



American Society of Human Genetics

discover. educate. advocate.

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The Honorable Marcy Kaptur
United States House of Representatives
2186 Rayburn House Office Building
Washington, DC 20515

8 August 2018

Dear Congresswoman Kaptur:

The American Society of Human Genetics (ASHG) wishes to thank you for your amendment strengthening genetic privacy in the draft fiscal year 2019 Labor, Health and Human Services, and Education funding bill. If enacted into law, your amendment will protect the genetic privacy of immigrant families by restricting the use of their genetic material and data to helping reunify family members.

ASHG, founded in 1948, is the world's largest genetics professional society, with some 7,000 members representing all areas of research and application in human genetics. The Society also includes scholars who study the ethical, legal and social issues associated with genetics, including the appropriate use of genetics tools in society, such as for law enforcement purposes.

Because of remarkable technology developments in the past few years, we have an ever-increasing ability to collect, analyze, and store personal genetic data. This is empowering genetic research and genomic medicine on an unprecedented scale, and being employed for other societal purposes. However, an individual's genome includes information on his or her risk for disease, their ancestry, and their relatedness to others, it is important that we protect the genetic privacy of people tested.

It can raise significant concerns about privacy and the potential misuse of this highly sensitive information when a government entity is collecting and analyzing samples for law enforcement purposes. While the Society supports DNA profiling as a law-enforcement tool to identify criminals and exonerate the innocent, the process must respect the public's right to privacy. Compelled DNA testing should be restricted to individuals convicted of or reasonably suspected of having committed a serious crime. Any genetic analysis should be restricted to the explicit purpose for which a person is being tested.

If enacted, your amendment will protect the genetic rights of DNA testing of immigrant families seeking to be reunified. It appropriately requires that the Office of Refugee Resettlement (OCR) restricts its use of DNA analysis to when it is truly needed to help establish relatedness, protects individuals' privacy, and ensures that the biological samples and data gathered cannot be used for other for other purposes.



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We strongly applaud your leadership in advancing measures to ensure individuals' genetic privacy as immigrant families seek to be reunified. Derek Scholes, Senior Director, Policy and Advocacy (dscholes@ashg.org; office: 301-634-7330) will reach out to your staff to see if the Society can be of any assistance.

Yours sincerely,

A handwritten signature in black ink that reads "David L. Nelson". The signature is fluid and cursive, with the first name being the most prominent.

David L. Nelson
President, American Society of Human Genetics