders and the Ethical Status of Germ-Line Gene Therapy." Journal of Medicine and Philosophy. December 16, 1991: 16(6); 667-683. (was reprinted in Medical Ethics, edited by Michael Boylan, 2000.)

Gert, B., E.M. Berger, G.F. Cahill, Jr. et al. Morality and the New Genetics: A Guide for Students and Health Care Providers. Boston: Jones and Bartlett, 1996. 242p.

Gert B. " Ethics and Research Subject Counseling," Genes, Ethics, and Cancer In The Work Environment, ed. by Sheldon W. Samuels and Arthur C, Upton, OEM Press and Ramazzini Institute, 1998, pp. 25-31.

Gert B. "Genetic Engineering: Is It Morally Acceptable?" USA TODAY, Vol. 127 / No. 2644, January 1999, pp. 28-30.

Gert B. "Die Auswirkungen des genetischen Wissens ouf unsere Gesundheits- und Krankheitsknozeptionen," Zukunftsentw rfe: Ideen f r eine Kultur der Ver,,,,bderung, edited by J""rn R sen, Hanna Leitgeb, and Norbert Jegelka, Campus Verlag, 1999, pp. 257- 269.

Gert B. "Morality and Human Genetic Engineering," Jahrbuch f r Recht und Ethik - Annual Review of Law and Ethics, Der analysierte Mensch - The Human Analyzed, edited by B. Sharon Byrd, Joachim Hruschka, Jan C, Joerden, Duncker & Humblot, 1999, pp. 41- 52.

Gert B. "Thinking about Huxley's Brave New World: Was it Wrong to Create a Genetic Hierarchical Society? Is it wrong to Prevent One?" in Etica Della Ricerca Biologica. edited by Cosimo Marco Mazzoni (Leo S. Olschki, 2000), pp. 125-133.

Gert B. "Genetic Engineering," Encyclopedia of Ethics, 2001, Second Edition, Edited by Lawrence Becker and Charlotte Becker. Volume I, pp. 602-606. 2001.

HILGARTNER, Stephen
Columbia University New York, New York
"Organizing the HGI: Social Impact and Technology Design"
Grant # R01 HG00417 Grant period: 06/14/91 - 05/31/96

This sociological study is a prospective field research project on the development of the human genome initiative during the first half of the 1990's. The study is examining how the genomics community goes about trying to build a technological and social system capable of mapping and sequencing large genomes. The study is motivated by the belief that it is likely that: (a) decisions about the technological and organizational structure of the genome project will influence the social impact of the HGP; and (b) decisions about how to manage scientific collaboration on this scale will affect research ethics and practices well beyond the genomics community. For this study, topics of particular interest include the setting of policy agendas; the patterns of collaboration, competition, and data sharing in the genomics community; the selection of technological and organizational strategies; and the interaction of diverse technological cultures (such as molecular biology and computer science). The study is examining the evolution of the HGP through interviewing and participant observation.

Hilgartner, S. "Biomolecular Databases: New Communication Regimes for Biology?" Science Communication. December 1995: 17(2): 240-263.

Hilgartner, S. and S.I. Brandt-Rauf. "Data Access, Ownership, and Control: Toward Empirical Studies of Access Practices." Knowledge: Creation, Diffusion, Utilization. June 1994:15(4); 355-372.

Hilgartner, S. "The Human Genome Project." In: Handbook of Science and Technology Studies, eds. S. Jasanoff et al. Thousands Oaks, California: Sage Publications, Inc.; 1995.

Hilgartner, S. "Access to Data and Intellectual Property: Scientific Exchange in Genome Research." Pp. 28-39 in National Academy of Sciences, Intellectual Property and Research Tools in Molecular Biology: Report of a Workshop. National Academy Press, 1997.

Hilgartner, S. "Data Access Policy in Genome Research." In : Private Science, ed. A. Thackray. University of Pennsylvania Press, April 1998. 304p.

Stemerding D. and S. Hilgartner. "Means of Coordination in Making Biological Science: On the Mapping of Plants, Animals, and Genes." In: Getting New Technologies Together : Studies in Making Sociotechnical Order (De Gruyter Studies in Organization , No 82), eds. C. Disco and B. van de Meulen. Hawthorne, NY: Aldine de Gruyter, November 1998.

HOLMES, Helen B.
Ferre Institute, Inc. Utica, New York
"Impact of the HGI on Society: A Women's Studies Approach"
Grant # R13 HG00793 Grant period: 05/18/95 - 05/17/96

The objectives of this group research project are to extend the analysis of ethical and social questions raised by the Human Genome Initiative by utilizing insights and methodology recently developed in 4 new subfields of women's studies: feminist ethics, medical ethics, science analysis, and technology studies. The project will use these new approaches in an expressly collaborative methodology, to focus on hopes of, concerns of, and implications for women, especially by seeking and valuing input from potential end-users of HGI discoveries and from groups marginalized by society. During Year I, an explicitly diverse group of 60 researchers will meet in a 3-day Workshop I. A year later, the researchers will convene a final workshop. Results will be presented at a 1-day session open to the public and the media. The P.I., the co-investigators, and several participants will transmit recommendations to private and government organizations. Members will present papers at meetings and follow through on the policy recommendations.

Mahowald, M. "Feminist Fashion in Genetics: The WAGICS Workshop in Zanesville." Newsletter of the Network on Feminist Approaches to Bioethics. July 1996; 4(1): 3.

Johnson, A. "Ethics and Genetics." VHL Family Forum, September 1996; 4(3): 10.

Kenen, R. "Women and Genetics in Contemporary Society (WAGICS) Workshop." National Women's Health Network News (forthcoming)

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Anticipating Enhancement: Ethical, Legal and Social Issues"
Grant # (R55) R01 HG01446 Grant period: 9/30/96 - 1/31/99

This project will delineate the major ethical, legal and social issues accompanying the use of genomic information to enhance normal traits in individuals and families, and to identify the precedents that best illuminate those issues for policy-making purposes. The study will use a traditional policy analysis approach to generate specific positions on five issues of genetic enhancement policy issues: 1) Do the human subjects of clinical research on genetic enhancement interventions require special protections? 2) How should the professionally acceptable limits of genomic services be drawn? 3) What constitutes fair access to genetic enhancement services? 4) How should genetic enhancement technologies be regulated? 5) How should support for research towards germ-line gene therapy be affected by genomics' genetic enhancement capacities?

Whitehouse, P.J., E.T. Juengst, T.H. Murray and M.J. Mehlman. "Enhancing Cognition in the Intellectually Intact." The Hastings Center Report. May-June 1997; 27: 14-23.

Juengst, E.T. "Can Prevention be Distinguished from Enhancement in Genetic Medicine?" Journal of Medicine and Philosophy. 1997; 22: 125-142.

Juengst, ET. "What Does Enhancement Mean?" p. 29-47, in Enhancing Human Traits: Ethical and Social Implications, E. Parens (ed.) Washington, DC: Georgetown University Press, 1998.

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Enhancement: Professional Ethical and Public Policy Issues"
Grant # R01 HG01446 Grant period: 2/10/97 - 6/30/01 (Competitive Renewal)

In their previous project, these investigators examined the ethical and legal issues raised by the prospect of using the products of human genome research for enhancement purposes. This work identified three critical challenges to the development of social poicy in this area. First, most interventions that can be used for enhancement are likely to be initially developed and approved for therapeutic use. However, once so approved, the current regulatory structure provides no adequate means of managing the "off-label" use of such interventions for enhancement purposes by clinicians and their clients. Second, any enhancement interventions performed on pre-implantation embryos are likely to be undertaken in the largely unregulated context of clinical reproductive biology and infertility medicine. While the previous project has allowed the investigators to outline the considerations relevant to professional ethics in this area, it is still not clear how those standards would be best enforced. Finally, the availability of either pre-implantation or post-implantation genetic enhancement interventions will also depend on policies regarding access to these interventions outside the boundaries of the U.S. This new project will undertake a close-grained analysis of these three problems as they challenge the management of genetic enhancement technologies, and will develop specific policy recommendations for public policy makers that would allow the issues to be addressed within the framework of considerations set out in the previous project. The project's methods will be primarily analytic and discursive: they will be critiquing, constructing, and proposing policy positions on the basis of literature about the closest precedents for each of these problems by continuing the regimen of regular research meetings and collaborative writing that has propelled their work to date.

Juengst, ET and L. Walters. "Ethical Issues in Human Gene Transfer Research." p. 691-712, in The

Development of Human Gene Therapy, T. Friedman (ed.) Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 1999.

Juengst, E.T. "Anticipating Enhancement: A Conceptual and Ethical Challenge for Gene Therapy Regulation." p.97-109, in Gene Therapy and Ethics, A. Nordgren (ed.) Uppsala: Acta Universitatis Upsaliensis, 1999.

Juengst, E.T. "Concepts of Disease after the Human Genome Project." p. 125-152, in Ethics and Values in Health Care on the Frontiers of the Twenty-First Century, S. Wear and James (eds.) (Bono Philosophy and Medicine Book Series, Volume) Uppsala: Uppsala University Library, 1999.

Juengst, E.T. and E. Parens. "Germ-line Dancing: Definitional Considerations for Science Policy Makers." In Points to Consider Regarding Inherited Genetic Modifications in Human Beings, A. Chapman and M. Frankel (eds.) Washington, DC: AAAS. (in press)

Juengst, E.T. "Enhancement: Ethical Issues." in The Encyclopedia of Ethical, Legal and Political Issues in Biotechnology, T. Murray and M. Mehlman, (eds.) New York: John Wylie & Sons, 2000. (In press)

Mehlman, M.J. "How Will We Regulate Genetic Enhancement?" Wake Forest Law Review. Fall 1999; 34(3): 671-714.

Mehlman, M.J. "The Human Genome Project and the Courts: Gene Therapy and Beyond." Judicature. Nov-Dec 1999; 83(3): 124-130.

Mehlman, M.J. "The Law of Above Averages: Leveling the New Genetic Enhancement Playing Field." Iowa Law Review. 2000: 85; 124-130.

Mehlman, M.J. "Genetic Enhancement and the Regulation of Acquired Genetic Advantages." in The Encyclopedia of Ethical, Legal and Political Issues in Biotechnology, T. Murray and M. Mehlman, (eds.) New York: John Wylie & Sons, 2000. (In press)

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Enhancement Ethics and the Molecular Genetics of Aging"
Grant # R01 AG020916 Grant period: 9/30/01 - 8/31/04 (Competitive Renewal)

Advances in the molecular genetics of cellular aging raise the prospect of intervening in the human aging process to dramatically extend the human life span. The development of such interventions would confront society with the challenge of interpreting, using and regulating the ultimate genetic enhancement technology: a technology that could allow us to change a basic constant of human life at the cellular level. This project is designed to combine the work of two ongoing research programs to begin to address these challenges. The first is the research that Eric Juengst, Maxwell Mehlman and Thomas Murray have been conducting on the ethical and public policy challenges that are posed generically by genetic enhancement technologies. The framework for ethical analysis and public policy development generated by that research would be applied here to the case of anti-aging interventions, both as a test of the framework and to see what it yields in this case. The second resource is the work of the other co-investigators, Stephen Post, Peter Whitehouse and Robert Binstock, on the clinical and social meanings of the human aging process. That research will be used to identify the issues to analyze in this project, by providing the landscape of contemporary social practices, values and beliefs that radical life extensions could challenge. Collaboratively, the two groups will seek to anticipate the issues that anti-aging interventions could raise for three constituencies: the individuals and families that might use them, the health professionals that might provide them, and the public-policy makers that will shape the context in which they might become available. The project's methods will be analytic and discursive: the investigators will be critiquing, constructing and proposing arguments on the basis of existing information and previous work, through a regimen of regular research meetings and collaborative writing. This work will be overseen by an expert group of advisors; Carol Donley, Co-director, Center for Literature, Medicine and the Health Profession at Hiram College; Michael Fossel, Editor, Journal of Anti-Aging Medicine; Linda George, Associate Director, Center for the Study of Aging and Human Development, Duke University; and Thomas Murray, President, The Hastings Center.

KAHN, Jeffrey P.
University of Minnesota Twin Cities Minneapolis, Minnesota
"Genetics & Disability Insurance Ethics, Law & Policy"
Grant # R01 HG02089 Grant period: 8/1/00 - 7/31/02

The University of Minnesota Center for Bioethics and the University's Joint Degree Program in Law, Health & the Life Sciences will complete a comprehensive investigation of the ethical, legal, and policy issues in the use of genetic information in private and public disability insurance and to recommend policies based on our findings. To achieve the goals for this project, the investigators will convene an interdisciplinary working group comprised of some of the best U.S. scholars and experts working on ethical, legal, and social issues raised by genetics, insurance, and disability. The group will include members from the field of ethics, policy and law, social science, medical science, people who live with disabilities, and the insurance industry. The Working Group will convene four times during a two-year period. In conjunction with the group's third meeting, the investigators will host an invitational national conference on the ethical, legal and policy issues raised by genetic testing and disability insurance. Through these efforts, the investigators will clarify the issues; develop a consensus about effective responses; author a consensus paper with our recommendations; and produce the first comprehensive collection of articles on the issues to be published as a journal symposium.

