

# Translating Ethical, Legal and Social Implications of Genomic Research

**International conference, May 1-3,  
2008, Renaissance Hotel,  
downtown Cleveland, Ohio**



## **Schedule**

(Rev. 2/28; times and sessions subject to change)

### **Thursday, May 1**

#### **1-2 p.m. Opening Session**

##### **"The Past as Prologue, Revisited: ELSI from 1990-2008"**

Patricia King, J.D., Carmack Waterhouse Professor of Law, Medicine, Ethics, and Public Policy, Georgetown University

Professor King's expertise is in the study of law, medicine, ethics and public policy. She is also an adjunct professor in the Department of Health Policy and Management, School of Hygiene and Public Health at Johns Hopkins University. She is the co-author of *Cases and Materials on Law, Science and Medicine*. She offers a seminar in Bioethics and the Law. She is a member of the American Law Institute and the Institute of Medicine and a Fellow of the Hastings Center. Her work in the field of bioethics has included service on the HEW-Advisory Recombinant DNA Advisory Committee, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, and the Ethics, Legal and Social Issues Working Group of the Human Genome Project. She is a fellow of the Harvard Corporation and a member of the Board of Trustees of Wheaton College.

#### **2:30-4 p.m. Concurrent Sessions**

##### *Research Track: Intellectual Property and Biological Inventions*

- Panel: Intellectual Property, Genomics and Innovation  
Authors: Cook-Deegan, R.; Chandrasekharan, S.; Arti, R.
- Patents and the New Zealand Genetic Services and Biotechnology Sectors  
Author: Green, A.
- Synthetic Biology  
Author: Mukhopadhyay, A.
- Technology Transfer Offices—The Reason to Repeal or Repair Bayh-Dole  
Author: Greenbaum, D.

##### *Clinical Track: Pediatric Genetic Testing*

- PANEL: Genetic Testing and Research in Children: Ethical and Policy Implications  
Authors: Wilfond, B.; Tarini, B.; Goldenberg, A.; Botkin, J.

##### *Societal Track: Genomic Research in Native Communities*

- PANEL: Working with Native Communities  
Authors: Au, S.; Brilliant, M.; Hasegawa; Wood, T.
- Ethical and Cultural Implications of Specimen Banking Among Alaska Native People: A Framework for Analysis from Two Pilot Focus Groups  
Authors: Dillard, D.; Brown, J.; Etzel, R.

#### **4-4:30 p.m. Break refreshments**

#### **4:30-6:30 p.m. Concurrent Sessions**

##### *Research Track: Genome-Wide Association Studies*

- PANEL: Developing Conceptual Frameworks for Translational ELSI Research in Biobanking and GWAS  
Authors: McGuire, A.; Burke, W.; Wright Clayton, E.; Beskow, L.; Koenig, B
- In the Laboratory with Genome Wide Association Studies: Conceiving Populations  
Author: Ossorio, P.

##### *Clinical Track: Genetic Risk Assessment for Alzheimer Disease*

- PANEL: The Challenges of Providing Genetic Risk Information for Common, Complex Disease: Lessons Learned from the REVEAL Study  
Authors: Green, R.C.; Roberts, J. S.; Whitehouse, P.; Cook-Deegan, R.
- A Qualitative Exploration of Reactions to Risk Assessment in a Randomized Trial of Genetic Counseling in Alzheimer's Disease  
Author: Whitehouse, P.
- Genetic Testing for Dementia Risk and the Problem of Rational Suicide  
Author: Davis, D.

##### *Societal Track: Lessons from History and Lessons for History*

- PANEL: Lessons from History for a Genomic Future  
Authors: Schneider, W.; Stern, A.; Mehlman, M.
- Thomas Jefferson's DNA: Evolving Standards of Consent for Genetic Research  
Author: Lombardo, P.
- Double Helix, Double Standards: Private Matters and Public People  
Author: Brown, T.
- Tales from the Crypt: Scientific, Ethical, and Legal Considerations for Biohistorical Analysis of Deceased Historical Figures  
Authors: Andrews, L; Paradise, J.

