

2015healthprivacysummit

5th International Summit on the Future of Health Privacy



Health Information in the Age of Surveillance

JUNE 3 – 4, 2015

Washington, D.C.

O'NEILL
INSTITUTE
FOR NATIONAL & GLOBAL HEALTH LAW
GEORGETOWN LAW

patientprivacyrights

www.healthprivacysummit.org

Please Join Us For

The Celebration of Privacy

June 3, 2015, 6:00 – 8:00 PM

Hyatt Regency Washington on Capitol Hill
400 New Jersey Avenue, NW • Washington, D.C.



Louis D. Brandeis Privacy Award

Presented to

Professor Masao Horibe

2015

Awarded by

patientprivacyrights



Louis D. Brandeis Privacy Award

Presented to

Professor Alex Pentland

2015

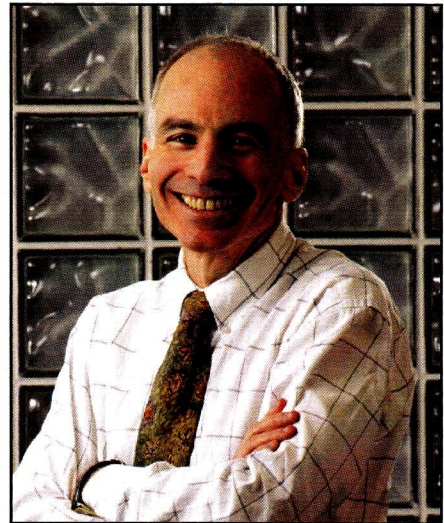
Awarded by

patientprivacyrights

DEAR FRIENDS,

On behalf of Georgetown University and the O'Neill Institute for National and Global Health Law, it is my great pleasure to welcome you to the 5th International Summit on the Future of Health Privacy.

Now is the time to examine and celebrate privacy as a great necessity in the lives of people across the globe. The health system gathers, stores, and widely disseminates unimaginable amounts of personal information – in health insurance, medical practices, hospitals, and public health agencies. These collections offer a wealth of information that can be used in tremendous ways for the public's good, but without reasonable assurances of privacy, the unauthorized disclosure of health information can be incredibly detrimental to all. This 5th International Summit on 'Health information in the Age of Surveillance' offers us the opportunity to think, research, and act on the need for health information privacy. Georgetown Law and the O'Neill Institute are proud to join with our inspiring partner, Patient Privacy Rights, to host this important conference.



This Summit denotes an essential piece of the O'Neill Institute's mission to discover innovative solutions to the most pressing health concerns facing the nation and the world. The essential vision for the O'Neill Institute rests upon the proposition that the law has been, and will remain, a fundamental tool for solving critical health problems in our local, national, and global communities. By contributing to a more powerful and deeper understanding of the multiple ways in which law can be used to improve health, the O'Neill Institute hopes to encourage key decision-makers in the public, private, and civil society sectors to use the law as a positive tool to enable individuals and populations in the United States and throughout the world to lead healthier lives.

We are excited to hear your varied perspectives in the next few days. As always, we hope this summit, with its national and international perspectives on health privacy problems and solutions, will lead to further developments within the field in the coming year.

I would like to thank Deborah Peel and Patient Privacy Rights, as well as our distinguished guests and all of our generous sponsors, for helping to create this outstanding opportunity for ongoing discourse and progress.

Regards,

Lawrence O. Gostin Faculty Director | O'Neill Institute for National and Global Health Law
University Professor | Georgetown University
Linda and Timothy O'Neill Professor of Global Health Law | Georgetown Law

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WELCOME!

Dear Friends,

Patient Privacy Rights and our academic, civil society and privacy advocacy partners and sponsors welcome you to the 5th International Summit on the Future of Health Privacy. Thank you for making this unique-in-the world event possible!

Patient Privacy Rights' mission is to restore patient control over personal health information. *To accomplish our mission, we educate and work collaboratively with patients and organizations to restore the ethical right to health information privacy, the foundation of the patient-physician relationship, in law, policy, and technology.*

This year's summit focuses on "Health Information in the Age of Surveillance." In 2002, HHS amended HIPAA, ending 2,400 years of medical ethics that required physicians keep patient records private, unless patients gave consent for disclosure. Data holders were granted rights to sell patient health data, legitimizing 100,000 hidden health data suppliers covering 780,000 daily data feeds. They exported this business model worldwide.

Millions of people have access to US patient data, but patients cannot access it for personal use. US technology locks patients out of control over data about their minds and bodies.

Does surveillance affect people? Our speakers will examine the impacts of disclosing information about distressed babies, students, employees, hospital patients, and epidemics on parents, families, workplaces, communities, and nations— and propose solutions.

Our key international speakers will contrast their approaches to data privacy protections with ours.

It's a great privilege to welcome our speakers, including:

- ✦ Professor Masao Horibe, first Chairman of the Specific Personal Information Protection Commission, Government of Japan will give the international Keynote address.
- ✦ Deanna Fei, author of the memoir GIRL IN GLASS, will give the opening keynote.
- ✦ Professor Sandy Pentland, one of the 'seven most powerful data scientists in the world', will speak on 'A World That Counts.'
- ✦ Two top HHS officials, Jocelyn Samuels, Director of the Office of Civil Rights and Lucia Savage, Chief Privacy Officer at the Office of the National Coordinator, will discuss their initiatives.
- ✦ The closing luncheon keynote will be delivered by Dean Andrew Dillon, whose work addresses the need to Tshape the inevitable advance of technology and commerce for human and social benefit.

This year's Celebration of Privacy will honor Professors Masao Horibe and Sandy Pentland with Patient Privacy Rights' 2015 Louis D. Brandeis Privacy Awards.

I want to especially thank our generous co-host, the O'Neill Institute for National and Global Health Law, for giving us the opportunity to meet at Georgetown Law Center.

Regards,

Deborah C. Peel, MD

Founder & Chair | Patient Privacy Rights

[patientprivacyrights](http://patientprivacyrights.org)



5th International Summit on the Future of Health Privacy Health Information in the Age of Surveillance



—DAY ONE: WEDNESDAY, JUNE 3, 2015—

Georgetown Law Center

8:00 – 8:30 AM Registration | Light Breakfast & Coffee

8:30 – 9:00 AM Opening Session

Lawrence Gostin | Director O'Neill Institute for National and Global Health Law, Georgetown University Law Center

Deborah C. Peel | Founder and Chair Patient Privacy Rights

Barry P. Chaiken | Chief Medical Information Officer Infor Healthcare, Master of Ceremonies

9:00 – 9:45 AM Keynote: Whose Distressed Baby Is It? The Growing Threat to Our Medical Privacy in the American Workplace

Deanna Fei | Author of *Girl In Glass* (Bloomsbury, July 2015)

9:50 – 10:50 AM Session 1: Watching Wellness in the Workplace

MODERATOR—

Jordan Robertson | Reporter Bloomberg Businessweek

SPEAKERS—

Michelle DeMooy | Deputy Director Consumer Privacy Project, Center for Democracy & Technology

Ifeoma Iajunwa | Assistant Professor David Clark School of Law, University of the District of Columbia

Craig Konnoth | Sharswood Fellow & Lecturer in Law, University of Pennsylvania Law School

Lindsay F. Wiley | Associate Professor Washington College of Law, American University

CONVENER—

Frank Pasquale | Professor of Law University of Maryland Carey School of Law

10:50 – 11:10 AM Break

11:10 – 11:55 AM Keynote: The Evolution of Privacy in Japan Over the Past Half-Century — Lessons from American Privacy Law

Professor Masao Horibe | Professor Emeritus Hitotsubashi University & Chairman Specific Personal Information Protection Commission, Government of Japan

12:00 – 1:00 PM Box Lunch

1:00 – 1:55 PM Session 2: Promoting Research While Respecting Privacy — The Promise & Challenge of Using Patient Healthcare Data in Research

MODERATOR—

Joe Ali | Co-Lead Ethics and Regulatory Task Force, Patient Centered Outcomes Research Network & Research Scholar Johns Hopkins Berman Institute of Bioethics

SPEAKERS—

Donna Cryer | President and CEO Global Liver Institute & Member Privacy Roundtable, Patient Centered Outcomes Research Network

