IN MEMORIAM

Alan F. Westin
“The Father of Modern Day Privacy”
1929—2013

“Privacy is the claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.”

—Alan F. Westin, Privacy and Freedom
Bill Turner, CICSIO
Chief Privacy & Security Officer, Allium Healthcare

Mr. Turner is a Senior Leader with over 20 years of Healthcare Privacy, Security and Information Technology. His expertise is in analyzing the changes and additions to new federal and state regulations that affect privacy and security, and he has extensive experience leading, building and protecting health information. Before joining Allium, Bill held positions as Chief Security Officer for APS Healthcare, Director of Technology and Strategy for a 90 county children’s hospital system, and as Director of Client Enterprise Services for VHA a network of 1,800+ community-owned hospitals and 8,000+ physicians. He also worked in the defense industry working in Advanced Electronic Warfare. Mr. Turner holds a degree in Social Work with an emphasis on social statistics from the University of Texas at Arlington. He has completed advanced coursework at Kellogg School of Business, Southern Methodist University, MIT, and Harvard Business School.

Gen Kelsang Varahi
Resident Teacher, Vajrayogini Buddhist Center
Western Buddhist nun Gen Kelsang Varahi is a close disciple of Geshe Kelsang Gyatso, a renowned Buddhist Master and founder of the New Kadampa Tradition. She was appointed Resident Teacher at Vajrayogini Buddhist Center by Geshe Kelsang in 2000. She has been teaching Buddhism in the Washington, DC and metropolitan area for over 17 years and given public talks around the country and on the radio. Prior to her ordination, she was a graduate of Georgetown University Medical School and practiced medicine for over 22 years of experience. Gen Varahi brings sharp humor to her teachings on Buddhism and to her examples for applying Buddhist principles in daily life. She is remarkable in her love for studying the Dharma and how accessible her teachings are to her students.

Ronald S. Walters, M.D., M.S., M.B.A.
Associate VP of Medical Operations & Informatics; Professor of Clinical Medicine; Medical Director, Managed Care Programs; Medical Director, Texas MD Anderson Program; University of Texas MD Anderson Center; Houston, TX

Ron Walters is an associate vice president of medical operations and informatics at The University of Texas MD Anderson Cancer Center in The Texas Medical Center, applying more than 30 years of experience and knowledge here at MD Anderson. Dr. Walters is a breast medical oncologist and is responsible for the professional aspects of Clinical Operations including Medical Informatics, the Tumor Registry, the Transfer Center, Managed Care Programs, Uncompensated Charity Care, Clinical Safety and Effectiveness and our Physicians Network. He serves on multiple institutional committees striving for improvements in patient care, research and our support systems. Dr. Walters’ pursued his MBA at the University of Houston. He completed a masters program in the management of computing and information systems at Houston Baptist University.

Candice Weatherly, JD
Compliance & Privacy Manager
Candice Weatherly is the Compliance and Privacy Manager for CenterLight Health System, an integrated Long Term Care provider and former Long Term Care Organization in New York. She is responsible for managing CenterLight’s Privacy Program, including developing and administering all HIPAA training programs, conducting privacy investigations, facilitating the breach analysis and notification process, and overseeing the enterprise-wide privacy program awareness campaign, in addition to many compliance responsibilities. Prior to joining CenterLight, Ms. Weatherly served as the Assistant Manager, Compliance and Privacy Analyst for MetroPlus Health Plan. She is a licensed attorney in the State of New York and holds a Juris Doctor from The Benjamin N. Cardozo School of Law in NYC and a Bachelor of Arts degree in Journalism and Communications from The Pennsylvania State University. She is Certified in Healthcare Compliance (CHC) and Certified in Healthcare Privacy Compliance (CHPC) from the Compliance Certification Board (CCB) and is a member of the Health Care Compliance Association (HCCA).

Scott Weinstein, JD
Presidential Management Fellow, Office of the CPO, HHS
Mr. Weinstein is a Presidential Management Fellow in the Office of the Chief Privacy Officer in the Department of Health and Human Services. He is currently on a 6 month rotational assignment at the White House Office of National Drug Control Policy. He was the project manager for the Data Segmentation for Privacy Initiative, which identified an interoperable, standards-based way of enforcing granular disclosure policies. Mr. Weinstein earned a Juris Doctorate at The George Washington University Law School and a Graduate Certificate in Health Policy at The George Washington University School of Public Health and Health Services. While at graduate school, Mr. Weinstein was a research assistant at The George Washington University Department of Health Policy and co-authored two white papers on patient privacy: Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis and Data Segmentation In Electronic Health Information Exchange: Policy Considerations and Analysis. Mr. Weinstein earned his bachelor's degree at Georgetown University.

David Wiggin
Program Director, Healthcare & Life Sciences, Teradata

David Wiggin is the Program Director of Healthcare and Life Sciences for Teradata Corporation. His responsibilities include global industry strategy, marketing, offering development and field enablement and support. He is also a faculty member with the International Institute for Analytics, Health Care Analytics Research Council, and a regular speaker at Duke University Health Sector events. Prior to joining Teradata, David was with the healthcare business of Thomson Reuters. He has worked in a variety of roles including product management and development, data warehousing, operations management, and systems architecture. He has also held executive and management positions at Stern Stewart & Co. and Exxon Corporation.
Dear Friends,

On behalf of Patient Privacy Rights and the bipartisan Coalition for Patient Privacy, welcome to the 3rd International Summit on the Future of Health Privacy. Representing 10.3 million Americans, we work together to ensure that technology, policy, and law guarantee individuals the right to retain control over their sensitive health information.

Every year, millions of patients hide information or avoid or delay treatment for serious medical conditions due to privacy concerns. Without trustworthy systems, patients will continue to risk their health in an attempt to keep sensitive data private. To help make sure patients are willing to seek the care they need, we must move towards technologies that allow patients to control how their information is used and exchanged. In doing so, the U.S. can improve healthcare quality, transform research, lower costs, and prevent bad outcomes.

The Summit offers fresh perspectives on health privacy problems and solutions. The thoughtful debates we will have will play a significant role in raising public awareness and moving us towards privacy-preserving systems.

This is an auspicious year for privacy. President Obama’s 2012 Consumer Privacy Bill of Rights illuminated the gaps in data privacy protections in all sectors of the U.S. economy. Global interest in making health data available for commercial use is quickly growing. The European Union is revising its data protection framework to ensure personal data remains strongly protected in the EU. The 2013 Omnibus Privacy Rule took big steps to improve data security, but also weakened Congress’ intended privacy protections for health data.

Major corporations and technology start-up firms are responding to citizens’ concerns about the hidden collection and use of personal information; they are building privacy-enhancing products that give individuals control over personal data. Through our conversations at the Summit, we hope more companies will be encouraged to demonstrate respect for privacy by incorporating privacy-protective options when designing new software.

It is a great privilege to welcome Todd Park, United States Chief Technology Officer, as a keynote speaker. Mr. Park has the difficult job of helping the U.S. navigate the complex issues and infinite possibilities technology presents for collection and use of personal data. We are thankful the Obama Administration honors the key role Patient Privacy Rights and other organizations play in ensuring that the right to privacy is maintained in the Digital Age.

We are deeply honored that Peter Hustinx, the European Data Protection Supervisor, will give the opening keynote. Mr. Hustinx has the job of overseeing data protection for all citizens of the European Union. His keynote sets the stage for the many conversations we will have about health data privacy inside and outside of traditional healthcare systems, both in the U.S. and around the globe.

We also thank our academic and industry partners, international guests, government experts, and members of the bipartisan Coalition for Patient Privacy, for their participation and continued support. Most of all, we thank the American people for supporting this unique forum to examine urgent health privacy issues and solutions.

Regards,

Deborah C. Peel, MD
Founder & Chair
Patient Privacy Rights

David Staggs, JD
Chief Technology Officer (CTO), Jericho Systems Corporation
CTO David Staggs is a computer engineer and patent attorney with 30 years of experience in engineering information systems, defining business requirements, leading teams, and developing security standards. Prior to joining Jericho, Staggs managed a team supporting the Nationwide Health Information Network (NwHIN) / Virtual Lifetime Electronic Record (VLER) project sponsored by the Veterans Health Administration (VHA) within the Department of Veterans Affairs (VA). Staggs holds a J.D. from Thomas Jefferson School of Law, two B.A.s from University of California, Santa Cruz, and certification as an Information Systems Security Professional (CISSP). He has authored eight technical standards.

Latanya Sweeney, PhD
Professor, Harvard University
Latanya Sweeney, PhD has made a career of weaving technology and policy together. She has made numerous discoveries related to identifiable and privacy technologies and her work has received awards from numerous organizations, including the American Psychiatric Association, the American Medical Informatics Association, and the Blue Cross Blue Shield Association. Dr. Sweeney’s work has appeared in hundreds of news articles, numerous academic papers, was cited in the original publication of the HIPAA Privacy Rule and was praised in the TPAC Report that reviewed the Total Information Awareness Project of DARPA. She has also testified before the Privacy and Integrity Advisory Committee of the Department of Homeland Security and the European Union Commission. Dr. Sweeney currently serves as a Professor of Government and Technology in Residence at Harvard University and is the Director of the Data Privacy Lab at Harvard. She received her PhD in computer science from the Massachusetts Institute of Technology. Her undergraduate degree in computer science was completed at Harvard University.

Nicolais P. Terry, JD
Hall Render Professor of Law & Co-Director of the Hall Center for Law & Health, Indiana University McKinney School of Law
Nicolais P. Terry is the Hall Render Professor of Law at the Indiana University-Purdue University Indianapolis School of Law. He serves as Co-Director of the Hall Center for Law and Health. Professor Terry teaches Torts, Products Liability, Health Information Technology, Law & Science, and Health Care Quality. Educated at Kingstone University and the University of Cambridge, Professor Terry began his academic career as a member of the law faculty of the University of Exeter in England before joining the faculty at Saint Louis University School of Law. From 1996-1997 he was Director of Legal Education at LEKIS-NEXIS. He has been a Senior Fellow at Melbourne Law School and held visiting faculty positions at the law schools of Santa Clara University, the University of Missouri-Columbia, Washington University, and the University of Iowa. From 2000 to 2008 Professor Terry served as co-director of Saint Louis University’s Center for Health Law Studies and from 2008 to 2010 as the School of Law’s Senior Associate Dean. Professor Terry’s research interests lie primarily at the intersection of medicine, law, and information technology. He is one of the permanent bloggers at the HealthLawProf blog.

Aaron Titus, JD
Chief Privacy Officer, Identity Finder
Aaron Titus is an attorney specializing in Internet, Technology and Privacy law, and the Chief Privacy Officer for Identity Finder. Before coming to Identity Finder, Aaron spent four years as the Privacy Director for the Washington DC policy institute Liberty Coalition. He also developed Privacy Commons and NationalIDWatch.org. Mr. Titus is a member of a broad range of working groups, policy organizations, and privacy standards development organizations, including the Identity Ecosystem Steering Group, Privacy Coalition, several Kantara Privacy working groups, the Identity Commons Stewards Working Group, and others.

