



Advances in personal genetics and GINA: Expanding options and protecting civil rights

A Congressional briefing
Organized by the Personal Genetics Education Project,
Harvard Medical School

In cooperation with the offices of Congresswoman
Louise M. Slaughter and Senator Elizabeth Warren

October 3, 2014, 12:00 – 1:30 p.m.
Rayburn House Office Building
Washington, D.C.

Advances in personal genetics and GINA: Expanding options and protecting civil rights

A safe and fair integration of genetics into society will require an informed public, in which all individuals are aware of the benefits and implications of personal genetics. This briefing, the second in a series that pgEd has been invited to organize, will begin with an update on recent advances in genetic technologies (see schedule below) and then feature the latest research from the front lines of the Ebola outbreak, highlighting how scientists are using sequencing as a tool towards curbing this epidemic. It will then focus on the Genetic Information Nondiscrimination Act (GINA), wherein a panel of experts will look ahead to new challenges arising from developments in technology, medicine, genetics, neuroscience, and beyond, highlighting the opportunities and implications for civil rights brought about by the era of personal genetics and the memory of the country's earlier experience with eugenics. The panelists for this briefing will be:

Mildred Cho, PhD, Associate Director, Stanford Center for Biomedical Ethics; Professor of Pediatrics, Stanford University

James P. Evans, MD, PhD, Bryson Distinguished Professor of Genetics and Medicine, UNC School of Medicine; Director of Clinical Cancer Genetics, UNC Lineberger Comprehensive Cancer Center, University of North Carolina at Chapel Hill

Nita Farahany, JD, PhD, Member, Presidential Commission for the Study of Bioethical Issues; Director, Duke Science and Society; Director, Duke MA in Bioethics & Science Policy; Professor of Law and Philosophy, Duke University

Jessica L. Roberts, JD, Assistant Professor of Law, University of Houston Law Center

Pardis Sabeti, MD, PhD, Associate Professor of Organismic and Evolutionary Biology, Center for Systems Biology, Harvard University; Associate Professor of Immunology and Infectious Disease, Harvard School of Public Health; Senior Associate Member, Broad Institute

Ting Wu, PhD, Professor of Genetics, Harvard Medical School; Director, Personal Genetics Education Project (pgEd)

Agenda

12:00 *Opening remarks and update on recent scientific breakthroughs*

Welcome (*pgEd*)

On the forefront: Disease resistance, reversal of aging, possibilities for space travel (*Ting Wu, pgEd*)

Featured research highlight: Genomic surveillance of the 2014 Ebola virus outbreak (*Pardis Sabeti; introduced by Marie Shea, pgEd*)

12:25 *Personal genetics, GINA & visions for the future: science, medicine, bioethics, and law (moderated by Marnie Gelbart, pgEd)*

Raising public awareness: Launch of Map-Ed quiz on GINA (Map-Ed.org)
Kindly introduced by the Honorable Louise M. Slaughter, House of Representatives (video)

Tales from the frontiers of genomic medicine (*James Evans*)

Protections under GINA: a case study and legal outlook (*Jessica Roberts*)

Anticipating the impacts and implications of genetic technologies
(*Mildred Cho*)

Emerging questions at the intersection of law, neuroscience, and behavioral genetics (*Nita Farahany*)

1:10 *Round table discussion with panelists (moderated by Lauren Tomaselli, pgEd)*

1:30 *Conclusion*

Acknowledgements

pgEd is supported by the Department of Genetics at Harvard Medical School and is grateful to Autodesk for collaboration on Map-Ed.org. pgEd thanks the offices of Congresswoman Louise Slaughter and Senator Elizabeth Warren for co-hosting this briefing.

pgEd Mission and Strategies



The mission of the Personal Genetics Education Project (pgEd.org) is to raise awareness of personal genetics, make that awareness equally accessible across all segments of society regardless of socioeconomic, educational, ethnic, religious, or cultural background, and instill confidence in individuals to ask questions, make informed decisions, and respect the opinions of others. Our strategy is varied and includes:

Educating through high schools

pgEd is leveraging the infrastructure of high schools across the nation as a broad strategy for reaching young adults. These efforts include teacher trainings and conferences in order to address the challenge of scalability in expanding nationally. The response of students and teachers has been overwhelmingly positive.



