Genetic Justice: Data, Privacy, and Crime

Co-sponsored by the Mary and Michael Jaharis Health Law Institute and the Center for Intellectual Property Law & Information Technology (CIPLIT©)

Thursday, March 12th, 2020
8:30 am to 4:30 pm
#JAHARIS2020
Mary and Michael Jaharis Health Law Institute
Established in 1984, and supported by the Mary and Michael Jaharis Health Law Institute, DePaul’s health law program has consistently ranked among the top in the nation—currently among the top 25 in U.S. News & World Report. DePaul offers cutting-edge coursework and real world experience in the health law field, from policy, regulatory, and transactional work to bioethics, food and drug law, and medical malpractice. In recent years, the program has developed special expertise in the fast-growing specialties of health care compliance and the intersection between health law and intellectual property. Taught by distinguished faculty and practitioners and one of only 15 university programs nationally accredited by the Compliance Certification Board, DePaul’s health Law program is at the forefront of this growing field.

DePaul Journal of Health Care Law
As one of the few remaining peer-reviewed legal journals, the DePaul Journal of Health Care Law (JHCL) has long been one of the nation’s premiere student-run scholarly publications. Founded in 1996, JHCL is focused on providing insightful and progressive articles that analyze the legal complexities of the rapidly evolving health care world.

Center for Intellectual Property Law & Information Technology (CIPLIT®)
Since its founding in 1997, CIPLIT has stood at the forefront of IP/IT legal education. It offers a unique interdisciplinary learning experience that combines one of the most diverse and cutting-edge curricula in IP and technology in the country with innovative scholarship and research, outstanding career development and counseling, and an unparalleled range of extracurricular opportunities. CIPLIT’s recent curricular initiatives include a partnership with DePaul’s College of Computing & Digital Media, expanding available data privacy and technology courses to provide law students and professionals with a competitive advantage in the marketplace. With its ambitious activities and valuable opportunities, DePaul’s program has enjoyed national recognition for many years and continues to be ranked as one of the top IP programs in the country.

DePaul Journal of Art, Technology & Intellectual Property Law
The DePaul Journal of Art, Technology & Intellectual Property Law (JATIP) is a student-edited national law journal established by the College of Law in 1991. Published biannually, JATIP publishes articles by students, academics and legal practitioners that address current and developing legal and policy issues in the fields of visual and performing arts, cultural heritage, technology and intellectual property law.
Agenda

8:45 am
Welcome and Introductions

9:15 am
Panel 1: Justice in the Acquisition of Genetic Information: Inclusion and Representation in Genetics Research
Pilar Ossorio, Professor of Law & Bioethics, University of Wisconsin-Madison
Jennifer Wagner, Associate Director of Bioethics Research, Geisinger Health System
Jonathan Kahn, Professor of Law & Biology, Northeastern University
Moderator: Valerie Gutmann Koch, Jaharis Faculty Fellow, DePaul University

10:30 am
Refreshment Break

10:45 am
Panel 2: Use and Control of Genetic Information: Informed Consent and Privacy through a Justice Lens
Leslie Francis, Professor of Law & Philosophy, University of Utah
Anya Prince, Associate Professor of Law, University of Iowa
Stephen Hilgartner, Professor, Department of Science & Technology Studies, Cornell University
Moderator: Joshua Sarnoff, Professor of Law, DePaul University

12:15 pm
Lunch and Featured Speaker
Sheila Jasanoff, Professor of Science and Technology Studies, John F. Kennedy School of Government, Harvard University

1:30 pm
Panel 3: Genomics in the Justice System
Christopher Young, Intelligence Analyst, FBI-Chicago
Maya Sabatello, Assistant Professor of Clinical Bioethics and Co-Director of the Precision Medicine: Ethics, Politics, and Culture Project, Department of Psychiatry, Columbia University
Lauren Kaeseberg, Legal Director, Illinois Innocence Project
Moderator: Monu Bedi, Professor of Law, DePaul University

2:45 pm
Refreshment Break

3:00 pm
Panel 4: Using Genealogical Data to Solve Crimes
Christi Guerrini, Assistant Professor, Center for Medical Ethics & Health Policy, Baylor College of Medicine
Craig Klugman, Professor of Bioethics & Health Humanities, DePaul University
Sara Huston Katsanis, Research Assistant Professor, Northwestern University and Lurie Children's Hospital
Moderator: Wendy Netter Epstein, Professor of Law & Faculty Director of the Mary and Michael Jaharis Health Law Institute, DePaul University