Micky Tripathi, PhD
President & Chief Executive Officer, MA eHealth Collaborative
Micky Tripathi is President & CEO of the Massachusetts eHealth Collaborative (MeHC). He is also Chairman of the Board of Directors of the eHealth Initiative, the Chair of the Information Exchange Working Group of the national Health Information Technology Policy Committee, and a member of the Board of Directors of the New England Health Exchange Network. Prior to joining MeHC, Dr. Tripathi was a manager in the Boston office of the Boston Consulting Group. While at BCG, he served as the founding President and CEO of the Indiana Health Information Exchange. He holds a PhD in political science from the MA Institute of Technology, a Master of Public Policy from Harvard University, and an AB in Political Science from Vassar College.
The Value of Health Data vs. Privacy

Ronald Ross, PhD
Computer Scientist, NIST Fellow. National Institute of Standards & Technology (NIST). His areas of specialization include information security and risk management. Dr. Ross leads the Federal Information Security Management Act (FISMA) Implementation Project, where he is the principal architect of the Risk Management Framework and multi-tiered approach for integrating the suite of FISMA standards and guidelines into a comprehensive enterprise-wide information security program. Dr. Ross also leads the Joint Task Force Transformation Initiative, which aims to develop a unified information security framework for the federal government. Dr. Ross previously served as the Director of the National Information Assurance Partnership and received the Scientific Achievement Award and the Defense Superior Service Medal. He is also a three-time recipient of the Federal 100 award and a recipient of the Department of Commerce Gold and Silver Medal Awards. Dr. Ross has been inducted into the Information Systems Security Association (ISSA) Hall of Fame and given its highest honor of ISSA Distinguished Fellow.

Theodore Ruger, JD
Professor of Law, University of Pennsylvania Law School

Theodore Ruger, JD, is a professor at the University of Pennsylvania Law School, where he teaches and writes in the fields of health law, constitutional law, food and drug law, and statutory interpretation. Before joining Penn Law’s faculty in September 2004 Ruger was a law professor for three years at Washington University in St. Louis, and prior to that practiced health law and general litigation at Williams & Connolly in Washington, D.C and Ropes & Gray in Boston. Ruger clerked for Justice Stephen Breyer on the U.S. Supreme Court and Judge Michael Boudin on the U.S. First Circuit Court of Appeals. In fall 2012 he was Visiting Professor of Law at New York University School of Law.

David “Doc” Searls
Journalist; Director of Project VRM, Harvard University; Fellow, CITS, University of California at Santa Barbara

Doc Searls is the author of The Intention Economy: When Customers Take Charge (Harvard Business Review Press, 2012), and co-author of The Cluetrain Manifesto: The End of Business as Usual (Basic Books, 2000, 2010). He is also Senior Fellow at Linux Journal, a fellow at the Center for Information Technology & Society at UC Santa Barbara, and founder of ProjectVRM at the Berkman Center for Internet & Society at Harvard University, where he served as a fellow from 2006 to 2010. Currently, he is a visiting scholar at the Arthur L. Carter Journalism Institute at NYU.

Brian Selfridge, CISSP
Managing Director, Meditology Services

Mr. Selfridge currently serves as Managing Director at Meditology Services, which achieves successful outcomes to a healthcare organization’s technology challenges by providing experienced professionals who deliver high-quality, reliable, and responsive services. There, he is responsible for Meditology’s IT Risk Management Services practice, which is dedicated to delivering expertise and leadership in information security, privacy, and security, compliance, and audit, specifically for healthcare. Prior to joining Meditology, Mr. Selfridge served as the Chief Information Security Officer (CISO) for AtlantaCare and as a Senior Security Consultant with PricewaterhouseCoopers, LLP. He also served as one of the founding members of the Anti-Spam investigation unit for the Pennsylvania Office of Attorney General, Bureau of Consumer Protection, where he investigated and prosecuted sources of unsolicited emails for Pennsylvania residents.

Kathryn Serkes
Founder, Doctor Patient Medical Association

Kathryn Serkes is Chair and Co-Founder of the Doctor Patient Medical Association (DPMA) and the Patient Power Alliance, the first national group of patients AND doctors working for freedom in medicine, which was prompted by grassroots activism during the debate on healthcare reform in 2009-2010. She was one of the chief strategists organizing the efforts against socialized medicine legislation, speaking at more than 35 rallies and town halls, and appearing on numerous radio and television shows.

Natasha Singer
Reporter, The New York Times

Natasha Singer is a reporter for The New York Times where she covers the business of consumer data and writes a monthly column called Slipstream. Her Sunday Business series on the surveillance economy, called “You for Sale,” won a 2012 Best in Business award for personal finance journalism from the Society of American Business Editors and Writers. Ms. Singer previously covered the pharmaceutical industry and medical ethics, also for the Business section. She was part of a team at The Times whose investigative series on cancer, “The Forty Years War,” was a finalist for a Pulitzer Prize in explanatory reporting in 2010. She also developed the Skin Deep column for The Times’ Thursday Styles section, where she covered the beauty industrial complex. Prior to joining The Times in 2005, she was a correspondent for Outside Magazine and a health and beauty editor at W Magazine. She also worked in Russia as the Moscow bureau chief of The Forward, the editor-at-large of Russian Vogue, and a correspondent for Women’s Wear Daily.
## Agenda

**WEDNESDAY, JUNE 5, 2013**

**Hart Auditorium, McDonough Hall**

Georgetown University Law Center
600 New Jersey Avenue, NW
Washington, D.C. 20001

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<tr>
<th>Time</th>
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<tr>
<td>7:30–8:40 am</td>
<td>Registration &amp; Light Breakfast</td>
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<tr>
<td>8:40–8:50 am</td>
<td>Opening &amp; Introduction</td>
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<td>Lawrence O. Gostin, JD, O'Neill Institute for National &amp; Global Health Law</td>
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<td>Deborah C. Peel, MD, Patient Privacy Rights</td>
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<tr>
<td>8:55–9:45 am</td>
<td>Opening Keynote: “A Health Check on Data Privacy”</td>
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<td>Peter Hustinx, European Data Protection Supervisor</td>
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<td>Q &amp; A</td>
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<td>9:50–11:15 am</td>
<td>The Value of Health Data OUTSIDE Healthcare</td>
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<td>Moderator: Natasha Singer, New York Times</td>
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<td>Panelists: Michelle DeMoor, Consumer Action; Ranieri Guerra, MD, Italian Embassy</td>
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<td>Cora Han, JD, Federal Trade Commission; David “Doc” Searls, Harvard University; David Wiggin, Teradata</td>
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<td>11:30–12:20 pm</td>
<td>Presentation of theDataMap™</td>
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<td>Latanya Sweeney, PhD of Harvard University’s Data Privacy Lab will present the progress of theDataMap™</td>
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<td>Q &amp; A</td>
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<td>12:20–1:15 pm</td>
<td>Lunch</td>
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<td>Provided in McDonough Atrium upstairs from Hart Auditorium</td>
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<td>1:15–2:05 pm</td>
<td>Keynote: “The Constitution &amp; Privacy: Why the Supreme Court Cares”</td>
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<td>Marc Rotenberg, JD, Executive Director of the Electronic Privacy Information Center (EPIC)</td>
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<td>Following his keynote, Ted Ruger from the University of Pennsylvania Law School will serve as the discussant.</td>
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<td>Q &amp; A</td>
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**William Pewen, PhD**
Assistant Professor of Public Health, Marshall University
Dr. William Pewen is Assistant Professor of Public Health and Family Medicine at Marshall University. He holds both a doctorate in Infectious Diseases and Microbiology and M.P.H. in Epidemiology from the University of Pittsburgh. His work has included cardiology research at UC San Diego and the Veterans Administration, where he also worked in early efforts to create an electronic health record. Dr. Pewen subsequently developed both systems and applications software used in research and medical applications. In 2003, Dr. Pewen was named a Congressional Fellow of the American Society for Microbiology. He subsequently served as Senior Health Policy Advisor to U.S. Senator Olympia J. Snowe. His congressional legislative and oversight work included a broad spectrum of health policy issues, which culminated in work in the creation of health reform legislation which formed the core of the enacted Patient Protection and Affordable Care Act (ACA).

**Deborah C. Peel, MD**
Founder & Chair, Patient Privacy Rights
Dr. Peel has been a practicing physician and psychoanalyst for over thirty years. In 2004, she formed Patient Privacy Rights (PPR), which has become the nation’s and the world’s leading consumer health privacy advocacy organization. PPR has over 12,000 members in all 50 states, and leads the bi-partisan Coalition for Patient Privacy, representing over 10.3 million Americans. In 2011, she conceived the idea of the 1st International Summit on the Future of Health Privacy, partnering with the University of Texas LBJ School of Public Affairs and many others to make it a reality.

**Joy Pritts, JD**
Chief Privacy Officer, Office of the National Coordinator for Health IT, HHS
Joy Pritts joined the Office of the National Coordinator for Health Information Technology (ONC) in February 2010 as Chief Privacy Officer. Ms. Pritts provides critical advice to the Secretary and the National Coordinator in developing and implementing ONC’s HITECH privacy and security programs. She works closely with the Office for Civil Rights and other operating divisions of HHS, as well as with other government agencies to help ensure a coordinated approach to key privacy and security issues.

**James C. Pyles, JD**
Co-Founder & Principal; Powers, Pyles, Sutter & Verville
Jim Pyles is a co-founder of Powers, Pyles, Sutter, & Verville and has nearly 40 years of experience in litigation, counseling, and lobbying in the field of health law. Mr. Pyles has more than 20 years of experience in the law of health information privacy at all levels of the federal judiciary, both houses of Congress, and with the Executive branch of the government. Mr. Pyles has testified on numerous occasions before Congress, appeared in court as an expert witness, and made numerous appearances on national television.

**Patricia Rehmer, MSN**
Commissioner, Department of Mental Health & Addiction Services
Pat Rehmer began her career in 1982 as a staff nurse at The Institute of Living in Hartford, Connecticut and became the Chief Executive Officer at Capitol Region Mental Health Center. In 2003, Ms. Rehmer was appointed to serve on the Executive Management team of the Department of Mental Health & Addiction Services, where she assisted with strategic planning, and clinical program design to ensure that value driven, cost effective care was available throughout the state. She was later appointed to the position of Deputy Commissioner for DMHAS, then nominated and confirmed as Commissioner in 2009 and 2010. Her responsibilities include oversight of the Department that oversees behavioral health care for over 90,000 individuals annually. She has also been responsible for oversight of a budget of 700 million dollars and has worked closely with Federal agencies to secure additional funding for prevention, services and Research opportunities. Ms. Rehmer earned a Bachelor’s degree in Nursing from Stidmore College in 1981 and a Master of Science in Nursing from St. Joseph College in 1988.

**Jordan Robertson**
Reporter, Bloomberg News
Jordan Robertson is a technology writer in the San Francisco office 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.
The Value of Health Data vs. Privacy

Scott Monteith
Physician & Medical Informaticist, Michigan University
Dr. Scott Monteith is a graduate of the University of Michigan and Michigan State University. He was chief resident in his psychiatric residency, is board-certified in psychiatry, and a Fellow of the American Psychiatric Association. He is a Clinical Assistant Professor in the departments of Psychiatry and Family Medicine at Michigan State University, has worked with his local community mental health center for nearly 20 years, and is a founder of Behavioral Medicine Associates, PLLC.

Sherri Morgan, JD
Associate Counsel, Legal Defense Fund, National Association of Social Workers
Sherri L. Morgan, MSW, JD, is Associate Counsel to the National Association of Social Workers (NASW) Legal Defense Fund (LDF) and Office of Ethics and Professional Review. NASW is the largest professional association of social workers in the world with nearly 140,000 individual members. Morgan advises NASW’s national and state leaders and staff on legal, ethical and policy issues and responds to social workers’ legal concerns nationally. She has written and edited numerous legal reference publications for social workers, including titles in the NASW Law Notes Series and 110 LDF “Legal Issue of the Month” articles. She has primary responsibility for the Association’s HIPAA privacy and security resources and national HIPAA training materials for member social workers. Morgan facilitates NASW’s participation as amicus curiae in significant legal cases in state and federal appellate courts, including such issues as confidentiality of mental health records, psychotherapist-patient privilege, and client decision-making autonomy. With training and experience as both an attorney and a clinical social worker, she has previously served as the legislative liaison for the Maryland Chapter of NASW and as a clinician and manager for Family & Children’s Services in Baltimore, Maryland. Morgan holds a Master of Social Work degree and a Juris Doctor from the University of Maryland in Baltimore.