Building an online curriculum

pgEd develops self-contained lessons, which are freely available on-line at www.pgEd.org. These lessons include an overview of the main issues as well as detailed lesson plans and activities. They are accessible to general audiences without a scientific background and are intended for use in biology classrooms as well as those targeting health, social studies, literature, and beyond.

Interfacing with producers and writers in the entertainment industry



ABC/Danny Feld,
Boston Magazine

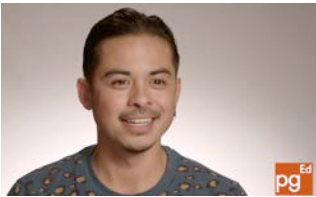
pgEd is working with Hollywood, Health & Society at the USC Annenberg Norman Lear Center as well as The Science & Entertainment Exchange of the National Academy of Sciences to advance storylines that promote awareness of personal genetics in television and film. pgEd has advised shows, including *Grey's Anatomy*, which can reach millions within a single hour.

Promoting genetics awareness online through Map-Ed quizzes

pgEd has developed an online tool called Map-Ed (Map-Ed.org) with the potential to educate millions with the click of a button. Map-Ed invites players to work through short quizzes on key concepts and topics in genetics and then pin themselves on a world map. Map-Ed has spread to all 7 continents and includes pins from pioneers at all three U.S. research stations in Antarctica and from the *Curiosity* rover on Mars. pgEd is launching its newest quiz on the Genetic Information Nondiscrimination Act (GINA) with Congresswoman Louise Slaughter entering the first pin.



Developing online videos, “Personal Conversations/Personal Genetics”



pgEd has launched a video series, called “Personal Conversations/Personal Genetics,” produced by Emmy Award-winning filmmaker Marilyn Ness and Big Mouth Productions. These video vignettes relate insights, experiences, and visions for the future of personal genetics and invite viewers to “join the conversation.”

Accelerating public awareness at the GETed Conference

pgEd brings together experts in education, genetics research, health, entertainment, and policy at the GETed Conference to brainstorm strategies for raising awareness about personal genetics. GETed embraces a ‘let’s-get-it-done’ attitude and has proven itself to be a unique conference in terms of its content, productivity, opportunities for developing new collaborations, as well as representation of diverse communities.



Expanding pgEd’s impact

Other pgEd activities include holding its first Congressional briefing in May on advances in personal genetics and strategies for accelerating public awareness, serving on the education advisory board for the Smithsonian's *Genome: Unlocking Life's Code* exhibit, working with the Boston Museum of Science, and advising educational efforts.

Avoiding genetic discrimination: Know your rights

Map-Ed.org

pgEd is launching its latest Map-Ed quiz on GINA. Be among the first in your district to pin yourself by going online to Map-Ed.org and answering five multiple-choice questions, listed below along with possible responses. Everyone gets 5 out of 5, whether you get them all right the first time or learn along the way. Please help pgEd raise awareness by sharing Map-Ed with your constituents!