Celeste Castillo-Lee | Program Manager for Patient and Family Centered Care, University of Michigan Health System & Member Patient Council, Patient Centered Outcomes Research Network

Bradley Malin | Vice Chair Biomedical Informatics, Vanderbilt University School of Medicine & Co-Chair Data Privacy Task Force, Patient Centered Outcomes Research Network

Deven McGraw | Partner, Manatt Phelps & Phillips LLP & Co-Chair Data Privacy Task Force, Patient Centered Outcomes Research Network

Lisa Schlager | Vice President Community Affairs & Public Policy, Facing Our Risk of Cancer Empowered

FIRST RESPONSE—

Magdalena Góralczyk | Senior Research Associate Institute for Legal Informatics, Gottfried Wilhelm Leibniz Universität

CONVENER—

Joe V. Selby | Executive Director Patient-Centered Outcomes Research Institute

2:00 – 2:45 PM Keynote: A World That Counts

Alex Pentland | MIT, Advisor UN Secretary General's Office, World Economic Forum

2:45 – 2:55 PM Break

2:55 – 3:50 PM Breakout Sessions

1a – Recent Developments in Genetic Privacy

MODERATOR & CONVENER—

Mark A. Rothstein | Director Institute for Bioethics, Health Policy and Law,
University of Louisville School of Medicine

SPEAKERS—

Jean McEwen | Program Director Division of Genomics and Society, the
National Human Genome Research Institute

Barbara J. Evans | Director Center on Biotechnology & Law, University of
Houston Law Center

Sharon Terry | President and CEO Genetic Alliance

1b – Somebody Call the Doctor! Stitching Up Student Privacy

MODERATOR & CONVENER—

Khaliah Barnes | Director Student Privacy Project, Electronic Privacy Information
Center

SPEAKERS—

Dissent | Pogo Was Right

Bill Fitzgerald | Founder FunnyMonkey

Dale King | Director Family Policy Compliance Office, US Department of
Education

Cameron Russell | Executive Director Fordham Center on Law and
Information Policy, Fordham University School of Law

1c – The Low-Hanging Fruit: Why Data Breaches Continue

MODERATOR & CONVENER—

Michelle DeMooy | Deputy Director Consumer Privacy Project, Center for
Democracy & Technology

SPEAKERS—

Bob Gregg | CEO ID Experts

Maneesha Mithal | Associate Director Division of Privacy and Identity
Protection, US Federal Trade Commission

Ann Patterson | SVP, Program Director Medical Identity Fraud Alliance

Stu Vaeth | SVP Business Development for the US identity network
business, SecureKey

Josephine Wolff | Berkman Center for Internet & Society, Harvard University

**1d – Health Data: A Bone of Contention between Patients and Researchers —
Protecting Privacy and Security of Patient-controlled Health Data**

MODERATOR—

Bill Pewen | Program Director of the Graduate Program in Public Health,
Marshall University

SPEAKERS—

Alan Dahi | Senior Research Associate Institute for Legal Informatics, Gottfried
Wilhelm Leibniz Universität

Magdalena Góralczyk | Senior Research Associate Institute for Legal
Informatics, Gottfried Wilhelm Leibniz Universität

William Yasnoff | Health Information Technology Consultant

CONVENER—

William Yasnoff | Health Information Technology Consultant

3:50 – 3:55 PM Break

3:55 – 4:50 PM Session 3: Intimate Wearables and Big Data

MODERATOR—

Debbie Bucci | Program Lead at the Office of Standards and Interoperability,
Office of the National Coordinator for Health Information
Technology

SPEAKERS—

Adrian Gropper | CTO Patient Privacy Rights

Joy Pritts | Health Information Privacy Consultant

Bill Turner | HIPAA Privacy & Information Security Officer, Globalhealth

Benjamin West | Co-Founder Nightscout Project

CONVENER—

Deborah Hurley | Principal Hurley

4:55 – 5:40 PM Keynote: A Conversation with Jocelyn Samuels

Jocelyn Samuels | Director Office for Civil Rights, US Department of Health
and Human Services

INTERLOCUTOR—

Shahid N. Shah | CEO Netspective Communications

5:40 – 5:45 PM Day One Closing Remarks

Deborah C. Peel | Founder and Chair Patient Privacy Rights

—————**CELEBRATION OF PRIVACY**—————

Hyatt Regency Washington on Capitol Hill (near Georgetown Law Center)
400 New Jersey Avenue, NW

6:00 – 8:00 PM 2015 Louis D. Brandeis Privacy Awards Ceremony

AWARDEES—

Alex Pentland | MIT, Advisor UN Secretary General's Office, World Economic Forum

Professor Masao Horibe | Chairman Specific Personal Information Protection Commission, Government of Japan



—————**DAY TWO: THURSDAY, JUNE 4, 2015**—————

Georgetown Law Center

8:30 – 9:00 AM Light Breakfast & Coffee

9:00 – 9:05 AM Welcome: Day Two

Deborah C. Peel | Founder and Chair Patient Privacy Rights

9:05 – 9:50 AM Keynote: Looking Around the Corner — Emerging Issues in Electronic Health Information and Privacy

Lucia Savage | Chief Privacy Officer US Office of the National Coordinator for Health Information Technology

INTERLOCUTOR—

Adam Tanner | Fellow, Institute for Quantitative Social Science, Harvard University

9:55 – 10:45 AM Session 4: Limiting Patient Rights to Access Personal Health Data

MODERATOR & CONVENER—

Adrian Gropper | CTO Patient Privacy Rights

SPEAKERS—

Janelle Burns | Corporate Privacy & Security Officer Baptist Memorial Health Care Corporation

Hugo Campos | ePatient, Data Liberation Advocate

Barbara J. Evans | Director Center on Biotechnology & Law, University of Houston Law Center

Randy Farmer | Chief Operating Officer Delaware Health Information Network

Mark Scrimshire | Entrepreneur-in-Residence US Department of Health and Human Services

10:45 – 11:00 AM Break

11:00 – 12:00 AM Session 5: Privacy and Public Spaces — Privacy and Epidemics, School Laptops and Spying

Case Study: Protecting Privacy While Responding to the Public Health Threat of an Ebola Epidemic

Judge Clay Jenkins | Director of Homeland Security and Emergency Management, Dallas County, Texas

Case Study: How School Administrators Became Peeping Toms Using School-supplied Laptops

Mr and Mrs Robbins | What would you do if your child's school used a mandatory school-issued laptop to secretly spy on your kid and your family? The Robbins will share their answers to this question.

INTERLOCUTOR—

Deborah C. Peel | Founder and Chair Patient Privacy Rights

————— **PRIVACY LUNCHEON & CLOSING KEYNOTE** —————

Hyatt Regency Washington on Capitol Hill (near Georgetown Law Center)
400 New Jersey Avenue, NW

12:15 – 1:30 PM Keynote: Privacy in the New Ecology of Information

Andrew Dillon | Dean School of Information, School of Information University of Texas at Austin

FEATURED SPEAKERS



Andrew Dillon

Andrew studies the human response to information technology with a focus on the appropriate design and deployment of IT to augment and improve the human condition. A graduate from the National University of Ireland (Cork, M.A. first class) and Loughborough University, he was a Research Fellow at the Human Sciences & Advanced Technology Research Institute in the UK before moving to Indiana University in 1994 where, amongst other duties, he developed and served as the founding Director of the Masters in Human-Computer Interaction and as a founding faculty member of IU's School of Informatics. He joined the University of Texas at Austin in January 2002 as Dean and Louis T. Yule Regents Professor of the School of Information. Defying professional categorization, he has held academic appointments in cognitive science, computer science, psychology, instructional systems technology, management information systems, library and information science, and informatics. Having published more than 100 articles and books on various aspects of human information behavior and design, Andrew has served on the editorial boards of many leading scholarly journals, received research funding from NSF, Microsoft, and CEC among others, and he most recently completed a year as President of the Association for Information Science and Technology.



Deanna Fei

Deanna Fei is the author of the memoir *GIRL IN GLASS*, forthcoming from Bloomsbury in July 2015, and the award-winning novel *A Thread of Sky* (Penguin, 2010). Her recent essay, "My Baby and AOL's Bottom Line," went viral worldwide and sparked national conversations about medical privacy, corporate accounting, employer-sponsored health care, and the value of a human life. She also appeared on the "Today" show, CBS Evening News, NPR, CNN, and MSNBC to discuss her decision to speak out about her "distressed baby."