David Muntz
Principal Deputy National Coordinator
Office of the National Coordinator for Health IT, U.S. Department of Health & Human Services
David Muntz serves as the Principal Deputy National Coordinator at the Office of the National Coordinator for Health Information Technology (ONC), U.S. Department of Health and Human Services in Washington, DC. In this role, David works directly with the National Coordinator, Dr. Farzad Mostashari, and oversees the activities of the four offices within ONC. Prior to joining ONC, Mr. Muntz was the Senior Vice President and Chief Information Officer for the Baylor Health Care System. For the first 18 years of his career, David worked at the Wadley Research Institute and Blood Bank in Dallas, Texas, starting as a biostatistician and ultimately assuming the role of CEO. He returned to health care information technology (IT) at Texas Health Resources, where he functioned as Senior Vice President and Chief Information Officer for 15 years. In 2011, he was included on Information Week 500’s inaugural list of the “Top 25 Most Influential Leaders in Healthcare IT” and profiled as one of eight “Health IT Leaders to Watch” by Health Data Management.

Asim Padela, MD
Assistant Professor of Medicine, Emergency Medicine & General Internal Medicine, University of Chicago
Dr. Asim Padela is an Assistant Professor of Medicine and the Director of the Initiative on Islam and Medicine at the University of Chicago. He also serves as faculty at the MacLean Center for Clinical Medical Ethics. Dr. Padela’s scholarship focuses on the intersection of religion, ethics, and minority health through the experiences of American Muslim patients and healthcare providers. Dr. Padela completed undergraduate degrees in Biomedical Engineering and Classical Arabic & Literature at the University of Rochester, an MD from Weill Cornell Medical College, and an MS in health research from the Univ. of Michigan. His Islamic studies training began at Darul Hanania, a traditional seminar, and have continued with traditional ‘ulema in Islamic theological, fiqh, and Qur’anic studies. In 2010 he was also a Visiting Fellow at the Centre of Islamic Studies at Oxford University, working on projects related to Islamic theological ethics and moral obligation. He continues his studies and Islamic bioethics work with scholars at Darul Gasiim in Chicago.

Frank Pasquale, JD
Schering-Plough Professor in Health Care Regulation & Enforcement, Seton Hall University School of Law
Along with his current roles at Seton Hall Law School and Yale Law School, Mr. Pasquale was the Chair of the American Association of Law Schools’ Section on Privacy and Defamation in 2011. He has been a visiting professor at Yale and Cardozo Law Schools, and a visiting fellow at Princeton’s Center for Information Technology Policy. Pasquale has testified before Congress (appearing with the General Counsels of Google and Microsoft), and has twice presented to committees at the National Academy of Sciences on surveillance technologies. He received a JD from Yale Law School, a M. Phil from Oxford University, and a BA summa cum laude from Harvard University.
The Value of Health Data vs. Privacy How Can the Conflict Be Resolved

THURSDAY, JUNE 6, 2013

8:20–8:50 am Registration & Light Breakfast

8:55–9:25 am Opening Keynote: "Information is Powerful Medicine"
Leon Rodriguez, Director of the Office for Civil Rights of the Department of Health and Human Services

9:30–10:00 am Patient Story About Loss of Privacy
Scott Monteith, MD will interview a patient whose health information became readily available online without her knowledge or consent.

10:05–11:15 am The Value of Health Data INSIDE Health Care
Moderator: Joseph Conn of ModernHealthcare.
Panelists: David Chao, PhD, The Advisory Board; Barbara Evans, JD, University of Houston Health Law & Policy Institute; Anil Jain, MD, Explorys; David Muntz, HH/HS/ONC; Kathryn Serkes, Doctor Patient Medical Association

11:30–12:30 pm Day 2 Breakout Sessions

2A: CIOs and Privacy
Moderator: Cliff Baker, Meditology Services
Panelists: M. Peter Adler, JD, SRA International, Inc.; Leo Dittemore, Healthcare Partners; Omar Khawaja, Verizon; Bill Turner, Allium Healthcare

2B: The Omnibus Privacy Rule – Are We Done Now?
Moderator: Nicolas P. Terry, JD, Indiana University McKinney School of Law
Panelists: Susan McAndrew, JD, Office for Civil Rights; Sherri Morgan, JD, National Association of Social Workers; Brian Selfridge, CISSP, Meditology Services; Candice Weatherly, JD, CenterLight Health System

2C: Newtown & the Privacy of Psychiatric Data
Moderator: H. Westley Clark, MD, Substance Abuse & Mental Health Services Administration
Panelists: Demelza Baer, JD, American Civil Liberties Association; James C. Pyles, JD, Powers Pyles Sutter & Verville; Patricia A. Rehm, Department of Mental Health & Addiction Services

Kimberly Little, PhD
Director of Market Planning, Identity Management Solutions, LexisNexis
Kimberly Little, Director of Identity Management Strategy, LexisNexis® Risk Solutions is responsible for identifying and guiding LexisNexis’ solution response to the constantly evolving market needs for identity proofing and multiple factors authentication in commercial and government organizations. With nearly 20 years of experience leading global business strategy, product management, and technology business consulting, Kim’s responsibilities have spanned collaborating on international standards, cross-industry best practices and benchmarking to developing best-of-breed solution offerings. Kim is active in a number of broader industry initiatives ranging from serving on the Management Council of the Identity Ecosystem Steering Group (IDESG) to the Open Identity Exchange and the UT-Center for Identity.

Mark Luker, PhD
Associate Director of the National Coordination Office, The Networking and Information Technology Research & Development Program
Dr. Mark A. Luker is the Associate Director of the National Coordination Office for the Networking and Information Technology Research and Development Program (NITRD). His appointment comes after joining the National Institute of Standards and Technology (NIST), Information Technology Laboratory (ITL). Prior to joining NIST, he served as a Telecommunications Policy Specialist at the National Telecommunications and Information Administration in the U.S. Department of Commerce on the Broadband Technology Opportunities Program (BTOP). Dr. Luker has also served as the Vice President (VP) of EDUCAUSE, where he led the Washington DC-based EDUCAUSE policy program as well as Net@EDU. He has also served as the Program Director for advanced networking at the National Science Foundation and as the CIO of the University of Wisconsin-Madison campus. Dr. Luker received his Ph.D. in Mathematics from the University of California, Berkeley and served as a faculty member in computer science and as Acting Dean of Science and Engineering at the University of Minnesota, Duluth.

Susan McAndrew, JD
Deputy Director for Health Information Privacy, Senior Policy Specialist, Office for Civil Rights, HHS
Susan D. McAndrew is the Deputy Director for Health Information Privacy and Security, Office for Civil Rights (OCR) at the United States Department of Health and Human Services. As Deputy Director, Ms. McAndrew has responsibility for developing, implementing and enforcing the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules. She began her work on the HIPAA Privacy Rule for HHS in May 2000 and serves as the senior advisor to the Director of OCR on health information privacy matters. Ms. McAndrew has over 20 years of federal government experience. Ms. McAndrew received her J.D. from Georgetown University Law Center.

John McDaniel
Healthcare CIO, NetApp
John McDaniel has more than 35 years of experience as a healthcare CIO, consulting services executive and as an executive with large healthcare solution companies. John currently works with NetApp and is responsible for cultivating C-level executive relationship, understanding emerging requirements and collaborating with the development teams at NetApp to ensure NetApp’s solutions meet market-driven operational, scalability and cost efficiency requirements. John also manages NetApp’s partnerships with large healthcare GSI’s. As a CIO, John worked with St. Vincent Catholic Medical Center, McLaren Health Care Corporation and The Emory Clinic where he also served as Director of Medical Informatics. John served as a member of the Board of Directors for NYC-based HIE: NYCLIX. As a consulting services executive he worked with Deli Services, Deloitte Consulting and EMR Transitions. Serving the clinical applications space, John has worked with Siemens as Project Director and was SVP at, McKesson.

Maneecha Milath
Associate Director, Division of Privacy and Identity Protection, Federal Trade Commission, Bureau of Consumer Protection
Maneecha Milath is the Associate Director of the Federal Trade Commission's Division of Privacy and Identity Protection. In this capacity, she supervises work in the area of data security, identity theft, credit reporting, behavioral advertising, and general privacy. She has held numerous positions with the Federal Trade Commission, including Chief of Staff of the Bureau of Consumer Protection and Assistant Director of the International Division of Consumer Protection. Prior to joining the Federal Trade Commission in 1999, Ms. Milath was an attorney at the Washington law firm of Covington & Burling, where she practiced in the commercial litigation, international litigation, and legislative areas. Ms. Milath earned her law degree from the Georgetown University Law Center and her undergraduate degree from Georgetown University.

Pablo Molina, PhD
Adjunct Professor, Georgetown University
Pablo Molina has been Associate Vice President for Information Technology since 2007 and Campus Chief Information Officer since 2000 at Georgetown University. He regularly speaks at conferences on technology in law and higher education, such as Computer Assisted Legal Instruction, American Bar Association, etc. Pablo serves on national higher education committees and served recently as chair of the EDUCAUSE's Evolving Technologies Committee.
The Value of Health Data vs. Privacy

How Can the Conflict Be Resolved

11:30–12:30 pm
Continuation of Breakout Sessions

2D: Consent for Research -- Do We Need It?
Moderator: Ron Walters, MD, MD Anderson Cancer Center
Panelists: Phil Booth, medConfidential; Kelly Caine, PhD, Clemson University School of Computing; Adrian Gropper, MD, PPR; Micky Tripathi, PhD, MA eHealth Collaborative

2E: What's Next for Data Segmentation
Introduction: Joy Pritts, JD, Office of the National Coordinator for Health IT, Department of Health & Human Services (ONC/HHS)
Moderator: Scott Weinstein, JD, ONC/HHS
Panelists: Matthew Arnheiter, Netsmart; Duane DeCouteau, Edmund Scientific; David Stagg, JD, Jericho Systems

Please proceed to the Washington Court Hotel for the Seated Lunch Keynote
525 New Jersey Avenue, NW, Washington, DC 20001

12:40–1:45 pm
Luncheon Keynote: "Louis Brandeis and the Origins of a Right to Privacy"
Melvin Urofsky, PhD – Biographer of Louis D. Brandeis
Dr. Urofsky will autograph copies of his book after his keynote:
Louis D. Brandeis: A Life

Melvin I. Urofsky
Professor of Law & Public Policy
Virginia Commonwealth University

Melvin I. Urofsky is Professor of Law & Public Policy and Professor Emeritus of History at Virginia Commonwealth University. Before joining VCU as chair of the History Department, he taught at the Ohio State University and the State University of New York at Albany. He was James Pinckney Harrison Visiting Professor of History at the College of William & Mary and from 1995 until his semi-retirement in 2003, he served as the director of the doctoral program in Public Policy & Administration. Mr. Urofsky was a Rich Fellow at Oxford University’s Center for Jewish Studies, a Fulbright Lecturer at the University of New South Wales Law School in Sydney, a Rockefeller Foundation Fellow at the Bellagio Center in Italy, and a visiting scholar at Ben-Gurion University in Israel. He writes widely on constitutional history, and has been the editor for the past seventeen years of the Journal of Supreme Court History. His newest work, Louis D. Brandeis: A Life, was published by Pantheon in September 2009. It won the Jewish Book Council’s Everett Award as the Book of the Year, was chosen for the Ambassador’s Award by the English-Speaking Union of the United States, and the Griswold Prize of the Supreme Court Historical Society.
Keynote Speakers

Peter J. Hustinx
Supervisor
European Data Privacy Supervisor

Peter J. Hustinx has been European Data Protection Supervisor since January 2004. In this position he is entrusted with monitoring and applying the provisions of Regulation (EC) No. 45/2001 to the processing of personal data carried out by the EU institutions and bodies. He is also responsible for advising those institutions and bodies on all matters concerning the processing of personal data.