KAY, Lily
Massachusetts Institute of Technology Cambridge, Massachusetts
"Information and the Transformation of Molecular Biology"
Grant # R01 HG00901 Grant period: 12/27/93 - 12/31/95

How did scientists come to view organisms and molecules as information storage and retrieval systems? By which processes did life come to be conceptualized as a text written in a natural language? By posing these questions, the investigator aims to reconstruct a critical history of the development of the genetic code in relation to the concepts of information storage and retrieval. Leading to a published book, this research will focus on the years 1953-1973, when researchers unraveled salient mechanisms of DNA function, representing it as information transfer: the transcription and translation of DNA into proteins. The study will examine how this new language has altered our basic concepts of nature, organisms, health, disease, and behavior. It will also underscore the constraints that culture, language, and ideology place on the production of scientific knowledge: mediating our representations of nature and the articulation of life processes. The research methodology will include the use of primary and secondary scientific sources as well as archival records and interviews.

Kay, L.E. Who Wrote the Book of Life? A History of the Genetic Code. Stanford University Press, February 2000.

MAHOWALD, Mary
University of Chicago Chicago, Illinois
"The Human Genome Project and Women"
Grant # R01 HG00641 Grant period: 05/01/92 - 04/30/96

The objectives of this project are to determine the impact of the HGP on women, to examine whether this impact meets standards of fairness or gender justice, and to identify ways of avoiding or reducing the possibility of unfairness or gender injustice in the formulation of institution and social policies. The specific aims include the development of a common core of scientific, psychosocial, legal, and ethical knowledge regarding the impact, or probable impact, of the HGP on women; identification of criteria against which the possibility of gender justice may be measured; application of these criteria to three areas of research: cystic fibrosis, sickle cell disease, and breast cancer; determination of an agenda for future research; public education concerning impact of HGP on women; and recommendations for ways in which gender justice may be preserved or promoted by HGP research and its applications.

Mahowald, M.B. "Toward Gender Justice in Genetics." Proceedings of the International Social Philosophy Conference. Helsinki, Finland: University of Helsinki, August 1993.

Mahowald, M.B. Women and Children in Health Care: An Unequal Majority. New York: Oxford University Press, 1993.

Mahowald, M.B. "Reproductive Genetics and Gender Justice." In: Women and Prenatal Testing: Facing the Challenges of Genetic Technology, eds. K. Rothenberg and E. Thompson. Columbus: Ohio State University Press, 1994. 304p.

Lester, L. et al. "The Human Genome Project and Women: Cystic Fibrosis, a Case Study." Journal of Women's Health, December 1995: 4; 623-635.

Mahowald, M.B. et al. "The New Genetics and Women." The Milbank Quarterly. 1996: 74; 239-283.

Mahowald, M.B. ed. and author. "The Human Genome Project and Women." and "Gender Justice in Genetics." Women's Health Issues. July/August 1997; 7(4): 281p.

Ravin, A.J., M.B. Mahowald and C.B. Stocking. "Genes or Gestation? Attitudes of Women and Men about Biologic Ties to Children." Journal of Women's Health. 1997; 6(6): 639-647.

MARKEL, Howard
Johns Hopkins University Baltimore, Maryland
"The Stigma of Disease: Implications of Genetic Testing"
Grant # F32 HG00037 Award date: 07/27/91

The purpose of this project is to investigate the stigmatization of the sick as it applies to new developments in genetic testing, screening, and diagnostics. Using the methods of medical and social historiography, historical case studies of social alienation and isolation will be analyzed, compared, and contrasted to the potential social and ethical problems we face with the vast scientific knowledge to be gained from the HGP. A particularly useful historical paradigm for assessing the potential of stigmatization of carriers or sufferers of genetic diseases are the uses and abuses of quarantine in the United States over the past 150 years. This study intends on broadening the concept of quarantine to include any attempt society makes to place divisions between groups of people perceived to be "diseased" be the reasons medical, moral, or social, and the mainstream society fearing contamination. These historical paradigms will be discussed in the context of society's responses to genetic screening programs during the 1970s in order to analyze the potential risks of a "genetic quarantine" of people with "undesirable" traits or characteristics.

Markel, H. "The Stigma of Disease: Implications of Genetic Screening." American Journal of Medicine. August 1992: 93; 209-15.

Markel, H. Quarantine! East European Jewish Immigrants and the New York City Epidemics of 1892. Baltimore, Maryland: The Johns Hopkins University Press. 1997. 262p.

Markel, H. "Knocking out the Cholera': Cholera, Class, and Quarantines in New York City, 1892." Bull. Hist. Med.. 1995; 69: 420-457.

Markel, H. "Di Goldine Medina (The Golden Land): Historical Perspectives of Eugenics and the East European (Ashkenzai) Jewish-American Community, 1880-1925." Health Matrix: Journal of Law-Medicine. Winter 1997; 7(1): 49-64.

MEHLMAN, Maxwell
Case Western University Cleveland, Ohio
"Access to the Genome: Justice at the Frontier of Science"
Grant # R01 HG00683 Grant period: 05/13/92 - 04/30/94

This project will examine the issue of affording access to the technologies that are expected to emerge from the Human Genome Project (HGP). The potential impact of these technologies on the fate of individuals, families, and ultimately, the species itself, will make the question of who is given access to them highly controversial. By matching the characteristics of these new technologies as closely as possible to technologies that currently exist, this study will project the degree of access to these genetic services that would result if access were governed by the principles of distributive justice currently embodied in major public health care programs. It will then compare this result with the patterns of access that would emerge from the application of alternate models of distributive justice. The study will conclude with recommendations for how access to these new technologies can best accomplish the goals of distributive justice.

Mehlman, M.J. and K. Visocan. "Medicare and Medicaid: Are They Just Health Care Systems?" Houston Law Review: Winter 1992; 29(4): 835-

Mehlman, M, J. Botkin and A. Scarrow. "Coverage of genetic technology under national health reform." Am J Hum Genet. 1994;55:1054-1060.

Botkin J. "Fetal privacy and confidentiality." Hastings Center Report. 1995;25(5):32-40.

Mehlman, M.J. and J.R. Botkin. Access to the Genome: The Challenge to Equality. Washington, DC: Georgetown University Press. 1998. 152p.

Botkin, J, W. McMahon and L. Francis (eds). Genetics and Criminality: The Potential Misuse of Scientific Information in Court. The American Psychological Association Press, 1999.

MURRAY, Thomas
Case Western Reserve University Cleveland, Ohio
"The Human Genome Initiative and Access to Health Care"
Grant # R01 HG00503 Grant period: 09/30/91 - 08/31/94

This project will provide an overview of the impact of the HGP on access to health care. In addition to scholarly articles, the product of this research will be a book on the HGP and access to health care, which will address the HGP's impact on health care needs, the likely availability of resources, and our concepts of health, illness, and personal responsibility for health and illness. The project will also examine the impact of the HGP on the health care enterprise in the US, focusing on access, and how decisions about financing may be affected. It will incorporate studies of the impact on health insurance, government programs affecting access and reimbursement, employer health benefits, and the distribution of scarce medical resources. Finally, the book will analyze the HGP's overall impact on the practice of medicine, biomedical ethical issues, and legal issues and policy options. This final section will suggest priorities for future research as well as potential options for policy.

Murray, T.H. "Genetics and the Moral Mission of Health Insurance." Hastings Center Report: 1992; 22(6); 12-17.

Murray, T.H. "Ethics, Genetic Prediction, and Heart Disease." American Journal of Cardiology. September 1993: 72(10); 80D-84D.

Murray, T.H., M.A. Rothstein, and R.F. Murray, Jr. The Human Genome Project and the Future of Health Care. Bloomington, IN: Indiana University Press, 1996.

Murray, T.H. "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information," in Mark A. Rothstein, Ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era. New Haven: Yale University Press, 1997.

NELKIN, Dorothy
New York University New York, New York
"Human Heredity in American Popular Culture"
Grant # R01 HG00447 Grant period: 08/01/91 - 08/31/96

This study will explore the meaning of human genetics in popular culture, within the context of changing ideas about heredity and eugenics since the turn of the century. Drawing on the methods of social historians and communication studies, fiction, film, newspaper accounts and specialized publications will be examined. Key images and ideas about human heredity will be articulated, their meaning interpreted, and their roles in shaping the public response to findings in human genetics suggested. Preliminary work has focused attention on five themes that preoccupy the popular mindset: notions of "genetic essentialism", the importance of blood relations, the importance of "nature" in determining individual traits, genetic stereotypes, and a fear of "tampering" with genes. Preliminary findings also show the renewed popular interest in old claims of behavior psychology, given legitimacy by molecular studies. But the major appeal of genetic explanations lies in their resonance with current social and political concerns. Popular images can help us understand the popular ideas that ultimately affect social policies, human relationships, and health care decisions, as well as public receptivity to genetics research.

Dreyfus, R.C., and D. Nelkin. "The Jurisprudence of Genetics." Vanderbilt Law Review. 1992; 45(2):313-348.

Nelkin, D. "Prospecting for Genes." Scientist. November 23, 1992.

Nelkin, D. "The Social Power of Genetic Information." In: The Code of Codes: Scientific and Social Issues in the Human Genome Project, eds. D.J. Kevles and L. Hood. Cambridge: Harvard University Press; 1992.

Nelkin, D. "The Grandiose Claims of Geneticists." Chronicle of Higher Education. March 3, 1993: B1-B2.

Nelkin, D. "After Daubert: The Relevance and Reliability of Genetic Information." Cardozo Law Review. April 1994: 15(6-7); 2119-2128.

Nelkin, D. "Promotional Metaphors and Their Popular Appeal." Public Understanding of Science. 1994: 3; 25-31.

Nelkin, D. "Forms of Intrusion: Comparing Resistance to Information Technology and Biotechnology." In: Resistance to Technology, ed. Martin Bauer. Cambridge: Cambridge University Press; 1995.
Nelkin, D. and L. Tancredi "Health Screening and Testing in the Public Health Context." In: Encyclopedia of Bioethics--Revised Edition. New York: Simon & Schuster MacMillan, 1995. 1129-1132p.

Nelkin, D. "The Media'ted Gene: Stereotyping Gender and Race." In: Deviant Bodies, eds. J. Urla and J. Terry. Bloomington: Indiana University Press; 1995. 416p.

Nelkin, D. and M.S. Lindee. The DNA Mystique: The Gene as a Cultural Icon. New York: W.H. Freeman and Company, 1995. 276p.

PARENS, Erik
The Hastings Center Briarcliff Manor, New York
"Prenatal Testing for Genetic Disability"
Grant # R01 HG01168 Grant period: 12/01/95 - 06/01/98

This project will investigate the nature of disability to articulate, for public policy, the purposes for which emerging testing capabilities ought ethically to be used. To analyze the nature of disability, the project participants--including experts from disability studies, medical geneticists, genetic counselors, philosophers, and others--will examine two distinctions that are not well addressed in the literature: the distinction between nondisease and disease traits, and the distinction between medical and social disabilities. The project will draw on the social scientific data already available and on the expertise of project participants to examine the psychological, social, and economic dimensions of the impact of disability on families and society through a series of case studies in sickle cell anemia, Down syndrome, Alzheimer disease, schizophrenia, deafness, male homosexuality, and gender. In tandem with its investigation of existing data concerning what the impact of people with disabilities is, the project will explore the normative questions of how families and society ought to think about and respond to different kinds of disability. The project will produce a policy statement on the nature of disability and about the values that ought to be considered in decisions about prenatal testing aimed at the elimination of disabling conditions.

Parens, E and A. Asch. "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations." Special Supplement, Hastings Center Report.
September- October 1999; 29(5): S1-S22.

Parens, E and A. Asch. eds. Prenatal Testing and Disability Rights. Washington, D.C.: Georgetown University Press, 2000. 371p.

PETERS, Theodore
Graduate Theological Union Berkeley, California
"Theological Questions Raised by the Human Genome Initiative"
Grant # R01 HG00487 Grant period: 09/30/91 - 03/31/95

The Center for Theology and the Natural Sciences will monitor the ongoing research of the HGP by drawing out its implications for theology and ethics. The project's long range value will be to provide interpretations of the data for use in public policy discussion and in genetic counseling. Six topics on the impact of new genome knowledge will be the subject of research: 1) human nature, especially the relationship between biological determinism and human freedom; 2) the relationship between divine and human agency in the creative process; 3) evil and moral failure; 4) reactions by different denominations and traditions in our society; 5) articulating broad ethical issues; and 6) the future of genetic counseling in the face of decisions regarding health and procreation. The primary research will be pursued by a core group of scholars drawn from the fields of genetics, theology, and ethics. An advisory committee will provide updates regarding genome research as well as enter into the process of evaluating the resulting papers. This committee will involve specialists in philosophy, theology, medicine, and genetics.