Deanna was born in Flushing, New York, and graduated from Amherst College and the Iowa Writers' Workshop. She has received a Fulbright Grant and a New York Foundation for the Arts fellowship. Her debut novel, *A Thread of Sky*, was named a New York Times Editors' Choice selection, Best Book by the Chinese American Librarians' Association, and winner of Late Night Library's Debut-litzer Prize. Her essays have appeared in the New York Times, Slate, The Millions, the Huffington Post, and other publications. She has taught writing, led workshops, and counseled at-risk youth through the Asian American Writers' Workshop, CASES, and New York City public schools. She lives in Brooklyn with her husband and two children.



Masao Horibe

Masao Horibe is Professor Emeritus, Hitotsubashi University, and Chairman, Specific Personal Information Protection Commission, Government of Japan. On January 1, 2014, Dr. Masao Horibe was appointed as the first Chairman of the Specific Personal Information Protection Commission, a new independent data protection authority, by the Prime Minister, with the consent of both Houses of the Diet. He has been researching both privacy and data protection and freedom of information for more than half a century. Horibe has written extensively in the areas of privacy, data protection, freedom of information, media law, etc. He served as Vice-Chair of WPISP (the Working Party on Information Security and Privacy) of the OECD (1996-2008). He is "Privacy by Design Ambassador" of the Information and Privacy Commissioner of Ontario, Canada, and one of the five honorary members of the Digital Enlightenment Forum, established as a not-for-profit organization in Luxembourg in 2011. Horibe was

a member of the Sub-Committee on Disclosure of Administrative Information of the Administrative Reform Committee (1995-1996), as well as Chairperson of the Working Party on Personal Data Protection of the Information Technology (IT) Strategy Headquarters (1999-2000) headed by the Prime Minister. He was a member of the Board of Governors of the Japan Broadcasting Corporation (NHK) (1999-2005) (appointed by the Prime Minister with the consent of both Houses of the Diet). At the local level, he has been involved in drafting Ordinances of Disclosure of Information (1981-82) and Protection of Personal Information of Kanagawa Prefectural Government (1988-90) and Tokyo Metropolitan Government (1983-85 and 1989-90). He was Vice-Chair and Chairperson of its Review Board of Kanagawa for more than 30 years (1983-2013) and a member and President of the Council relating to these Ordinances of Tokyo Metropolitan Government for 22 years (1991-2013). Horibe served as Chairman of the Working Group on Personal Data Protection relating to the National ID of the Social Security and Tax, Cabinet Secretariat, Government of Japan (2011-12). He is sometimes called "Mr. Privacy" or "Dr. Privacy" on account of his remarkable knowledge of, and experience in, privacy and personal information protection, and is widely recognized as "the founder of the information disclosure system". Born in 1936, Horibe was graduated from the Master of Laws Course at the University of Tokyo in 1962. He served as Assistant, Associate and full Professor of Law and Dean at Hitotsubashi University, one of the oldest national universities, for more than 30 years and Professor of Law at Chuo University, one of the oldest private universities, for 10 years. Horibe served as President of various academic societies, including the Law and Computers Association of Japan (1987-2002), the Comparative Law Association (1998-2002), and the Japan Society of Information and Communication Research (2000-2004). He was also a member of the Science Council of Japan (2000-2003).



Alex Pentland

Alex 'Sandy' Pentland has helped create and direct MIT's Media Lab, the Media Lab Asia, and the Center for Future Health. He chairs the World Economic Forum's Data Driven Development council, is Academic Director of the Harvard-MIT Data-Pop Alliance, and is a member of Advisory Boards for the United Nations Secretary General. In 2012 Forbes named Sandy one of the 'seven most powerful data scientists in the world', along with Google founders and the CTO of the United States.



Jocelyn Samuels

Jocelyn Samuels is the Director of the HHS Office for Civil Rights, where she leads that Office's work to enforce federal laws that help to ensure non-discrimination and equity in federally funded health and human services. She also spearheads enforcement of federal laws that protect the privacy and security of medical information and the rights of individuals to their health records. Ms. Samuels was previously the Acting Assistant Attorney General for Civil Rights at the United States Department of Justice, where she managed the operations of the Civil Rights Division. She also served as Principal Deputy Assistant Attorney General for Civil Rights and as Senior Counselor to the Assistant Attorney General.

Prior to her tenure at the Department of Justice, Ms. Samuels was the Vice President for Education and Employment at the National Women's Law Center in Washington, D.C. Her prior experience also includes work as a Labor Counsel to Senator Edward M. Kennedy, then Ranking Member and subsequently Chair of the Senate Committee on Health, Education, Labor and Pensions, and as a senior policy attorney at the Equal Employment Opportunity Commission. Ms. Samuels has additional experience in the private sector and as a law clerk to a federal judge on the U.S. Court of Appeals for the Ninth Circuit. She is an experienced litigator with an extensive knowledge of civil rights legislation and a passionate advocate for the rights of the underserved. Ms. Samuels received her law degree from Columbia University, where she was a Notes Editor of the Law Review, and her bachelor's degree from Middlebury College, where she graduated magna cum laude and was elected to Phi Beta Kappa.

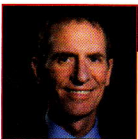


Lucia Savage

Lucia Savage joined the Office of the National Coordinator for Health Information Technology, Department of Health & Human Services in October 2014 as the Chief Privacy Officer. Lucia was the Senior Associate General Counsel at UnitedHealthcare, where she supervised a team that represents UnitedHealthcare in its work in large data transactions related to health information exchanges, healthcare transparency projects, and other data-driven health care innovation projects. She has served on the Governance Board of the Centers for Medicare & Medicaid Services' Multi-Payer Claims data base project (2011-2013), and collaborated with health information exchanges and state agencies in their planning with payers.

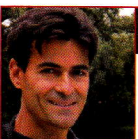
Prior to joining UnitedHealthcare, Lucia was General Counsel at the non-profit Pacific Business Group on Health, where she oversaw the legal affairs and state policy initiatives for one of the nation's oldest employer healthcare purchasing coalitions and its small group health insurance exchange, PacAdvantage. At PBGH, Lucia applied her 15 years of experience as an employee benefit attorney, in both compliance and litigation, and expanded her practice to include healthcare regulation, data transactions, and health care reform, and HIPAA implementation. Before joining PBGH, she served as Stanford University's benefits compliance officer.

Most recently, she has been emphasizing the importance of cost and quality transparency in health care, and has been working on the complex issues of maintaining patient privacy while working to fully realize the potential of health information exchange for better patient care in a learning health care system.



Barry P. Chaiken

Barry P. Chaiken, MD, MPH, FHIMSS has over 25 years experience in healthcare information technology, patient safety, clinical transformation, and public health. Currently Chief Medical Information Officer at Infor, he previously worked with the National Institutes of Health, U.K's. National Health Service, McKesson, and BearingPoint. Chaiken served as a Board member (2006-2010), Board Liaison to HIMSS Europe (2006-2009), and Board Chair (2009-2010), and continues his involvement as a Fellow of the Health Information Management and Systems Society (HIMSS). He currently writes a column on technology and quality for the journal *Patient Safety and Quality Health Care*. Chaiken is board certified in General Preventive Medicine and Public Health. Chaiken received his medical degree from SUNY Downstate Medical Center and his MPH degree from the Harvard School of Public Health. He acquired his specialty training from the Centers for Disease Control as an Epidemic Intelligence Service officer and from the NJ Department of Health as a preventive medicine resident.



Adam Tanner

Adam Tanner is the author of *What Stays in Vegas. The World of Personal Data-Lifeblood of Big Business-and the End of Privacy as We Know It.* The Washington Post named the book one of 50 books notable works of non-fiction in 2014. He is a Fellow at the Institute for Quantitative Social Science at Harvard University, where he's been since 2011, initially as a Nieman fellow. From 1995-2011 he was a correspondent at Reuters, including as bureau chief for the Balkans for 2008-2011 and San Francisco bureau chief from 2003-2008. He is now writing a book on the business of personal medical data.