Mr. Hustinx has been closely involved in the development of data protection legislation from the start, both at the national and at the international level. Before entering his office, he was President of the Dutch Data Protection Authority for a period of more than twelve years. He received law degrees at the University of Nijmegen, the Netherlands (LLM 1970), and at the University of Michigan Law School in Ann Arbor, U.S.A. (MCL 1971).

Todd Park
United States Chief Technology Officer
Office of Science & Technology Policy

In March 2012, Todd Y. Park was appointed the Chief Technology Officer of the United States. In this capacity, he directs the Office of Science and Technology Policy to apply the most current technology and innovative advances to make the Federal government address national challenges and respond better to the needs of American people.

Todd joined the Administration in August 2009 as Chief Technology Officer of the U.S. Department of Health and Human Services (HHS). In this role, he served as a change agent and "entrepreneur-in-residence," helping HHS harness the power of data, technology, and innovation to improve the health of the nation.

Prior to his position at HHS, Mr. Park co-founded Athenahealth and co-led its development into one of the most innovative health IT companies in the industry. He also co-founded Castlight, a web-based health care shopping service for consumers. Mr. Park has also served in a volunteer capacity as a Senior Fellow at the Center for American Progress, where he focused on health IT and health reform policy, and as senior health care advisor to Ashoka, a leading global incubator of social entrepreneurs, where he helped start Healthpoint Services, a venture to bring affordable telehealth, drugs, diagnostics, and clean water to rural India.

Mr. Park graduated magna cum laude and Phi Beta Kappa from Harvard College with an A.B. in economics.

Deborah Golden
Principal, Deloitte & Touche, LLP

Deborah Golden is a Principal in Deloitte & Touche LLP’s Security & Privacy Services practice, with over eighteen (18) years of information technology, security, and privacy experience encompassing various industries, with a specialization in Identity & Access Management, as well as within the Federal, Health Sciences, and Financial Services industries. Deborah previously served as the Deloitte & Touche LLP Security & Privacy leader for Health Plans to provide leadership in the definition and deployment of integrated solutions addressing compliance with regulatory requirements such as HITRUST, HIPAA, and HITECH. Deborah’s primary focus is acting as the Lead Delivery Principal for Technology Risk engagements.

Lawrence O. Ostin, JD
Linda D. and Timothy J. O’Neill Professor of Global Health Law, Faculty Director, Center for Law and the Public’s Health, Georgetown University Law Center

Lawrence O. Ostin, an internationally acclaimed scholar, is the Linda D. and Timothy J. O’Neill Professor of Global Health Law at the Georgetown University Law Center, where he directs the O’Neill Institute for National and Global Health Law. Professor Ostin is the Director of the World Health Organization Collaborating Center on Public Health Law and Human Rights. He is also Professor of Public Health at the Johns Hopkins University and Director of the Center for Law & the Public’s Health at Johns Hopkins and Georgetown Universities.

Bob Gregg
Chief Executive Officer, ID Experts

Bob Gregg joined ID Experts in January 2009. Prior to that he was Executive Vice President of Worldwide Sales and Services for FEI Company, the President and CEO for Unircu, Inc., and the Chief Financial Officer at Sequent Computer Systems. In the initial founding group at Sequent, he was a key player in growing the company from a start-up to over $800 million in revenue with sales in 55 countries. Prior to Sequent, Gregg spent nine years at the international accounting firm Price Waterhouse. He is a C.P.A and a graduate of the University of Oregon.

Adrian Gropper, MD
Chief Technology Officer, Patient Privacy Rights

Dr. Gropper holds an engineering degree from MIT and an MD from Harvard Medical School. Early work on telemedicine and picture archiving and communications systems (PACS) introduced him to MIT’s Guardian Angel project. In 1995, Dr. Gropper founded AMICAS (NAS:AMCS) as the first Web-based radiology PACS and the first to provide direct links to diagnostic imaging in electronic health records. Dr. Gropper founded MedComs and has participated in many early standardization efforts including IHE, HITSP, Liberty Alliance and the Continuity of Care Record steering committee. He also serves on the Massachusetts Health Information Exchange Exchange Technology Workgroup, the Massachusetts Medical Society Committee for Information Technology and Markie Foundation panels. Currently he participates as a patient-access advocate on the NuWHi Direct Project and consults on image-enabling patient portals, NuWHi secure messages and electronic health records as well as health information technology in the cloud.

Ranieri Guerra, MD
Scientific Attaché, Italian Embassy

Ranieri Guerra is a physician, specialized in public health in Italy and the UK. He has practised in several areas of the world, besides Italy, belonging to the small club of visitors to more than 150 countries. His professional interests and experiences range from emergency and rescue operations (especially in war torn areas) to the design and implementation of health reforms in less developed and in transitional countries. Before moving to DC, where he is scientific attaché at the Embassy of Italy, he was research director at the Italian National Institute of Health (where he conducted large trials mainly in telematics and ehealth) and director of health at UNRWA, the UN agency for Palestinian Refugees. He served also in the Technical Review Panel of the Global Fund for AIDS, TB and Malaria and with the EU development aid in several ACP countries.

Cora Han, JD
Attorney, Division of Privacy and Identity Protection, Federal Trade Commission

Cora Tung Han is an attorney in the Federal Trade Commission’s Division of Privacy and Identity Protection where she investigates and prosecutes violations of federal laws protecting the privacy and security of consumer information, and works on related policy matters. Her law enforcement actions have included the Commission’s settlements with Twitter and Facebook. In addition, Cora was one of the principal authors of the FTC’s Health Breach Notification Rule. Prior to joining the FTC, Cora was an attorney with Witiem Culler Pickering Hale and Dorr LLP, where her practice focused on trademark, copyright, and media law. She is a graduate of the University of Chicago Law School.
The Value of Health Data vs. Privacy

Beatrice Covassi
Counselor, Digital Economy & ICT, Delegation of the European Union

Beatrice Covassi works as Counselor for the Digital Agenda and ICT matters at the EU Delegation to the US in Washington DC. Prior to joining the Delegation in October 2010, she was an EU official in the DG Information Society and Media of the European Commission. At DG INFSO she held the position of deputy of the Unit responsible for the Lisbon strategy and i2010 (the Digital Agenda), head of the digital broadcasting sector and assistant to the Director for Electronic Communications Policy. Her areas of specialization include the digital single market and new media. In addition to her native Italian, Ms. Covassi is fluent also in English, French and Portuguese.

Duane DeCouteau
Senior Software Engineer, Edmond Scientific Company

Duane DeCouteau currently leads development efforts in the Dept. of Veterans Affairs (VA), Veterans Health Administration’s (VHA) Emerging Health Technologies Advancement Center(ETHAC), which focuses on the security and privacy needs of our Veterans. Most recently Mr. DeCouteau led the efforts on an advanced technology demonstration of the Office of the National Coordinator for Health Information Technology (ONC) Data Segmentation for Privacy Initiative (DS4P) pilot between VA and Substance Abuse and Mental Health Services Administration (SAMHSA). The pilot utilized a standards-based approach for privacy metadata to achieve interoperability and appropriate sharing of protected information. With the VA, Mr. DeCouteau has co-authored 3 fully ratified international Oasis standards addressing patient security and privacy concerns: the Cross-Enterprise Security and Authorization (XPSA) Profiles of Security Assertion Markup Language (SAML), eXtensible Access Control Markup Language(XACML), and WS-Trust for Healthcare.

Michelle DeMooey
Senior Associate, National Priorities, Consumer Action

Michelle DeMooey, Senior Associate, National Priorities, joined Consumer Action in January 2008 after 10 years of working on behalf of social justice. She advocates for consumers on privacy concerns, both in the digital and health arenas, as well as on issues in pre-dispute mandatory arbitration. Prior to Consumer Action, Michelle was a Senior Consultant for eCampaigns at M&V Strategic Services and provided strategic marketing, communications and technology consulting for non-profits and universities in the Philadelphia area. At the Women’s Law Project in Philadelphia, she aided in the agency’s efforts to pursue high-impact litigation and public policy for gender equality concerns, including reproductive rights, contraceptive equity and Title IX programs.

Debra N. Diener, JD, CIPP/G
Privacy & Identity Management Consultant; Blogger, Privacy Made Simple

Debra N. Diener is a highly regarded consultant providing strategic privacy and identity management guidance and expertise to industry and non-profit organizations. Ms. Diener served in senior legal and policy positions in all three branches of the Federal Government, including as the Deputy Director for Privacy Policy, IRS, and as the Senior Advisor and Director of Privacy Policy, Department of Homeland Security. During her years with IRS and DHS, Ms. Diener was the Co-chair of the Identity Management Subcommittee of the CIO Council’s Privacy Committee where she helped spearhead privacy and identity management collaborations with private sector groups. Ms. Diener has a consumer oriented privacy blog (www.PrivacyMadeSimple.net).

Leo Dittemore
Director of Technical Services, Healthcare Partners

Leo Dittemore is the Director of Information Services Security for DaVita HealthCare Partners – a position he has held for seven years. He has extensive data protection, project management, and systems design and operations experience in all facets of electronic business. He has held technical and managerial positions at other consulting groups, a large computer manufacturer, and aerospace companies prior to joining HealthCare Partners. He has a Bachelor’s degree in Computer Science from West Coast University and done graduate work in information networks at Carnegie Mellon. He is a member of the California Office of Health Information Integrity Policy Steering Team.

Barbara Evans, JD
Professor of Law, Co-director, Health Law & Policy Institute, Director, Center on Biotechnology & Law, University of Houston Law Center

Barbara Evans is a Professor, Co-director of Health Law, and Director of the Center on Biotechnology & Law at the University of Houston Law Center. She is also a Greenwall Foundation Faculty Scholar in Bioethics for the period 2010-2013. Earlier in her career, she was a Moscow-based partner in the international regulatory practice of a large New York law firm and later advised clients on U.S. and European medical device regulatory matters, before serving as Director of the Program in Pharmacogenomics, Ethics, and Public Policy at the Indiana University School of Medicine. Her current research projects include studies of privacy and data access issues affecting large interoperable health data networks and constitutional issues with CLIA regulation of genetic tests.

How Can the Conflict Be Resolved

Keynote Speakers

Leon Rodriguez
Director
U.S. Department of Health & Human Services

Leon Rodriguez is the Director of the Office for Civil Rights of the Department of Health and Human Services. Previously he served as the Chief of Staff and Deputy Assistant Attorney General for the Department of Justice Civil Rights Division. He also led Montgomery County, Maryland as the County Attorney devoting his time working with the County’s Department of Health and Human Services as well as its Office of Human Rights. In 2004, Leon was named “Outstanding Health Care Litigator” by Nightingale Health Care News. While in private practice, Leon served on the board of the Montgomery County Primary Care Coalition, an organization that developed and implemented health care programs for uninsured County residents.