Peters, T. and R.J. Russell. "The Human Genome Project: What Questions Does It Raise for Theology and Ethics?" Midwest Medical Ethics. Summer 1992: 8(1); 12-17.

Shannon, T.A. "Ethical Issues in Genetic Engineering: A Survey." Midwest Medical Ethics. Summer 1992; 8(1): 26-29.

Cole-Turner, R. The New Genesis: Theology and the Genetic Revolution. Westminster: John Knox Press, 1993. 127p.

Cole-Turner, R. "Religion and the Human Genome Project." Journal of Religion and Health. 1993: 31(2); 161-173.

Peters, T. "Genome Project Forces New Look at Ethics, Law." Forum for Applied Research and Public Policy: Fall 1993; 8(3): 5-13.

Cole, R. D. "Genetic Predestination." dialog: a Journal of Theology. 1994: 33(1); 17-22.

Cole-Turner, R. "Genetic Counseling and Pastoral Counseling." dialog. 1994: 33(1): 49-53.

Heffner, P. "Determinism, Freedom, and Moral Failure." dialog. 1994: 33(1): 23-29.

Lebacqz, K. "Genetic Privacy: No Deal for the Poor." dialog. 1994:33(1): 39-48.

Peters, T. "On the Gay Gene: Back to Original Sin Again?" dialog. 1994: 33(1): 30-38.

Cole-Turner, R. "The Genetics of Moral Agency." In: The Genetic Frontier: Ethics, Law and Policy, eds. M. Frankel and A. Teich. Washington, DC: AAAS, 1994.

Peters, T. "Intellectual Property and Human Dignity." in: The Genetic Frontier: Ethics, Law and Policy, eds. Frankel and Teich. Washington, DC: AAAS, 1994.

Peters, T. ed. Genetics: Issues of Social Justice. Cleveland: Pilgrim Press, 1998.

PROCTOR, Robert
Penn State University State College, Pennsylvania
"Cancer and the Human Genome: Ethical Implications"
Grant # R01 HG00573 Grant period: 03/15/92 - 09/14/93

Using historical methods, this project explores the relevance of eugenics to genomics for the specific case of cancer theory and policy. The project will first examine the history of eugenics to see how genetic information was used in the 1920's-1940's to stigmatize or discriminate against specific individuals or members of groups. A second part examines the history of recent cancer theory to determine the extent to which evidence has been found that cancer is genetic, in the various senses of that term. The discovery of oncogenes and genes predisposing certain individuals or groups to specific types of cancer will be traced, along with policy implications conceived to flow from these discoveries. A third and final part compares and contrasts the potential dangers implicit in the biological determinism of eugenics and genomics. Efforts will be made to assess the extent to which the biological determinism often associated with genomics will have different social consequences from the determinism of earlier eugenics.

Proctor, R. Cancer Wars: How Politics Shapes What We Know and Don't Know about Cancer. New York; BasicBooks (Division of HarperCollins Publishers), 1995. 356p.

ROTHMAN, David J.
Columbia University New York, New York
"The Genome Project and Technologies of Enhancement"
Grant # R01 HG01505 Grant period: 07/01/96 - 06/30/97

The goal of this project is to identify and analyze the challenges that genetic enhancements pose for American health policy and social policy. It will place genetics into the context of other medical technologies of enhancement, and, thereby, clarify the dynamics promoting their use and evaluate the strengths and weaknesses of regulatory practices. Although genetic enhancement is still in a fledgling state, technologies under development are soon likely to create new and powerful interventions. Accordingly, the project will conduct intensive analysis of three critical areas: 1) the discovery of hormones and the origins of enhancement technologies, 1900-1940; 2) the recent experience with physical enhancement through the use of growth hormones; and recent experience with performance enhancement through the use of psychopharmacological agents. The project will then apply the findings of this research to the public policy issues presented by genetic enhancement. The relevance and significance of this project rests in its presentation of a new and more comprehensive framework for understanding and responding to genetic enhancements.

ROTHSCHILD, Joan
University of Massachusetts Lowell, Massachusetts
"Science, Technology and the Perfect Child: An Ethics and Values Critique"
Agreement # Y02 HG00010 (Co-funded with NSF) Agreement period: 08/07/90 - 09/30/90

Dr. Rothschild will complete part three of her book in progress, Engineering Birth: Human Perfectibility and the Technological Dream. The project will evaluate the bioethics and feminist literature relevant to the book's central thesis: as the new reproductive technologies interact with values and beliefs about human perfectibility, norms are being set for the "perfect child," recalling, yet transforming, an old ideology. The book asks why, even as the bioethics and feminist literature invokes the possibility of creating new or improved human beings, does much of this work still fail to discuss how standards are being set, the criteria themselves, and what the meaning might be for the future direction and use of such reproductive research. The project will argue that these perspectives can play a positive role in integrating ethical perspectives and in setting frameworks for meaningful dialogue between ethical evaluators and those who pursue, apply, and experience scientific and technological research.

Rothschild, Joan. "Engineering the 'Perfect Child': Feminist Responses," in M. Pellikan-Engel, ed., Against Patriarchal Thinking: A Future Without Discrimination? Amsterdam: VU University Press, 1992. pp. 233-41

Rothschild, Joan. "The Perfect Baby," in B.K. Rothman and D.L. King, eds., Encyclopedia of Childbearing: Critical Perspectives. Phoenix, AZ: Oryx Press, 1993. pp. 302-03

ROTHSTEIN, Mark
University of Houston Houston, Texas
"Legal and Ethical Issues Raised by the Human Genome Project"
Grant # R13 HG00160 Grant period: 08/01/90-09/30/91 Conference date: March 7-9, 1991, Houston,TX.

The purpose of this project is to support a coordinated and wide-ranging research project focusing on the legal and ethical issues raised by the human genome project. The nation's leading experts in the fields of genetics, law and ethics will be assembled to study the long-term legal and ethical implications of the genome project. Each expert will be assigned a topic and asked to produce a manuscript identifying the emerging issues and discussing legislative priorities and possible solutions. In March 1991, the experts will assemble in Houston for a conference to present and discuss their research findings. The conference proceedings will be published with copies distributed to members of Congress, officials of government agencies, and other interested individuals and organizations. Ten of the conference panelists will prepare more detailed legal articles to be published in October 1991 in a special genome project symposium issue of the Houston Law Review.

Rothstein, M.A., ed. Legal and Ethical Issues Raised by the Human Genome Project. Houston, Texas: University of Houston Health Law and Policy Institute, March 1991. 449p.

Billings, P.A. et al. "Case Study: But Is He Genetically Diseased?" Hastings Center Report. Jul-Aug 1992: 22(4)Special Supplement; S18-20.

Health Law Issue. "Symposium: Legal and Ethical Issues Raised by the Human Genome Project." University of Houston Law Review. Spring 1992: 29(1).

SAGOFF, Mark
University of Maryland College Park College Park, Maryland
Concepts of Nature, Biotechnology, and the Human Genome
Grant # R01HG002363 Grant period: 7/20/2001 - 6/30/2003

The proposed research seeks to analyze arguments in the literature of philosophy, theology and public policy that take the genome in its integrity, contingency, or historical authenticity to be what ground humanity as natural or as part of nature. According to this view, insofar as human beings deliberately alter or control the human genome, they alienate themselves from their evolutionary history and from the natural world. The idea is, in effect, that humanity remains a part of nature as long as nature -- in the form of non-manipulated genome - - remains part of humanity. The proposed study will examine the form of "genetic exceptionalism" that invokes the concept of "nature" and the "natural" judgments, usually critical, concerning the manipulation of the human genome. The researchers would then evaluate arguments that -- on the basis of the relation between nature and the genome - - support restriction on genetic engineering. Specifically, the research team will 1) analyze the extent to which criticisms and concerns about the instrumental manipulation of the human genome rest on controversial assumptions about nature, human nature, and the connection between humanity and nature; and it will assess the validity of those assumptions. The project, will 2) produce a series of essays to be collected into a book, along with other articles, conference presentations, and policy-related papers, all of which will evaluate proposals that appeal to conceptions of nature as reasons to regulate or limit or ban various applications of genetic engineering.

Sagoff M. "Genetic Engineering and the Concept of the Natural." Philosophy & Public Policy Quarterly. 21(2/3):2-10 (Spring/Summer 2001)

SARKAR, Sahotra
Dibner Institute Cambridge, Massachusetts
"Genetic Reductionism--Its Sources and Implications"
Grant # R01 HG00912 Grant period: 09/01/93 - 08/31/95

In the context of the Human Genome Project, this project will attempt to clarify reductionist claims respecting human physical and complex mental and behavioral traits. It will analyze the nature of genetic reductionism and provide a method for resolving controversies over claims of the reduction of traits. In a conceptual clarification of genetic reductionism, the investigator will distinguish genetic reductionism from physical reductionism and place these concepts within the context of causation and explanation theories and heredity-environment debates. Next, the project will trace the history of genetic reductionism in 20th century biology and attempt to judge the probability of success of the application of the theory of genetic reductionism to the Human Genome Project. This history of reductionism will be related to eugenics and a tentative list will be developed of cases where a claim of genetic reductionism is justified and cases where it is not. The purpose of this list will be to shed light on the more difficult and controversial cases of genetic reductionism, including complicated human psychological traits.

Sarkar, S. Genetics and Reductionism. Cambridge University Press. November 1998.

SCHNEIDER, William
Indiana University Indianapolis, Indiana
"Research and Application of Genetics Blood Group: 1900-1950" Agreement # Y01 HG10004
Agreement period: 10/01/90 - 09/30/91

The goal of this project is to study an historical precursor and parallel to the HGP: the discovery of the inheritance of the ABO blood system and the attempt to use it as a genetic marker for a variety of human traits and disorders. The literature published during the period from 1919 to 1939 will be analyzed based on research done world-wide on blood group distribution as a definition of race and the links between blood type and criminality, insanity and disease. Articles will be coded for several variables to permit statistical analysis of the overall pattern of research. Archival material of the major researchers will also be consulted to give greater depth to the picture that emerged. At least one follow-up study will be done on the period after the Second World War concerning how misapplications were recognized in attempts to define races. The anticipated result of the study is to provide human genome researchers and policy makers with a broader historical perspective that will help them recognize the new ground they are breaking while avoiding the pitfalls of similar experiences in the past.

Schneider, W.H. "The History of Research on Blood Group Genetics: Initial Discovery and Diffusion." History and Philosophy of the Life Sciences (W.H. Schneider, guest editor) 1996: 18(3); 277-303.

Schneider WH. "The Grouping of Blood: How Karl Landsteiner's Discovery Changed Medicine." NEH Magazine. 1996; 17: 48-50

Schneider WH. "Blood Group Research in Great Britain, France and the United States between the World Wars." Yearbook of Physical Anthropology. 1995; 38: 77-104

Schneider WH. "La Recherche sur les Groupes Sanguins avant la DeuxiŠme Guerre mondiale." Les sciences biologiques et m,dicales en France 1920-1950, eds. Claude Debru, Jean Gayón et Jean-Fran‡ois Picard (Paris: CNRS-Editions, 1994), 311-27

Schneider WH. "H,r,dit,, sang et opposition ... l'immigration dans la France des ann,es trente," Ethnologie fran‡aise, 24 (1994), 104-17

Schneider, William H., guest ed. special issue of History and Philosophy of the Life Sciences on "The First Genetic Marker: Blood group Research, Race and Disease, 1900-1950," 18 (1996), 273-362.

TEICH, Albert
American Association for the Advancement of Science Washington, DC
"Ethical and Legal Implications of Genetic Testing"
Grant # R13 HG00119 Grant period: 09/26/90 - 06/30/93 Conference dates: June, 14-16, 1991, Berkeley Springs, WV; March 13-15, 1992, Charleston, SC; June 18-20, 1992, Los Alamos, NM.

This project will examine the ethical, legal and policy issues that arise in using emerging genetic testing technologies in four areas: medical research and practice; the workplace; insurance; and law enforcement. The aims of this project are to: focus ethical and legal deliberations by providing an appropriate context with a solid foundation in science; conduct an examination of the key values and ethical issues that must be considered; and address specific legal problems that require resolution. To accomplish this, a series of three interdisciplinary, invitational conferences that will build upon one another will be held. Thirty-five participants--scientists, health care professionals, legal experts, policymakers, ethicists, industry representatives, and others--will be invited to each conference. The first conference will detail the scientific base of genetic testing and the potential capabilities enhanced by the HGP. The second conference will explore the values and ethical con-cerns that underlie assessment of the social implications of genetic testing as well as the develop-ment of professional standards and public policy. The third conference will address key legal problems and develop recommendations for consideration by lawyers, policymakers and other professional and industry groups. Dissemination strategies for conference findings will include wide distribution of conference reports and final project report, symposia and panels at professional or trade association meetings, and seminars for journalists and policymakers.