1. The Genetic Information Nondiscrimination Act (GINA) was signed into United States law in 2008. GINA protects against genetic discrimination with respect to:
 - a) *Employment and health insurance*
 - b) *Long-term care, disability, and life insurance*
 - c) *All of the above*

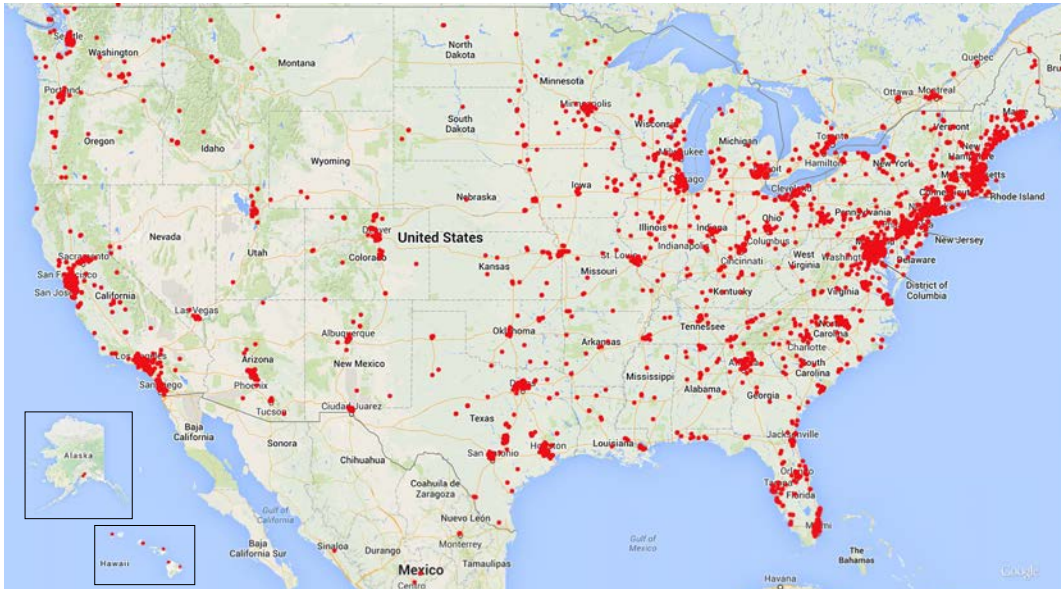
2. Information about a person's genetic make-up can be obtained through a genetic test. A genetic test might:
 - a) *Indicate whether a person is likely to develop a disease*
 - b) *Help diagnose or treat a medical condition*
 - c) *Reveal information about a person's ancestry*
 - d) *Uncover information that could lead to discrimination*
 - e) *All of the above*

3. True or False: GINA only applies to people who have undergone genetic testing.
 - a) *True*
 - b) *False*

4. Is it legal for health insurers to deny coverage or increase rates for people who have a family history of cancer or test positive for a genetic variant that greatly increases their risk for cancer?
 - a) *Yes*
 - b) *No*

5. GINA prevents employers from asking employees for information about their genetic make-up (with a few narrow exceptions) or requiring them to take a genetic test. Has a boss who overhears an employee talking about a sick family member violated GINA?
 - a) *Yes*
 - b) *No*

pgEd is honored to have Congresswoman Louise Slaughter enter the first pin and share Map-Ed through her video message. pgEd is grateful to Autodesk, DB Design, and SADA Systems for tremendous efforts in technical development of Map-Ed.



Aggregate map for pgEd's first four Map-Ed quizzes (taken 9/26/14)



Map for pgEd's new Map-Ed quiz on GINA (*just launched*)
 First pin entered by Congresswoman Louise Slaughter (Rochester, NY)
 Join pgEd in raising awareness and help us fill the map!

Briefing participants

Mildred Cho

Professor of Pediatrics, *Stanford University*

Associate Director, *Stanford Center for Biomedical Ethics*

Director, *NIH Center for Excellence in Ethical, Legal and Social Implications Research*

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Mildred Cho is a Professor in the Division of Medical Genetics of the Department of Pediatrics at Stanford University, Associate Director of the Stanford Center for Biomedical Ethics, and Director of the Center for Integration of Research on Genetics and Ethics (an NIH-supported Center for Excellence in Ethical, Legal and Social Implications Research). She received her B.S. in Biology in 1984 from the Massachusetts Institute of Technology and her Ph.D. in 1992 from the Stanford University Department of Pharmacology. Her post-doctoral training was in Health Policy as a Pew Fellow at the Institute for Health Policy Studies at the University of California, San Francisco and at the Palo Alto VA Center for Health Care Evaluation. She is a member of international and national advisory boards, including for Genome Canada, the March of Dimes, and the Board of Reviewing Editors of *Science* magazine.