Marc Rotenberg
Executive Director
Electronic Privacy Information Center (EPIC)

Marc Rotenberg is Executive Director of the Electronic Privacy Information Center (EPIC) in Washington, DC. He teaches information privacy law at Georgetown University Law Center and has testified before Congress on many issues, including access to information, encryption policy, consumer protection, computer security, and communications privacy. He testified before the 9-11 Commission on "Security and Liberty: Protecting Privacy, Preventing Terrorism." He has served on several national and international advisory panels, including the expert panels on Cryptography Policy and Computer Security for the OECD, the Legal Experts on Cyberspace Law for UNESCO, and the Countering Spam program of the ITU. He currently chairs the ABA Committee on Privacy and Information Protection. He is the former Chair of the Public Interest Registry, which manages the .ORG domain. He is editor of Privacy and Human Rights and The Privacy Law Sourcebook, and co-editor (with Daniel J. Solove and Paul Schwartz) of Information Privacy Law (Aspen Publishing 2007). He is a graduate of Harvard College and Stanford Law School. He served as Counsel to Senator Patrick J. Leahy on the Senate Judiciary Committee after graduation from law school. He is a Fellow of the American Bar Foundation and the recipient of several awards including the World Technology Award in Law. A tournament chess player, Marc won the 2007 Washington, DC Chess Championship.
Summit Speakers

M. Peter Adler, JD
VP, Health and Cybersecurity Counsel; CFO, Government Affairs; SRA International, Inc.
M. Peter Adler is a Vice President at SRA International, Inc., where he serves as the company’s Chief Privacy Officer and Senior Counsel, Cybersecurity and Health, and leads the Government Affairs Office. In these capacities, he advises the company on compliance with legal and contractual requirements under privacy and cybersecurity laws, regulations and standards. Peter has responsibility for policies and procedures for data privacy and cybersecurity and is the lead attorney for the SRA’s Health Group. Peter previously served as a partner in various law firms located in Washington DC, where he advised clients on U.S. and international cybersecurity and privacy law and regulations. Immediately prior to joining SRA, Peter was the Chief Privacy Officer of UnitedHealth Group.

Matthew Arnhelde, JD
VP, Innovations, Netsmart
Matthew Arnhelde, JD, is the Vice President of Innovations at Netsmart.

Demetra Baer, JD
Policy Counsel, American Civil Liberties Union
As Policy Counsel in the American Civil Liberties Union’s Washington Legislative Office, Ms. Baer focuses on disability rights, racial justice issues, human rights, and housing policy. Ms. Baer previously served as counsel to the U.S. House Judiciary Committee for Representative John Conyers, Jr. Prior to law school, Ms. Baer worked on justice policy research for the Urban Institute. Ms. Baer volunteers with the D.C. Volunteer Lawyers Project, which provides free legal services to low-income D.C. residents in family law cases; she is listed on the 2012 Capital Pro Bono Honor Roll for her volunteer work. Ms. Baer has a J.D. magna cum laude from Tulane University Law School, where she received a Dean’s Scholarship, and served as the Chief Justice of the Tulane Law School Moot Court Board and as a member of the Tulane Journal of Technology & Intellectual Property. She received her B.A. with Honors from Northwestern University.

Cliff Baker
Managing Partner, Meditology Services
Cliff Baker is an industry leader in healthcare information technology risk management, privacy, and security and has over eighteen years of experience in the industry. He has worked with the nation’s leading healthcare organizations across all sectors of the industry, working on multi-year complex system implementations and assisting organizations with board level management decisions. Mr. Baker has served as an executive advisor for key industry affiliations and companies to define reasonable practices that are adopted broadly across the industry. He is the lead author of the HITRUST Common Security Framework and author of various IT Risk Management standards and publications. Prior to leading Meditology, Mr. Baker was the Chief Strategy Officer for HITRUST and also led PricewaterhouseCoopers’ healthcare security practice.

Lara Ballard, JD
Special Advisor for Privacy & Technology, U.S. Department of State
Lara Ballard is currently serving as the Special Advisor for Privacy and Technology in the Office of Communications and Information Policy at the U.S. Department of State. She is the head of the U.S. Delegation to the Working Party on Information Security and Privacy (WPISP) at the Organization for Economic Cooperation and Development (OECD) in Paris and has been an active participant in the OECD’s ongoing review of its 1980 Guidelines Governing the Protection of Privacy and Transborder Flows of Data. She served as an Attorney-Adviser at the State Department from 1999 to 2012. She is a Certified Information Privacy Professional (CIPP) and has served as the State Department lead attorney on privacy and technology law.

Phil Booth
U.K. Privacy Advocate; Founder, medConfidential
Phil Booth is a campaigner for privacy and data protection from the UK. Phil led the non-partisan NO2ID campaign from 2004-2011, campaigning successfully to defeat the introduction of ID cards and other ‘database state’ initiatives. His work has been recognized by awards from Privacy International (2008) and Liberty (2010), and by ministers in Parliament, one of whom described NO2ID as “one of the most successful pressure groups in history”. Phil now coordinates medConfidential, a campaign with partners across the UK and Europe and around the world fighting for patient privacy, consent and confidentiality in health and social care.

Peter A. Bootma, MD
Counselor for Health, Welfare, & Sports, Royal Netherlands Embassy
Peter A. Bootma, M.D. is presently the Counselor for Health, Welfare and Sports at the Royal Netherlands Embassy in Washington D.C. representing Dutch health and welfare interests in the United States and Canada. Previously, Mr. Bootma was Regional Director at the Netherlands Health Care Inspectorate, the (Acting) Director for Innovation, Professions and Ethics at the Netherlands Ministry of Health, and the Counselor for Health at the Netherlands Embassy. Prior to this Washington D.C. assignment, he was Deputy Head of the Bureau for International Cooperation at the Netherlands’ National Institute of Public Health where he was responsible for technical assistance projects and health development projects in West and East-European countries and a part of the former Soviet Union.

Kelly Caine, PhD
Assistant Professor, Clemson University
Kelly Caine is Assistant Professor in the Human-Centered Computing Division of the School of Computing at Clemson University. Additionally, she serves as Senior Research Associate for the Institute for Information Infrastructure Protection and the ACM Special Interest Group on Computer-Human Interaction Health Community co-chair. Dr. Caine’s research sits at the intersection of human factors, privacy and health informatics. Her recent work has focused on designing, building and studying ways to make privacy-enhanced health technologies more user-friendly. She has received numerous awards for her work including best security and privacy paper at the ACM Health Informatics conference and 1st prize at the American Public Health Association conference.

Barry P. Chalken, MD, MPH, FHMSS
Chief Medical Information Officer, Infor; Adjunct Professor, Boston University
Senior Fellow, Institute for Health Technology Transformation
Barry P. Chalken, MD, MPH, FHMSS has over 20 years experience in healthcare information technology, patient safety, clinical transformation, and public health. Chalken is currently Chief Medical Information Officer at Infor where he offers his expertise in strategy development, clinical transformation, and quality improvement. He is board certified in General Preventive Medicine and Public Health, as well as Health Care Quality Management. During his career, he worked with the National Institutes of Health, U.K.’s. National Health Service, McKesson, and BearingPoint. He is currently on the editorial board of the Journal of Patient Safety and the journal of Patient Safety and Quality Healthcare in addition to serving as Conference Chair of the annual Digital Healthcare Conference.

David Chao, PhD
Chief Technology Officer, The Advisory Board
As the Chief Technology Officer of Crimson, David leads product development across the entire Crimson portfolio of products. David has authored 19 publications in refereed journals and has researched the models of fundamental forces of nature, as well as applications of computational techniques, from neural networks to theoretical and experimental physics. David holds a bachelor’s degree and a PhD in physics from the University of Texas at Austin, with research in the field of theoretical particle physics. Prior to Crimson, he was the cofounder of SC Global Strategies and helped lead enterprise software product teams at Softbrands Hospitality and Trilogy.

H. Westley Clark, MD
Director, Center for Substance Abuse Treatment, Substance Abuse & Mental Health Services Administration
Dr. H. Westley Clark is the director of the Center for Substance Abuse Treatment under the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. He leads the agency’s efforts to provide effective and accessible treatment to all Americans with addictive disorders. Dr. Clark’s areas of expertise include substance abuse treatment, methadone maintenance, pain management, dual diagnosis, psychopharmacology, anger management, and medical and legal issues. Dr. Clark has received numerous awards for his contribution to the field of substance abuse treatment and is also a noted author, clinician, teacher and spokesperson in the field of addiction and forensic psychiatry.

Joseph Conn
Reporter, Modern Healthcare
Joseph Conn is a member of Modern Healthcare’s team of reporters. He joined Modern Healthcare in 2001 and reports on information technology, quality, patient safety and the Joint Commission on Accreditation of Healthcare Organizations. Mr. Conn covers healthcare business news in Idaho, Nevada, Utah and Wyoming. His background includes 24 years of reporting and editing with various news publications, teaching journalism at Valparaiso (Ind.) University and working as a Peace Corps volunteer in Sierra Leone. Mr. Conn holds a BA in English from Valparaiso University.

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Assistant Professor, Clemson University

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Barry P. Chalken, MD, MPH, FHIMSS
Chief Medical Information Officer, Infor; Adjunct Professor, Boston University

Senior Fellow, Institute for Health Technology Transformation

Barry P. Chalken, MD, MPH, FHIMSS has over 20 years experience in healthcare information technology, patient safety, clinical transformation, and public health. Chalken is currently Chief Medical Information Officer at Infor where he offers his expertise in strategy development, clinical transformation, and quality improvement. He is board certified in General Preventive Medicine and Public Health, as well as Health Care Quality Management. During his career, he worked with the National Institutes of Health, U.K.’s National Health Service, McKesson, and BearingPoint. He is currently on the editorial board of the Journal of Patient Safety and the journal of Patient Safety and Quality Healthcare in addition to serving as Conference Chair of the annual Digital Healthcare Conference.

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Dr. H. Westley Clark is the director of the Center for Substance Abuse Treatment under the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services. He leads the agency’s efforts to provide effective and accessible treatment to all Americans with addictive disorders. Dr. Clark’s areas of expertise include substance abuse treatment, methadone maintenance, pain management, dual diagnosis, psychopharmacology, anger management, and medical and legal issues. Dr. Clark has received numerous awards for his contribution to the field of substance abuse treatment and is also a noted author, clinician, teacher and spokesperson in the field of addiction and forensic psychiatry.

Joseph Conn
Reporter, Modern Healthcare

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How Can the Conflict Be Resolved

The Value of Health Data vs. Privacy

Summit Speakers

M. Peter Adler, JD
VP, Health and Cybersecurity Counsel; CPO, Government Affairs; SRA International, Inc.

M. Peter Adler is a Vice President at SRA International, Inc., where he serves as the company’s Chief Privacy Officer and Senior Counsel, Cybersecurity and Health, and leads the Government Affairs Office. In these capacities, he advises the company on compliance with legal and contractual requirements under privacy and cybersecurity laws, regulations and standards. Peter has responsibility for policies and procedures for data privacy and cybersecurity and is the lead attorney for the SRA’s Health Group. Peter previously served as a partner in various law firms located in Washington DC, where he advised clients on U.S. and international cybersecurity and privacy law and regulations. Immediately prior to joining SRA, Peter was the Chief Privacy Officer of UnitedHealth Group.

Matthew Armheiter, JD
VP, Innovations, Netsmart

Matthew Armheiter, JD, is the Vice President of Innovations at Netsmart.

Demelza Baer, JD
Policy Counsel, American Civil Liberties Union

As Policy Counsel in the American Civil Liberties Union’s Washington Legislative Office, Ms. Baer focuses on disability rights, racial justice issues, human rights, and housing policy. Ms. Baer previously served as counsel to the U.S. House Judiciary Committee for Representative John Conyers, Jr. Prior to law school, Ms. Baer worked on justice policy research for the Urban Institute. Ms. Baer volunteers with the D.C. Volunteer Lawyers Project, which provides free legal services to low-income D.C. residents in family law cases; she is listed on the 2012 Capital Pro Bono Honor Roll for her volunteer work. Ms. Baer has a J.D. magna cum laude from Tulane University Law School, where she received a Dean’s Scholarship, and served as the Chief Justice of the Tulane Law School Moot Court Board and as a member of the Tulane Journal of Technology & Intellectual Property. She received her B.A. with Honors from Northwestern University.