Conference Proceedings: The Genome, Ethics, and the Law: Issues in Genetic Testing. Washington, DC: AAAS (publication Number 92-115), 1992. 124p.

Frankel M. and A. Teich. Ethical and Legal Issues in Pedigree Research. Washington, DC: AAAS, 1993. 216p.

Frankel, M. and A. Teich, eds. The Genetic Frontier: Ethics, Law and Policy. Washington, DC: AAAS, 1994. 240p.

WACHBROIT, Robert
University of Maryland College Park, Maryland
"Reassessing Health, Normality, and Confidentiality"
Grant # R01 HG00419 Grant period: 04/01/92 - 03/31/96

As we learn more and more about the genetic causal factors for various diseases, there will in many cases be a shift to explaining these diseases in terms of genetics. First, this project will trace the conceptual connections underlying these shifts and to assess their justifications. Second, the project will examine some of the ethical and policy consequences of these shifts. Specifically, the project team will 1) examine the impact of the new genetic information on our understanding of health, normality, disease causation, and explanation; 2) articulate assumptions in medical genetics about disease causation, explanation, and normality, especially in diagnoses of genetic susceptibility, and compare them with the assumptions about causation and normality embodied in legal theory, case law, and statutes; 3) analyze the legal and practical consequences associated with greater awareness of genetic susceptibilities, assess the related policy options, and formulate model legislation; and 4) examine the impact of changes in medical diagnoses and medical explanation arising from the HGP on the traditional conception of confidentiality.

Wachbroit, R. "Rethinking Medical Confidentiality: The Impact of Genetics." Suffolk University Law Review. Winter 1993: 27(4); 1391-1410.

Wasserman, D. "Disability, Discrimination, and Fairness." Report from the Institute for Philosophy & Public Policy. 1993: 13; 7-12. Wulfsberg, E.A. et al. "Alpha-Antitrypsic Deficiency: Impact of Genetic Discovery on Medicine and Society." JAMA. 1994: 271(3); 217-222.

Hoffmann, D.E. and E.A. Wulfsberg. "Testing Children for Genetic Predispositions: Is it in Their Best Interest?" The Journal of Law, Medicine & Ethics. Winter 1995: 23(4); 331-344.

WASSERMAN, David T.
University of Maryland College Park, Maryland
"Genetic Factors in Crime--Findings, Uses & Implications"
Grant # R13 HG00703 Grant period: 05/01/92 - 03/16/95

The goal of the project will be to address and clarify the methodological, legal and philosophical issues raised by research on genetic factors in crime, and to introduce the public to this emerging debate. The project will convene a conference in the Fall of 1992 to bring together 1) researchers investigating the genetics and neurobiology of criminal, violent and impulsive acts, and of related behavioral and psychiatric disorders; 2) historians, sociologists and philosophers who will put the scientific research into historical, cultural and intellectual perspective; 3) criminal justice specialists who will gauge the impact of this research on criminal investigation and adjudication; and 4) legal scholars and moral philosophers who will discuss how the discovery of genetic predispositions may affect our practice of punishment and our conception of moral responsibility. The conference organizers will videotape the proceedings for distribution to the media and educational groups, produce a special conference issue of The Report from the Institute for Philosophy and Public Policy, the Institute's widely-read quarterly, circulate conference papers as part of the Institute's Working Paper Series, and edit an anthology of conference papers for publication.

Wasserman, D. "Research into Genetics and Crime: Consensus and Controversy." Politics and the Life Sciences. March 1996: 15(1); 107-109.

WASSERMAN, David T.
University of Maryland College Park, Maryland
"Genetic Testing, Disabilities, and the Quality of Life"
Grant # R01 HG01979 Grant period: 07/01/99 - 06/30/01

This study will examine the significance accorded to disability in judgements about quality and value of human lives, focusing on two domains in which such judgments are of central importance prenatal testing by prospective parents, and the use of disability-adjusted life years (DALYs) to determine the cost-effectiveness of health care interventions. To address these issues, the investigators will convene an interdisciplinary working group of researchers with backgrounds in philosophy, law, genetics, counseling, public health, economics, and social science. The group will 1) analyze the extent to which the justifications for actual and proposed uses of prenatal testing and DALYs rest on controversial assumptions about disability and quality of life, and debate the validity of those assumptions; and 2) in response to these concerns, consider proposals to regulate or limit the availability of prenatal testing for the purpose of selective abortion, and the use of DALYs for the allocation of scarce health care resources.

WIKLER, Daniel
University of Wisconsin Madison, Wisconsin
"Human Genome Research in an Interdependent World"
Grant # R13 HG00431 Grant period: 09/28/90 - 12/31/91
Conference date: June 2-4, 1991, Bethesda, MD.

While many of the ethical, social, and legal issues which human genome research create can and should be debated and resolved within the borders of particular countries and regions, there are a number of issues which cannot be satisfactorily resolved without international understandings, negotiations, and accords. This group includes: international sharing of research burdens, benefits, and information; use of genetic information by the police and military; use of genetic information in identification of racial groups and in eugenic initiatives; and responsibilities of HGR scientists worldwide in determining the direction of their work. This conference will bring together approximately 40 scientists, officials, and ethicists from around the world to prepare an agenda of these issues for consideration by the appropriate national and international agencies. The conferees will compare views on the need for international cooperation on a number of issues and attempt to reach consensus on which issues require international accords and which do not. The resulting agenda for international action will be drawn up and published under the supervision of the planning committee.

Capron, A. "Human Genome Research in an Interdependent World." Kennedy Institute of Ethics Journal. September 1991. (Consensus Report including a proposal for Coordination of International ELSI issues by HUGO.)

ELSI Research in the Humanities–Project Abstracts & Publications
(Alpha by Investigator)

ARONOWITZ, Robert
Cooper Hospital/University Medical Center, Camden, New Jersey
"History of Breast Cancer Risk, 1900-Present"
Grant # 1 R01 HG01837 Grant Period: 08/01/98-01/31/2001

This project is focused on the ways in which two diagnostic technologies--screening mammography and genetic testing--emerged, diffused, interacted with medical and social thought and values, and provoked controversy. The central research questions are: What are the factors that have led to the dramatic shift in beliefs about, and practices surrounding, breast cancer risk over the past fifty years? What have been the consequences? The investigators will focus on key comparisons, transitions, and developments in the history of breast cancer risk which have produced visible, significant, and stable social responses. They will collect and examine a broad range of primary and secondary material that might yield clues to the changing perception of breast risk and its consequences. This project's underlying hypothesis is that the contemporary controversies over the proper ways to incorporate genetic testing in clinical practice, establish the meaning of genetic information, conduct research with human subjects, and protect the privacy of individuals undergoing or contemplating genetic testing are largely the result of unresolved conflicts among competing values and interests (in addition to the more evident problem of scientific uncertainty). One goal of this historical project is to make these conflicting values and interests explicit, and thus allow them to be debated and resolved and thus contribute to better integration of genetic knowledge in clinical and public health practices.

BOTKIN, Jeffrey R.
University of Utah Salt Lake City, Utah
"Prenatal Diagnosis and the Selection of Children"
Grant # R01 HG0966 Grant period: 09/30/99 - 08/31/01

Given the current and anticipated capabilities to perform prenatal diagnosis, the medical profession, and society more broadly, must decide how these technologies should be used. Specifically, what prenatal diagnostic tests should professionals offer prospective parents or provide on request? Should there be limits on the tests made available to prospective parents or should choices be unlimited, restricted only by the individual values of informed couples? This project will analyze the literature relevant to the development of professional standards for the application of this technology. Particular attention will be paid to literature from the disability community as well as the broad range of medical and bioethics literature. The principal product of this two year project will be a book titled "The Transparent Womb: Prenatal Diagnosis and the Biologic Selection of Children." The book will be written for the educated lay community, as well as for the medical profession and bioethics communities. This project will develop a clear proposal on the appropriate uses of prenatal diagnosis and will foster a broad debate on these important issues.

BUCHANAN, Allen E.
University of Wisconsin Madison, Wisconsin
"The Human Genome Initiative and Limits of Ethical Theory"
Grant # R01 HG01023 Grant period: 08/18/93 - 07/31/96

This project will investigate many general and far-reaching moral issues raised by the Human Genome Initiative, from distributive and intergenerational justice to concepts of personal identity, eugenics, and the implications of moral theories for policy development in genetics. The research will build upon sources in contemporary ethical work on the moral status of future generations, distributive justice including Rawls, equality of opportunity, and personal identity. The specific objectives of the research include examination of the implications of the possibilities for genetic intervention for equality of opportunity, investigation of the implications of anticipated advances in genetic knowledge and genetic intervention for conceptions of the nature of the self, comparison between modern genetic research and eugenics, and determination of the extent to which ethical theorizing can provide guidance for private individuals and public policy makers. Aided by outstanding scientists, the investigators will attempt to remedy the failure of contemporary ethical literature to engage with concrete problems of individual decision making or public policy. The methodology of this project is that of a historically contextualized, rigorous conceptual and normative analysis of the moral foundations of the pursuit of genetic knowledge and of capacities for genetic intervention.

Buchanan, AE, DW Brock, N Daniels, and D Wickler. From Chance to Choice: Genetics & Justice. Cambridge, UK: Cambridge University Press, 2000. 398p.

CALLAHAN, Daniel
The Hastings Center Briarcliff Manor, New York
"Ethical Priorities in for Clinical Uses of Genome Research"
Grant # R01 HG00418 Grant period: 04/01/91 - 03/31/95

This study will focus on setting priorities in the screening, testing, counseling, and treatment of pre-symptomatic and contingent genetic conditions. Under the assumption that unlimited resources will not be immediately available for smoothly introducing genome research into the clinical arena, this project will develop an ethically sound set of priorities to guide this process. In order to structure the introduction of novel technologies in ways appropriate to individual and societal notions of health and well-being, The Hastings Center will develop, analyze, and assess strategies for responding to these practical concerns. We are asking: What clinical priorities, if any should be established from information arising out of genetic research? Should there be any relative priority among disease groups and population served? and What should be the relative priority of clinical resources directed toward genetics compared to other clinical endeavors? To provide a context for these efforts, the Center will also formulate a theory of the goals of medicine designed to accommodate changing understandings of genetic health and simultaneously point to priorities that can direct rational implementation of clinical services.

Wilfond, B.S. and K. Nolan. "National Policy Development for the Clinical Application of Genetic Diagnostic Technologies: Lessons from Cystic Fibrosis." JAMA. December 1993; 270(24): 2948-2954.

Boyle, P.J. et al. "Public Priorities for Genetic Services." Hastings Center Report. May-June 1995; 25(3, Special Supplement).

CALLAHAN, Daniel
The Hastings Center Briarcliff Manor, New York
"The Genetic Prism: Understanding Health and Responsibility"
Grant # R13 HG00432 Grant period: 09/30/90 - 06/30/92 Conf dat:April 8-9, 1991 Berkeley, CA

This project is designed to support a conference on the implications for our understanding of health and moral responsibility of the Genome Project. The purpose of the conference will be to better anticipate the cultural impact that knowledge generated by the Genome Project will have on society. The conference will be held on the campus of the University of California, Berkeley in March or April of 1991. It will draw together speakers from the fields of medicine and genetics, philosophy, history, and the social sciences. The four major themes of the conference will encompass: cultural understandings of diseases and illness, moral responsibility, the political implications of genetic classifications, and the moral imperative to seek a cure for disease in general and genetic disease in particular. The program will be open to the public but will particularly be aimed at the researchers and others involved in the Genome Project in Northern California and the Bay Area. A conference report designed for wide circulation will help to assure wide distribution of the conference results.

Boyle, P.J. et al. "Genetic Grammar: Health, Illness, and the Human Genome Project." Hastings Center Report. 1992; Special Supplement 22(4): S1.

CASKEY, C. Thomas
Baylor College of Medicine Houston, Texas
"National Study Conference on Genetics, Religion, and Ethics" Agreement # Y01 HG20003 (Co-funded with DOE) Agreement period: 10/01/91 - 09/30/92

This project will assemble persons of diverse religious commitments to study the religious and ethical implications of genome research. Four regional inter-disciplinary study groups will produce preparatory papers for an international, ecumenical conference, in March 1992. The papers will be supplemented by several addresses with respondents, interpretations of case studies on recent genetic research, and by presentations on diverse religious points of view. Topics addressed include: the impact of prevailing theologies of human life and new knowledge of molecular biology; modifying human nature by genetic manipulation; defining the limits of scientific inquiry and technology; religious organizations as educators on genetics; the role of women in science and the impact of the genome project on reproductive decisions; and concerns about screening, confidentiality, and factors affecting genetic counseling. The corpus of addresses, reports, case studies and discussions will be published in book form.