SUMMIT SPEAKERS

Joe Ali



Mr. Ali is a Research Scholar with the Johns Hopkins Berman Institute of Bioethics. He received an honours BA in Bioethics and Philosophy from the University of Toronto where he served on the editorial board of the University of Toronto Journal of Bioethics. He received a Juris Doctorate and Health Law Certificate from the University of Pittsburgh School of Law, where he specialized in bioethics and health law. At the Berman Institute, Mr. Ali's work advances pedagogical quality in bioethics, identifying best methods for bioethics education and working with colleagues to develop new academic program offerings. His scholarly work also seeks to address a range of ethical challenges in domestic and international research ethics-from policy to practice. He serves as Co-Lead, PCORnet Ethics and Regulatory Task Force at the Patient –Centered Outcomes Institute (PCORI) to identify and address ethical challenges that arise from the conduct of comparative effectiveness, quality improvement, and related national research efforts.

Khaliah Barnes



Khaliah Barnes is Director of the Student Privacy Project at EPIC, the Electronic Privacy Information Center. Khaliah created the Student Privacy Bill of Rights. Khaliah defends student privacy rights before federal regulatory agencies and federal court. She has testified before states and local districts on the need to safeguard student records. Khaliah is a frequent panelist, commentator, and writer on student data collection. Khaliah is also the EPIC Administrative Law Counsel. In this role, she researches proposed federal agency privacy regulations pertaining to government collection, retention, and dissemination of personal information. Khaliah has drafted almost forty agency comments concerning the right to privacy set out in the Privacy Act on such matters as information security, air traveler rights, student privacy, consumer rights, automotive privacy, drones and domestic surveillance, and medical privacy. She has also written extensive administrative agency comments on proposed Freedom of Information Act regulations. Khaliah has provided commentary to local and national media, including CBS This Morning, the New York Times, NPR, Fox Business, CNN, Education Week, Politico, USA Today, and Time Magazine. She is admitted to practice in Maryland, Washington, D.C., and the United States District Court for the District of Columbia. She is a member of the American Bar Association's (ABA) Administrative Law Section and ABA Privacy and Information Security Committee.

Debbie Bucci



Debbie Bucci is a lead IT Architect, Office of Standards and Interoperability, in the Department of Health and Human Services, Office of the National Coordinator for Health IT (ONC). Her primary focus is on the privacy and security aspects of Health Information Exchange. She has been previously recognized, both within HHS and nationally, for her work in Federated Identity Management.

Janelle Burns



Janelle Burns currently serves in the role of Corporate Privacy & Security Officer for Baptist Memorial Health Care Corporation in Memphis, Tennessee, overseeing compliance with patient privacy laws for fourteen hospitals and approximately 150 physician practices located in Tennessee, Mississippi, and Arkansas. Ms. Burns began her career with Baptist in January 2002 when she was hired to become the in-house subject matter expert for legal issues related to HIPAA. Ms. Burns served as a staff attorney and senior staff attorney in the Corporate Legal Services Department until September 2012, when Baptist elevated the role of Corporate Privacy & Security Officer to a full-time position. Ms. Burns received her Doctor of Jurisprudence and a Certificate in Health Law from the University of Tulsa College of Law in 1999.

Hugo Campos



Hugo Campos, ePatient and Data Liberation Advocate is a thought leader in the ePatient movement. He is a vocal advocate for the rights of pacemaker and ICD patients to gain electronic access to the data collected by their devices. He is passionate about participatory medicine, connected health, and patient empowerment through the use of technology. He has spoken at TEDx and has been featured on NPR and in The Wall Street Journal. He is Emeritus Member of the Stanford Medicine X ePatient Advisory Board; member of the Stakeholder Advisory Board (SAB), National Steering Committee for pSCANNER (Patient-Centered SCALable National Network for Effectiveness Research); former advisory board member for the UC San Diego Calit2 Health Data Exploration Project: Personal Data for the Public Good; and former member-at large for the Executive Committee of the Society for Participatory Medicine. A native of Rio de Janeiro, Campos lives in the San Francisco Bay Area.

Donna Cryer



Ms. Donna Cryer has channeled her personal experience as an IBD and liver transplant patient into a distinguished career in professional advocacy spanning two decades. Her e-health experience includes participating in the launch of the Office of National Coordinator for HIT (ONC) consumer engagement campaign and serving on the ONC technical expert panel on patient-generated health data. She has participated as a member of the White House e-health equity taskforce and the judging panel on the White House design challenge on innovating the electronic patient medical record.

Ms. Cryer is a patient representative to the U.S. Food and Drug Administration, a merit reviewer for the Patient Centered Outcomes Research Institute (PCORI), and a member of Stakeholder Advisory Group to the NIH Learning Health System Research Collaboratory. Ms. Cryer received an undergraduate degree from Harvard/Radcliffe Colleges and received a Juris Doctorate from the Georgetown University Law Center.

Alan Dahi

Alan is a Senior Research Associate at the *Institute for Legal Informatics* at the Leibniz Universität Hannover, Germany, where he advises on data protection issues in European Union funded ICT for Health projects. He also enjoys lecturing on European e-commerce law and conducting research on topics such as the use of icebergs as a fresh water resource and Bitcoin. He studied law in Germany, New Zealand and the United States, is a German qualified lawyer and a small business owner. Ever privacy conscious, he offers customers a discount if they send him a GPG encrypted email.

Michelle DeMooy



Michelle De Mooy is Deputy Director, Consumer Privacy Project at the Center for Democracy & Technology. Her work is focused on promoting strong consumer privacy rights through pro-privacy legislation and regulation, working with industry to build and implement good privacy practices, and analyzing emerging privacy concerns. Michelle has testified before Congress, been interviewed and profiled in national media, and been a panelist and featured speaker at many events related to digital privacy, including Federal Trade Commission workshops, the Internet Governance Forum, Health Privacy Summit, and the State of the Mobile Net. At CDT, Michelle is currently focused on health privacy, including personal monitoring technology and the impact of big data on the commercial, government, and clinical environments. Prior to CDT, Michelle was Senior Associate, National Priorities at Consumer Action, a national nonprofit focused on empowering underserved and disadvantaged consumers. In this role, she worked extensively with federal agencies, industries, and privacy advocates to build innovative and practical solutions to privacy problems, focusing especially on harms associated with underrepresented communities.

Dissent



Pogo Was Right: www.PogoWasRight.org, www.pogowasright.org

Barbara Evans



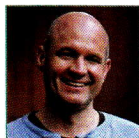
Professor Evans joined the University of Houston Law Center in 2007. She is George Butler Research Professor and Director of the Center for Biotechnology and Law at UHLC and is an affiliated member of the Center for Medical Ethics and Health Policy at Baylor College of Medicine. She was named a Greenwall Foundation Faculty Scholar in Bioethics for the period 2010-2014 and conducts an active research agenda including projects funded by the National Institutes of Health and Food and Drug Administration. Her research interests include governance, privacy, and financing issues with large health information networks and tissue repositories; regulatory and judicial uses of evidence from large-scale observational studies; and legal barriers to clinical translation of pharmacogenomics. Earlier in her career, she was a partner in the international regulatory practice of a large New York law firm and subsequently advised clients on U.S. privacy, research, and medical device regulatory matters. Prior to joining the University of Houston Law Center, she was a Research Professor of Medicine and Director of the Program in Pharmacogenomics, Ethics, and Public Policy at the Indiana University School of Medicine/Center for Bioethics. She holds an electrical engineering degree from the University of Texas at Austin; M.S. and Ph.D. degrees from Stanford University; a J.D. from Yale Law School; and she completed a post-doctoral Fellowship in Clinical Ethics at the M.D. Anderson Cancer Center.

Randall J. Farmer



Randy Farmer joined DHIN in September of 2011 as Director of Provider Relations and Business Development and assumed the role of Chief Operating Officer in October 2013. Reporting directly to DHIN's Chief Executive Officer, Farmer focuses on ensuring the integrated commercial success of DHIN. As the COO, he drives the overarching commercial strategy, specifically in the areas of marketing, brand development, product development, operational integrity, business development and customer service. Farmer joined DHIN after a decade at JP Morgan Chase in Wilmington, where he served most recently as senior segment manager of strategic partnerships. During his tenure, Farmer managed all aspects of the co-brand credit card relationships with Sony Electronics, N.A., Toys 'R' Us, Philips Electronics, Borders Books & Music, the American Medical Association and several other household brand names. He also served as senior communication and public affairs manager during his 10 years at Chase.