Cliff Baker
Managing Partner, MediPoint Services

Cliff Baker is a recognized leader in healthcare information technology risk management, privacy, and security and has over eighteen years of experience in the industry. He has worked with the nation’s leading healthcare organizations across all sectors of the industry, working on multi-year complex system implementations and assisting organizations with board level risk management decisions. Mr. Baker has served as an executive advisor for key industry alliances and companies to define reasonable practices that are adopted broadly across the industry. He is the lead author of the HITRUST Common Security Framework and author of various IT Risk Management standards and publications. Prior to leading MediPoint, Mr. Baker was the Chief Strategy Officer for HITRUST and also led PricewaterhouseCoopers’ healthcare security practice.

Lara Ballard, JD
Special Advisor for Privacy & Technology, U.S. Department of State

Lara Ballard is currently serving as the Special Advisor for Privacy and Technology in the Office of Communications and Information Policy at the U.S. Department of State. She is the head of the U.S. Delegation to the Working Party on Information Security and Privacy (WPISP) at the Organization for Economic Cooperation and Development (OECD) in Paris and has been an active participant in the OECD’s ongoing review of its 1980 Guidelines Governing the Protection of Privacy and Transborder Flows of Data. She served as an Attorney-Advisor at the State Department from 1999 to 2012. She is a Certified Information Privacy Professional (CIPP) and has served as the State Department lead attorney on privacy and technology law.

Phil Booth
U.K. Privacy Advocate; Founder, medConfidential

Phil Booth is a campaigner and privacy advocate from the UK. Phil led the non-partisan NO2ID campaign from 2004-2011, campaigning successfully to defeat the introduction of ID cards and other ‘database state’ initiatives. His work has been recognized by awards from Privacy International (2008) and Liberty (2010), and by ministers in Parliament, one of whom described NO2ID as “one of the most successful pressure groups in history”. Phil now coordinates medConfidential, a campaign with partners across the UK and Europe and around the world fighting for patient privacy, consent and confidentiality in health and social care.
The Value of Health Data vs. Privacy

Keynote Speakers

Leon Rodriguez
Director
U.S. Department of Health & Human Services

Leon Rodriguez is the Director of the Office for Civil Rights of the Department of Health and Human Services. Previously he served as the Chief of Staff and Deputy Assistant Attorney General for the Department of Justice Civil Rights Division. He also led Montgomery County, Maryland as the County Attorney devoting his time working with the County’s Department of Health and Human Services as well as its Office of Human Rights. In 2004, Leon was named “Outstanding Health Care Litigator” by Nightingale Health Care News. While in private practice, Leon served on the board of the Montgomery County Primary Care Coalition, an organization that developed and implemented health care programs for uninsured County residents.

How Can the Conflict Be Resolved

Marc Rotenberg
Executive Director
Electronic Privacy Information Center (EPIC)

Marc Rotenberg is Executive Director of the Electronic Privacy Information Center (EPIC) in Washington, DC. He teaches information privacy law at Georgetown University Law Center and has testified before Congress on many issues, including access to information, encryption policy, consumer protection, computer security, and communications privacy. He testified before the 9-11 Commission on “Security and Liberty: Protecting Privacy, Preventing Terrorism.” He has served on several national and international advisory panels, including the expert panels on Cryptography Policy and Computer Security for the OECD, the Legal Experts on Cyberspace Law for UNESCO, and the Countering Spam program of the ITU. He currently chairs the ABA Committee on Privacy and Information Protection. He is the former Chair of the Public Interest Registry, which manages the .ORG domain. He is editor of Privacy and Human Rights and The Privacy Law Sourcebook, and co-editor (with Daniel J. Solove and Paul Schwartz) of Information Privacy Law (Aspen Publishing 2007). He is a graduate of Harvard College and Stanford Law School. He served as Counsel to Senator Patrick J. Leahy on the Senate Judiciary Committee after graduation from law school. He is a Fellow of the American Bar Foundation and the recipient of several awards including the World Technology Award in Law. A tournament chess player, Marc won the 2007 Washington, DC Chess Championship.

Beatrice Covassi
Counselor, Digital Economy & ICT, Delegation of the European Union

Beatrice Covassi works as Counselor for the Digital Agenda and ICT matters at the EU Delegation to the US in Washington DC. Prior to joining the Delegation in October 2010, she was an EU official in the DG Information Society and Media of the European Commission. At DG INFSO she held the position of deputy of the Unit responsible for the Lisbon strategy and i2010 (the Digital Agenda), head of the digital broadcasting sector and assistant to the Director for Electronic Communications Policy. Her areas of specialization include the digital single market and new media. In addition to her native Italian, Ms. Covassi is fluent also in English, French and Portuguese.

Duane DeCouteau
Senior Software Engineer, Edmund Scientific Company

Duane DeCouteau currently leads development efforts in the Dept. of Veterans Affairs (VA), Veterans Health Administration’s (VHA) Emerging Health Technologies Advancement Center(ETHAC), which focuses on the security and privacy needs of our Veterans. Most recently Mr. DeCouteau led the efforts on an advanced technology demonstration of the Office of the National Coordinator for Health Information Technology (ONC) Data Segmentation for Privacy Initiative (DSIP) pilot between VA and Substance Abuse and Mental Health Services Administration (SAMHSA). The pilot utilized a standards-based approach for privacy metadata to achieve interoperability and appropriate sharing of protected information. With the VA, Mr. DeCouteau has co-authored 3 fully ratified international Oasis standards addressing patient security and privacy concerns: the Cross-Enterprise Security and Authorization (XPSA) Profiles of Security Assertion Markup Language(SAML), eXtensible Access Control Markup Language(XACML), and WS-Trust for Healthcare.

Michelle DeMooey
Senior Associate, National Priorities, Consumer Action

Michelle DeMooey, Senior Associate, National Priorities, joined Consumer Action in January 2008 after 10 years of working on behalf of social justice. She advocates for consumers on privacy concerns, both in the digital and health arenas, as well as on issues in pre-dispute mandatory arbitration. Prior to Consumer Action, Michelle was a Senior Consultant for eCampaigns at MrR Strategic Services and provided strategic marketing, communications and technology consulting for non-profits and universities in the Philadelphia area. At the Women’s Law Project in Philadelphia, she aided in the agency’s efforts to pursue high-impact litigation and public policy for gender equality concerns, including reproductive rights, contraceptive equity and Title IX programs.

Debra N. Diener, JD, CIPP/G
Privacy & Identity Management Consultant; Blogger, Privacy Made Simple

Debra Diener is a highly regarded consultant providing strategic privacy and identity management guidance and expertise to industry and non-profit organizations. Ms. Diener served in senior legal and policy positions in all three branches of the Federal Government, including as the Deputy Director for Privacy Policy, IRS, and as the Senior Advisor and Director of Privacy Policy, Department of Homeland Security. During her years with IRS and DHS, Ms. Diener was the Co-chair of the Identity Management Subcommittee of the CIO Council’s Privacy Committee where she helped spearhead privacy and identity management collaborations with private sector groups. Ms. Diener has a consumer oriented privacy blog (www.PrivacyMadeSimple.net).

Leo Dittemore
Director of Technical Services, Healthcare Partners

Leo Dittemore is the Director of Information Services Security for DaVita HealthCare Partners – a position he has held for seven years. He has extensive data protection, project management, and systems design and operations experience in all facets of electronic business. Leo has held technical and managerial positions at other consulting groups, a large computer manufacturer, and aerospace companies prior to joining HealthCare Partners. He has a Bachelor’s degree in Computer Science from West Coast University and done graduate work in information networks at Carnegie Mellon. He is a member of the California Office of Health Information Integrity Policy Steering Team.

Barbara Evans, JD
Professor of Law, Co-director, Health Law & Policy Institute, Director, Center on Biotechnology & Law, University of Houston Law Center

Barbara Evans is a Professor, Co-director of Health Law, and Director of the Center on Biotechnology & Law at the University of Houston Law Center. She is a Greenwall Foundation Faculty Scholar in Bioethics for the period 2010-2013. Earlier in her career, she was a Moscow-based partner in the international regulatory practice of a large New York law firm and later advised clients on U.S. and European medical device regulatory matters, before serving as Director of the Program in Pharmacogenomics, Ethics, and Public Policy at the Indiana University School of Medicine. Her current research projects include studies of privacy and data access issues affecting large interoperable health data networks and constitutional issues with CLIA regulation of genetic tests.
Mr. Hustinx has been closely involved in the development of data protection legislation from the start, both at the national and at the international level. Before entering his office, he was President of the Dutch Data Protection Authority for a period of more than twelve years. He received law degrees at the University of Nijmegen, the Netherlands (LLM 1970), and at the University of Michigan Law School in Ann Arbor, U.S.A. (MCL 1971).

Todd Park
United States Chief Technology Officer
Office of Science & Technology Policy

In March 2012, Todd Y. Park was appointed the Chief Technology Officer of the United States. In this capacity, he directs the Office of Science and Technology Policy to apply the most current technology and innovative advances to make the Federal government address national challenges and respond better to the needs of American people.

Todd joined the Administration in August 2009 as Chief Technology Officer of the U.S. Department of Health and Human Services (HHS). In this role, he served as a change agent and "entrepreneur-in-residence," helping HHS harness the power of data, technology, and innovation to improve the health of the nation.

Prior to his position at HHS, Mr. Park co-founded Athenahealth and co-led its development into one of the most innovative health IT companies in the industry. He also co-founded Castlight, a web-based health care shopping service for consumers. Mr. Park has also served in a volunteer capacity as a Senior Fellow at the Center for American Progress, where he focused on health IT and health reform policy, and as senior health care advisor to Ashoka, a leading global incubator of social entrepreneurs, where he helped start Healthpoint Services, a venture to bring affordable telehealth, drugs, diagnostics, and clean water to rural India.

Mr. Park graduated magna cum laude and Phi Beta Kappa from Harvard College with an A.B. in economics.
The Value of Health Data vs. Privacy

How Can the Conflict Be Resolved

11:30–12:30 pm

Continuation of Breakout Sessions

2D: Consent for Research -- Do We Need It?

Moderator: Ron Walters, MD, MD Anderson Cancer Center
Panelists: Phil Booth, medConfidential; Kelly Caine, PhD, Clemson University School of Computing; Adrian Gropper, MD, PPR; Micky Tripathi, PhD, MA eHealth Collaborative

2E: What's Next for Data Segmentation

Introduction: Joy Pritts, JD, Office of the National Coordinator for Health IT, Department of Health & Human Services (ONC/HHS)
Moderator: Scott Weinstein, JD, ONC/HHS
Panelists: Matthew Arnheiter, Netsmart; Duane DeCouteau, Edmund Scientific; David Stagg, JD, Jericho Systems

Please proceed to the Washington Court Hotel for the Seated Lunch Keynote
525 New Jersey Avenue, NW, Washington, DC 20001

12:40–1:45 pm

Luncheon Keynote: “Louis Brandeis and the Origins of a Right to Privacy”

Melvin Urofsky, PhD – Biographer of Louis D. Brandeis
Dr. Urofsky will autograph copies of his book after his keynote: Louis D. Brandeis: A Life

Deborah Hurley
Founder, Hurley

Deborah Hurley is the Principal of the consulting firm she founded in 1996, which advises governments, international organizations, non-governmental organizations, and foundations on advanced science and technology policy. 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, nanotechnology, environmental and energy technology fields. She was responsible for the drafting, negotiating and final adoption of the OECD Guidelines for the Security of Information Systems, and she directed the Harvard University Information Infrastructure Project. Hurley is Chair, Board of Directors, Electronic Privacy Information Center, and she received the Namur Award of the International Federation of Information Processing in recognition of outstanding contributions, with international impact, to awareness of social implications of information technology.