Genetics, Religion and Ethics Project, The Institute of Religion and Baylor College of Medicine, the Texas Medical Center, Houston, Texas, June 1, 1992, "Summary Reflection Statement" Human Gene Therapy. October 1992; 3(5): 525-527.

Nelson, J.R. On the New Frontiers of Genetics and Religion. Grand Rapids, MI: William B. Eerdmans, 1994. 212p.

CONDIT, Celeste M.
University of Georgia Athens, Georgia
"An Empirical Study of Change in Public Genetic Discourse"
Grant # R01 HG01362 Grant period: 01/02/96 - 12/31/97

This study employs a critical content analytic approach to ascertain the degree of perfectionist, essentialist and discriminatory social norms associated with the rise in public discourse about genetic medicine. It employs a coding protocol with demonstrated intercoder reliability. Using this protocol, coders will be able to produce a quantitative survey of a structured random sample of congressional discourse, newspapers, popular magazines, and television coverage from 1950 to 1995. The resulting comparative and proportional description of changes in public norms regarding human reproduction, health, and identity will enable more accurate forecasting of future uptake of genetic medicine and will help to highlight appropriate precautions and opportunities.

Condit, C.M., N. Ofulue and K. Sheedy. "Determinism and Mass Media Portrayals of Genetics." American Journal of Human Genetics. April 1998; 62: 979-84.

Condit, C.M. "Reply to Nelkin and Lindee." American Journal of Human Genetics. August 1998; 63: 663-4.

Condit, C.M. The Meanings of the Gene: Heredity in 20th Century American Public Discourse. University of Wisconsin Press (In press)

CONDIT, Celeste M.
University of Georgia, Athens, Georgia
Race and Public Communication about Human Variation
Grant # R01 HG002191 Grant period: 06/01/01 - 05/31/04

This project explores the feasibility of producing messages about human genetic variation that are nondiscriminatory in their impact on public attitudes. Toward this end it pursues three research objectives. First, the project employs focus groups to describe existing lay understandings of the relationships among genetics, race, and human characteristics (including disease). Second, building on the results of the focus groups, it will use a representative population survey and a message impact study to identify vocabularies and to generate sample messages for communicating about human variation in nondiscriminatory ways. Third, it will develop a reliable and appropriate measurement scale for assessing the discriminatory impact of messages about human genetic variation. The project will focus on the concerns of African Americans about discrimination and genetics and on attitudes about African Americans and genetics held by European Americans and the general population.

CONRAD, Peter
Brandeis University Waltham, Massachusetts
"Genetics and Behavior in the News Media--1945-1995"
Grant # R55 HG00849 Grant period: 09/30/94 - 09/29/96

This sociological and historical study examines how the news media have presented information, findings and theories about genetics and behavior from 1945 to 1995. Specifically, it examines news reporting of findings related to "behavioral genetics", focusing on the most frequently-reported genetic-behavior studies, alcoholism and mental illness. Other genetic-behavioral issues in the news, such as achievement (e.g., I.Q. and gender and math), hyperactivity, homosexuality, and criminal behavior, will also be investigated as a comparative case. By using a sociological framework, the study investigates how the news is selected, shaped and presented, and what frameworks, emphases, and "biases" appear in the news stories. By examining these presentations over time and by comparing the various cases, key assumptions and factors used in presenting genetic findings in the news can be identified. Data for this study will come from a systematic examination of major newspapers and news magazines, televised national evening news, and wire service reports, supplemented by interviews with science and medicine journalists and editors of key scientific journals.

COWAN, Ruth
State University of New York Stonybrook, New York
"History of Prenatal Diagnosis" Agreement # Y01 HG10005 Agreement period: 10/01/90 - 09/30/91 (Co funded with NEH)

This project involves the research and writing of a history of modern prenatal diagnosis. Recent scholarly work in the history of science, technology, and medicine will provide the conceptual perspectives for the work. Resources to be used include the professional literatures of medicine, genetic counseling, bioethics, genetics, and medical administration; the popular literature of medical advice to the general public; the literature of the women's health movement; published legal records; archival records; and the secondary literature on the abortion controversy and on the women's movement since 1950. The book which will result from this research will be intended for a general audience of intelligent readers -- and will, hopefully, demonstrate the way in which historical research and analysis can be fruitfully brought to bear in making social and moral decisions.

Cowan, R. "Aspects of the History of Prenatal Diagnosis." In: "Reproductive Genetic Testing: Impact upon Women." Fetal Diagnosis and Therapy, eds. Evans, Rothenberg and Thomson. 1993; 8(supplement): 10-17.

Cowan, R. "Genetic Technology and Reproductive Choice: An Ethics for Autonomy." In: The Code of Codes: Scientific and Social Issues in the Human Genome Project, eds. D.J. Kevles and L. Hood. Cambridge, MA; Harvard University Press, 1992. 244-264.

ELLIOT, Bruce C. Jr.
University of Minnesota Minneapolis, Minnesota
"Ethnicity, Citizenship, Family: Identity after the HGP"
Grant # 1 R01 HG02196-01 Grant period: 05/01/2000 04/30/2002

This project will bring together an interdisciplinary working group of scholars to explore these questions. During a three year period, it will meet to develop the language, criteria, and conceptual framework for exploring issues related to genetic variation research and social identity. Specifically the project will address ways in which the information emerging from research into human genetic variation may affect three overlapping domains: concepts of identity and authenticity; concepts of identity and community; and concepts of identity, family, and kinship. The multidisciplinary working group that will explore these complex and novel issues includes scholars from genetics, philosophy, religious studies, sociology, cultural anthropology, and history, as well as scholars whose work is intimately tied to questions of race and ethnicity, such as those working in African-American studies, Jewish Studies, and Native American Studies. At the end of the project, we will be prepared to both publish the scholarly discourse to the academic community and disseminate the results of our reflections to a wider audience via the Internet.

Paul Brodwin: "Genetics, identity, and the anthropology of essentialism." Anthropological Quarterly, March 2002.

GERT, Bernard
Dartmouth College Hanover, New Hampshire
"Ethical and Legal Studies Relating to the Program to Map and Sequence The Human Genome"
Grant # R01 HG00130 Grant period: 08/01/90 - 04/30/94

This project will first identify and analyze a series of specific ethical concerns or questions that have, or will arise as a consequence of the HGP, including genetic screening and diagnosing genetic disorders or predispositions, privacy, ownership, and security of HGP data, and genetic variations within and between groups. These concerns will be analyzed in the context of morally relevant variables that emerge from the application of a formal moral theory. Analyses based on the application of other moral theories will be done to control for unintentional biases. The research team will apply a formal set of moral rules in order to establish relevant variables that permit a distinction between morally acceptable and unacceptable policy alternatives, in order to address the ethical concerns and questions that are likely to arise in considering policy alternatives relating to the knowledge and information acquired by the HGP. Finally, a series of mechanisms for informing and involving the various constituencies in a discussion of issues and policy options will be examined. These include research articles, a book, and summer workshops.

Berger, E.M. and B. Gert. "Genetic Disorders and the Ethical Status of Germ-Line Gene Therapy." Journal of Medicine and Philosophy. December 16, 1991: 16(6); 667-683. (was reprinted in Medical Ethics, edited by Michael Boylan, 2000.)

Gert, B., E.M. Berger, G.F. Cahill, Jr. et al. Morality and the New Genetics: A Guide for Students and Health Care Providers. Boston: Jones and Bartlett, 1996. 242p.

Gert B." Ethics and Research Subject Counseling," Genes, Ethics, and Cancer In The Work Environment, ed. by Sheldon W. Samuels and Arthur C, Upton, OEM Press and Ramazzini Institute, 1998, pp. 25-31.

Gert B. "Genetic Engineering: Is It Morally Acceptable?" USA TODAY, Vol. 127 / No. 2644, January 1999, pp. 28-30.

Gert B. "Die Auswirkungen des genetischen Wissens ouf unsere Gesundheits- und Krankheitsknozeptionen," Zukunftsentw rfe: Ideen f r eine Kultur der Ver,,,,bderung, edited by J""rn R sen, Hanna Leitgeb, and Norbert Jegelka, Campus Verlag, 1999, pp. 257- 269.

Gert B. "Morality and Human Genetic Engineering," Jahrbuch f r Recht und Ethik - Annual Review of Law and Ethics, Der analysierte Mensch - The Human Analyzed, edited by B. Sharon Byrd, Joachim Hruschka, Jan C, Joerden, Duncker & Humblot, 1999, pp. 41- 52.

Gert B. "Thinking about Huxley's Brave New World: Was it Wrong to Create a Genetic Hierarchical Society? Is it wrong to Prevent One?" in Etica Della Ricerca Biologica. edited by Cosimo Marco Mazzoni (Leo S. Olschki, 2000), pp. 125-133.

Gert B. "Genetic Engineering," Encyclopedia of Ethics, 2001, Second Edition, Edited by Lawrence Becker and Charlotte Becker. Volume I, pp. 602-606. 2001.

HILGARTNER, Stephen
Columbia University New York, New York
"Organizing the HGI: Social Impact and Technology Design"
Grant # R01 HG00417 Grant period: 06/14/91 - 05/31/96

This sociological study is a prospective field research project on the development of the human genome initiative during the first half of the 1990's. The study is examining how the genomics community goes about trying to build a technological and social system capable of mapping and sequencing large genomes. The study is motivated by the belief that it is likely that: (a) decisions about the technological and organizational structure of the genome project will influence the social impact of the HGP; and (b) decisions about how to manage scientific collaboration on this scale will affect research ethics and practices well beyond the genomics community. For this study, topics of particular interest include the setting of policy agendas; the patterns of collaboration, competition, and data sharing in the genomics community; the selection of technological and organizational strategies; and the interaction of diverse technological cultures (such as molecular biology and computer science). The study is examining the evolution of the HGP through interviewing and participant observation.

Hilgartner, S. "Biomolecular Databases: New Communication Regimes for Biology?" Science Communication. December 1995: 17(2): 240-263.

Hilgartner, S. and S.I. Brandt-Rauf. "Data Access, Ownership, and Control: Toward Empirical Studies of Access Practices." Knowledge: Creation, Diffusion, Utilization. June 1994:15(4); 355-372.

Hilgartner, S. "The Human Genome Project." In: Handbook of Science and Technology Studies, eds. S. Jasanoff et al. Thousands Oaks, California: Sage Publications, Inc.; 1995.

Hilgartner, S. "Access to Data and Intellectual Property: Scientific Exchange in Genome Research." Pp. 28-39 in National Academy of Sciences, Intellectual Property and Research Tools in Molecular Biology: Report of a Workshop. National Academy Press, 1997.

Hilgartner, S. "Data Access Policy in Genome Research." In : Private Science, ed. A. Thackray. University of Pennsylvania Press, April 1998. 304p.

Stemerding D. and S. Hilgartner. "Means of Coordination in Making Biological Science: On the Mapping of Plants, Animals, and Genes." In: Getting New Technologies Together : Studies in Making Sociotechnical Order (De Gruyter Studies in Organization , No 82), eds. C. Disco and B. van de Meulen. Hawthorne, NY: Aldine de Gruyter, November 1998.

HOLMES, Helen B.
Ferre Institute, Inc. Utica, New York
"Impact of the HGI on Society: A Women's Studies Approach"
Grant # R13 HG00793 Grant period: 05/18/95 - 05/17/96

The objectives of this group research project are to extend the analysis of ethical and social questions raised by the Human Genome Initiative by utilizing insights and methodology recently developed in 4 new subfields of women's studies: feminist ethics, medical ethics, science analysis, and technology studies. The project will use these new approaches in an expressly collaborative methodology, to focus on hopes of, concerns of, and implications for women, especially by seeking and valuing input from potential end-users of HGI discoveries and from groups marginalized by society. During Year I, an explicitly diverse group of 60 researchers will meet in a 3-day Workshop I. A year later, the researchers will convene a final workshop. Results will be presented at a 1-day session open to the public and the media. The P.I., the co-investigators, and several participants will transmit recommendations to private and government organizations. Members will present papers at meetings and follow through on the policy recommendations.

Mahowald, M. "Feminist Fashion in Genetics: The WAGICS Workshop in Zanesville." Newsletter of the Network on Feminist Approaches to Bioethics. July 1996; 4(1): 3.

Johnson, A. "Ethics and Genetics." VHL Family Forum, September 1996; 4(3): 10.

Kenen, R. "Women and Genetics in Contemporary Society (WAGICS) Workshop." National Women's Health Network News (forthcoming)

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Anticipating Enhancement: Ethical, Legal and Social Issues"
Grant # (R55) R01 HG01446 Grant period: 9/30/96 - 1/31/99

This project will delineate the major ethical, legal and social issues accompanying the use of genomic information to enhance normal traits in individuals and families, and to identify the precedents that best illuminate those issues for policy-making purposes. The study will use a traditional policy analysis approach to generate specific positions on five issues of genetic enhancement policy issues: 1) Do the human subjects of clinical research on genetic enhancement interventions require special protections? 2) How should the professionally acceptable limits of genomic services be drawn? 3) What constitutes fair access to genetic enhancement services? 4) How should genetic enhancement technologies be regulated? 5) How should support for research towards germ-line gene therapy be affected by genomics' genetic enhancement capacities?