Dr. Cho's major areas of interest are the ethical and social impacts of genetic research and its applications, and how conflicts of interest affect the conduct of academic biomedical research. Her current research projects examine ethical and social issues in research on prenatal genetic testing, genetics of behavior, the human microbiome, and synthetic biology. In addition, she established the Benchside Ethics Consultation Service at Stanford University in 2005 and is chair of a working group to develop a national collaborative research ethics consultation service.

James P. Evans

Bryson Distinguished Professor of Genetics and Medicine, *UNC School of Medicine*

Director of Clinical Cancer Genetics, *UNC Lineberger Comprehensive Cancer Center*

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Dr. Evans is the Bryson Distinguished Professor of Genetics and Medicine at The UNC School of Medicine and Director of Clinical Cancer Genetics at UNC Lineberger Comprehensive Cancer Center. He directs Adult Genetic Services and is Editor-in-Chief

of *Genetics in Medicine*, the journal of the American College of Medical Genetics. After obtaining his MD and Ph.D from the University of Kansas he served as Resident and Chief Resident of Internal Medicine at The University of North Carolina. He trained in Medical Genetics at The University of Washington in Seattle and is board certified in three disciplines, Internal Medicine, Medical Genetics and Molecular Diagnostics. He remains clinically active in both Genetics and General Medicine.

Dr. Evans's research focuses on the use of new genomic technologies in clinical medicine, cancer genetics and public health. He is also interested in broad issues of how genetic information is used and perceived.

He has been extensively involved in policy issues related to genetics and medicine, publishing widely in journals including *Science*, *Nature*, *NEJM* and *JAMA*. He was an advisor to the US Secretary of Health and Human Services on "Genetics, Health and Society" from 2004-2010 and is actively involved nationally and internationally in the scientific education of high court judges as described in the *New York Times* in July of 2008.

Dr. Evans has testified before the US Congress regarding the regulation of direct-to-consumer genetic testing and advised the Government Accountability Office on this subject. He has addressed the US Presidential Commission on Bioethics regarding genetic testing. He lives in Chapel Hill, North Carolina.

Nita Farahany

Member, *Presidential Commission for the Study of Bioethical Issues*

Director, *Duke Science and Society*

Director, *Duke MA in Bioethics & Science Policy*

Professor of Law and Philosophy, *Duke University*

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Nita A. Farahany is a leading scholar on the ethical, legal, and social implications of biosciences and emerging technologies, particularly those related to neuroscience and behavioral genetics. She is the Director of Duke Science & Society, the Duke MA in Bioethics & Science Policy, and a Professor of Law & Philosophy. In 2010, Farahany was appointed by President Obama to the Presidential Commission for the Study of Bioethical Issues, and continues to serve as a member.

Farahany presents her work widely including to audiences at the Judicial Conferences for the Second and Ninth Circuits, the National Judicial College, the American Association for the Advancement of Science, National Academies of Science Workshops, the American Academy of Forensic Sciences, the National Association of

Criminal Defense lawyers, the American Society for Political and Legal Philosophy, and by testifying before Congress. She is an elected member of the American Law Institute, Chair of the Criminal Justice Section of the American Association of Law Schools, on the Board of the International Neuroethics Society, and the recipient of the 2013 Paul M. Bator award given annually to an outstanding legal academic under 40.

