



U.S. DEPARTMENT OF HEALTH
& HUMAN SERVICES

Genomics in Perspective

**A lecture series presented by
the National Library of Medicine
May-June 2006**

Organizer: David Cantor Ph.D.

**Lister Hill Auditorium, Building 38A
National Institutes of Health
Bethesda, Maryland**

Genomics in Perspective

NLM is pleased to announce *Genomics in Perspective*, a lecture series that presents historical and social science perspectives on genomics to an audience of scientists, physicians, policy makers, and the general public.

Genomics can be a confusing issue to the public. For some, it promises a radical and abrupt transformation in medical practice; others suggest that the new genetics has not and will not revolutionize the way common diseases are identified or prevented. Some welcome genomics as ushering in a golden age of new and more effective treatments, better diagnostic interventions, and more powerful means of biological investigation through bioinformatics, genetic analysis, measurement of gene expression, and determination of gene function. Others caution against over-optimism, and point to the importance of culture, society and history to an understanding of the complexity of interaction between biology, genes, and environment. The lectures in this series explore some of these issues from historical and social science perspectives. Together they seek to stimulate discussion of the social, historical, and cultural meanings and uses of genomics; to help to put genomics in perspective.

Each event will feature

- A lecture by a historian or social scientist.
- A response by a physician, scientist or policy maker.
- A discussion period

Admission is free and all are welcome.

Program

| | |
|--------------------|--|
| Start time: | All lectures will start at 4.00 pm |
| Location: | Lister Hill auditorium, Building 38A, NIH Campus (directions below). |
| Lecture: | 45 minutes |
| Response | 5-10 minutes |
| Discussion | 30-45 minutes |

2nd May 2006: Genes, Railroads and Regulation: Intellectual Property and the Public Interest

Lecture: Professor Daniel Kevles, Yale University.

Response: Claire T. Driscoll, M.S., Director, Technology Transfer Office, National Human Genome Research Institute.

9th May 2006: Transdisciplinarity in SPORE Funded Brain Tumor Research at the University of California San Francisco

Lecture: Professor Dorothy Porter, University of California, San Francisco.

Response: Brian Kimes, Ph.D., former Director, Office of Centers, Training and Resources (OCTR), National Cancer Institute.

16th May 2006: Standing on the Biological Horizon

Lecture: Professor Rayna Rapp, New York University

Response: Sharon F. Terry, M.A., President and C.E.O., Genetic Alliance, 4301 Connecticut Avenue, N.W., Suite 404, Washington, D.C.

6th June 2006: Genes and Disease: The Rise of Genomic Medicine in the United States

Lecture: Professor Susan Lindee, University of Pennsylvania.

Response: Alan E. Guttmacher, M.D., Deputy Director, National Human Genome Research Institute.

13th June 2006: Depicting Pasts, Projecting Futures: Making Histories of the New Biology

Lecture: Professor Stephen Hilgartner, Cornell University.

Response: Eric D. Green, M.D., Ph.D., Scientific Director, Division of Intramural Research, National Human Genome Research Institute.

20th June 2006: The Molecular Reinscription of Race: New Technologies Re-Generating a Dead-End Debate

Lecture: Professor Troy Duster, New York University.

Response: Vivian Ota Wang, Ph.D., Program Director, Ethical, Legal and Social Implications Research Program, National Human Genome Research Institute, and Senior Advisor, Office of Behavioral & Social Sciences Research, Office of the Director, National Institutes of Health.

Genomics in Perspective

ABSTRACTS

2nd May 2006: Genes, Railroads and Regulation: Intellectual Property and the Public Interest

Professor Daniel Kevles
Yale University.

