

Institute for Policy in Medicine & Law **PLANNING SYMPOSIUM**

Monday, September 18, 2017

8:00am - 6:30pm

Washington University School of Law

Anheuser-Busch Hall

Bryan Cave Moot Courtroom (AB310)



SYMPOSIUM SCHEDULE

- 8:00am **Breakfast** (outside Bryan Cave Moot Courtroom)
- 8:30am **Welcome**
Jon Heusel: *Mission of the IPML and goals for the planning symposium*
Tim Eberlein & Nancy Staudt: *Vision for the IPML*
- 9:00am **SESSION 1. Clinical Genomics at WU and Current Challenges for Precision Medicine**
Moderators: Sam Garner and Kirk Nahra
Kirk Nahra: *Challenges in clinical data sharing, ambiguities of HIPAA*
Susan Dutcher: *From discovery to delivery of healthcare*
Session discussion
- 10:00am **Morning Break**
- 10:15am **SESSION 2. Consent, Ownership and Transparency**
Moderators: Sam Garner and Elizabeth Sepper
Frank Pasquale: *The law and ethics of data management in the learning health care system*
Mary Ebeling: *Is data transparency possible in the age of big consumer health data?*
Session discussion
- 11:30am **Working Lunch** (Faculty Seminar Room, AB320)
In partnership with the Institute for Informatics (I²)
Philip Payne: *Harmonization of informatics*
John Wilbanks: *Consent and data sharing policy*
Session discussion
- 12:45pm **Break**

- 1:00pm **SESSION 3: Privacy and Harm**
Moderators: Sam Garner and Rachel Sachs
Paul Ohm: *The need to inject friction into medical research*
Andrew Serwin: *Privacy, standing, and harm*
Session discussion
- 2:00pm **Afternoon Break**
- 2:15pm **SESSION 4: Panel Discussion on Ethics and Trust, ELSI in Genomic Medicine**
Moderator: Sam Garner
James DuBois: *Biomedical ethics*
Sarah Hartz: *Statistics, quantitative phenotyping*
Jessica Mozersky: *Biomedical ethics*
- 3:30pm **Afternoon Break**
- 4:00pm **SESSION 5: Future Directions for the IPML**
Karen Seibert & Philip Payne: *Symposium synopsis and focused discussion*
- 4:30pm **Closing Remarks by Neil Richards**
- 4:45pm **Reception** (Crowder Courtyard)

All sessions will take place at the Bryan Cave Moot Courtroom (AB310), unless otherwise noted.

INVITED SPEAKERS

James DuBois, DSc, PhD

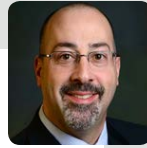
Steven J. Bander Professor of Medical Ethics and Professionalism and Professor of Psychology, Washington University

James DuBois is a professor at Washington University School of Medicine and serves as the director of the Center for Clinical Research Ethics

He is a Board Certified Coach specialized in career coaching for researchers and leads the Professional and Social Issues Lab, helping researchers conduct high-quality research with integrity by fostering good decision-making, management, and leadership practices. He also directs the NIH-funded Professionalism and Integrity Program.

He is the founding co-Editor of *Narrative Inquiry in Bioethics: A Journal of Qualitative Research* (Johns Hopkins University Press).

DuBois completed his PhD in philosophy at the International Academy of Philosophy in Liechtenstein and his DSc in psychology at the University of Vienna in Austria, where he focused on cross-cultural moral psychology.



Mary Ebeling, PhD

Associate Professor of Sociology and Director of Women's and Gender Studies, Drexel University

Mary Ebeling is associate professor of sociology and director of Women's and Gender Studies at Drexel University.

Ebeling is an ethnographic sociologist and researches the intersections of marketing, health, biomedical science and digital life. Her new book, *Healthcare and Big Data: Digital Specters and Phantom Objects* (2016, Palgrave Macmillan) is focused on data brokers, data mining, marketing surveillance, private health data, and algorithmic identities.

Her work has received support from the National Science Foundation, the Economic and Social Research Council (UK) and the European Union (5th Framework Programme). She has been awarded a Regional Faculty Fellowship at the Wolf Humanities Center at the University of Pennsylvania for the 2017-18 academic year.