She received her AB in genetics, cell, and developmental biology at Dartmouth College, a JD and MA from Duke University, as well as a PhD in philosophy; her dissertation was entitled "Rediscovering Criminal Responsibility through Behavioral Genetics." Farahany also holds an ALM in biology from Harvard University. In 2004-2005, Farahany clerked for Judge Judith W. Rogers of the U.S. Court of Appeals for the D.C. Circuit, after which she joined the faculty at Vanderbilt University. In 2011, Farahany was the Leah Kaplan Visiting Professor of Human Rights at Stanford Law School.

Marnie Gelbart

Director of Program Development & National Initiatives

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Marnie Gelbart is leading initiatives for advancing national awareness about the benefits as well as ethical, legal, and social implications of knowing one's genome. She is the scientific advisor for pgEd's curriculum and leads professional development trainings and classroom workshops for teachers and students. Marnie served on the educational advisory committee for the Smithsonian exhibit "Genome: Unlocking Life's Code" and was an invited participant at the 2011 NHGRI workshop on genomic literacy. She organizes the GETed Conference, works with television writers and producers in conjunction with Hollywood, Health & Society, and is developing Map-Ed (Map-Ed.org) as a tool to disseminate important information on key concepts in genetics and related topics. Prior to joining pgEd, Marnie was a post-doctoral fellow at Brigham & Women's Hospital investigating the role of chromosome organization in gene regulation. She received her B.S. in biology from Haverford College and her Ph.D. in Molecular and Cellular Biology from the Fred Hutchinson Cancer Research Center.

Jessica L. Roberts

Assistant Professor of Law

University of Houston Law Center

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Jessica L. Roberts is an Assistant Professor of Law at the University of Houston Law Center and Affiliated Faculty with the Baylor Center for Medical Ethics and Health Policy. Professor Roberts teaches Foundational Issues in Health Law, Disabilities & the Law, and Genetics & the Law. Prior to UH, she was an Associate-in-Law at Columbia Law School, where she served as a founding member of the Columbia University Center for Excellence in Genetic Research. Immediately after law school, she clerked for the Honorable Dale Wainwright of the Texas Supreme Court and the Honorable Roger L. Gregory of the Fourth Circuit Court of Appeals. An expert on the Genetic Information Nondiscrimination Act, Professor Roberts has spoken to audiences across the county about genetic-information discrimination. Her work has appeared or is forthcoming in the William and Mary Law Review, Iowa Law Review, the Minnesota Law Review, the Vanderbilt Law Review, the Notre Dame Law Review, the University of Illinois Law Review, and the University of Colorado Law Review, among others. She is a graduate of the University of Southern California and the Yale Law School.

Pardis Sabeti

Associate Professor, *Center for Systems Biology, Harvard University*

Associate Professor, *Harvard School of Public Health*

Senior Associate Member, *Broad Institute of Harvard and MIT*

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Dr. Pardis Sabeti is an Associate Professor at the Center for Systems Biology and Department of Organismic and Evolutionary Biology at Harvard University and the Department of Immunology and Infectious Disease at the Harvard School of Public Health, and a Senior Associate Member of the Broad Institute of Harvard and MIT.

Dr. Sabeti is a computational geneticist with expertise developing algorithms to detect genetic signatures of adaption in humans and the microbial organisms that infect humans. Her lab's key research areas include: (1) Developing analytical methods to detect and investigate evolution in the genomes of humans and other species (2) Examining host and viral genetic factors driving disease susceptibility to the devastating and deadly disease widespread in West Africa, Lassa hemorrhagic fever virus. (3) Investigating the genomes of microbes, including Lassa virus, Ebola virus, *Plasmodium falciparum* malaria, *Vibrio cholera*, and *Mycobacterium tuberculosis* to help in the development of intervention strategies.

Dr. Sabeti completed her undergraduate degree at MIT, her graduate work at Oxford University as a Rhodes Scholar, and her medical degree *summa cum laude* from Harvard Medical School as a Soros Fellow. Dr. Sabeti is a World Economic Forum (WEF) Young Global Leader and serves on the WEF's Global Agenda Council on Personal and Precision Medicine. She received the 2012 Smithsonian American Ingenuity Award for Natural Science, and is a National Geographic Emerging Explorer. Dr. Sabeti is also the lead singer of the rock band Thousand Days.