Railroads are huge and genes are tiny, but the processes by which they came to figure in the American economy are marked by significant similarities. In the latter third of the nineteenth century, the transcontinental railroad system was developed with munificent federal patronage to private railroad companies. Operating in an otherwise laissez-faire environment, the companies built the transcontinental railroads and served the day's national interest by joining East and West in a system of rapid transport. In the late twentieth century, the field of molecular biology grew and flourished in supported by federal patronage, notably through the National Institutes of Health. Research in the field produced increasing knowledge of human genes, especially after the creation of the Human Genome Project. Particularly important progress was made in identifying genes responsible for or at least implicated in disease. Patents on these genes were sought and many obtained, not least as a result of the Bayh-Dole Act, in 1980, which strongly encouraged the patenting of innovations arising from federally sponsored research. Patented genes formed the principal capital basis of a number of start-up biotechnology companies and thus figured significantly in the rise of the biotechnology industry.

The biotechnology industry, particularly the branch of it that rests on human genes, may be on the same course that led to state regulation of the railroad industry. The profit-maximizing policies and practices of the railroad companies disadvantaged small farmers and other suppliers of freight. Thus diverging from the service of an equitable public interest, increasing demands were raised for regulation of the railroads. The companies objected, insisting that such regulation would interfere with their private property, but the demands were sufficient to result in the passage of the state Grange Laws and then, in 1887, of the federal Interstate Commerce Act. While the biotechnology industry, like the railroad industry before it, serves an essential public interest in the areas of medicine and food, some companies are exploiting their intellectual property rights in human genes in ways that run counter to sound medical practice. This paper argues that, despite objections raised by the biotechnology industry, the time has come to regulate the property rights represented by patents in human genes, just as society established regulation of property rights in railroads more than a century ago.

Daniel J. Kevles is the Stanley Woodward Professor of History at Yale University. His publications include *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (1985), perhaps the standard text on the history of eugenics in the United States; and *The Baltimore Case: A Trial of Politics, Science, and Character* (1998), a study of accusations of scientific fraud. He also co-edited with Leroy Hood *The Code of Codes: Scientific and Social Issues in the Human Genome Project* (1992). He is currently working on a history of intellectual property protection in living organisms and their parts from the late eighteenth century to the present.

9th May 2006: Transdisciplinarity in SPORE Funded Brain Tumor Research at the University of California San Francisco

Professor Dorothy Porter
University of California, San Francisco.

For over a decade, academic and commercial biomedicine has advocated the re-generation of clinical science through the development of a translational research (TR) paradigm that will speed up and reduce the costs of the discovery, development and delivery of novel therapeutics. Within this context, effective transdisciplinarity – that is, the dissolving of disciplinary boundaries to facilitate the synthetic emergence of a new paradigm - has been a central concern of governmental and foundational funding bodies and commercial producers. However, amongst the current literature discussing avenues and obstacles to transdisciplinarity none has focused specifically on the interaction of the conceptual systems and disciplinary cultures that characterize scientific, clinical research and population research. The integration of concepts, methods and values is critical to the operation of intellectual disciplines and the formation of conceptual paradigms. This paper will describe a project which aims to dissect these complex relationships by analyzing the historical and social foundations of transdisciplinarity within the context of translational research in brain cancer.

The paper will outline a new methodology which is being used to analyze translational research undertaken in a Specialized Program of Research Excellence (SPORE) into Brain Tumors established at the University of California San Francisco (UCSF) in 2002 and the prehistory of clinical and basic scientific collaboration undertaken in the UCSF Department of Neurosurgery since the 1940s. The UCSF Brain SPORE program was established on the basis of thirty years of successful translational brain tumor research developed through the UCSF Brain Tumor Research Center (BTRC) since 1972. UCSF's translational brain tumor research emerged from a tradition linking clinical and basic scientific enquiry that had been embedded in the department of Neurosurgery since the 1940s. This paper discusses how this history influenced the creation of the highly successful model of translational science currently operating in the UCSF Brain SPORE program today.

Dorothy Porter, is Chair History of Medicine and Health Sciences, Department of Anthropology, History & Social Medicine, University of California, San Francisco. She has published widely on the history of public health, medical ethics, and social medicine, her numerous books include *Health, Civilization and the State: a History of Public Health from Ancient to Modern Times* (1999); with Roy Porter, *Patient's Progress. Doctors and Doctoring in Eighteenth-Century England*, (1989) and also with Roy Porter, *In Sickness and In Health: the British Experience 1650-1850* (1988).