4:15 pm
Concluding Remarks

Agenda is subject to change. Symposium materials can be found at go.depaul.edu/jhlisymposiumdocuments.
Sheila Jasanoff, JD, PhD
Pforzheimer Professor of Science and Technology Studies, Harvard Kennedy School of Government

Sheila Jasanoff currently serves as the Pforzheimer Professor of Science and Technology Studies at the John F. Kennedy School of Government at Harvard University. Previously, she was founding chair of Cornell University’s Department of Science and Technology Studies. At Harvard, she founded and directs the Program on Science, Technology and Society; she also founded and coordinates the Science and Democracy Network. Professor Jasanoff’s research centers on the interactions of law, science and politics in democratic societies. She has written more than 120 articles and book chapters and authored or edited more than 15 books, including THE FIFTH BRANCH, SCIENCE AT THE BAR, and DESIGNS ON NATURE. An edited volume, DREAMSCAPES OF MODERNITY, was published in 2015. Her most recent books, THE ETHICS OF INVENTION and CAN SCIENCE MAKE SENSE OF LIFE?, appeared in 2016 and 2019, respectively. Professor Jasanoff has held distinguished professorships in the US, Europe, Australia and Japan. She was a fellow of the Wissenschaftskolleg zu Berlin and Karl W. Deutsch Guest Professor at the Wissenschaftszentrum Berlin. Her awards include a Guggenheim fellowship, the 2018 A.O. Hirschman prize of the Social Science Research Council, the Reimar-Lüst Prize of the Humboldt Foundation, the Austrian Government’s Ehrenkreuz, the Bernal award of the Society for Social Studies of Science, and honorary doctorates from the Universities of Twente and Liège.

Leslie Francis, JD, PhD
Professor of Law & Philosophy, University of Utah

Leslie P. Francis holds joint appointments as Alfred C. Emery Professor of Law and Professor of Philosophy, and adjunct appointments in Family and Preventive Medicine (in the Division of Public Health), Internal Medicine (in the Division of Medical Ethics) and Political Science. She was appointed to the rank of distinguished professor in 2009 and became director of the University of Utah Center for Law and Biomedical Sciences in 2015. Professor Francis was president of the Pacific Division of the American Philosophical Association in 2015-2016. From 2015-2019, she served as the elected secretary-general of the International Society for Philosophy of Law and Social Philosophy. She is a past member of the Ethics Committee of the American Society for Reproductive Medicine, and past co-chair of the Privacy, Confidentiality and Security Subcommittee of the National Committee on Vital and Health Statistics, where she currently serves as a member of the Working Group on Data Access and Use. Professor Francis also has been a member of the Medicare Coverage Advisory Committee and of the American Bar Association’s Commission on Law and Aging.

Christi Guerrini, JD, MPH
Assistant Professor, Center for Medical Ethics & Health Policy, Baylor College of Medicine

Christi Guerrini teaches medical ethics and health policy and conducts research focused on the ethical, legal and social implications of genetic and other biotechnologies. She is the principal investigator of research on citizen science initiatives involving genetic data, and she has served or currently serves as a co-investigator of research directed to gene patents and the cancer genomic commons. Professor Guerrini has published over 20 articles on these and related topics in traditional law reviews and scientific journals, including Science, Nature Biotechnology, and Genetics in Medicine. Related to her recent work on investigative genetic genealogy, she is an appointed member of the Committee of Correspondence on Forensic Genealogy to the Scientific Working Group on DNA Analysis Methods (SWGDAM). She also is a member of the Ethics Working Group of the Citizen Science Association. Prior to joining Baylor, Professor Guerrini litigated intellectual property and commercial disputes in biotechnology and other industries as a practicing attorney and also served as the intellectual property fellow at Chicago-Kent College of Law.
Stephen Hilgartner, PhD  
Professor, Department of Science & Technology Studies, Cornell University

Stephen Hilgartner’s research examines the social dimensions and politics of contemporary and emerging science and technology, especially in the life sciences. Professor Hilgartner’s most recent monograph is REORDERING LIFE: KNOWLEDGE AND CONTROL IN THE GENOMICS REVOLUTION (MIT Press 2017), which examines how quasi-legal “knowledge-control regimes” took shape during the Human Genome Project. He also co-edited two recent collections: THE HANDBOOK OF GENOMICS, HEALTH AND SOCIETY (Routledge 2018) and SCIENCE & DEMOCRACY: MAKING KNOWLEDGE AND MAKING POWER IN THE BIOSCIENCES AND BEYOND (Routledge 2015). His book, SCIENCE ON STAGE: EXPERT ADVICE AS PUBLIC DRAMA, won the Society for Social Studies of Science’s Rachel Carson Prize. He is currently completing a project on the politics of making knowledge about risk. Professor Hilgartner is a fellow of the American Association for the Advancement of Science.