#### **6:30-7:30 p.m. Networking Reception in Exhibit Hall with poster presentations**

### **Friday, May 2**

#### **7:30 a.m.-5 p.m.**

#### **Poster presentations displayed in Exhibit Hall**

#### **7:30-8 a.m. Continental Breakfast**

#### **8-10 a.m.**

#### **"Scanning the Whole Genome Horizon: Where Genomics Is Going Next"**

Panelists include: E. Liu, M. Olsen and C. Rotimi

#### **10-10:30 a.m. Break refreshments**

*10:15 a.m.-12:30 p.m. Special Symposium: New Issues for a Settled Practice: Newborn Screening and the Ethics of Public Health Genetics*

- Public Health Follow up of abnormal newborn screening results  
Authors: Riley, C.; Watts, C.; Burke, W.
- Astigmatism in the Public Eye: An Analysis of Gaps in The Media Coverage of the Ethical and Social Issues Regarding Newborn Genetic Screening  
Authors: Schlesinger, M.; Grob, R
- Qualitative Perspectives on Quality and Quantity in Newborn Screening  
Author: Grob, R.
- Expansion of Newborn Screening in Israel: Routinization of a New Technology, Knowledge Construction, and Public Understanding  
Author: Zuckerman, S.
- Shared Decision-Making: A Paradigm Shift for Newborn Screening Programs  
Author: Lewis, M.

### **10:30-Noon Concurrent sessions**

#### *Research Track: Biobanking and Health Registry Research*

- Biobanks and Genomic Research: Empirical Evidence and Challenges Ahead  
Authors: Boggio, A.; Elger, B.; Ganguli-Mitra, A.; Biller-Andorno, N.; Mauron, A.; Capron, A.
- Mapping the Language of Research—Biobanks and Health Registries  
Authors: Helge Solbakk, J.; Holm, S.; Hofmann, B.
- Informed Consent Requirements for Biobanking Research: From the Maze of the Current Regulations to the Construction of a Unified Model of Informed Consent to Collect and Store Human Biomaterials for Research. The Local Experience of the Italian Biobank  
Author: Salvaterra, E.
- Biobanks, IP and Deliberative Democracy: Generating IP Policy Concerns from Public Deliberation.  
Authors: Hartell, D.

#### *Clinical Track: Familial Issues in Genetic Testing*

- Making Choices: The Family Experience of Genetic Testing/Prenatal Screening for Down syndrome: More Than a Simple Blood Test and a Picture of the Baby  
Author: Van Riper, M.
- Prenatal Genetic Therapy: Making Children Healthy vs. Making Healthy Children  
Authors: Asch, A.; Wasserman, D.
- Parent-Child Communication about Hereditary Disease Risks: ELSI Translations From Cancer to Genomic Medicine  
Authors: Tercyak, K., Peshkin, B., Peterson, S., Patenaude, A.
- Managing Information in Families with Children who have Genetic Conditions  
Authors: Gallo, A.; Knafl, K.; Angst, D.
- Storm clouds ahead: The impact of a genetic diagnosis on Mexican-immigrant siblings suffering neurodegenerative disease  
Authors: Browner, C.; Preloran, M.

#### *Societal Track: Genetics, Race, and Ancestry*

- PANEL: Genetic Testing, Race, and Community Identity  
Authors: Davis, D.; Fullerton, M.; Jeungst, E.; Sharp, R.; Yu, Joon-Ho; Zuckerman, S.  
Genetic Inference of Ancestry: Challenges and Solutions  
Author: Mountain, J.

#### *1-6 p.m.: Special Symposium: Newborn Screening for Less Treatable Conditions\*\*(additional no-cost registration required) hosted by the Law-Medicine Center at Case Western Reserve University*

- Schedule to be announced
- PANEL: Critical ELSI Issues of Expanded Newborn Screening  
Authors: Bailey, D.; Skinner, D.; Davis A.; Howell, R.; Powell, C.

### **1:30-3 p.m. Concurrent Sessions**

#### *Research Track: Public Involvement in Genomic Research Planning*

- PANEL: Deliberative Democracy and Biobanks: Involving the Public in Policy Formation  
Authors: Koenig, B.; Burgess, M.; Walmsley, H.; O'Doherty, K.; Hudson, K.

#### *Clinical Track: Genomics and Health Disparities*

- PANEL: Will Genomic Medicine Exacerbate Health Disparities? Investigating Access to and Utilization of Available Genetic Tests Among Underserved Populations  
Authors: Shin, P.; Shields, A.; Burke, W.; Levy, D.
- Genomics, Ethics, and Health Disparities: The Importance of Community Voices in Addressing Equity Issues Related to Genomic Science and Policy Development  
Authors: Goldenberg, A.; Platt Garcia, J.