16th May 2006: Standing on the Biological Horizon

Professor Rayna Rapp
New York University

This lecture focuses on the activist coalitions and projects that genetic support groups forge with scientific researchers and medical clinicians in search of new genetic knowledge and potential health resources. Based on three years of fieldwork in genetics laboratories; among clinicians caring for patients with genetic syndromes, and in the offices, conferences, and internet work of support groups like DebRA, LPA, NMF, and the FD Foundation, this lecture reports on the volatile and rapidly changing “genetic politics” in which different expert constituencies engage. This empirical investigation is set against a background analysis of the changing investment patterns and public familiarity with biotechnology in the USA, and the aspirations for genetic medicine which are now widely circulating not only in North America, but in many parts of the world. I report on research concerning the social-scientific impact of mapping the Human Genome; and raise questions concerning activism and the promissory note that genetics offers.

Rayna Rapp, Professor of Anthropology, works on new reproductive technologies, the social impact of genome research, and kinship and disabilities. Her prize winning book *Testing Women, Testing the Fetus: the Social Impact of Amniocentesis in America* (1999) explored the social impacts and meanings of amniocentesis, illuminating how communication problems between practitioners and patients were the result of profound differences in beliefs about what makes a good parent, what risk means, the proper balance between personal autonomy and commitments to family, the nature of disability, and the moral status of the fetus. Her new collaborative research is on genetic knowledge. She has also been active in an international research group tracking the impact of new medical technologies; and two bioethics projects concerned with the re-inscription of race as a medical category through genomic research.

6th June 2006: Genes and Disease: The Rise of Genomic Medicine in the United States

Professor Susan Lindee
University of Pennsylvania

The idea that all disease is genetic disease played a critical political role in justifying public funding for the Human Genome Project, and continues to play an important role in the commercial development of genetic testing and potential genetic interventions. Yet all disease is, obviously, not any one thing, except in the trivial sense that human beings are embodied creatures. Diseases can be caused by bacteria, prions, and viruses, by war, injustice, diet, violence, environmental toxins, and many other things. Hereditary disease is of growing importance in the total disease burden in privileged populations, and genes do cause many terrible disorders and do seem to play a complicated role in differential risk for some chronic diseases. But the idea that increasing access to genes will result, eventually, in the complete control of human disease is better understood as a political claim, and a reflection of the networks of industrialization and commodification that have reshaped the biomedical sciences more generally over the last half-century.

In this paper I explore the history of the idea that all disease is genetic disease, considering how and why genetic disease rose to public and biomedical prominence in a critical period, from about 1955 until about 1985. I show that genetics research emerged in this period as an exciting biomedical research frontier, with the rise of public health genetics, cytogenetic testing, the new behavioral genetics, the catalogue Mendelian Inheritance in Man, and the interest in cancer genetics sparked by the discovery of the Philadelphia chromosome. After 1955, rapid institutional and social change brought genetic disease to the attention to a biomedical community increasingly sympathetic to new research in the field, and enthralled by discoveries that promised to explain mental retardation, mental illness, cancer, and well-known genetic diseases like sickle cell anemia. This paper explores the people, technologies and institutions that rapidly reconfigured genetic disease and laid the foundation for one of the most high-profile research enterprises of the late twentieth century, the Human Genome Project.

Susan Lindee's research focuses on the history of twentieth-century biological and biomedical sciences, particularly radiation biology, human genetics and genomics. Her publications include *Suffering Made Real: American Science and the Survivors at Hiroshima* (1994), an account of the Atomic Bomb Casualty Commission; *The DNA mystique: The gene as a cultural icon* with Dorothy Nelkin, an exploration of the gene in popular culture; *Genetic Nature/Culture: Anthropology and Science Beyond the Two Culture Divide* co-edited with Alan Goodman and Deborah Heath (2003); and *Moments of Truth: Genetic Disease in American Culture* (2005) a history of medical and human genetics in America.

13th June 2006: Depicting Pasts, Projecting Futures: Making Histories of the New Biology

Professor Stephen Hilgartner
Cornell University.