David Jacobs, JD
Consumer Protection Counsel, Electronic Privacy Information Center

David Jacobs is the Consumer Protection Counsel at the Electronic Privacy Information Center. He focuses on representing consumers’ privacy interests before Congress, in the courts, and before federal regulatory agencies. He is a graduate of the University of Wisconsin—Eau Claire and Harvard Law School. At Harvard, he was involved with the Cyberlaw Clinic at the Berkman Center for Internet and Society, and worked as a research assistant to Professor John Palfrey. Before joining EPIC, he clerked at the United States Department of Justice, the American Civil Liberties Union, and the United States Senate Subcommittee on Antitrust, Competition Policy and Consumer Rights.

Anil Jain, MD
Chief Medical Information Officer, Explorys

Dr. Anil Jain is Senior VP and Chief Medical Information Officer of Explorys, Inc., where he leads Informatics and Analytics, Product Management, Training and Solutions Delivery. He began his career at the Cleveland Clinic, most recently as Senior Executive Director of IT where he led several Health IT innovations, including creating interactive dashboards to monitor the “meaningful use” of the Electronic Health Record. He continues to practice medicine and teach medical residents as Consultant Staff at Cleveland Clinic’s Department of Internal Medicine. He was formerly co-Chair of the Information Management Committee of Better Health Greater Cleveland (BHGC) and had previously served as co-Director of the Biomedical Research Informatics core of the Clinical & Translational Research Collaborative (CTSC) at the Case Western School of Medicine and Instructor at Cleveland Clinic Lerner College of Medicine. Dr. Jain also serves on the Board of Directors of Care Alliance and is on several advisory boards of Health IT companies across the country.

Omar Khawaja
Global Product Manager, Verizon

Omar Khawaja has spent over a decade delivering, developing and managing enterprise security solutions. Recently, Khawaja has been building solutions around data protection, mobility and cloud security. In the past year, Khawaja has advised executives of the Global 1000 and spoken at industry conferences (RSA, CIAA, ISF, MWC, ...). On the topic of making security more business-centric, on 5 continents. Khawaja has been quoted in media outlets such as Financial Times, NY Times and CNBC. Khawaja is a CCSK and CISSP. He has a BS in electrical engineering from Georgia Tech and an MBA from University of Virginia’s Darden School of Business.

Rev. J. Michael Little, JD
Senior Pastor, Friendship Baptist Church

The Reverend John Michael Little was licensed to preach at age 20, and ordained at 26. Since then, he has served as a Youth Pastor, Christian Education Director, and for the last twenty years, as a Pastor at churches in New Jersey, Virginia, and here in Washington, DC, where he is the esteemed Pastor of Friendship Baptist Church. Reverend Little attended Morehouse College, where he graduated with honors, and earned a Master of Divinity degree from Virginia Union University. He later enrolled in Georgetown University Law Center, where he earned a Juris Doctor degree. Reverend Little is also the founder of Jeremiah’s Circle of Friends, Neighborhood Legal Clinic. JCF, which was born of his belief that, “above all, the poor must have access to justice.” In partnership with the law firm Kirkland & Ellis and the Legal Aid Society of The District of Columbia JCF offers low-income residents of Washington DC, Maryland, and Virginia free legal services in a variety of civil matters.

Melvin I. Urofsky
Professor of Law & Public Policy
Virginia Commonwealth University

Melvin I. Urofsky is Professor of Law & Public Policy and Professor Emeritus of History at Virginia Commonwealth University. Before joining VCU as chair of the History Department, he taught at the Ohio State University and the State University of New York at Albany. He was James Pinckney Harrison Visiting Professor of History at the College of William & Mary and from 1995 until his semi-retirement in 2003, he served as the director of the doctoral program in Public Policy & Administration. Mr. Urofsky was a Rich Fellow at Oxford University’s Center for Jewish Studies, a Fulbright Lecturer at the University of New South Wales Law School in Sydney, a Rockefeller Foundation Fellow at the Bellagio Center in Italy, and a visiting scholar at Ben-Gurion University in Israel. He writes widely on constitutional history, and has been the editor for the past seventeen years of the Journal of Supreme Court History.
His newest work, Louis D. Brandeis: A Life, was published by Pantheon in September 2009. It won the Jewish Book Council’s Everett Award as the Book of the Year, was chosen for the Ambassador’s Award by the English-Speaking Union of the United States, and the Griswold Prize of the Supreme Court Historical Society.
Kimberly Little, PhD
Director of Market Planning, Identity Management Solutions, LexisNexis

Kimberly Little, Director of Identity Management Strategy, LexisNexis® Risk Solutions is responsible for identifying and guiding LexisNexis® solution response to the constantly evolving market needs for identity proofing and multiple factors authentication in commercial and government organizations. With nearly 20 years of experience leading global business strategy, product management, and technology business consulting, Kim’s responsibilities have spanned collaborating on international standards, cross-industry best practices and benchmarking to developing best-of-breed solution offerings. Kim is active in a number of broader industry initiatives ranging from serving on the Management Council of the Identity Ecosystem Steering Group (IDESG) to the Open Identity Exchange and the UT-Center for Identity.

Mark Luker, PhD
Associate Director of the National Coordination Office, The Networking and Information Technology Research & Development Program

Dr. Mark A. Luker is the Associate Director of the National Coordination Office for the Networking and Information Technology Research and Development Program (NITRD). His appointment comes after joining the National Institute of Standards and Technology (NIST), Information Technology Laboratory (ITL). Prior to joining NIST, he served as a Telecommunications Policy Specialist at the National Telecommunications and Information Administration in the U.S. Department of Commerce on the Broadband Technology Opportunities Program (BTOP). Dr. Luker has also served as the Vice President (VP) of EDUCAUSE, where he led the Washington DC-based EDUCAUSE policy program as well as Net@EDU. He has also served as the Program Director for advanced networking at the National Science Foundation and as the CIO of the University of Wisconsin-Madison campus. Dr. Luker received his Ph.D. in Mathematics from the University of California, Berkeley and served as a faculty member in computer science and as Acting Dean of Science and Engineering at the University of Minnesota, Duluth.

Susan McAndrew, JD
Deputy Director for Health Information Privacy, Senior Policy Specialist, Office for Civil Rights, HHS

Susan D. McAndrew is the Deputy Director for Health Information Privacy and Security, Office for Civil Rights (OCR) at the United States Department of Health and Human Services. As Deputy Director, Ms. McAndrew has responsibility for developing, implementing and enforcing the HIPAA Privacy, Security, Breach Notification, and Enforcement Rules. She began her work on the HIPAA Privacy Rule for HHS in May 2000 and serves as the senior advisor to the Director of OCR on health information privacy matters. Ms. McAndrew has over 20 years of federal government experience. Ms. McAndrew received her J.D. from Georgetown University Law Center.

John McDaniel
Healthcare CIO, NetApp

John McDaniel has more than 35 years of experience as a healthcare CIO, consulting services executive and as an executive with large healthcare solution companies. John currently works with NetApp and is responsible for cultivating C-level executive relationship, understanding emerging requirements and collaborating with the development teams at NetApp to ensure NetApp's solutions meet market-driven operational, scalability and cost efficiency requirements. John also manages NetApp's partnerships with large healthcare GSI's. As a CIO, John worked with St. Vincent Catholic Medical Center, McLaren Health Care Corporation and The Emory Clinic where he also served as Director of Medical Informatics. John served as a member of the Board of Directors for NYC-based HIE: NYCLIX. As a consulting services executive he worked with Dell Services, Deloitte Consulting and EMR Transitions. Serving the clinical applications space, John has worked with Siemens as Project Director and was SVP at, McKesson.

Maneesha Mithal
Associate Director, Division of Privacy and Identity Protection, Federal Trade Commission, Bureau of Consumer Protection

Maneesha Mithal is the Associate Director of the Federal Trade Commission's Division of Privacy and Identity Protection. In this capacity, she supervises work in the area of data security, identity theft, credit reporting, behavioral advertising, and general privacy. She has held numerous positions with the Federal Trade Commission, including Chief of Staff of the Bureau of Consumer Protection and Assistant Director of the International Division of Consumer Protection. Prior to joining the Federal Trade Commission in 1999, Ms. Mithal was an attorney 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.

Pablo Molina, PhD
Adjunct Professor, Georgetown University

Pablo Molina has been Associate Vice President for Information Technology since 2007 and Campus Chief Information Officer since 2000 at Georgetown University. He regularly speaks at conferences on technology in law and higher education, such as Computer Assisted Legal Instruction, American Bar Association, etc. Pablo serves on national higher education committees and served recently as chair of the EDUCAUSE's Evolving Technologies Committee.
The Value of Health Data vs. Privacy

How Can the Conflict Be Resolved?

WEDNESDAY, JUNE 5, 2013
Hart Auditorium, McDonough Hall
Georgetown University Law Center
600 New Jersey Avenue, NW
Washington, D.C. 20001

7:30–8:40 am Registration & Light Breakfast

8:40–8:50 am Opening & Introduction
Lawrence O. Gostin, JD, O'Neill Institute for National & Global Health Law
Deborah C. Peel, MD, Patient Privacy Rights

8:55–9:45 am Opening Keynote: “A Health Check on Data Privacy”
Peter Hustinx, European Data Protection Supervisor
Q & A

9:50–11:15 am The Value of Health Data OUTSIDE Healthcare
Moderator: Natasha Singer, New York Times
Panelists: Michelle DeMooy, Consumer Action; Ranieri Guerra, MD, Italian Embassy; Cora Han, JD, Federal Trade Commission; David “Doc” Sears, Harvard University; David Wiggin, Teradata

11:30–12:20 pm Presentation of theDataMap™
Latanya Sweeney, PhD of Harvard University’s Data Privacy Lab will present the progress of theDataMap™
Q & A

12:20–1:15 pm Lunch
Provided in McDonough Atrium upstairs from Hart Auditorium

1:15–2:05 pm Keynote: “The Constitution & Privacy: Why the Supreme Court Cares”
Marc Rotenberg, JD, Executive Director of the Electronic Privacy Information Center (EPIC)
Following his keynote, Ted Ruger from the University of Pennsylvania Law School will serve as the discussant.
Q & A

William Pewen, PhD
Assistant Professor of Public Health, Marshall University
Dr. William Pewen is Assistant Professor of Public Health and Family Medicine at Marshall University. He holds both a doctorate in Infectious Diseases and Microbiology and M.P.H. in Epidemiology from the University of Pittsburgh. His work has included cardiology research at UC San Diego and the Veterans Administration, where he also worked in early efforts to create an electronic health record. Dr. Pewen subsequently developed both systems and applications software used in research and medical applications. In 2003, Dr. Pewen was named a Congressional Fellow of the American Society for Microbiology. He subsequently served as Senior Health Policy Advisor to U.S. Senator Olympia J. Snowe. His congressional legislative and oversight work included a broad spectrum of health policy issues, which culminated in work in the creation of health reform legislation which formed the core of the enacted Patient Protection and Affordable Care Act (ACA).

Deborah C. Peel, MD
Founder & Chair, Patient Privacy Rights
Dr. Peel has been a practicing physician and psychoanalyst for over thirty years. In 2004, she formed Patient Privacy Rights (PPR), which has become the nation’s and the world’s leading consumer health privacy advocacy organization. PPR has over 12,000 members in all 50 states, and leads the bi-partisan Coalition for Patient Privacy, representing over 10.3 million Americans. In 2011, she conceived the idea of the 1st International Summit on the Future of Health Privacy, partnering with the University of Texas LBJ School of Public Affairs and many others to make it a reality.

Joy Pritts, JD
Chief Privacy Officer, Office of the National Coordinator for Health IT, HHS
Joy Pritts joined the Office of the National Coordinator for Health Information Technology (ONC) in February 2010 as Chief Privacy Officer. Ms. Pritts provides critical advice to the Secretary and the National Coordinator in developing and implementing ONC’s HIT/privacy and security programs. She works closely with the Office for Civil Rights and other operating divisions of HHS, as well as with other government agencies to help ensure a coordinated approach to key privacy and security issues.

