

Congresswoman Louise Slaughter and Senator Elizabeth Warren Host Panel on Genetics and Law Enforcement: Improving Public Safety, Ensuring Justice, and Balancing Civil Rights

Lawmakers, Scientists, and Scholars Brief Stakeholders on Opportunities and Challenges Associated with Genetic Privacy

WASHINGTON – Today, Congresswoman Louise M. Slaughter (D-NY) and Senator Elizabeth Warren (D-MA) hosted a panel on Capitol Hill regarding how laws protecting the privacy of genetic information impact law enforcement. In 2008, Congresswoman Slaughter’s Genetic Information Non-discrimination Act (GINA) passed into law after 14 years of work on the issue. The legislation protects Americans from discrimination in health care and employment based on their genetic information. After its passage, the late Senator Ted Kennedy called GINA the "first major civil rights bill of the new century."

The experts at the hearing focused on how new genetic technologies and privacy laws are impacting forensics and the criminal justice system. Specifically, the panelists discussed the collection, storage, and analysis of DNA, the development of new technologies that are creating new possibilities for law enforcement to enhance public safety, and the implications for privacy and racial justice. These issues are central to an on-going dialogue about a safe and fair integration of genetics into society.

Participating in the panel were Claire M. Fraser, PhD, Director of the Institute for Genome Sciences at the University Of Maryland School Of Medicine; Duana Fullwiley, PhD, Associate Professor of Anthropology at Stanford University; Henry T. Greely, JD, Director of the Center for Law and the Biosciences; Professor of Law and Professor, by courtesy, of Genetics at Stanford University; and David Kaye, JD, Associate Dean for Research at Penn State Law; Graduate Faculty at the Forensic Science Program at the College of Science at Pennsylvania State University.

This briefing is the third in a series about personal genetics sponsored by the Personal Genetics Education Project (pgEd.org). The group’s mission 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.

Congresswoman Louise Slaughter said: “I fought for 14 years to pass GINA because, while scientists were mapping the human genome and unlocking the potential of genetic medicine, Americans were losing their jobs and their health care due to their genetic information being used against them. We should all be able to enjoy the benefits of genetic medicine like genetic testing while feeling secure that discovering a predisposition to a condition that may or may not develop won't cost us our job. I appreciate pgEd and all of the panelists for their support and for conducting this briefing to discuss new opportunities and challenges.”

Marnie Gelbart, Ph.D., Director of Program Development and National Initiatives at the Personal Genetics Education Project at Harvard Medical School said: “pgEd first came to Washington, DC last May to conduct a briefing on developments in the fields of genetics and precision medicine, and their impact on medicine, business, education, athletics and many other fields, including law enforcement. We sensed such enthusiasm for this topic that we launched a series of four more briefings

to explore emerging policy questions at the leading edge of genetics. That this, our third briefing, has drawn its audience from so many offices in the House and Senate, the State Department, the FBI, the DoJ, and beyond speaks volumes about the interest in the opportunities genetics is unlocking and the urgency of the issues being raised. pgEd thanks Congresswoman Slaughter, Senator Warren, and our panelists for encouraging these discussions amongst our nation's leaders."

Claire M. Fraser, Ph.D., Director of the Institute for Genome Sciences at the University of Maryland School of Medicine said: "As we apply powerful genomic tools to facilitate clinical research and microbial forensic investigations, it's important to continue the careful management of genomic data analysis and storage."

Duana Fullwiley, Ph.D., Associate Professor of Anthropology at Stanford University said: "As a society we are seeing incredible advances in genetic technologies, but we're still struggling to advance on basic social and racial justice fronts. We need to be very mindful of how we roll out genetic testing and forensic DNA technologies that may exacerbate the idea that race is genetic, or that might unfairly target certain groups. From Ferguson to many other American cities, we are still in our infancy in addressing racial bias in policing. First we need public awareness of the new technologies so this briefing is essential. Next, we need a series of ethical discussions to assess the racial impact of new DNA forensic tools on minority citizens. This is a true civil rights issue."

Henry T. Greely, J.D., Director of the Center for Law and the Biosciences; Professor of Law and Professor, by courtesy, of Genetics at Stanford University said: "DNA has proven an invaluable tool for identification, not just for crimes but for missing persons, human remains, and other good purposes. But as genomic analysis becomes easier and cheaper, genomics becomes more integrated into our everyday world, whether used for medicine, genealogy, and even just curiosity. This increases the chance that information taken for legitimate identification purposes will be linked to other, more personal data that goes beyond those legitimate ends. We need to watch these changes carefully to see if new restrictions on some of uses of DNA – or perhaps better public understanding of the possibilities– are needed."

David Kaye, J.D., Associate Dean for Research at Penn State Law; Graduate Faculty at the Forensic Science Program at the College of Science at the Pennsylvania State University said: "In the past quarter century, DNA science has captured the imagination of the public, transformed forensic science, and been both sword and shield in the criminal justice system. As the science of genomics and genetics advances, continued attention to -- and an accurate understanding of -- the power and limits of the technology and its impact on genetic privacy are imperative."