Accounts of the history of the new biology are an important tool for shaping its future. Not only are progress reports and reviews of recent technological trends frequently used to create “anticipatory knowledge” about future possibilities, but accounts of the past are also deployed in debates about a variety of public issues. This paper examines one highly-visible technique for depicting the history of biotechnology: the creation and display of timelines on the Internet. The paper analyzes the use of this literary/visual form in promoting particular visions of the past and future of the new life sciences. The conclusions are relevant to several domains of scholarly and political interest, including social studies of genomics; sociology of historical knowledge; science communication; and public engagement in debates over emerging technologies.

Stephen Hilgartner’s research focuses on social studies of science and technology, especially biology, biotechnology, and medicine; biology, ethics, and politics; science as property; ethnography of science; and risk. His book *Science on Stage: Expert Advice as Public Drama* (2000) explores the processes through which the expertise of science advisors is established, contested, and maintained. Hilgartner is chair of the Ethical, Legal, and Social Issues (ELSI) committee of the Cornell Genomics Initiative. He has been a member of the Council of the Society for Social Studies of Science (4S) and a member of the Steering Group of the Section on Societal Impacts of Science and Engineering of the American Association for the Advancement of Science (AAAS). He is currently completing a book on the social world of genome mapping and sequencing in the 1990s.

20th June 2006: The Molecular Reinscription of Race: New Technologies Re-Generating a Dead-End Debate

Professor Troy Duster
New York University.

From pharmacogenomics to forensics, the application of new computer technology to DNA analysis has re-generated an old debate about the utility of human taxonomies of race. The debate has taken an unfortunate binary turn that pits one side against the other - when what is needed is a far more nuanced and contextually situated approach to "when and where and why" the category of race should and should not be deployed in scientific work.

Troy Duster is the author of many publications and articles regarding science, race, and public policy, with a particular emphasis in recent years on the social and political impacts of developments in molecular biology. His publications include *Backdoor to Eugenics* (1990, 2003), which traced a dangerous slide toward a "covert eugenics" that has emerged as "old mythologies" about intelligence and crime are "dressed in the biological sciences." Duster's most recent book is *Whitewashing Race: The Myth of a Color-Blind Society* (2003; co-authored with Brown, Carnoy, Currie, Oppenheimer, Shultz, and Wellman). Duster served as a member and then chair of the advisory committee on Ethical, Legal and Social Issues (ELSI) program at the National Human Genome Research Institute (Human Genome Project).

Visiting the NIH

The NIH has changed in recent years. It is no longer the open campus it once was. A new security fence surrounds the grounds. Cars are searched at the entrances, and guards will ask to see a government-issued photo ID (passport; US driver's license) before you enter. Please allow sufficient time to pass through the various security checkpoints.

The easiest way to get to NIH is via the Metro (Medical Center on the Red Line) or by bus or on foot. Drivers should enter the campus by the South Drive entrance from Rockville Pike. See the map below for visitor parking areas. Visitor parking is very limited. Metro access is recommended.