Bill Fitzgerald



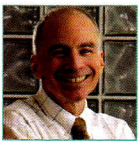
Bill is the CEO of FunnyMonkey. He's has worked in education as an English and history teacher, an administrator, and a technology director. Bill initially discovered the Internet in the mid-1990's at the insistence of a student who wouldn't stop talking about it.

Magdalena Góralczyk



Magdalena is a Senior Research Associate and PhD candidate at the *Institute for Legal Informatics* at the Leibniz Universität Hannover, Germany. Her main work and research focus is on data protection and privacy. In the medical domain she is passionate about the balancing act between patients' and researchers' interests— something she has explored in a number of European Union funded projects dealing with, inter alia, consent and the sharing of medical data in an ethical and legally compliant manner. On a broader spectrum she is interested in the privacy-data protection coupling, especially parallels and differences of the two concepts, as well as the societal and psychological challenges wrought by the changing privacy landscape and the ways the law may respond to those— topics she investigated in her recently submitted PhD on the notion of anonymity. She previously studied in Poland and Italy.

Lawrence Gostin



Lawrence Gostin is University Professor and the Founding Linda and Timothy O'Neill Chair in Global Health Law; Faculty Director of the O'Neill Institute for National and Global Health Law; and Director of the WHO Collaborating Center on Public Health Law & Human Rights. He has chaired numerous National Academy of Sciences committees; proposed a Framework Convention on Global Health endorsed by the UN Secretary General; served on the WHO Director's Advisory Committee on Reforming the WHO; drafted a Model Public Health Law for WHO and the CDC; and directed the National Council of Civil Liberties and the National Association for Mental Health in the United Kingdom, where he wrote the British Mental Health Act and brought landmark cases before the European Court of Human Rights. He was awarded the Delbridge Memorial Prize for the person who has "most influenced Parliament and government to act for the welfare of society."

Robert "Bob" Gregg



Bob Gregg joined ID Experts Corporation in January, 2009 as the Chief Executive Officer. ID Experts is a leader in the protection of individuals from harm caused by identity theft. Prior to that he was Executive Vice President of Worldwide Sales and Services for FEI Company, a \$600 million public company in the nanotechnology tools business. Prior to joining FEI, Bob was the President and CEO for Unicru, Inc., a leading provider of hiring management software. Previously, for 16 years, Mr. Gregg was the Chief Financial Officer at Sequent Computer Systems, a global computer company, based in Beaverton, Oregon. In the initial founding group at Sequent, he was a key player in growing the company from a startup to over \$800 million in revenue with sales in 55 countries.

Mr. Gregg is also on the Board of Trustees of Oregon Health Sciences University Foundation, as well as past President of the Board of the Oregon Historical Society and is currently president of the board of the Oregon Sports Authority, where he is heading the effort to bring the National Hockey League to Portland.

Adrian Gropper



Adrian Gropper, MD, is the Chief Technology Officer of Patient Privacy Rights, a national organization representing 10 million patients and is a veteran of patient-centered health information infrastructure. As an entrepreneur and physician-developer he has founded a number of software-intensive medical device companies. He consults on Federal pilots and participates in numerous health data policy standards groups including MIT-KIT and as a co-founder of OpenID/HEART to develop standards and profiles for the JASON Public API. He serves on the Board of NSTIC / IDESG and as vice-chair of their health care workgroup. He is active in the MA Medical Society Committee on IT and the Task Force on Physician Choice. He helped create Blue Button, Direct Project, and Blue Button Plus and speaks frequently on privacy engineering in health care. Gropper holds an engineering degree from MIT and an MD from Harvard Medical School.

Deborah Hurley



Deborah Hurley is the Principal of the consulting firm she founded in 1996, which advises governments, international organizations, companies, civil society, and foundations on advanced science and technology policy. She is a Fellow of the Institute for Quantitative Social Science, Harvard University. At the Organization for Economic Cooperation and Development, in Paris, France, she identified emerging legal, economic, social, and technological issues related to information and communications technologies, biotechnology, environmental and energy technologies, and nanotechnology. Hurley was responsible for drafting, negotiation and adoption of the OECD *Guidelines for the Security of Information Systems*. She also initiated OECD activities on cryptography technologies and policy in the early 1990s. She practiced computer and intellectual property law in the United States. Hurley has served on many boards and committees, including for the International Federation for Human Rights, US State Department, the American Association for the Advancement of Science, and the National Academy of Sciences Research Council. She carried out a Fulbright study in Korea. She is the author of *Pole Star: Human Rights in the Information Society*. Hurley received the Namur Award of the International Federation for Information Processing in recognition of outstanding contributions, with international impact, to awareness of social implications of information technology.

Ifeoma Ijunwa



Professor Ijunwa is an Assistant Professor of Law, teaching Contracts, Health Law, and Intellectual Property Law at the David A Clarke School of Law at the University of the District of Columbia. Prior to joining the faculty in Fall 2014, Professor she was a Fellow at Columbia Law School and she was a Visiting Teaching Fellow at Case Western Reserve University School of Law. She completed her undergraduate education at UC Davis, where she was a McNair Scholar, and earned her law degree from the University of San Francisco, where she received the AAUW Selected Professions Fellowship and served as an editor with the Intellectual Property Law Bulletin and the Journal of Law and Social Challenges. She is a Ph.D. Candidate at Columbia University in the Sociology Department (concentration in Organizational Studies and Law and Society). Professor Ijunwa is admitted to the Bar in California and New York. Before her career in academia, Professor Ijunwa practiced Business and Intellectual Property Law in San Francisco and she was a legal consultant to a multinational IP Law firm in Thailand. She also served as a *pro bono* attorney for Centro Legal De La Raza in California during which she represented immigrants at bond hearings. She has also volunteered with the ACLU of NY (the NYCLU) and has been a researcher with UNESCO in New York City.

Judge Clay Jenkins



Since taking office in 2011, Dallas County Judge Clay Jenkins has quickly become a strong voice for the County. Through his leadership, Dallas County continues to guide national conversation toward moral and compassionate responses. His advocacy on the Commissioners Court has helped balance several budget deficits without increasing taxes while simultaneously ensuring County business was both productive and less acrimonious. Judge Jenkins has been an outspoken advocate for expanded health coverage in Dallas County and throughout the State of Texas. Working with hospitals, physicians, business groups, and faith leaders to improve health care and reduce the burden on taxpayers and others who bear the cost for uncompensated care. He has worked closely with federal and local partners on the Health Insurance Marketplace and the Dallas County Affordable Care Act Coalition has been recognized by the White House as one of the best in the nation. As the chief-elected official of the county, Judge Jenkins is also the Director of Homeland Security and Emergency Management, as displayed in Dallas County's response to the Ebola virus. Dallas County balanced public health with personal dignity, establishing the national standard. In 2011, he passed the most comprehensive local transparency and ethics reform in the state and continues to strengthen Dallas County's procurement process through building relationships with business partners and the community. Jenkins is a public official whose business acumen and unparalleled compassion have revitalized the office of Dallas County Judge.

Michael Kiehl



Mike Kiehl is the Executive Director of Patient Privacy Rights. He has been an IT industry analyst/consultant at multiple organizations providing insight and support in most aspects of information technology strategy, technology, and competitive analysis. He was an executive with IBM in both the Systems and Software Group business units for over 30 years with practical experience in management, strategy, business development, and software architecture and development, especially in distributed systems and their security and communication underpinnings. As a consultant, he worked with firms ranging from technology start-ups to established technology leaders such as HP, IBM, Microsoft, and others.

Dale King



Dale King is the Director of the Family Policy Compliance Office (FPCO) for the U.S. Department of Education. FPCO administers the Family Educational Rights and Privacy Act (FERPA) for the U.S. Department of Education. Prior to becoming FPCO Director, Dale served as the Director of Policy, Research, and Evaluation Services within the Department's Office of Vocational and Adult Education. Dale began his federal career in 2001 as a program specialist in the Office of Special Education Programs (OSEP) and also served as a policy analyst in the Office of Special Education and Rehabilitative Services (OSERS). Dale has over 25 years of experience in education, including being an education specialist with the Tennessee State Department of Education, and the Director of Psychological Services for the Hamilton County School District in Chattanooga, Tennessee.