Lauren Kaesberg, JD  
Legal Director, Illinois Innocence Project

Lauren Kaesberg represents clients in both DNA and non-DNA actual innocence cases. She received her BA, cum laude, from DePaul University in Secondary Education, and after teaching high school in Chicago, she attended Cardozo School of Law in New York City where she was in the inaugural class of Public Service Scholars. While in law school, Ms. Kaesberg participated in the Innocence Project clinic program for over two years as a clinic student, an intern and a teaching assistant. After graduating from law school, she moved back to Chicago and began working as a private criminal defense attorney in Lake County, Illinois. She then joined the defense team of Former Illinois Governor Rod Blagojevich, who she represented at both federal trials and on appeal. Ms. Kaesberg has extensive experience in trial level, post-conviction and appellate cases. She has been with the Illinois Innocence Project since 2013 and is a frequent presenter on issues surrounding wrongful convictions.

Jonathan Kahn, JD, PhD  
Professor of Law & Biology, Northeastern University

Jonathan Kahn’s current research focuses on the intersections of law and biotechnology, with particular attention to how regulatory mandates intersect with scientific, clinical and commercial practice in producing legal understandings of race and racism in American society. Professor Kahn received two grants from the National Human Genome Research Institute’s Ethical, Legal and Social Implications Research Program to support projects exploring the ethical and legal ramifications of the increasing use of racial and ethnic categories in the context of gene patenting and drug development. He received a three-year grant from the National Library of Medicine to support the writing of his book, RACE IN A BOTTLE: THE STORY OF BIDIL AND RACIALIZED MEDICINE IN A POST-GENOMIC AGE (Columbia University Press 2013). His newest book is RACE ON THE BRAIN: RETHINKING IMPLICIT BIAS AND RACISM (Columbia University Press 2018).

Sara Huston Katsanis, MS  
Research Assistant Professor, Northwestern University and Lurie Children’s Hospital

Sara Huston Katsanis currently directs the Genetics and Justice Laboratory at Lurie Children’s Hospital, which is a dry lab focused on policy and ethics research on genetic testing applications in humanitarian efforts, medicine and law enforcement. She is exploring policy challenges for applying scientific technologies to human identification in human rights contexts, such as human trafficking, migration and adoption fraud. From 1998-2000, Professor Katsanis worked as a DNA analyst at the Harris County Medical Examiner’s Office. From 2002, she managed the Johns Hopkins DNA Diagnostic Laboratory in Baltimore and in 2006, she transitioned to working in genetics policy research, starting with the Genetics & Public Policy Center at Johns Hopkins in Washington, DC. From 2009-2019, Professor Katsanis was a faculty member at Duke University.
Craig Klugman, PhD
Professor of Bioethics & Health Humanities, DePaul University

Craig Klugman co-directs the bioethics and society minor program at DePaul University and serves on the Ethics Committee at Northwestern University Hospital. Dr. Klugman is the author of over 450 articles, book chapters, OpEds, and blog posts on such topics as bioethics, digital medicine, professionalism, end-of-life issues, public health ethics, research ethics, education, health/medical humanities, ethics of execution and health policy. He is the blog editor and frequent writer for bioethics.net, as well as creator of the BioethicsTV column. Dr. Klugman is the editor of several books including RESEARCH METHODS IN THE HEALTH HUMANITIES (Oxford 2019), MEDICAL ETHICS (Gale Cengage 2016), and ETHICAL ISSUES IN RURAL HEALTH (Hopkins 2013; 2008). He is the executive producer of the award-winning film “Advance Directives” and has developed programs for using art and improvisational theater to teach health students. He frequently gives talks to universities, medical and nursing groups, companies and community organizations, as well as consults with hospitals, pharmaceutical and tech companies. Dr. Klugman has been interviewed for The New York Times, LA Times, ABC News, HBO Vice, New Republic, National Geographic, Men’s Health and NPR.