Whitehouse, P.J., E.T. Juengst, T.H. Murray and M.J. Mehlman. "Enhancing Cognition in the Intellectually Intact." The Hastings Center Report. May-June 1997; 27: 14-23.

Juengst, E.T. "Can Prevention be Distinguished from Enhancement in Genetic Medicine?" Journal of Medicine and Philosophy. 1997; 22: 125-142.

Juengst, ET. "What Does Enhancement Mean?" p. 29-47, in Enhancing Human Traits: Ethical and Social Implications, E. Parens (ed.) Washington, DC: Georgetown University Press, 1998.

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Enhancement: Professional Ethical and Public Policy Issues"
Grant # R01 HG01446 Grant period: 2/10/97 - 6/30/01 (Competitive Renewal)

In their previous project, these investigators examined the ethical and legal issues raised by the prospect of using the products of human genome research for enhancement purposes. This work identified three critical challenges to the development of social poicy in this area. First, most interventions that can be used for enhancement are likely to be initially developed and approved for therapeutic use. However, once so approved, the current regulatory structure provides no adequate means of managing the "off-label" use of such interventions for enhancement purposes by clinicians and their clients. Second, any enhancement interventions performed on pre-implantation embryos are likely to be undertaken in the largely unregulated context of clinical reproductive biology and infertility medicine. While the previous project has allowed the investigators to outline the considerations relevant to professional ethics in this area, it is still not clear how those standards would be best enforced. Finally, the availability of either pre-implantation or post-implantation genetic enhancement interventions will also depend on policies regarding access to these interventions outside the boundaries of the U.S. This new project will undertake a close-grained analysis of these three problems as they challenge the management of genetic enhancement technologies, and will develop specific policy recommendations for public policy makers that would allow the issues to be addressed within the framework of considerations set out in the previous project. The project's methods will be primarily analytic and discursive: they will be critiquing, constructing, and proposing policy positions on the basis of literature about the closest precedents for each of these problems by continuing the regimen of regular research meetings and collaborative writing that has propelled their work to date.

Juengst, ET and L. Walters. "Ethical Issues in Human Gene Transfer Research." p. 691-712, in The

Development of Human Gene Therapy, T. Friedman (ed.) Cold Spring Harbor, NY: Cold Spring Harbor Laboratory Press, 1999.

Juengst, E.T. "Anticipating Enhancement: A Conceptual and Ethical Challenge for Gene Therapy Regulation." p.97-109, in Gene Therapy and Ethics, A. Nordgren (ed.) Uppsala: Acta Universitatis Upsaliensis, 1999.

Juengst, E.T. "Concepts of Disease after the Human Genome Project." p. 125-152, in Ethics and Values in Health Care on the Frontiers of the Twenty-First Century, S. Wear and James (eds.) (Bono Philosophy and Medicine Book Series, Volume) Uppsala: Uppsala University Library, 1999.

Juengst, E.T. and E. Parens. "Germ-line Dancing: Definitional Considerations for Science Policy Makers." In Points to Consider Regarding Inherited Genetic Modifications in Human Beings, A. Chapman and M. Frankel (eds.) Washington, DC: AAAS. (in press)

Juengst, E.T. "Enhancement: Ethical Issues." in The Encyclopedia of Ethical, Legal and Political Issues in Biotechnology, T. Murray and M. Mehlman, (eds.) New York: John Wylie & Sons, 2000. (In press)

Mehlman, M.J. "How Will We Regulate Genetic Enhancement?" Wake Forest Law Review. Fall 1999; 34(3): 671-714.

Mehlman, M.J. "The Human Genome Project and the Courts: Gene Therapy and Beyond." Judicature. Nov-Dec 1999; 83(3): 124-130.

Mehlman, M.J. "The Law of Above Averages: Leveling the New Genetic Enhancement Playing Field." Iowa Law Review. 2000: 85; 124-130.

Mehlman, M.J. "Genetic Enhancement and the Regulation of Acquired Genetic Advantages." in The Encyclopedia of Ethical, Legal and Political Issues in Biotechnology, T. Murray and M. Mehlman, (eds.) New York: John Wylie & Sons, 2000. (In press)

JUENGST, Eric T.
Case Western Reserve University Cleveland, Ohio
"Enhancement Ethics and the Molecular Genetics of Aging"
Grant # R01 AG020916 Grant period: 9/30/01 - 8/31/04 (Competitive Renewal)

Advances in the molecular genetics of cellular aging raise the prospect of intervening in the human aging process to dramatically extend the human life span. The development of such interventions would confront society with the challenge of interpreting, using and regulating the ultimate genetic enhancement technology: a technology that could allow us to change a basic constant of human life at the cellular level. This project is designed to combine the work of two ongoing research programs to begin to address these challenges. The first is the research that Eric Juengst, Maxwell Mehlman and Thomas Murray have been conducting on the ethical and public policy challenges that are posed generically by genetic enhancement technologies. The framework for ethical analysis and public policy development generated by that research would be applied here to the case of anti-aging interventions, both as a test of the framework and to see what it yields in this case. The second resource is the work of the other co-investigators, Stephen Post, Peter Whitehouse and Robert Binstock, on the clinical and social meanings of the human aging process. That research will be used to identify the issues to analyze in this project, by providing the landscape of contemporary social practices, values and beliefs that radical life extensions could challenge. Collaboratively, the two groups will seek to anticipate the issues that anti-aging interventions could raise for three constituencies: the individuals and families that might use them, the health professionals that might provide them, and the public-policy makers that will shape the context in which they might become available. The project's methods will be analytic and discursive: the investigators will be critiquing, constructing and proposing arguments on the basis of existing information and previous work, through a regimen of regular research meetings and collaborative writing. This work will be overseen by an expert group of advisors; Carol Donley, Co-director, Center for Literature, Medicine and the Health Profession at Hiram College; Michael Fossel, Editor, Journal of Anti-Aging Medicine; Linda George, Associate Director, Center for the Study of Aging and Human Development, Duke University; and Thomas Murray, President, The Hastings Center.

KAHN, Jeffrey P.
University of Minnesota Twin Cities Minneapolis, Minnesota
"Genetics & Disability Insurance Ethics, Law & Policy"
Grant # R01 HG02089 Grant period: 8/1/00 - 7/31/02

The University of Minnesota Center for Bioethics and the University's Joint Degree Program in Law, Health & the Life Sciences will complete a comprehensive investigation of the ethical, legal, and policy issues in the use of genetic information in private and public disability insurance and to recommend policies based on our findings. To achieve the goals for this project, the investigators will convene an interdisciplinary working group comprised of some of the best U.S. scholars and experts working on ethical, legal, and social issues raised by genetics, insurance, and disability. The group will include members from the field of ethics, policy and law, social science, medical science, people who live with disabilities, and the insurance industry. The Working Group will convene four times during a two-year period. In conjunction with the group's third meeting, the investigators will host an invitational national conference on the ethical, legal and policy issues raised by genetic testing and disability insurance. Through these efforts, the investigators will clarify the issues; develop a consensus about effective responses; author a consensus paper with our recommendations; and produce the first comprehensive collection of articles on the issues to be published as a journal symposium.

KAY, Lily
Massachusetts Institute of Technology Cambridge, Massachusetts
"Information and the Transformation of Molecular Biology"
Grant # R01 HG00901 Grant period: 12/27/93 - 12/31/95

How did scientists come to view organisms and molecules as information storage and retrieval systems? By which processes did life come to be conceptualized as a text written in a natural language? By posing these questions, the investigator aims to reconstruct a critical history of the development of the genetic code in relation to the concepts of information storage and retrieval. Leading to a published book, this research will focus on the years 1953-1973, when researchers unraveled salient mechanisms of DNA function, representing it as information transfer: the transcription and translation of DNA into proteins. The study will examine how this new language has altered our basic concepts of nature, organisms, health, disease, and behavior. It will also underscore the constraints that culture, language, and ideology place on the production of scientific knowledge: mediating our representations of nature and the articulation of life processes. The research methodology will include the use of primary and secondary scientific sources as well as archival records and interviews.

Kay, L.E. Who Wrote the Book of Life? A History of the Genetic Code. Stanford University Press, February 2000.

MAHOWALD, Mary
University of Chicago Chicago, Illinois
"The Human Genome Project and Women"
Grant # R01 HG00641 Grant period: 05/01/92 - 04/30/96

The objectives of this project are to determine the impact of the HGP on women, to examine whether this impact meets standards of fairness or gender justice, and to identify ways of avoiding or reducing the possibility of unfairness or gender injustice in the formulation of institution and social policies. The specific aims include the development of a common core of scientific, psychosocial, legal, and ethical knowledge regarding the impact, or probable impact, of the HGP on women; identification of criteria against which the possibility of gender justice may be measured; application of these criteria to three areas of research: cystic fibrosis, sickle cell disease, and breast cancer; determination of an agenda for future research; public education concerning impact of HGP on women; and recommendations for ways in which gender justice may be preserved or promoted by HGP research and its applications.

Mahowald, M.B. "Toward Gender Justice in Genetics." Proceedings of the International Social Philosophy Conference. Helsinki, Finland: University of Helsinki, August 1993.

Mahowald, M.B. Women and Children in Health Care: An Unequal Majority. New York: Oxford University Press, 1993.

Mahowald, M.B. "Reproductive Genetics and Gender Justice." In: Women and Prenatal Testing: Facing the Challenges of Genetic Technology, eds. K. Rothenberg and E. Thompson. Columbus: Ohio State University Press, 1994. 304p.

Lester, L. et al. "The Human Genome Project and Women: Cystic Fibrosis, a Case Study." Journal of Women's Health, December 1995: 4; 623-635.

Mahowald, M.B. et al. "The New Genetics and Women." The Milbank Quarterly. 1996: 74; 239-283.

Mahowald, M.B. ed. and author. "The Human Genome Project and Women." and "Gender Justice in Genetics." Women's Health Issues. July/August 1997; 7(4): 281p.

Ravin, A.J., M.B. Mahowald and C.B. Stocking. "Genes or Gestation? Attitudes of Women and Men about Biologic Ties to Children." Journal of Women's Health. 1997; 6(6): 639-647.

MARKEL, Howard
Johns Hopkins University Baltimore, Maryland
"The Stigma of Disease: Implications of Genetic Testing"
Grant # F32 HG00037 Award date: 07/27/91

The purpose of this project is to investigate the stigmatization of the sick as it applies to new developments in genetic testing, screening, and diagnostics. Using the methods of medical and social historiography, historical case studies of social alienation and isolation will be analyzed, compared, and contrasted to the potential social and ethical problems we face with the vast scientific knowledge to be gained from the HGP. A particularly useful historical paradigm for assessing the potential of stigmatization of carriers or sufferers of genetic diseases are the uses and abuses of quarantine in the United States over the past 150 years. This study intends on broadening the concept of quarantine to include any attempt society makes to place divisions between groups of people perceived to be "diseased" be the reasons medical, moral, or social, and the mainstream society fearing contamination. These historical paradigms will be discussed in the context of society's responses to genetic screening programs during the 1970s in order to analyze the potential risks of a "genetic quarantine" of people with "undesirable" traits or characteristics.

Markel, H. "The Stigma of Disease: Implications of Genetic Screening." American Journal of Medicine. August 1992: 93; 209-15.

Markel, H. Quarantine! East European Jewish Immigrants and the New York City Epidemics of 1892. Baltimore, Maryland: The Johns Hopkins University Press. 1997. 262p.

Markel, H. "Knocking out the Cholera': Cholera, Class, and Quarantines in New York City, 1892." Bull. Hist. Med.. 1995; 69: 420-457.

Markel, H. "Di Goldine Medina (The Golden Land): Historical Perspectives of Eugenics and the East European (Ashkenzai) Jewish-American Community, 1880-1925." Health Matrix: Journal of Law-Medicine. Winter 1997; 7(1): 49-64.

MEHLMAN, Maxwell
Case Western University Cleveland, Ohio
"Access to the Genome: Justice at the Frontier of Science"
Grant # R01 HG00683 Grant period: 05/13/92 - 04/30/94

This project will examine the issue of affording access to the technologies that are expected to emerge from the Human Genome Project (HGP). The potential impact of these technologies on the fate of individuals, families, and ultimately, the species itself, will make the question of who is given access to them highly controversial. By matching the characteristics of these new technologies as closely as possible to technologies that currently exist, this study will project the degree of access to these genetic services that would result if access were governed by the principles of distributive justice currently embodied in major public health care programs. It will then compare this result with the patterns of access that would emerge from the application of alternate models of distributive justice. The study will conclude with recommendations for how access to these new technologies can best accomplish the goals of distributive justice.