Craig Konnoth

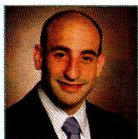
Craig Konnoth is the Sharswood Fellow & Lecturer in Law at the University of Pennsylvania Law School. He works at the intersection of health and privacy law, and health law and LGBT issues. He focuses on the ethical justification for information collection in the health context, and on how the collection of information is determined by, and in turn, determines and constructs, the institutions and entities that collect the information, and from whom the information is collected. Previously, Craig was a Deputy Solicitor General and the Inaugural Earl Warren Fellow at the California Department of Justice where he litigated primarily before the United States Supreme Court, and also before the California Supreme Court and the Ninth Circuit Court of Appeals, in cases ranging from the contraceptive mandate in the Affordable Care Act and Sexual Orientation Change Efforts to cellphone searches by police and Facebook privacy policies. Before moving into government, Craig was the R. Scott Hitt Fellow in Law & Policy at the Williams Institute at UCLA Law School, where he focused on issues affecting same-sex partners as well as health related matters, such as long term care and post-marriage recognition Medicaid coverage issues, and drafted HIV rights legislation. He is a graduate of the Yale Law School (J.D., 2010), where he supervised the LGBT Litigation Project and received the Parker Prize for his history on early gay rights litigation strategies, the University of Cambridge (M.Phil., 2007) and Fordham University (B.A., 2005).

Celeste Castillo Lee



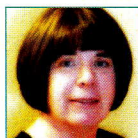
Celeste Castillo Lee currently is the Program Manager for Patient and Family Centered Care at the University of Michigan Health System. Most importantly, Celeste is a 33 year kidney patient currently on in-center hemodialysis. She has been on pd and had a kidney transplant for 10 years. She is a patient advisor in non-profit health organizations, governmental agencies, research projects as an advisor, peer mentor and advocate nationally, and internationally. Celeste has multiple memberships in non-profit health organizations keeping her busy as an advisor and advocate in Michigan, North Carolina, nationally, and internationally. Celeste is a strategic patient partner and leader such as a board member for the public/private partnership between the American Society for Nephrology and the FDA, Kidney Health Initiative, and also Chair of the newly formed Patient and Family Partnership Council to KHI, a member of the Steering Committee for the Vasculitis Patient-Powered Research Network, and as a member of the PCORnet National Patient Advisory Council.

Bradley Malin



Bradley Malin is an Associate Professor and the Vice Chair of Biomedical Informatics in the School of Medicine, an Associate Professor of Computer Science in the School of Engineering, and an Affiliated Faculty Member of the Center for Biomedical Ethics and Society at Vanderbilt University. He is the founder and current director of the Health Information Privacy Laboratory (HIPLab), an interdisciplinary endeavor that was established to address the growing need for data privacy research and development for the rapidly expanding health information technology sector. He is an investigator in the PCORI-sponsored Mid-South Clinical Data Research Network and Chicago Area Patient-Centered Outcomes Research Network and for the past year has served as co-chair of the PCORnet Data Privacy Task Force. Dr. Malin completed his education at Carnegie Mellon University, where he received his B.S. in biological sciences, his M.S. in data mining and knowledge discovery, a master's of philosophy in public policy and management, and his Ph.D. in computer science.

Jean McEwen



Dr. McEwen came to the he National Human Genome Research Institute in 1999 following a career in law practice, teaching, and research. She manages a grant portfolio related to the ethical, legal and social implications (ELSI) of genomic research, focusing particularly on legal, regulatory and public policy issues (including intellectual prortery and data sharing), as well as issues related to race and genetics, behavioral genetics, and prenatal testing. Dr. McEwen also coordinates the ELSI component of the Clinical Sequencing Exploratory (CSER) Consortium, provides guidance on ethical issues for the Sample Repository for Human Genetic Research at the Coriell Institute, and participates in a variety of other ELSI-related trans-NHGRI and trans-NIH initiatives and programs. Jean received her B.A. in philosophy from the University of Minnesota in 1977, a J.D. from Northwestern University in 1982, and a Ph.D. in social policy from Brandeis University in 1996.

Deven McGraw



Deven McGraw is a partner in the healthcare practice of Manatt, Phelps & Phillips, LLP. She provides legal, regulatory and strategic policy and business counsel to healthcare providers, payers and other healthcare organizations with respect to the adoption and implementation of health IT and electronic health information exchange. Her areas of focus include HIPAA/privacy advice and compliance, data security, data governance, research and health data analytics, health IT policy, and patient engagement. Previously, Ms. McGraw was the Director of the Health Privacy Project at the Center for Democracy & Technology (CDT). In this role she led efforts to develop and promote workable privacy and security protections for electronic personal health information.

Maneesha Mithal



Maneesha Mithal is the Associate Director of the Federal Trade Commission's Division of Privacy and Identity Protection. Ms. Mithal's areas of expertise include international privacy and security, international spam, cross-border fraud, international litigation, ICANN-related issues, and building consumer trust in a global marketplace. Ms. Mithal has served on the U.S. delegations of various international organizations, including the OECD Committee on Consumer Policy, the OECD Information, Communications and Computer Policy Committee, the APEC Electronic Commerce Steering Group, and the Hague Conference on Private International Law. Prior to joining the Federal Trade Commission in 1999, she was an associate at the Washington law firm of Covington & Burling, where she practiced in the commercial litigation, international litigation, and legislative areas. Ms. Mithal earned her law degree from the Georgetown University Law Center and her undergraduate degree from Georgetown University.

Frank Pasquale



Frank Pasquale is a Professor of Law at the Carey School of Law at the University of Maryland. His research agenda focuses on challenges posed to information law by rapidly changing technology, particularly in the health care, internet, and finance industries. He has published over 30 scholarly articles, and his book *The Black Box Society: The Hidden Algorithms Behind Money and Information* was published by Harvard University Press in 2014. His article 'Grand Bargains for Big Data: The Emerging Law of Health Information' offers a broad overview of the opportunities and perils posed by the growing use of predictive analytics in the medical field. Pasquale graduated summa cum laude from Harvard University, received an MPhil at Oxford University as a Marshall Scholar, and received his JD from Yale Law School. He has been a Visiting Fellow at Princeton's Center for Information Technology, a Visiting Professor at Yale Law School and Cardozo Law School, and was a Marshall Scholar at Oxford University. He has testified before the Judiciary Committee of the House of Representatives (appearing with the General Counsels of Google, Microsoft, and Yahoo) and presented before a Department of Health & Human Services/Federal Trade Commission Roundtable and panels of the National Academy of Sciences.

Ann Patterson

Ann Patterson is SVP and Program Director for the Medical Identity Fraud Alliance (MIFA). She oversees member programming, including committees, working groups, deliverables, member engagement and meetings, and manages member recruitment, retention and marketing. Prior to MIFA, Ann was VP of Member Relations and Communications at BITS/Financial Services Roundtable, focused on delivering value through member programs and executing the communications and press relations program. She also managed the Product Certification Program, a software testing program that allowed companies to certify against security criteria. Previously, she worked in communications for Ernst & Young Technologies, PricewaterhouseCoopers and the Department of Defense.

Deborah C. Peel



Deborah C. Peel, MD, is the Founder and Chair of Patient Privacy Rights. She is also a practicing physician, a Freudian psychoanalyst, and a national and international speaker on health information privacy, privacy trust frameworks, and the policy, laws, and technology needed to ensure patients' willingness to share sensitive information.

Patient Privacy Rights' mission is to restore patient control over personal health information. *To accomplish our mission, we educate and work collaboratively with patients and organizations to restore the ethical right to health information privacy, the foundation of the patient-physician relationship, in law, policy, and technology.*

Patient Privacy Rights has over 20,000 members in all 50 states. Patient Privacy Rights leads the bipartisan Coalition for Patient Privacy, which includes over 50 national organizations, representing 10.3 million people who want to control the use of personal health information. Peel has been named one of ModernHealthcare magazine's "100 Most Influential in Healthcare" four times since 2007. She was also named one of the "Top Ten Influencers in Health InfoSec" by HealthcareInfoSecurity in 2013.