Pilar Ossorio, JD, PhD
Professor of Law & Bioethics, University of Wisconsin-Madison

Pilar N. Ossorio is a professor of law and bioethics at the University of Wisconsin-Madison (UW) and the scholar-in-residence and program lead for the Ethics Program at the UW-affiliated, non-profit Morgridge Institute for Research. Dr. Ossorio has served on numerous national and international policy and ethics advisory committees including: The Novel and Exceptional Technology and Research Advisory Committee; the Secretary’s Advisory Committee on Human Research Protections (2012-2016); the National Heart, Lung, and Blood Advisory Committee (2015-2018); and the National Human Genome Research Advisory Committee (2008-2011). She is a member of the Board of Reviewing Editors for the journal Science. The main themes in Dr. Ossorio’s research involve ethics and governance of emerging technologies; ethics and regulation of research with human participants; and the use of racial concepts in biomedical research and health care. Her recent publications have appeared in Nature Medicine; the Journal of Law, Medicine & Ethics; the American Journal of Bioethics; and the Hastings Center Report, among others.

Anya Prince, JD, MPP
Associate Professor of Law, University of Iowa

Anya Prince’s research explores the ethical, legal and social implications of genomic technologies, with a particular focus on insurer use of genetic information. She has published a variety of articles in legal, bioethics and medical journals, including the American Journal of Bioethics; Journal of Law, Medicine & Ethics; and Genetics in Medicine. Professor Prince has presented and been an invited speaker at conferences across the country, and she was recently awarded a Pathway to Independence Award from the National Human Genome Research Institute to examine the use of genetic information by life, long-term care and disability insurers.

Maya Sabatello, LLB, PhD
Assistant Professor of Clinical Bioethics and Co-Director of the Precision Medicine: Ethics, Politics, and Culture Project, Department of Psychiatry, Columbia University

Maya Sabatello’s research focuses on law, society, medicine and disability, and on the ethical, legal and social implications of genetics. Recent projects explored the uses of psychiatric genetics evidence in civil litigation; the psychosocial impact of genomic data on adolescents and family relations; social and policy dilemmas in reproductive technologies; and disability inclusion in precision medicine research. Dr. Sabatello has extensive experience in policy-making and work with national and international organizations to promote human and disability rights. She serves as a member at various genomic- and ethics-related committees at Columbia University and elsewhere, including the Institutional Review Board of the national Precision Medicine Initiative, the All of Us Research Program.
Christopher Young
Intelligence Analyst, FBI-Chicago

Christopher Young joined the FBI in Chicago as an Intelligence Analyst in 2018 after retiring from the 5th Weapons of Mass Destruction Civil Support Team, Illinois Army National Guard. He has worked with weapons of mass destruction and hazardous materials since 1999, during which time he provided subject matter expertise related to chemical, biological, radioactive and nuclear materials before, during and after potential weapons of mass destruction terrorist events and worked with a vast array of federal, state and local agencies to include the FBI, the US Department of Energy, US Department of Homeland Security, Illinois Emergency Management Agency and the Illinois Department of Public Health.

Jennifer Wagner, JD, PhD
Associate Director of Bioethics Research, Geisinger Health System

Jennifer K. Wagner's research focuses on the intersection of genetics, technology and law, including privacy and anti-discrimination rights. Professor Wagner completed post-doctoral research appointments at Duke University's Institute for Genome Sciences & Policy and the University of Pennsylvania's Center for the Integration of Genetic Healthcare Technologies. She was a contributing editor of the Genomics Law Report, and her work has been cited by the U.S. Supreme Court. Prior to joining Geisinger, Dr. Wagner served in a U.S. Senator's office in Washington, DC as a 2014-2015 AAAS Congressional Fellow. She has served as chair of the Social Issues Committee for the American Society of Human Genetics (2018 and 2019), as co-chair of the Ethics Committee for the American Association of Physical Anthropologists (2015-2018), and is a current member of the Scientific Advisory Board for Sage Bionetworks.