Mehlman, M.J. and K. Visocan. "Medicare and Medicaid: Are They Just Health Care Systems?" Houston Law Review: Winter 1992; 29(4): 835-

Mehlman, M, J. Botkin and A. Scarrow. "Coverage of genetic technology under national health reform." Am J Hum Genet. 1994;55:1054-1060.

Botkin J. "Fetal privacy and confidentiality." Hastings Center Report. 1995;25(5):32-40.

Mehlman, M.J. and J.R. Botkin. Access to the Genome: The Challenge to Equality. Washington, DC: Georgetown University Press. 1998. 152p.

Botkin, J, W. McMahon and L. Francis (eds). Genetics and Criminality: The Potential Misuse of Scientific Information in Court. The American Psychological Association Press, 1999.

MURRAY, Thomas
Case Western Reserve University Cleveland, Ohio
"The Human Genome Initiative and Access to Health Care"
Grant # R01 HG00503 Grant period: 09/30/91 - 08/31/94

This project will provide an overview of the impact of the HGP on access to health care. In addition to scholarly articles, the product of this research will be a book on the HGP and access to health care, which will address the HGP's impact on health care needs, the likely availability of resources, and our concepts of health, illness, and personal responsibility for health and illness. The project will also examine the impact of the HGP on the health care enterprise in the US, focusing on access, and how decisions about financing may be affected. It will incorporate studies of the impact on health insurance, government programs affecting access and reimbursement, employer health benefits, and the distribution of scarce medical resources. Finally, the book will analyze the HGP's overall impact on the practice of medicine, biomedical ethical issues, and legal issues and policy options. This final section will suggest priorities for future research as well as potential options for policy.

Murray, T.H. "Genetics and the Moral Mission of Health Insurance." Hastings Center Report: 1992; 22(6); 12-17.

Murray, T.H. "Ethics, Genetic Prediction, and Heart Disease." American Journal of Cardiology. September 1993: 72(10); 80D-84D.

Murray, T.H., M.A. Rothstein, and R.F. Murray, Jr. The Human Genome Project and the Future of Health Care. Bloomington, IN: Indiana University Press, 1996.

Murray, T.H. "Genetic Exceptionalism and 'Future Diaries': Is Genetic Information Different from Other Medical Information," in Mark A. Rothstein, Ed., Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era. New Haven: Yale University Press, 1997.

NELKIN, Dorothy
New York University New York, New York
"Human Heredity in American Popular Culture"
Grant # R01 HG00447 Grant period: 08/01/91 - 08/31/96

This study will explore the meaning of human genetics in popular culture, within the context of changing ideas about heredity and eugenics since the turn of the century. Drawing on the methods of social historians and communication studies, fiction, film, newspaper accounts and specialized publications will be examined. Key images and ideas about human heredity will be articulated, their meaning interpreted, and their roles in shaping the public response to findings in human genetics suggested. Preliminary work has focused attention on five themes that preoccupy the popular mindset: notions of "genetic essentialism", the importance of blood relations, the importance of "nature" in determining individual traits, genetic stereotypes, and a fear of "tampering" with genes. Preliminary findings also show the renewed popular interest in old claims of behavior psychology, given legitimacy by molecular studies. But the major appeal of genetic explanations lies in their resonance with current social and political concerns. Popular images can help us understand the popular ideas that ultimately affect social policies, human relationships, and health care decisions, as well as public receptivity to genetics research.

Dreyfus, R.C., and D. Nelkin. "The Jurisprudence of Genetics." Vanderbilt Law Review. 1992; 45(2):313-348.

Nelkin, D. "Prospecting for Genes." Scientist. November 23, 1992.

Nelkin, D. "The Social Power of Genetic Information." In: The Code of Codes: Scientific and Social Issues in the Human Genome Project, eds. D.J. Kevles and L. Hood. Cambridge: Harvard University Press; 1992.

Nelkin, D. "The Grandiose Claims of Geneticists." Chronicle of Higher Education. March 3, 1993: B1-B2.

Nelkin, D. "After Daubert: The Relevance and Reliability of Genetic Information." Cardozo Law Review. April 1994: 15(6-7); 2119-2128.

Nelkin, D. "Promotional Metaphors and Their Popular Appeal." Public Understanding of Science. 1994: 3; 25-31.

Nelkin, D. "Forms of Intrusion: Comparing Resistance to Information Technology and Biotechnology." In: Resistance to Technology, ed. Martin Bauer. Cambridge: Cambridge University Press; 1995.
Nelkin, D. and L. Tancredi "Health Screening and Testing in the Public Health Context." In: Encyclopedia of Bioethics--Revised Edition. New York: Simon & Schuster MacMillan, 1995. 1129-1132p.

Nelkin, D. "The Media'ted Gene: Stereotyping Gender and Race." In: Deviant Bodies, eds. J. Urla and J. Terry. Bloomington: Indiana University Press; 1995. 416p.

Nelkin, D. and M.S. Lindee. The DNA Mystique: The Gene as a Cultural Icon. New York: W.H. Freeman and Company, 1995. 276p.

PARENS, Erik
The Hastings Center Briarcliff Manor, New York
"Prenatal Testing for Genetic Disability"
Grant # R01 HG01168 Grant period: 12/01/95 - 06/01/98

This project will investigate the nature of disability to articulate, for public policy, the purposes for which emerging testing capabilities ought ethically to be used. To analyze the nature of disability, the project participants--including experts from disability studies, medical geneticists, genetic counselors, philosophers, and others--will examine two distinctions that are not well addressed in the literature: the distinction between nondisease and disease traits, and the distinction between medical and social disabilities. The project will draw on the social scientific data already available and on the expertise of project participants to examine the psychological, social, and economic dimensions of the impact of disability on families and society through a series of case studies in sickle cell anemia, Down syndrome, Alzheimer disease, schizophrenia, deafness, male homosexuality, and gender. In tandem with its investigation of existing data concerning what the impact of people with disabilities is, the project will explore the normative questions of how families and society ought to think about and respond to different kinds of disability. The project will produce a policy statement on the nature of disability and about the values that ought to be considered in decisions about prenatal testing aimed at the elimination of disabling conditions.

Parens, E and A. Asch. "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations." Special Supplement, Hastings Center Report.
September- October 1999; 29(5): S1-S22.

Parens, E and A. Asch. eds. Prenatal Testing and Disability Rights. Washington, D.C.: Georgetown University Press, 2000. 371p.

PETERS, Theodore
Graduate Theological Union Berkeley, California
"Theological Questions Raised by the Human Genome Initiative"
Grant # R01 HG00487 Grant period: 09/30/91 - 03/31/95

The Center for Theology and the Natural Sciences will monitor the ongoing research of the HGP by drawing out its implications for theology and ethics. The project's long range value will be to provide interpretations of the data for use in public policy discussion and in genetic counseling. Six topics on the impact of new genome knowledge will be the subject of research: 1) human nature, especially the relationship between biological determinism and human freedom; 2) the relationship between divine and human agency in the creative process; 3) evil and moral failure; 4) reactions by different denominations and traditions in our society; 5) articulating broad ethical issues; and 6) the future of genetic counseling in the face of decisions regarding health and procreation. The primary research will be pursued by a core group of scholars drawn from the fields of genetics, theology, and ethics. An advisory committee will provide updates regarding genome research as well as enter into the process of evaluating the resulting papers. This committee will involve specialists in philosophy, theology, medicine, and genetics.

Peters, T. and R.J. Russell. "The Human Genome Project: What Questions Does It Raise for Theology and Ethics?" Midwest Medical Ethics. Summer 1992: 8(1); 12-17.

Shannon, T.A. "Ethical Issues in Genetic Engineering: A Survey." Midwest Medical Ethics. Summer 1992; 8(1): 26-29.

Cole-Turner, R. The New Genesis: Theology and the Genetic Revolution. Westminster: John Knox Press, 1993. 127p.

Cole-Turner, R. "Religion and the Human Genome Project." Journal of Religion and Health. 1993: 31(2); 161-173.

Peters, T. "Genome Project Forces New Look at Ethics, Law." Forum for Applied Research and Public Policy: Fall 1993; 8(3): 5-13.

Cole, R. D. "Genetic Predestination." dialog: a Journal of Theology. 1994: 33(1); 17-22.

Cole-Turner, R. "Genetic Counseling and Pastoral Counseling." dialog. 1994: 33(1): 49-53.

Heffner, P. "Determinism, Freedom, and Moral Failure." dialog. 1994: 33(1): 23-29.

Lebacqz, K. "Genetic Privacy: No Deal for the Poor." dialog. 1994:33(1): 39-48.

Peters, T. "On the Gay Gene: Back to Original Sin Again?" dialog . 1994: 33(1): 30-38.

Cole-Turner, R. "The Genetics of Moral Agency." In: The Genetic Frontier: Ethics, Law and Policy, eds. M. Frankel and A. Teich. Washington, DC: AAAS, 1994.

Peters, T. "Intellectual Property and Human Dignity." in: The Genetic Frontier: Ethics, Law and Policy, eds. Frankel and Teich. Washington, DC: AAAS, 1994.

Peters, T. ed. Genetics: Issues of Social Justice. Cleveland: Pilgrim Press, 1998.

PROCTOR, Robert
Penn State University State College, Pennsylvania
"Cancer and the Human Genome: Ethical Implications"
Grant # R01 HG00573 Grant period: 03/15/92 - 09/14/93

Using historical methods, this project explores the relevance of eugenics to genomics for the specific case of cancer theory and policy. The project will first examine the history of eugenics to see how genetic information was used in the 1920's-1940's to stigmatize or discriminate against specific individuals or members of groups. A second part examines the history of recent cancer theory to determine the extent to which evidence has been found that cancer is genetic, in the various senses of that term. The discovery of oncogenes and genes predisposing certain individuals or groups to specific types of cancer will be traced, along with policy implications conceived to flow from these discoveries. A third and final part compares and contrasts the potential dangers implicit in the biological determinism of eugenics and genomics. Efforts will be made to assess the extent to which the biological determinism often associated with genomics will have different social consequences from the determinism of earlier eugenics.

Proctor, R. Cancer Wars: How Politics Shapes What We Know and Don't Know about Cancer. New York; BasicBooks (Division of HarperCollins Publishers), 1995. 356p.

ROTHMAN, David J.
Columbia University New York, New York
"The Genome Project and Technologies of Enhancement"
Grant # R01 HG01505 Grant period: 07/01/96 - 06/30/97

The goal of this project is to identify and analyze the challenges that genetic enhancements pose for American health policy and social policy. It will place genetics into the context of other medical technologies of enhancement, and, thereby, clarify the dynamics promoting their use and evaluate the strengths and weaknesses of regulatory practices. Although genetic enhancement is still in a fledgling state, technologies under development are soon likely to create new and powerful interventions. Accordingly, the project will conduct intensive analysis of three critical areas: 1) the discovery of hormones and the origins of enhancement technologies, 1900-1940; 2) the recent experience with physical enhancement through the use of growth hormones; and recent experience with performance enhancement through the use of psychopharmacological agents. The project will then apply the findings of this research to the public policy issues presented by genetic enhancement. The relevance and significance of this project rests in its presentation of a new and more comprehensive framework for understanding and responding to genetic enhancements.

ROTHSCHILD, Joan
University of Massachusetts Lowell, Massachusetts
"Science, Technology and the Perfect Child: An Ethics and Values Critique"
Agreement # Y02 HG00010 (Co-funded with NSF) Agreement period: 08/07/90 - 09/30/90

Dr. Rothschild will complete part three of her book in progress, Engineering Birth: Human Perfectibility and the Technological Dream. The project will evaluate the bioethics and feminist literature relevant to the book's central thesis: as the new reproductive technologies interact with values and beliefs about human perfectibility, norms are being set for the "perfect child," recalling, yet transforming, an old ideology. The book asks why, even as the bioethics and feminist literature invokes the possibility of creating new or improved human beings, does much of this work still fail to discuss how standards are being set, the criteria themselves, and what the meaning might be for the future direction and use of such reproductive research. The project will argue that these perspectives can play a positive role in integrating ethical perspectives and in setting frameworks for meaningful dialogue between ethical evaluators and those who pursue, apply, and experience scientific and technological research.

Rothschild, Joan. "Engineering the 'Perfect Child': Feminist Responses," in M. Pellikan-Engel, ed., Against Patriarchal Thinking: A Future Without Discrimination? Amsterdam: VU University Press, 1992. pp. 233-41

Rothschild, Joan. "The Perfect Baby," in B.K. Rothman and D.L. King, eds., Encyclopedia of Childbearing: Critical Perspectives. Phoenix, AZ: Oryx Press, 1993. pp. 302-03

ROTHSTEIN, Mark
University of Houston Houston, Texas
"Legal and Ethical Issues Raised by the Human Genome Project"
Grant # R13 HG00160 Grant period: 08/01/90-09/30/91 Conference date: March 7-9, 1991, Houston,TX.