Marie Shea

Program Assistant and Design Consultant

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Marie Shea is a photographer and model in Boston, MA. She has worked for CB magazine since 2012 and completed her photography thesis at Massachusetts College of Art and Design in 2013. Her lifelong interest in genetics led her to merge her interests at pgEd, where she is working to expand Map-Ed (Map-Ed.org) to new topics including Alzheimer's disease and alcoholism.

Tsion Tesfaye

Washington, D.C. Liaison

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Tsion is interested in the issues at the nexus of bioethics and public policy. She was a research fellow at the Yale Interdisciplinary Center for Bioethics, where she examined bioethical issues in persons living with disabilities, medical scope of practice legislation, and the use of games to promote public health in medically underserved communities. She received her B.A. from Virginia Commonwealth University and previously worked in the rural health care division of USAC, a Federal Communications Commission program.

Lauren Tomaselli

Director of Curriculum and Training

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Lauren Tomaselli leads pgEd's effort to develop scientifically precise and engaging curriculum for use in secondary and college classrooms, with a special emphasis on accessibility to learners of different levels and backgrounds. She organizes and executes professional development workshops to train teachers about the ethical and social issues in personal genetics and travels extensively to engage with students and teachers on these issues. Recent projects include writing new curriculum, planning a summer professional development workshop, and launching a pilot of pgEd's lessons with teachers in New England. Lauren received her B.A. in English and Women's Studies from Syracuse University, and her Masters of Social Studies Education from New York University. She taught social studies in New York City public schools for six years and brings an interdisciplinary approach to curriculum planning, allowing pgEd to create materials not just for biology classrooms, but also health, social studies, history and law.

Dana Waring

Education Director & Co-founder

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Dana Waring is Education Director at pgEd. Her role includes speaking at national forums, such as the GET Conference and meetings of the National Science Teachers Association about the promises and emerging questions in widespread genome sequencing. Her expertise includes the social, familial and legal landscape in personal genetics, and she has a special interest in athletes and genetic testing, the genetics of complex traits, and reproductive technology. Dana develops educational materials and conducts courses and workshops with a focus on the use and impact of personal genetics throughout the world. Her training in sociology, history of science, and women's studies allows her to bring an interdisciplinary approach to her teaching and curricula that includes of a diversity of viewpoints. Recent projects include teaching in the Summer Course in Genomics at Mount Desert Island Biology Lab and developing new content for pgEd's website. Based in both Massachusetts and Maine, Dana has travelled extensively and talked with thousands of students about personal genetics and how it may impact them personally and as a member of society. She holds a Bachelor's degree from Syracuse University, and a Master of Liberal Arts from Harvard University.

Ting Wu

Director & Co-founder, *Personal Genetics Education Project, Harvard Medical School*

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Ting Wu is involved in all aspects of pgEd, including teaching in high schools, workshops, and conferences across the nation, contributing to the online curricula, organizing the GETed conferences, working with producers and writers in the entertainment industry, and developing Map-Ed. Ting is also a Professor of Genetics at Harvard Medical School, where her research group studies the manner in which chromosome structure and behavior govern inheritance and genome activity (<http://www.homologyeffects.org/>). She received her B.A. from Harvard University in Biology and her Ph.D. from Harvard Medical School in Genetics. She did her postdoctoral training at Yale University and the Station for Natural Studies, after which she was a Fellow in Molecular Biology at the Massachusetts General Hospital. She is now a Professor in the Department of Genetics at Harvard Medical School. Most recently, Dr. Wu was honored as a recipient of an NIH Director's 2012 Pioneer Award for her work on chromosome organization and inheritance.



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