Bill Pewen



William Pewen is Assistant Professor of Public Health and Family Medicine at Marshall University, where he directs the Graduate Program in Public Health and serves as Associate Dean of Research in the College of Health Professions. He holds a doctorate in Infectious Diseases and Microbiology and M.P.H. in Epidemiology from the University of Pittsburgh. Pewen previously served as Senior Health Policy Advisor to U.S. Senator Olympia J. Snowe (R-ME), and his health policy work included critical issues of both health information technology and genetic discrimination, as well as efforts to create health reform legislation which formed the core of the enacted Patient Protection and Affordable Care Act (ACA).

Pewen has long been engaged in efforts to ensure the security and privacy of health records and address broader civil rights implications of the use of health information, having worked in the passage of the Genetic Information Nondiscrimination Act of 2008 as well as the drafting of the HITECH Act. His health policy writing has been featured in the New York Times, Health Affairs and The Atlantic.

Joy Pritts



Joy Pritts is a nationally recognized expert in health information privacy. For over 15 years, Pritts has led efforts to improve peoples' rights in their health information. Pritts served for 4 ½ years as the first Chief Privacy Officer for the Office of the National Coordinator for Health Information Technology at the US Department of Health and Human Services. There, she provided critical advice on privacy to the Secretary and the National Coordinator. Among other accomplishments, Pritts spearheaded the release of regulations that give people nation-wide the right to see and get an electronic copy of their test results directly from clinical laboratories. Pritts also worked closely with the other federal bodies, including the FTC, to coordinate federal efforts to protect health information that falls outside the bounds of the HIPAA Privacy and Security Rules. Prior to HHS, Pritts founded and led the Center on Medical Records Rights at Georgetown University's Health Policy Institute, where she wrote extensively on health information privacy and patient access issues. She is now acting as an independent consultant on health information in the private sector.

Mr and Mrs Robbins

Mr and Mrs Robbins are the parents of a student whose school laptop spied on him.

Jordan Robertson



Jordan Robertson is a technology writer at the Washington DC bureau of Bloomberg News, covering security, privacy and health data issues. He previously worked at The Associated Press, covering enterprise computing. His recent projects have included Putting Patient Privacy at Risk, a series that ran in 2012 and included stories on hackers extorting doctors by stealing their electronic medical records; data-mining techniques used to find the mystery causes of some diseases; and the quiet collection of millions of patients' data as part of state-run health information exchanges. His work appears across Bloomberg's media properties, including the Bloomberg newswire, Bloomberg.com, Bloomberg Businessweek and Bloomberg TV.

Mark A. Rothstein



Mark A. Rothstein is the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy, and Law at the University of Louisville School of Medicine. Professor Rothstein has concentrated his research on health privacy, bioethics, genetics, and public health. He is a past president of the American Society of Law, Medicine and Ethics, an elected member of the American Law Institute, and an elected fellow of the Hastings Center. He serves as Editor for Public Health Ethics of the *American Journal of Public Health* and he writes a regular column on bioethics for the *Journal of Law, Medicine & Ethics*. He is the author or editor of 19 books and over 250 book chapters and articles. Professor Rothstein was a 2013 recipient of the Louis D. Brandeis Privacy Award from Patient Privacy Rights.

Cameron Russell



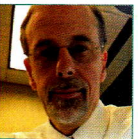
N. Cameron Russell is the Executive Director of the Fordham Center on Law and Information Policy at Fordham University School of Law. Prior to becoming Executive Director, Cameron served as a fellow at CLIP, practiced law as a partner in the Wender Law Group in New York, and worked as a music manager for then up-and-coming pop star Rihanna. In addition to his role with CLIP, Cameron teaches as an adjunct professor at Fordham Law School. Cameron earned his undergraduate degree from UNC-Chapel Hill's Kenan-Flagler Business School and his J.D. from the University of Denver. He is also a magna cum laude LL.M graduate of Fordham Law School in intellectual property and information technology law. Cameron is admitted to practice in New York and California.

Lisa Schlager



Lisa manages advocacy, strategic partnerships and community relations for FORCE. She joined the organization in 2008 as Coordinator for the Washington, D.C. outreach organization. Since learning of her BRCA1 mutation in 1999, Lisa's mission has been to educate others about the risks of hereditary cancer. Her recent successes include passage of National Hereditary Breast and Ovarian Cancer Week and National Previvor Day 2010; formulation of the EARLY Act, passed with the healthcare reform legislation in 2010; and testifying before the Secretary's Advisory Committee on Genetics, Health, and Science on issues related to direct-to-consumer marketing of genetic tests. A former marketing communications consultant, Lisa served clients including MCI Communications and Fannie Mae. She has a long history of volunteer work in her local community, synagogue, and schools. Lisa resides in Washington, DC with her husband Gary and two children.

Mark Scrimshire



Mark Scrimshire is part of the Entrepreneur-in-Residence (EIR) program at the U.S. Department of Health and Human Services (HHS). The program brings together talent from within and outside government to tackle high priority issues in health, health care, and the delivery of human services.

Joe V. Selby



Dr. Selby is the Executive Director of the Patient-Centered Outcomes Research Institute (PCORI). A family physician, clinical epidemiologist, and health services researcher, Dr. Selby has more than 35 years of experience in patient care, research, and administration. He is responsible for identifying strategic issues and opportunities for PCORI and implementing and administering programs authorized by the PCORI Board of Governors. Dr. Selby joined PCORI from Kaiser Permanente, Northern California, where he was Director of the Division of Research for 13 years and oversaw a department of more than 50 investigators and 500 research staff members working on more than 250 ongoing studies. He was with Kaiser Permanente for 27 years. An accomplished researcher, Dr. Selby has authored more than 200 peer-reviewed articles and continues to conduct research, primarily in the areas of diabetes outcomes and quality improvement. His publications cover a spectrum of topics, including effectiveness studies of colorectal cancer screening strategies; treatment effectiveness, population management, and disparities in diabetes mellitus; primary care delivery; and quality measurement. Dr. Selby was elected to membership in the Institute of Medicine in 2009 and was a member of the Agency for Healthcare Research and Quality study section for Health Care Quality and Effectiveness from 1999 to 2003. A native of Fulton, Missouri, Dr. Selby received his MD from Northwestern University and his MPH from the University of California, Berkeley. He was a commissioned officer in the Public Health Service Corps from 1976 to 1983 and received the Commissioned Officer's Award in 1981.

Shahid N. Shah



Shahid N. Shah is the CEO of Netspective Communications. He is an internationally recognized and influential healthcare IT thought leader, known as “The Healthcare IT Guy” across the Internet. He is a technology strategy consultant to many federal agencies and winner of Federal Computer Week’s coveted “Fed 100” award given to IT experts that have made a big impact in government. Shah has architected and built multiple clinical solutions over his almost 20 year career. He helped design and deploy the American Red Cross’s electronic health record solution across thousands of sites; he built several web-based EMRs now in use by hundreds of physicians; he designed large groupware and collaboration sites in use by thousands; and, as an ex-CTO for a billion dollar division of CardinalHealth, he helped design advanced clinical interfaces for medical devices and hospitals. Shah also serves as a senior technology strategy advisor to NIH’s and TATRC’s SBIR/STTR program helping small businesses commercialize their healthcare applications. Shah runs several successful blogs: <http://shahid.shah.org> he writes about architecture issues; <http://www.healthcareguy.com> he provides valuable insights on how to apply technology in health care; <http://www.federalarchitect.com> he advises senior federal technologists; and <http://www.hitsphere.com> he gives a glimpse of the health-care IT blogosphere as an aggregator.

Adam Tanner



Adam Tanner is a Fellow at the Institute for Quantitative Social Science, Harvard University. He is the author of *“What Stays in Vegas. The World of Personal Data-Lifeblood of Big Business-and the End of Privacy as We Know It.”* The Washington Post named the book one of 50 books notable works of non-fiction in 2014. He has been at Harvard since 2011, initially as a Nieman fellow. From 1995-2011 he was a correspondent at Reuters, including as bureau chief for the Balkans for 2008-2011 and San Francisco bureau chief from 2003-2008. He is now writing a book on the business of personal medical data.

