

EXPANDING THE CONVERSATION

Washington University's School of Law and School of Medicine are sponsoring a yearlong series of events to discuss legal, ethical, and social issues related to genetic advances.

When planners at the Washington University School of Law's Center for Interdisciplinary Studies and School of Medicine subtitled their January 2002 human genome conference "Expanding the Conversation," they intended a substantial expansion. The president of the American Law Institute, feminists, political theorists, an authority on race and culture, a noted international jurist, and a historian of technology joined leading figures in the global human genome mapping effort to consider the wide-ranging legal, ethical, and social issues stemming from genetics research.

Scientists have been talking about the human genome for years, and lawyers have been considering the legal issues for some time. But "The Human Genome Project: Expanding the Conversation" at Washington University on January 28–29, 2002, assembled scholars from widely divergent disciplines to examine the genomics revolution.

"We wanted to add new voices to the conversation," explains conference co-organizer Susan Frelich Appleton, associate dean of the law faculty and the Lemma Barkeloo & Phoebe Couzins Professor of Law. "We wanted to include smart, creative thinkers who would bring new insight to the Human Genome Project discussion."

One of the key figures in the conference was Francis S. Collins, director of the National Human Genome Research Institute at the National Institutes of Health, where he has overseen the last nine years of a 13-year effort to map the human genome by 2003. He previously pioneered a method called positional cloning to identify disease genes. With various colleagues, he identified the gene for cystic fibrosis (1989), neurofibromatosis (1990), and Huntington's Disease (1993).

He delivered the conference's opening keynote address on "Genomics, Medicine, and Society." In this address, he reviewed the progress of the Human Genome Project; forecast its consequences for medicine over the next 10–20 years; and outlined some of its ethical, legal, and social issues.

Nancy S. Wexler was the leader of the consortium (of which Collins was a member) that discovered the Huntington's Disease gene in 1993. The Higgins Professor of Neuropsychology at Columbia University and president of the Hereditary Disease Foundation, Wexler writes widely on genetic testing. In her keynote address, "Genetic Joy—Genetic Jeopardy," she brought not only professional experience to her presentation, but also personal experience through the presence of Huntington's Disease in her family.

Michael Traynor, a partner of Cooley Godward LLP, gave an address titled "The Selfish Genome?" that focused on the genomics revolution's vexing intellectual property issues. A widely respected authority in biotechnology, the environment, and information technology, Traynor represented the intersection of science and law. As president of the American Law Institute (ALI), a prestigious organization of judges, lawyers, and academics chartered in 1923, Traynor and other ALI members strive to encourage the clarification and simplification of the law, to improve its adaptation to social needs, and to advance scholarly and scientific legal work.

The fourth keynote speaker, Susan M. Okin, a political scientist and the Martha Sutton Weeks Professor of Ethics in Society at Stanford University, brought a feminist perspective to the discussion. According to Okin, scientists making observations of the physical world for centuries have tended to see what they expected to see and have considered the behaviors of living beings as purposive when it may not have been appropriate to view them in such a way. In "Genetics and the Persistence of Teleological Thinking," Okin focused on popular accounts of the findings of human genetics and genomics, and explored whether similar errors were being made in these modern scientific endeavors.

In planning the conference, Appleton says she was convinced that the Human Genome Project raised important

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(From the left) Keynote speakers Susan M. Okin, Francis S. Collins, Nancy S. Wexler, and Michael Traynor discussed diverse aspects of the Human Genome Project.

gender issues. When scientists map the genome and thus “redefine personhood,” she observes, it becomes important to hear from theorists about the significance of biology versus cultural factors.

Each of these sessions was followed by discussion, as well as by additional speakers responding and offering their own insights:

- Anita L. Allen, professor of law and philosophy at the University of Pennsylvania, an authority on privacy and bioethics.

- Robert A. Burt, the Alexander M. Bickel Professor of Law at Yale University, an expert on law and medicine, mental health law, and disability law.

- David R. Cox, co-director of the Stanford University Human Genome Center, chief scientific officer of Perlegen Sciences, and member of the National Bioethics Advisory Commission.

- Gerald L. Early, the Merle Kling Professor of Modern Letters at Washington University, a nationally recognized scholar on race and American culture.

- Amy Gutmann, provost and the Laurance S. Rockefeller University Professor of Politics and the University Center for Human Values, at Princeton University, a noted authority on democracy, ethics, and human values.

- Noëlle Lenoir, attorney with the international law firm of Herbert Smith in Paris, chair of the European Group on Ethics in Science and New Technologies, and formerly a justice on the French Constitutional Supreme Court.

- Joel Mogyk, the Robert H. Strotz Professor of Arts and Sciences and Professor of Economics and History at Northwestern University, a specialist on the economics of technological change.

- Margalit Birnbaum Mogyk, professor of biochemistry and molecular biology at the University of Illinois–Chicago.

- Robert H. Waterston, the James S. McDonnell Professor of Genetics, head of the Department of Genetics at Washington University’s medical school, and co-director of its Genome Sequencing Center.

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Reflecting on the conference, Collins says its multidisciplinary nature was a particularly important feature. “It is also gratifying that there was a mix of scholars who have worked on these issues for many years and others who were drawn into the field for the first time by the conference organizers,” he continues.

Richard K. Wilson, associate professor of genetics at Washington University’s medical school and co-director of its Genome Sequencing Center, co-organized the conference with Appleton. He found the event of critical importance in public education. “The better that people educate themselves about new technologies, whether it’s nuclear power or genomic science, the lower the chance of misunderstanding what technology is for,” Wilson says.

He saw the conference as a powerful opportunity for key professional people “to ask some good questions and develop some good thoughts as to what we do with the various issues that come with genome science, and to consider what kinds of legislation we need members of Congress to think about and what kind of guidelines we put in place to protect Joe Public.”

Support for the conference came from the Whitaker Foundation, the Washington University School of Medicine, and the Center for Interdisciplinary Studies at the Washington University School of Law.

The conference was the first of four events, with three colloquia following this spring: “Professional, Legal, and Social Challenges for Genetic Counseling and Testing” on March 22; “Germ Line Interventions and Human Research Ethics” on April 5; and “Patenting Genetic Products” on April 12–13.

Rebecca S. Dresser, the Daniel Noyes Kirby Professor of Law and professor of ethics in medicine, helped plan the conference. She is also teaching a related course this spring titled “The Human Genome Project: Law, Policy, and Ethics.” Students have attended both the conference and the colloquia, read and discussed pertinent material, and worked in teams to investigate specific conference topics like privacy, confidentiality, and discrimination; genetics in the courtroom; research and commercial uses of stored tissue samples; prenatal and presymptomatic genetic testing; and potential individual and group stigmatization from genetics research and testing. ◆