Susan Dutcher, PhD

Professor of Genetics and Interim Director of McDonnell Genome Institute, Washington University

Susan Dutcher is currently serving as interim director of the McDonnell Genome Institute to provide expert stewardship during a period of transition for this global leader in genome science.

Dutcher is a prominent geneticist and professor of genetics at Washington University School of Medicine. She started her career in science studying yeast cell cycle mutants with Leland Hartwell. With her use of comparative genomics to find human disease genes that affect cilia, her interests moved to understanding the cell biology behind many human ciliopathies using genomics, genetics and imaging.

During her academic career, she has held many leadership positions, such as graduate director of the molecular biology program at the University of Colorado and as graduate director of genetics at Washington University.



Sarah Hartz, MD, PhD

Assistant Professor of Psychiatry, Washington University

Sarah Hartz is an assistant professor of psychiatry at Washington University School of Medicine who combines training in biomedical statistics and genetics to better understand the genetics of substance dependency. She also seeks to define genetically the common comorbidity of substance use disorders and other severe mental illness.

In addition to her research activities, she has an active practice serving patients with severe mental illness.

Hartz completed her MD at the University of Iowa, followed by a residency in Psychiatry at the University of Iowa and Washington University/ Barnes-Jewish Hospital, where she went on to complete a fellowship in psychiatric genetics.



INVITED SPEAKERS

Jessica Mozersky, PhD, MBE

Assistant Professor of Medicine, Washington University

Jessica Mozersky is an assistant professor of medicine in the Division of General Medical Sciences at Washington University School of Medicine.

Her research explores the ethical and social implications of new biomedical and genomic technologies including cancer genetic testing, prenatal genetic screening, whole genome sequencing, and PET neuroimaging. Mozersky is the author of *Risky Genes: Genetics, Breast Cancer, and Jewish Identity* (Routledge 2013).

Prior to joining the faculty at WUSTL, Mozersky was a fellow in advanced biomedical ethics at the University of Pennsylvania's Department of Medical Ethics & Health Policy, where she also obtained a Masters in Bioethics.

Mozersky received her PhD in Anthropology from University College London's Interdisciplinary Institute of Human Genetics and Health.



Paul Ohm, JD

Professor of Law, Georgetown University Law Center

Paul Ohm is a professor of law at the Georgetown University Law Center, specializing in information privacy, computer crime law, intellectual property, and criminal procedure. He serves as a faculty director for the Center on Privacy and Technology at Georgetown.

His article *Broken Promises of Privacy: Responding to the Surprising Failure of Anonymization* (57 UCLA Law Review 1701) has sparked an international debate about the need to rethink the way we regulate privacy.

In 2016, he was appointed by the White House to the Commission on Evidence-Based Policymaking. From 2012 to 2013, Ohm worked for the Federal Trade Commission as a Senior Policy Advisor.

Ohm received his law degree from the UCLA School of Law and also has undergraduate degrees in computer science and electrical engineering from Yale University.



Kirk Nahra, JD

Partner at Wiley Rein, LLP, Washington DC

Kirk Nahra is a partner with Wiley Rein LLP in Washington, DC, where he is chair of the firm's Privacy Practice and co-chair of its Health Care Practice.

He assists companies across the country and internationally in virtually all industries in analyzing and implementing the requirements of privacy and security laws. Nahra provides advice on data breaches, enforcement actions, contract negotiations, business strategy, research and de-identification issues and privacy, data security and cyber security compliance.

A long-time member of the Board of Directors of the International Association of Privacy Professionals, he is also a founding Board Member of the Privacy Bar Section of the IAPP and a Certified Information Privacy Professional.

Nahra teaches privacy law at various institutions, including the Washington College of Law at American University.



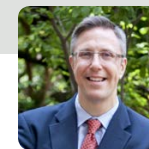
Frank Pasquale, MPhil, JD

Professor of Law, Carey School of Law, University of Maryland

Frank Pasquale, one of the 10 most cited scholars in US health law, is the co-host of The Week in Health Law, which has ranked as one iTunes' top 20 "Government & Organizations" podcasts.

Pasquale's research addresses the challenges posed to information law by rapidly changing technology, particularly in the health care, internet, and finance industries. He is a member of the NSF-funded Council for Big Data, Ethics, and Society, and an Affiliate Fellow of Yale Law School's Information Society Project. He frequently presents on the ethical, legal, and social implications of information technology for attorneys, physicians, and other health professionals.