Monu Bedi, JD, MPhil
Professor of Law, DePaul University

Monu Bedi joined DePaul University College of Law as an assistant professor and was promoted to associate professor in 2015. Professor Bedi received his JD from Harvard Law School, where he was a senior editor for the Harvard Civil Rights-Civil Liberties Law Review, his MPhil in philosophy from the University of Cambridge (King's College), and his AB, summa cum laude, from Dartmouth College. Prior to joining the faculty, Professor Bedi served as a Bruce R. Jacob Visiting Assistant Professor at Stetson Law School. Before entering academia, Professor Bedi clerked for the Honorable Laura Taylor Swain of the Southern District of New York and served as a Navy JAG where he prosecuted sailors accused of crimes ranging from drug possession to attempted murder. He also served as an associate in the Government Enforcement group at Ropes & Gray in Boston.

Wendy Netter Epstein, JD
Professor of Law & Faculty Director of the Mary and Michael Jaharis Health Law Institute, DePaul University

Wendy Netter Epstein joined the DePaul faculty as an assistant professor in 2013 and was promoted to full professor in 2018. Professor Epstein is the faculty director of DePaul's Jaharis Health Law Institute, and her teaching and research interests focus on health care law and policy, contracts and commercial law. Her work has most recently appeared or is forthcoming in the Southern California Law Review; Minnesota Law Review; Emory Law Journal; Washington Law Review; Yale Journal of Health Policy, Law, & Ethics; and Cardozo Law Review. As a Harvard law student, Professor Epstein was editor in chief of the Journal of Law, Medicine & Ethics [Recent Developments]; executive editor of the Journal of Law & Gender; and co-authored an Internet privacy course for Berkman Center for Internet & Society. Prior to coming to DePaul, Professor Epstein clerked for the Honorable Michael Daly Hawkins, U.S. Court of Appeals for the 9th Circuit and was a partner in commercial litigation at Kirkland & Ellis LLP. From 2011 to 2013, she was a visiting assistant professor at Chicago-Kent College of Law, and in 2017, she was a visiting associate professor at the University of Chicago Law School.
Valerie Gutmann Koch, JD  
Jaharis Faculty Fellow, DePaul University

Valerie Gutmann Koch is the Jaharis Faculty Fellow at DePaul College of Law and the Director of Law and ethics at the University of Chicago’s MacLean Center for Clinical Medical Ethics. As a scholar of bioethics, public policy and health law, Professor Koch concentrates on how medical and technological advances have informed and sometimes transformed various areas of law, identifying ways in which law and policy is—or is not—equipped to address changes in technology and practice. Previously, she was a visiting assistant professor at Chicago-Kent College of Law; a special advisor to the New York State Task Force on Life and the Law, the state’s bioethics commission; and served as the senior attorney to the Task Force. Following law school, she practiced in the intellectual property litigation practice at Kirkland & Ellis LLP. As a Harvard law student, Professor Koch was the co-editor of the recent developments section of the Journal of Law, Medicine & Ethics, and she graduated magna cum laude with an AB from Princeton University’s Woodrow Wilson School of International Affairs and Public Policy, with a focus in bioethics. Professor Koch is committed to public service, including serving as the chair of the ABA’s Special Committee on Bioethics and the Law and co-chair of the Law Affinity Group for the American Society for Bioethics and the Humanities.

Joshua Sarnoff, JD  
Professor of Law, DePaul University

Joshua Sarnoff is an internationally recognized expert on the intersections of intellectual property law, environmental law, health law, and constitutional, administrative and international law. His current research focuses on innovation policy and technology development; climate change technology and data, climate modification and governance; utility and design patent empirical analyses, history and theory; responses to pandemic diseases; and intellectual property rights in genetic and natural resources, diagnostics and therapeutics. Professor Sarnoff is the editor and co-author of the RESEARCH HANDBOOK ON INTELLECTUAL PROPERTY AND CLIMATE CHANGE (Edward Elgar Publishers 2016) and has published extensively in law reviews and peer reviewed journals. In 2014-2015, Professor Sarnoff served as the Thomas A. Edison Distinguished Scholar at the U.S. Patent & Trademark Office, and he previously directed the DePaul’s Center for Intellectual Property Law & Information Technology. He has substantial practice experience in the public and private sectors, and as an academic providing litigation, counseling and advocacy services addressing international and domestic environmental, intellectual property, and food and drug laws. He has consulted for or advocated on behalf of legislative coalitions, intergovernmental organizations, foundations, corporations, non-profit organizations and various groups of academics. He has filed numerous amicus briefs in the U.S. Supreme Court and the U.S. Court of Appeals for the Federal Circuit, including for the American Medical Association and for law professors.