The purpose of this project is to support a coordinated and wide-ranging research project focusing on the legal and ethical issues raised by the human genome project. The nation's leading experts in the fields of genetics, law and ethics will be assembled to study the long-term legal and ethical implications of the genome project. Each expert will be assigned a topic and asked to produce a manuscript identifying the emerging issues and discussing legislative priorities and possible solutions. In March 1991, the experts will assemble in Houston for a conference to present and discuss their research findings. The conference proceedings will be published with copies distributed to members of Congress, officials of government agencies, and other interested individuals and organizations. Ten of the conference panelists will prepare more detailed legal articles to be published in October 1991 in a special genome project symposium issue of the Houston Law Review.

Rothstein, M.A., ed. Legal and Ethical Issues Raised by the Human Genome Project. Houston, Texas: University of Houston Health Law and Policy Institute, March 1991. 449p.

Billings, P.A. et al. "Case Study: But Is He Genetically Diseased?" Hastings Center Report. Jul-Aug 1992: 22(4)Special Supplement; S18-20.

Health Law Issue. "Symposium: Legal and Ethical Issues Raised by the Human Genome Project." University of Houston Law Review. Spring 1992: 29(1).

SAGOFF, Mark
University of Maryland College Park College Park, Maryland
Concepts of Nature, Biotechnology, and the Human Genome
Grant # R01HG002363 Grant period: 7/20/2001 - 6/30/2003

The proposed research seeks to analyze arguments in the literature of philosophy, theology and public policy that take the genome in its integrity, contingency, or historical authenticity to be what ground humanity as natural or as part of nature. According to this view, insofar as human beings deliberately alter or control the human genome, they alienate themselves from their evolutionary history and from the natural world. The idea is, in effect, that humanity remains a part of nature as long as nature -- in the form of non-manipulated genome - - remains part of humanity. The proposed study will examine the form of "genetic exceptionalism" that invokes the concept of "nature" and the "natural" judgments, usually critical, concerning the manipulation of the human genome. The researchers would then evaluate arguments that -- on the basis of the relation between nature and the genome - - support restriction on genetic engineering. Specifically, the research team will 1) analyze the extent to which criticisms and concerns about the instrumental manipulation of the human genome rest on controversial assumptions about nature, human nature, and the connection between humanity and nature; and it will assess the validity of those assumptions. The project, will 2) produce a series of essays to be collected into a book, along with other articles, conference presentations, and policy-related papers, all of which will evaluate proposals that appeal to conceptions of nature as reasons to regulate or limit or ban various applications of genetic engineering.

Sagoff M. "Genetic Engineering and the Concept of the Natural." Philosophy & Public Policy Quarterly. 21(2/3):2-10 (Spring/Summer 2001)

SARKAR, Sahotra
Dibner Institute Cambridge, Massachusetts
"Genetic Reductionism--Its Sources and Implications"
Grant # R01 HG00912 Grant period: 09/01/93 - 08/31/95

In the context of the Human Genome Project, this project will attempt to clarify reductionist claims respecting human physical and complex mental and behavioral traits. It will analyze the nature of genetic reductionism and provide a method for resolving controversies over claims of the reduction of traits. In a conceptual clarification of genetic reductionism, the investigator will distinguish genetic reductionism from physical reductionism and place these concepts within the context of causation and explanation theories and heredity-environment debates. Next, the project will trace the history of genetic reductionism in 20th century biology and attempt to judge the probability of success of the application of the theory of genetic reductionism to the Human Genome Project. This history of reductionism will be related to eugenics and a tentative list will be developed of cases where a claim of genetic reductionism is justified and cases where it is not. The purpose of this list will be to shed light on the more difficult and controversial cases of genetic reductionism, including complicated human psychological traits.

Sarkar, S. Genetics and Reductionism. Cambridge University Press. November 1998.

SCHNEIDER, William
Indiana University Indianapolis, Indiana
"Research and Application of Genetics Blood Group: 1900-1950" Agreement # Y01-HG10004
Agreement period: 10/01/90 - 09/30/91

The goal of this project is to study an historical precursor and parallel to the HGP: the discovery of the inheritance of the ABO blood system and the attempt to use it as a genetic marker for a variety of human traits and disorders. The literature published during the period from 1919 to 1939 will be analyzed based on research done world-wide on blood group distribution as a definition of race and the links between blood type and criminality, insanity and disease. Articles will be coded for several variables to permit statistical analysis of the overall pattern of research. Archival material of the major researchers will also be consulted to give greater depth to the picture that emerged. At least one follow-up study will be done on the period after the Second World War concerning how misapplications were recognized in attempts to define races. The anticipated result of the study is to provide human genome researchers and policy makers with a broader historical perspective that will help them recognize the new ground they are breaking while avoiding the pitfalls of similar experiences in the past.

Schneider, W.H. "The History of Research on Blood Group Genetics: Initial Discovery and Diffusion." History and Philosophy of the Life Sciences (W.H. Schneider, guest editor) 1996: 18(3); 277-303.

Schneider WH. "The Grouping of Blood: How Karl Landsteiner's Discovery Changed Medicine." NEH Magazine. 1996; 17: 48-50

Schneider WH. "Blood Group Research in Great Britain, France and the United States between the World Wars." Yearbook of Physical Anthropology. 1995; 38: 77-104

Schneider WH. "La Recherche sur les Groupes Sanguins avant la DeuxiŠme Guerre mondiale." Les sciences biologiques et m,dicales en France 1920-1950, eds. Claude Debru, Jean Gayon et Jean-Fran‡ois Picard (Paris: CNRS-Editions, 1994), 311-27

Schneider WH. "H,r,dit,, sang et opposition ... l'immigration dans la France des ann,es trente," Ethnologie fran‡aise, 24 (1994), 104-17

Schneider, William H., guest ed. special issue of History and Philosophy of the Life Sciences on "The First Genetic Marker: Blood group Research, Race and Disease, 1900-1950," 18 (1996), 273-362.

TEICH, Albert
American Association for the Advancement of Science Washington, DC
"Ethical and Legal Implications of Genetic Testing"
Grant # R13 HG00119 Grant period: 09/26/90 - 06/30/93 Conference dates: June, 14-16, 1991, Berkeley Springs, WV; March 13-15, 1992, Charleston, SC; June 18-20, 1992, Los Alamos, NM.

This project will examine the ethical, legal and policy issues that arise in using emerging genetic testing technologies in four areas: medical research and practice; the workplace; insurance; and law enforcement. The aims of this project are to: focus ethical and legal deliberations by providing an appropriate context with a solid foundation in science; conduct an examination of the key values and ethical issues that must be considered; and address specific legal problems that require resolution. To accomplish this, a series of three interdisciplinary, invitational conferences that will build upon one another will be held. Thirty-five participants--scientists, health care professionals, legal experts, policymakers, ethicists, industry representatives, and others--will be invited to each conference. The first conference will detail the scientific base of genetic testing and the potential capabilities enhanced by the HGP. The second conference will explore the values and ethical con-cerns that underlie assessment of the social implications of genetic testing as well as the develop-ment of professional standards and public policy. The third conference will address key legal problems and develop recommendations for consideration by lawyers, policymakers and other professional and industry groups. Dissemination strategies for conference findings will include wide distribution of conference reports and final project report, symposia and panels at professional or trade association meetings, and seminars for journalists and policymakers.

Conference Proceedings: The Genome, Ethics, and the Law: Issues in Genetic Testing. Washington, DC: AAAS (publication Number 92-115), 1992. 124p.

Frankel M. and A. Teich. Ethical and Legal Issues in Pedigree Research. Washington, DC: AAAS, 1993. 216p.

Frankel, M. and A. Teich, eds. The Genetic Frontier: Ethics, Law and Policy. Washington, DC: AAAS, 1994. 240p.

WACHBROIT, Robert
University of Maryland College Park, Maryland
"Reassessing Health, Normality, and Confidentiality"
Grant # R01 HG00419 Grant period: 04/01/92 - 03/31/96

As we learn more and more about the genetic causal factors for various diseases, there will in many cases be a shift to explaining these diseases in terms of genetics. First, this project will trace the conceptual connections underlying these shifts and to assess their justifications. Second, the project will examine some of the ethical and policy consequences of these shifts. Specifically, the project team will 1) examine the impact of the new genetic information on our understanding of health, normality, disease causation, and explanation; 2) articulate assumptions in medical genetics about disease causation, explanation, and normality, especially in diagnoses of genetic susceptibility, and compare them with the assumptions about causation and normality embodied in legal theory, case law, and statutes; 3) analyze the legal and practical consequences associated with greater awareness of genetic susceptibilities, assess the related policy options, and formulate model legislation; and 4) examine the impact of changes in medical diagnoses and medical explanation arising from the HGP on the traditional conception of confidentiality.

Wachbroit, R. "Rethinking Medical Confidentiality: The Impact of Genetics." Suffolk University Law Review. Winter 1993: 27(4); 1391-1410.

Wasserman, D. "Disability, Discrimination, and Fairness." Report from the Institute for Philosophy & Public Policy. 1993: 13; 7-12. Wulfsberg, E.A. et al. "Alpha-Antitrypsic Deficiency: Impact of Genetic Discovery on Medicine and Society." JAMA. 1994: 271(3); 217-222.

Hoffmann, D.E. and E.A. Wulfsberg. "Testing Children for Genetic Predispositions: Is it in Their Best Interest?" The Journal of Law, Medicine & Ethics. Winter 1995: 23(4); 331-344.

WASSERMAN, David T.
University of Maryland College Park, Maryland
"Genetic Factors in Crime--Findings, Uses & Implications"
Grant # R13 HG00703 Grant period: 05/01/92 - 03/16/95

The goal of the project will be to address and clarify the methodological, legal and philosophical issues raised by research on genetic factors in crime, and to introduce the public to this emerging debate. The project will convene a conference in the Fall of 1992 to bring together 1) researchers investigating the genetics and neurobiology of criminal, violent and impulsive acts, and of related behavioral and psychiatric disorders; 2) historians, sociologists and philosophers who will put the scientific research into historical, cultural and intellectual perspective; 3) criminal justice specialists who will gauge the impact of this research on criminal investigation and adjudication; and 4) legal scholars and moral philosophers who will discuss how the discovery of genetic predispositions may affect our practice of punishment and our conception of moral responsibility. The conference organizers will videotape the proceedings for distribution to the media and educational groups, produce a special conference issue of The Report from the Institute for Philosophy and Public Policy, the Institute's widely-read quarterly, circulate conference papers as part of the Institute's Working Paper Series, and edit an anthology of conference papers for publication.

Wasserman, D. "Research into Genetics and Crime: Consensus and Controversy." Politics and the Life Sciences. March 1996: 15(1); 107-109.

WASSERMAN, David T.
University of Maryland College Park, Maryland
"Genetic Testing, Disabilities, and the Quality of Life"
Grant # R01 HG01979 Grant period: 07/01/99 - 06/30/01

This study will examine the significance accorded to disability in judgements about quality and value of human lives, focusing on two domains in which such judgments are of central importance prenatal testing by prospective parents, and the use of disability-adjusted life years (DALYs) to determine the cost-effectiveness of health care interventions. To address these issues, the investigators will convene an interdisciplinary working group of researchers with backgrounds in philosophy, law, genetics, counseling, public health, economics, and social science. The group will 1) analyze the extent to which the justifications for actual and proposed uses of prenatal testing and DALYs rest on controversial assumptions about disability and quality of life, and debate the validity of those assumptions; and 2) in response to these concerns, consider proposals to regulate or limit the availability of prenatal testing for the purpose of selective abortion, and the use of DALYs for the allocation of scarce health care resources.

WIKLER, Daniel
University of Wisconsin Madison, Wisconsin
"Human Genome Research in an Interdependent World"
Grant # R13 HG00431 Grant period: 09/28/90 - 12/31/91
Conference date: June 2-4, 1991, Bethesda, MD.

While many of the ethical, social, and legal issues which human genome research create can and should be debated and resolved within the borders of particular countries and regions, there are a number of issues which cannot be satisfactorily resolved without international understandings, negotiations, and accords. This group includes: international sharing of research burdens, benefits, and information; use of genetic information by the police and military; use of genetic information in identification of racial groups and in eugenic initiatives; and responsibilities of HGR scientists worldwide in determining the direction of their work. This conference will bring together approximately 40 scientists, officials, and ethicists from around the world to prepare an agenda of these issues for consideration by the appropriate national and international agencies. The conferees will compare views on the need for international cooperation on a number of issues and attempt to reach consensus on which issues require international accords and which do not. The resulting agenda for international action will be drawn up and published under the supervision of the planning committee.

Capron, A. "Human Genome Research in an Interdependent World." Kennedy Institute of Ethics Journal. September 1991. (Consensus Report including a proposal for Coordination of International ELSI issues by HUGO.)