His book *The Black Box Society: The Secret Algorithms that Control Money and Information* (Harvard University Press, 2015) develops a social theory of reputation, search, and finance.



INVITED SPEAKERS

Andrew Serwin, JD

Partner at Morrison & Foerster, San Diego, CA



Andrew Serwin, partner with Morrison & Foerster, is widely-regarded as one of the nation's premier privacy and data security lawyers.

Serwin advises Fortune 500 and emerging companies alike, with a particular emphasis on: international compliance; health privacy; the Electronic Communications Privacy Act and wiretap issues; electronic marketing concerns; and compliance with FTC requirements. He also handles some of the highest-profile data security incidents and privacy enforcement and litigation matters in the world.

Named Security Magazine's prestigious "25 Most Influential Industry Thought Leaders," Serwin is a noted public speaker and author. Among his numerous books and law review articles is the leading treatise on privacy and security, *Information Security and Privacy: A Guide to Federal and State Law and Compliance and Information Security and Privacy: A Guide to International Law and Compliance* (West 2006-2016).

John Wilbanks - KEYNOTE speaker

Chief Commons Officer, Sage Bionetworks



John Wilbanks is the Chief Commons Officer at Sage Bionetworks.

Previously, Wilbanks worked as a legislative aide to Congressman Fortney "Pete" Stark, served as the first assistant director at Harvard's Berkman Center for Internet & Society, founded and led the acquisition of the bioinformatics company Incellico, Inc., and was executive director of the Science Commons project at Creative Commons.

In February 2013, in response to a We the People petition that was spearheaded by Wilbanks and signed by 65,000 people, the U.S. government announced a plan to open up taxpayer-funded research data and make it available for free.

Wilbanks holds a BA in philosophy from Tulane University and also studied modern letters at the Sorbonne.

IPML MEMBER SPEAKERS

FOUNDERS

Tim Eberlein, MD | *Spencer T. & Ann W. Olin Distinguished Professor of Surgery and Director of the Siteman Cancer Center*

Nancy Staudt, JD, PhD | *Howard & Caroline Cayne Professor of Law and Dean of the Law School*

FOUNDING CO-DIRECTORS

Jon Heusel, MD, PhD | *Associate Professor of Pathology & Immunology*

Neil Richards, MA, JD | *Thomas & Karole Green Professor of Law*

SCHOOL OF MEDICINE

Karen Seibert, PhD | *Professor of Anesthesiology and Co-Director of the Center for Clinical Pharmacology*

SCHOOL OF LAW

Sam Garner | *Institute Fellow and JD Candidate, '19*

Rachel Sachs, MPH, JD | *Associate Professor of Law*

Elizabeth Sepper, JD, LLM | *Professor of Law*

INSTITUTE FOR INFORMATICS

Philip Payne, PhD, FACMI | *Robert J. Terry Professor, Professor of Computer Science and Engineering and founding Director of the Institute for Informatics*

ABOUT THE IPML

Advancing data toward enlightened healthcare

Recognizing the unique collection of scientists, clinicians, and legal scholars at the nexus of genomic medicine, the Washington University Institute for Policy in Medicine & Law (IPML) was conceived to facilitate the emergence of Precision Medicine. In its earliest incarnation, Precision Medicine is the application of human genetic and genomic information to improve healthcare, but the underlying legal and regulatory framework that we help to build will enable subsequent applications of 'big data' as technology continues to evolve and discoveries emerge.

Mission

The mission of the Institute is to advance legal concepts toward a vibrant policy framework that guides the ethical use of human information to promote health, the protection of individuals, and education of the public.

Founding principles

- Establishing a powerful and unique voice among the Medical, Scientific, and Legal communities dedicated to solving emerging legal issues and overcoming the challenges of complex human information, particularly with respect to genomic medicine and the deployment of human data-driven health technologies.
- Maintaining a focus on the individuals of our society, empowering patients, families, and communities to understand and utilize their information for their benefit.
- Serving as a trusted and accessible educational resource for the medical and legal professions, legislators, the judiciary, and especially the public in the areas of human information and healthcare policy.
- Training and inspiring the next generation of medical-legal scholars to build upon a tradition of excellence at Washington University, and to provide leadership at the nexus of medicine and law in perpetuity.

For more information, visit sites.wustl.edu/medlaw



NOTES



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University in St. Louis

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