Sharon Terry



Sharon F. Terry is President and CEO of Genetic Alliance, a large network of disease advocacy and health organizations. Genetic Alliance engages individuals, families and communities to transform health. She is the founding CEO of PXE International, a research advocacy organization. She discovered the PXE gene and diagnostic test, and conducts clinical trials.

Terry co-founded the Genetic Alliance Registry and Biobank. She leads consumer participation in genetics research, services and policy, serving the Accelerating Medicines Partnership, Institute of Medicine Science and Policy Board and Roundtable on Translating Genomic-Based Research for Health, PubMed Central National Advisory Committee, PhenX scientific advisory board, Global Alliance for Genomics and Health, International Rare Disease Research Consortium Executive Committee and as Founding President of EspeRare Foundation of Geneva, Switzerland. She is an editor of Genome. She led the coalition that secured passage of the Genetic Information Nondiscrimination Act. She received an honorary doctorate from Iona College for community engagement in 2006. In 2012, she became an honorary professor of Hebei United University in Tangshan, China. She is one of FDA’s “30 Heroes for the Thirtieth Anniversary of the Orphan Drug Act.” Terry won \$400,000 and \$1M contracts from PCORI for the Platform for Engaging Everyone Responsibly.

Bill Turner



Bill Turner – CIPM; C|CISO; CIPP /US, /G, /C; CIPT; CHPC

Mr. Turner has over 20 years of experience in privacy and security in the healthcare industry. Bill has currently accepted a new position as the HIPAA Privacy & Security Officer for a state-based healthcare organization. He served nine years as the Chief Security Officer for APS Healthcare, serving 22-million members in 28 states and Puerto Rico. Prior to APS, Bill was the Director of IT Strategy for Cook Children’s Healthcare System where he helped select a new enterprise-wide EHR. He also served as a direc-

tor at Voluntary Hospitals of America building a secure network to connect 1800 member hospitals. He has worked with CMS vendors, Medical Homes, healthcare analytics organizations, providers, and hospitals in building a culture of privacy and security.

Before going into healthcare, Mr. Turner worked in Electronic Warfare. He was a director of the Dallas chapter of the AF Electronic Warfare Association – Association of Old Crows. He also served on the Board of Directors for the Microcomputer Association. Mr. Turner holds a Bachelor degree in Social Work and has additional graduate level education in social statics and organizational development.

Stu Vaeth



Stu Vaeth is currently with SecureKey Technologies as SVP Business Development for the US identity network business. SecureKey currently operates privacy-enhanced federated ID and authentication networks for consumer online services in Canada and the US. Stu has over 25 years' industry experience in network and information security, identity management, authentication and mobility. Prior to joining SecureKey in 2012, he consulted with Akamai to develop their mobile identity strategy. Stu held prior positions as director of strategic alliances at RSA Security, CSO at Diversinet where he also served as co-chair of the Open Authentication (OATH) technology committee; and at nCipher as director of product marketing. He spent the first 12 years of his career at GTE in various roles including chief architect for the CyberTrust Certificate Authority platform. Stu received his MBA from Boston University and his bachelor's degree in electrical engineering from Bucknell University, and resides in Winchester, MA.

Benjamin West



Benjamin West is the co-founder of the Nightscout Project, which is building an open source system to put continuous glucose monitoring (CGM) information in the cloud, so that it is available from web browsers, smartphones, computers, tablets, and the Pebble smartwatch. Nightscout Project is working to reduce the burden of living with Type 1 Diabetes. West is also a member of the Board of Directors of the Nightscout Foundation. He is a software engineer passionate about usability and web architecture, with substantial experience developing web applications, scaling server-side performance, and developing new user interfaces and controls for "full stack" web applications. West is an advocate for open science and open source. Research interests include interaction between technology and society and measuring fidelity of therapy. He enjoys working on projects like Nightscout, which provide a forum for everyone to use their talents to increase liberty and decrease burden.

Lindsay F. Wiley



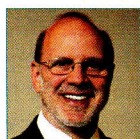
Professor Wiley is an Associate Professor of Law at Washington College of Law, American University. She teaches torts, health law, and public health law. Her research focuses on access to health care and healthy living conditions in the U.S. and globally. She serves on the Board of Directors of the American Society for Law, Medicine, and Ethics and the National Conference of Lawyers and Scientists. Prior to joining the faculty at WCL, Professor Wiley was the Global Health Law Program Director at the O'Neill Institute for National and Global Health Law at Georgetown University. She had also previously worked at the Center for Law and the Public's Health at the Johns Hopkins Bloomberg School of Public Health, the American Society for Law, Medicine, and Ethics, and Gordon, Feinblatt, Rothman LLC in Baltimore, MD. She received her AB and JD from Harvard, where she served on the Harvard Law Review, and her MPH from Johns Hopkins.

Josephine Wolff



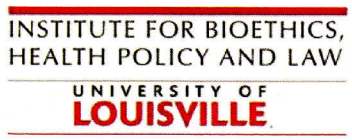
Josephine Wolff is at the Berkman Center for Internet & Society at Harvard and is a PhD candidate in the Engineering Systems Division at MIT studying cybersecurity and Internet policy. Her dissertation research focuses on understanding combinations of different types of defenses for computer systems, including the interactions among technical, social, and policy mechanisms. She has interned with Microsoft's Technology Policy Group, the Center for Democracy & Technology, the White House Office of Science and Technology Policy, and the Department of Defense. She has also written on computer security topics for Slate, Scientific American, and Newsweek. She holds an AB in mathematics from Princeton University, and an SM in Technology & Policy from MIT.

William Yasnoff

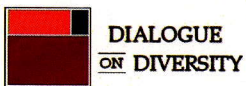


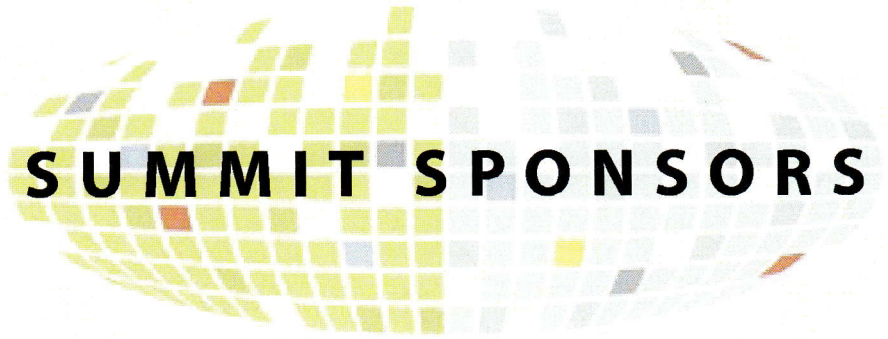
Dr. Yasnoff, a well-known national leader in health informatics, is Founder and Managing Partner of NHII Advisors, a consulting firm that helps communities and organizations successfully develop health information infrastructure systems and solutions. Previously, as Senior Advisor, NHII, Department of Health and Human Services, he initiated and organized the activities leading to the President's \$50 million FY05 budget request and creation of the Office of the National Coordinator for Health Information Technology, establishing the NHII as a widely recognized national goal. Prior to that, Dr. Yasnoff spent five years at CDC, where he became well-known for his work in public health informatics, including co-editing the textbook *Public Health Informatics and Information Systems*. Earlier, he developed and deployed Oregon's statewide immunization registry, which is still operating successfully today. He is an Associate Editor of the *Journal of Biomedical Informatics*, Adjunct Professor of Health Sciences Informatics at Johns Hopkins University and Health Management and Systems Sciences at the University of Louisville, was a Board Member of the American Medical Informatics Association in 2003-4, and is the author of over 250 publications and presentations, including the "Health Information Infrastructure and Public Health Informatics" chapter in the 3rd Edition of the widely-used textbook *Biomedical Informatics: Computer Applications in Healthcare and Medicine*. Dr. Yasnoff earned his Ph.D. in computer science and M.D. from Northwestern, was elected a Fellow of the American College of Medical Informatics in 1989, and in 2006 was recognized for his achievements with an honorary DrPH from the University of Louisville.

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