



May 27, 2022

Senator Patty Murray  
Chair, Senate Health, Education, Labor, and  
Pensions Committee  
154 Russell Senate Office Building  
Washington, DC 20520

Senator Richard Burr  
Ranking Member, Senate Health, Education,  
Labor, and Pensions Committee  
217 Russell Senate Office Building  
Washington, DC 20510

Representative Frank Pallone  
Chair, House Energy and Commerce Committee  
2107 Rayburn House Office Building  
Washington, DC 20515

Representative Cathy McMorris Rodgers  
Ranking Member, House Energy and  
Commerce Committee  
1035 Longworth House Office Building  
Washington, DC 20515

Dear Chair Murray, Ranking Member Burr, Chair Pallone, and Ranking Member McMorris Rodgers,

As national leaders dedicated to advancing science, thank you for your strong support for the nation's investment in biomedical research. The American Society of Human Genetics (ASHG), the field's primary professional membership organization comprised of nearly 8,000 human geneticists worldwide, appreciates your robust commitment to the National Institutes of Health (NIH) and to science as an engine to improve the lives and health of Americans.

We appreciate Congress' work to address issues of importance within the science and technology ecosystem through consideration of the *United States Innovation and Competition Act of 2021 (USICA)* and the *America COMPETES Act of 2022 (COMPETES)*. As these bills move to conference, we want to emphasize that provisions focused on national security should be carefully crafted to ensure that they do not impose unintended burdens on researchers whose work involves human genomic information. Such burdens could slow the pace of biomedical research and have a detrimental impact on discovery and innovation in the health sciences. Our organization is especially concerned about Section 6102 of USICA, which concerns NIH-funded research – human genomics research in particular – and national security. This section is not included in COMPETES, and **we urge the conference committee to exclude Section 6102 from the final competitiveness package.**

Now more than ever, the American people are benefiting from new genomic applications that are improving health, saving lives, and contributing to the U.S. economy. As a professional community dedicated to these advances, ASHG stresses the profound role genomic knowledge is playing in the transformation of all of biomedical research – from cancer to heart and lung disease, early child development, rare diseases, Alzheimer's disease, mental health, and so much more. We believe **that the inclusion of Section 6102 in the final innovation package will hinder continued scientific advances and unintentionally harm national security and competitiveness.** Our organization is concerned that the language included in Section 6102:

- Requires HHS to consider “appropriate national security risks” alongside medical research, without defining the risks, providing a substantial evidence base, or offering further guidance;

- Without justification, singles out human genetics and genomics research as exceptional relative to any other sensitive health data;
- Fails to consider the current legal and policy frameworks for the protection of human participants in federally funded research. These include the Common Rule, the Health Insurance Portability and Accountability Act (HIPAA), the Genetic Information Nondiscrimination Act, and the 21st Century Cures Act, and the NIH Genomic Data Sharing Policy;
- Could add unwarranted and potentially significant administrative burden and restrictions on US researchers through roadblocks to data sharing, which is already heavily regulated and has been an essential scientific component and value since the Human Genome Project launch. This could decrease the global competitiveness of U.S. geneticists, allowing those in other countries to out-compete us for discoveries of both health and economic value. Losing our important advantage of shared data could challenge our leadership in genomics and thus weaken the United States;
- Blurs lines between important—but very different—policy issues, ranging from the global biomedical research enterprise, to national competitiveness, to abusive human rights violations around the world that the U.S. rightly decries; and
- Potentially harms responsible and vital global scientific collaboration that advances genomics research for the benefit of all.

The human genetics and genomics community takes data privacy and stewardship extremely seriously. For decades, our community has pursued both the opportunity and responsibility that come with research and responsible use of new knowledge. As with most research fields today, responsible large-scale data analysis is essential to advance genomic discoveries and, as with most medical information, these data must have strong protections. ASHG is a major policy advocate to advance these goals, supporting the Common Rule, the Genetic Information Nondiscrimination Act, the 21st Century Cures Act, and responsible NIH genomic data-sharing policies. Just as any scientific knowledge has the potential for misuse and harm, ASHG also speaks out to [oppose the misuse of genetic research](#) that could harm individuals or populations, including opposition to the coerced collection of genetic data, which violates our community's core values. Finally, genomic research is a global pursuit with valued academic and industry research leadership underway worldwide. Yet, we have shared our concern when cases are reported in which researchers have taken advantage of America's historically open and inclusive research environment.


To serve the American people, it is vital that the nation prioritize both robust medical progress and national security goals and ensure they co-exist and advance as two top priorities. But before requiring a major new national security framework on NIH-funded human genetics and genomics research, Congress should first commission a study that brings together leading scientists and national security experts as equals. The commission should determine and document what national threats exist, if any, given the statutory and regulatory frameworks in place protecting the privacy of human genetic information, and provide guidance to HHS and NIH on the interface of scientific and national security goals. If this study concludes that there is a body of evidence establishing a clear threat to national security, scientists should be empowered to work alongside—not subject to—the national security community to determine how to mitigate the threat while ensuring scientific progress. **ASHG would welcome the opportunity to serve as a resource to your committees on the development of legislative language authorizing such a study.**

Thank you for your continued leadership on science and technology issues and your commitment to supporting the U.S. biomedical research enterprise. We look forward to continuing to work with you to advance our shared goals of advancing the health and security of our nation, and please do not hesitate to reach out if ASHG can be of assistance moving forward.

Sincerely,

A handwritten signature in black ink, appearing to read 'Brendan Lee', enclosed in a thin black rectangular border.

Brendan Lee, M.D., Ph.D.  
ASHG President-Elect

A handwritten signature in blue ink, appearing to read 'Mona V. Miller', enclosed in a thin black rectangular border.

Mona V. Miller  
ASHG Chief Executive Officer