#### *Societal Track: Behavioral Genetics and the Media*

- PANEL: Behavioral Genetics in the Media  
Authors: Geller, G.; Condit, C.; Conrad, P.; Phelan, J.
- Ethical and Social Aspects of Behavioural Genomics: What are the Opinions of Life Scientists?  
Author: Higashijima, J.

### **3-3:30 p.m. Break refreshments**

### **3:30-5 p.m. Concurrent Sessions**

#### *Research Track: Secondary Research Uses of Stored Genetic Materials*

- The Use of Residual Newborn Screening Bloodspots for Genetic Research: Ethics at the Intersection between Biobanks and Public Health  
Author: Goldenberg, A.
- Permissible Uses of Retained Newborn Screening Blood Samples: Views of Mothers of Newborns  
Author: Lewis, M.
- Effect of Educational Consent Video on Genetic Research Participants' Preferences for Future Use of DNA  
Author: Lewis, S.
- Consent for Future Use of Retained DNA in Behavioral Research: Purpose of Empirical Data  
Author: Coors, M.; Mikulich-Gilbertson, S.; Raymond, K.; Crowley, T.

#### *Clinical Track: Pharmacogenomics in Theory and Practice*

- Regulating Pharmacogenetic Tests  
Authors: Javitt, G.; Hudson, K.
- News Coverage of Pharmacogenomics and Genetically-based Personalized Medicine for Stigmatized Versus Non-stigmatized Conditions  
Authors: Feldman, N.; Kuppin, S.; Phelan, J.
- The Issues of Pharmacogenetics Implementation in Quebec, Canada  
Author: Dubois, A.
- A Comparison of Claims and Evidence: CYP450 genotyping and SSRI Prescribing  
Authors: Katsanis, S.; Javitt, G.; Scott, J.; Hudson, K.
- The Place of Race in Patenting and Drug Development  
Author: Kahn, J.
- Race, Genes and Justice: Interpreting Population Differences in Pharmacogenomics  
Author: Lee, S.

#### *Societal Track: Personal Genomics and Personal Identity*

- Direct-to-Consumer Genetic Testing: An Overview of the European Regulatory Framework  
Author: Borry, P.
- Challenges of Direct-to-Consumer Genomics  
Author: Greely, H.
- Nutrigenomics and the Promise of Prevention: Representations and Realities  
Author: Caulfield, T.
- Reconceptualizing the Individual: Implications of Metagenomics  
Author: Huss, J.
- Genetic Perspectives on Identity and Identification  
Author: Nordgren, A.

## **Saturday, May 3**

### **7:30-8 a.m. Continental breakfast**

### **8 a.m.-3 p.m. Poster presentations exhibit**

### **8-9:30 a.m. Concurrent Sessions**

#### *Research Track: Reproductive Genetics and Gene Transfer Research*

- Mapping the quest for PGD in Norway  
Author: Skavoll, B.; Solbakk, J.H.; Hofmann, B; Holm, S.
- The New Zealand Bioethics Council Explores the Cultural, Ethical and Spiritual Aspects of Pre-Birth Testing  
Author: Thomas, C.
- Describing Benefit in Consent Forms: Lessons from Gene Transfer Research  
Author: King, N.
- Perceptions of Benefit in Gene Transfer Research: Disease Context, Subject Characteristics, and Decision-making  
Authors: Henderson, G.; Davis, A.
- Protecting Human Subjects in Genetic Enhancement Research  
Author: Mehlman, M.

#### *Clinical: International Perspectives on Genomics Policy Development*

- Formulating and Implementing Public Policy Related to Translational Genome Research: Iran and the United States  
Authors: Jillson, I.; Ekhitari, H.
- History and current status of ELSI and communication activities conducted by the Japanese genome research projects  
Author: Kato, K.
- PredictER: Indiana University's Experience in Translating Predictive Health Ethics Research into Practice  
Author: Meslin, E.
- From Gene Discovery to Health Policy: An ELSI\* Success Story in Atlantic Canada  
Author: Pullman, D.

#### *Societal Track: The Two Cultures Revisited: Science and Ethics in Dialogue*

- Geneticists' Views of the Societal and Ethical Implications of Research  
Authors: McCormick, J.; Boyce, A.; Cho, M.
- Beyond the Nature-Nurture Debate: Bioethics and the Integration of Knowledges  
Authors: Boyce, A.; McCormick, J.; Cho, M.
- Integrating ELSI into the scientific process: the PERF approach  
Author: Dressler, L.