James C. Pyles, JD
Co-Founder & Principal; Powers, Pyles, Sutter & Verville
Jim Pyles is a co-founder of Powers, Pyles, Sutter, & Verville and has nearly 40 years of experience in litigation, counseling, and lobbying in the field of health law. Mr. Pyles has more than 20 years of experience in the law of health information privacy at all levels of the federal judiciary, both houses of Congress, and with the Executive branch of the government. Mr. Pyles has testified on numerous occasions before Congress, appeared in court as an expert witness, and made numerous appearances on national television.

Patricia Rehmer, MSN
Commissioner, Department of Mental Health & Addiction Services
Pat Rehmer began her career in 1982 as a staff nurse at The Institute of Living in Hartford, Connecticut and became the Chief Executive Officer at Capitol Region Mental Health Center. In 2003, Ms. Rehmer was appointed to serve on the Executive Management team of the Department of Mental Health & Addiction Services, where she assisted with strategic planning, and clinical program design to ensure that value driven, cost effective care was available throughout the state. She was later appointed to the position of Deputy Commissioner for DMHAS, then nominated and confirmed as Commissioner in 2009 and 2010. Her responsibilities include oversight of the Department that oversees behavioral health care for over 90,000 individuals annually. She has also been responsible for oversight of a budget of 700 million dollars and has worked closely with Federal agencies to secure additional funding for prevention, services and Research opportunities. Ms. Rehmer earned a Bachelor’s degree in Nursing from Stidmore College in 1981 and a Master of Science in Nursing from St. Joseph College in 1988.

Jordan Robertson
Reporter, Bloomberg News
Jordan Robertson is a technology writer in the San Francisco office 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 extracting 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.

William Pewen, Deborah C. Peel, Joy Pritts, James C. Pyles, Patricia Rehmer, Jordan Robertson
The Value of Health Data vs. Privacy

Ronald Ross, PhD
Computer Scientist, NIST Fellow, National Institute of Standards & Technology

Ron Ross is a Fellow at the National Institute of Standards and Technology (NIST). His areas of specialization include information security and risk management. Dr. Ross leads the Federal Information Security Management Act (FISMA) Implementation Project, where he is the principal architect of the Risk Management Framework and multi-tiered approach for integrating the suite of FISMA standards and guidelines into a comprehensive enterprise-wide information security program. Dr. Ross also leads the Joint Task Force Transformation Initiative, which aims to develop a unified information security framework for the federal government. Dr. Ross previously served as the Director of the National Information Assurance Partnership and received the Scientific Achievement Award and the Defense Superior Service Medal. He is also a three-time recipient of the Federal 100 award and a recipient of the Department of Commerce Gold and Silver Medal Awards. Dr. Ross has been inducted into the Information Systems Security Association (ISSA) Hall of Fame and given its highest honor of ISSA Distinguished Fellow.

Theodore Ruger, JD
Professor of Law, University of Pennsylvania Law School

Theodore Ruger, JD, is a professor at the University of Pennsylvania Law School, where he teaches and writes in the fields of health law, constitutional law, food and drug law, and statutory interpretation. Before joining Penn Law’s faculty in September 2004 Ruger was a law professor for three years at Washington University in St. Louis, and prior to that practiced health law and general litigation at Williams & Connolly in Washington, D.C and Ropes & Gray in Boston. Ruger clerked for Justice Stephen Breyer on the U.S. Supreme Court and Judge Michael Boudin on the U.S. First Circuit Court of Appeals. In fall 2012 he was Visiting Professor of Law at New York University School of Law.

David “Doc” Searls
Journalist; Director of Project VRM, Harvard University; Fellow, CITS, University of California at Santa Barbara

Doc Searls is the author of The Intention Economy: When Customers Take Charge (Harvard Business Review Press, 2012), and co-author of The Cluetrain Manifesto: The End of Business as Usual (Basic Books, 2000, 2010). He is also Senior Fellow of Linux Journal, a fellow at the Center for Information Technology & Society at UC Santa Barbara, and founder of ProjectVRM at the Berkman Center for Internet & Society at Harvard University, where he served as a fellow from 2006 to 2010. Currently, he is a visiting scholar at the Arthur L. Carter Journalism Institute at NYU.

Brian Selfridge, CISSP
Managing Director, Meditology Services

Mr. Selfridge currently serves as Managing Director at Meditology Services, which achieves successful outcomes to a healthcare organization’s technology challenges by providing experienced professionals who deliver high-quality, reliable, and responsive services. There, he is responsible for Meditology’s IT Risk Management Services practice, which is dedicated to delivering expertise and leadership in information privacy and security, compliance, and audit, specifically for healthcare. Prior to joining Meditology, Mr. Selfridge served as the Chief Information Security Officer (CISO) for AtlantiCare and as a Senior Security Consultant with PricewaterhouseCoopers, LLP. He also served as one of the founding members of the Anti-Spam investigation unit for the Pennsylvania Office of Attorney General, Bureau of Consumer Protection, where he investigated and prosecuted sources of unsolicited emails for Pennsylvania residents.

Kathryn Serkes
Founder, Doctor Patient Medical Association

Kathryn Serkes is Chair and Co-Founder of the Doctor Patient Medical Association (DPMA) and the Patient Power Alliance, the first national group of patients AND doctors working for freedom in medicine, which was prompted by grassroots activism during the debate on healthcare reform in 2009-2010. She was one of the chief strategists organizing the efforts against socialized medicine legislation, speaking at more than 35 rallies and town halls, and appearing on numerous radio and television shows.

Natasha Singer
Reporter, The New York Times

Natasha Singer is a reporter for the Sunday Business section of The New York Times where she covers the business of consumer data and writes a monthly column called Slipstream. Her Sunday Business series on the surveillance economy, called “You for Sale,” won a 2012 Best in Business award for personal finance journalism from the Society of American Business Editors and Writers. Ms. Singer previously covered the pharmaceutical industry and medical ethics, also for the Business section. She was part of a team at The Times whose investigative series on cancer, “The Forty Years War,” was a finalist for a Pulitzer Prize in explanatory reporting in 2010. She also developed the Skin Deep column for The Times’ Thursday Styles section, where she covered the beauty industrial complex. Prior to joining The Times in 2005, she was a correspondent for Outside Magazine and a health and beauty editor at W Magazine. She also worked in Russia as the Moscow bureau chief of The Forward, the editor-at-large of Russian Vogue, and a correspondent for Women’s Wear Daily.

The Celebration of Privacy is the award reception for Summit attendees and guests, featuring the Louis D. Brandeis Privacy Awards.

The Louis D. Brandeis Privacy Awardees are recognized for their significant intellectual, legal, and technical contributions to the field of health information privacy. Standing on the shoulders of Supreme Court Justice Louis D. Brandeis, these heroes work to ensure that the “highest right of civilized man” remains the foundation for all electronic systems and for law and policy governing the use and control of sensitive health information.

2012 Louis D. Brandeis Privacy Awardees

Mark Rothstein
Herbert F. Boehl Chair of Law & Medicine & Founding Director
Institute for Bioethics, Health Policy & Law
University of Louisville School of Medicine

Peter J. Hustinx
European Data Protection Supervisor

“The right to be let alone is the most comprehensive of rights and the right most valued by civilized men.”

-Justice Brandeis, 1928, Olmstead v. United States, dissenting
Dear Friends,

On behalf of Patient Privacy Rights and the bipartisan Coalition for Patient Privacy, welcome to the 3rd International Summit on the Future of Health Privacy. Representing 10.3 million Americans, we work together to ensure that technology, policy, and law guarantee individuals the right to retain control over their sensitive health information.

Every year, millions of patients hide information or avoid or delay treatment for serious medical conditions due to privacy concerns. Without trustworthy systems, patients will continue to risk their health in an attempt to keep sensitive data private. To help make sure patients are willing to seek the care they need, we must move towards technologies that allow patients to control how their information is used and exchanged. In doing so, the U.S. can improve healthcare quality, transform research, lower costs, and prevent bad outcomes.

The Summit offers fresh perspectives on health privacy problems and solutions. The thoughtful debates we will have will play a significant role in raising public awareness and moving us towards privacy-preserving systems.

This is an auspicious year for privacy. President Obama’s 2012 Consumer Privacy Bill of Rights illuminated the gaps in data privacy protections in all sectors of the U.S. economy. Global interest in making health data available for commercial use is quickly growing. The European Union is revising its data protection framework to ensure personal data remains strongly protected in the EU. The 2013 Omnibus Privacy Rule took big steps to improve data security, but also weakened Congress’ intended privacy protections for health data.

Major corporations and technology start-up firms are responding to citizens’ concerns about the hidden collection and use of personal information; they are building privacy-enhancing products that give individuals control over personal data. Through our conversations at the Summit, we hope more companies will be encouraged to demonstrate respect for privacy by incorporating privacy-protective options when designing new software.

It is a great privilege to welcome Todd Park, United States Chief Technology Officer, as a keynote speaker. Mr. Park has the difficult job of helping the U.S. navigate the complex issues and infinite possibilities technology presents for collection and use of personal data. We are thankful the Obama Administration honors the key role Patient Privacy Rights and other organizations play in ensuring that the right to privacy is maintained in the Digital Age.

We are deeply honored that Peter Hustinx, the European Data Protection Supervisor, will give the opening keynote. Mr. Hustinx has the job of overseeing data protection for all citizens of the European Union. His keynote sets the stage for the many conversations we will have about health data privacy inside and outside of traditional healthcare systems, both in the U.S. and around the globe.

We also thank our academic and industry partners, international guests, government experts, and members of the bipartisan Coalition for Patient Privacy, for their participation and continued support. Most of all, we thank the American people for supporting this unique forum to examine urgent health privacy issues and solutions.

Regards,

Deborah C. Peel, MD
Founder & Chair
Patient Privacy Rights
Welcome,

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 3rd International Summit on the Future of Health Privacy.

Privacy is among the greatest challenges facing America and all nations that care about the dignity and well being of their people. The health system collects, stores, and widely disseminates unimaginable amounts of personal information – in health insurance, medical practices, hospitals, and public health agencies. These huge sources of data can be used for the public’s good, such as in research, quality assurance, and population health. But unless we maintain reasonable assurances of privacy and security, the unauthorized disclosure of health information can result in stigma, discrimination, and great harm. The 3rd International Summer on the Future of Health Privacy brings us together to think, research, and act on the need for health informational privacy. Georgetown Law and the O’Neill Institute are proud to join with our truly inspirational partner, Patient Privacy Rights, to host this important conference.

This Summit represents an integral part 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 employ the law as a positive tool to enable individuals and populations in the United States and throughout the world to lead healthier lives.

Now in its 3rd year, the International Summit on the Future of Health Privacy has been a collaboration between Patient Privacy Rights and Georgetown Law. I applaud Dr. Deborah Peel for her tireless work to address these critical issues facing our nation’s (and the world’s) health systems.

We greatly look forward to hearing your ideas over the next couple of days, in hopes that you help us identify how we can shape the future of health privacy versus health data in a way that values the practical applications of health IT development in a socially responsible and ethical manner. We hope this summit, with its national and international perspectives on health privacy problems and solutions, will lead to great movement within the field in the coming year.

To close, let me thank Deborah Peel and Patient Privacy Rights, along with our distinguished guests and all of our generous sponsors, for helping to make this forum a continuing dialogue for progress.

Regards,

Lawrence O. Gostin
Faculty Director, O’Neill Institute for National and Global Health Law
University Professor, Georgetown University
IN MEMORIAM

“Privacy is the claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.”

-Alan F. Westin, Privacy and Freedom

Alan F. Westin
“The Father of Modern Day Privacy”

1929—2013
3rd International Summit on the Future of Health Privacy

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Washington, D.C.

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