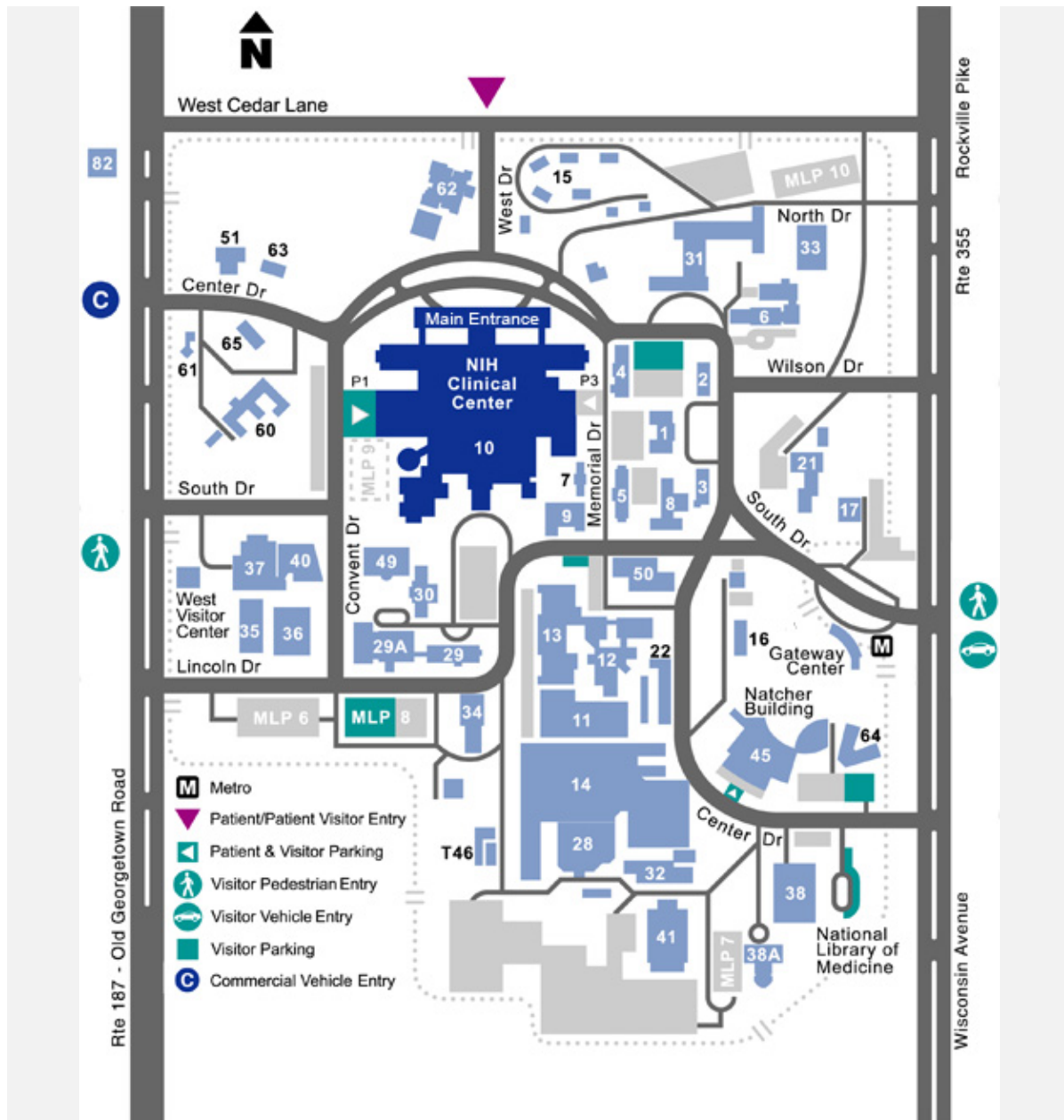
See NIH Map below for the visitor parking, and entries to the campus

For the most recent information please use the following websites

NIH security information is available at
<http://www.nih.gov/about/visitorsecurity.htm>

Travel information is available at:
<http://www.nlm.nih.gov/about/visitor.html>
<http://www.nih.gov/about/visitor/index.htm>

NIH Campus Map



Acknowledgments

Acknowledgements: Many people provided advice for this series, too many to thank all individually: but Barbara Dunn, David Ransohoff, Jaye Viner, and Francis Collins provided more than most. Elizabeth Fee provided encouragement, advice and institutional support.

Organizer:

David Cantor works as a historian for the National Library of Medicine and the National Cancer Institute in Bethesda, Maryland. His recent publications include “Cancer, Quackery and the Vernacular Meanings of Hope in 1950s America,” *Journal of the History of Medicine and Allied Sciences*, Advance Access published, March 24, 2006. doi:10.1093/jhmas/jrj048; and “The Frustrations of Families: Henry Lynch, Heredity, and Cancer Control, 1962-1975,” *Medical History*, 50, (3), July, 2006, in press. He is the editor of *Reinventing Hippocrates* (Ashgate, 2002); the guest editor of a special “cancer” issue of the *Bulletin of the History of Medicine* (Spring 2007, forthcoming); and series editor (edited collections) of *Studies in the Social History of Medicine* published by Routledge.

Revised: 26 April 2006.