- Defining Ambiguities: Towards a Genealogy of Gene-Environment Interaction  
Author: Shostak, S.

## **9:30-10 a.m. Break refreshments**

### **10 a.m.-Noon Concurrent Sessions**

#### *Research Track: Reporting Research Findings in Human Genetic Research*

- Achieving Consensus about the Challenges in Human Genetic Research (I and II)  
Author: Wiesner, G
- Disclosure and Confidentiality in Clinico-Genomic Research: Patients' Attitudes and Perspectives Towards Individual Donor Feedback  
Authors: Peterson, I.; Kollek, R
- Disclosing Individual Genetic Results to Research Participants  
Author: Ravitsky, V.
- Managing Incidental Findings in Human Subjects Research: From Imaging to Genomics  
Author: Wolf, S.
- Reconceptualizing and Managing Incidental Findings of Genetic Research  
Author: Parker, L.

#### *Clinical Track: Integrating Genomic Tools into Clinical Practice*

- The translational cycle in genomic research  
Authors: Kuszler, P.; Burke, W.; Starks, H.
- The standard of care for genetic tests: what role do clinical practice guidelines play?  
Authors: Laberge, A.; Kuszler, P.; Starks, H.; Burke, W.
- Translating Meaning: Report on an ELSI Methodology  
Authors: Brunger, F.; Darmonkov, V.; King, L.; Manual, A.
- What Have We Learned about Cancer Genetics? Findings and Retrospective Ruminations from the Cancer Genetics Studies Consortium  
Author: Press, N.
- Distress and Burnout Among Genetic Service Providers: Causes and Potential Manpower Consequences  
Author: Bernhardt, B.
- Found In Translation: Religion and Spirituality in Genetic Counseling  
Author: Fanning, J.

#### *Societal Track: Group Interests and Genomic Research*

- A Theory of Collective Autonomy: Can it Ground "Community Consent"?  
Author: Davis, D.
- Genome Justice: Genetics and Group Rights  
Author: McGregor, J.
- Groups and Rights in Genomics Research: A Conceptual Approach  
Author: Kanellopoulou, N.

### **1-2:30 p.m. Concurrent Sessions**

#### *Research Track: The Role of Racial Categories in Genomic Research*

- PANEL: ELSI Approaches to Race and Genetic Research: Talking with Researchers, Engaging Policy-makers and Examining the Public Impact  
Authors: Lee, S.; Mohahan, K.; Sankar, P.; Cho, M.
- Genetic Constructions of Racial Differences in News Media: 1985-2006  
Author: Phelan, J.

*Clinical Track: Public Perceptions of and Involvement in Genetics and Genomics*

- Public Health Genomics (PHG) and Public Participation  
Authors: Avard, D.; Bucci, L.; Burgess, M.; Kaye, J.; Heeney, C.; Farmer, Y.; Cambon-Thomsen, A.
- Visions of the Citizen in Population Research  
Author: Arnason, V.
- Perceptions of Population-Based Genetics Research: Views of Potential Participants and the General Public  
Authors: Somkin, C.; Altschuler, A.; Brown, E.; Rowell, S.; Schaefer, C.
- Roles of Advocacy Groups, Researchers and Parents in Genetic Research on Complex Traits: The Example of Autism  
Author: Tabor, H.
- Lay Genetic Explanations for Type II Diabetes and Alcoholism: Public Health Implications  
Author: Jayaratne, T.
- The Genomics Policy Process: A Model For Partnering Citizens, Experts and Policy Makers  
Author: Fowler, G.; Garland, M; Allison, K.C.

*Societal Track: Genomics and the Law*

- Genome-Wide Scans: ELSI Practices for the \$1000 Genome  
Author: Robertson, J.
- Judging Genes: Implications of the Second Generation of Genetic Tests in the Courtroom  
Author: Hoffman, D.
- Genetic Testing and Discrimination: A Comparison of United States Civilian and Military Law and Policy  
Author: Baruch, S.; Hudson, K.
- Genetic Testing in the Workplace: A Survey of Occupational Medicine Physicians  
Authors: Brandt-Rauf, P.

**2:30-3 p.m. Break refreshments**

**3-5 p.m. Closing Session**

**"From Where I Stand: Observations on ELSI Research Through the Lens of This Conference"**

Panelists include: S. Brownlee, P. Shepherd and P. Williams