



NATIONAL CONSUMERS LEAGUE URGES POLICYMAKERS TO PROTECT GENETIC PRIVACY

TO SAFEGUARD CONSUMERS' PRIVACY RIGHTS, CONGRESS MUST PASS LEGISLATION WHICH INCORPORATES THE FOLLOWING POLICIES:

- Requiring public sector entities, including federal agencies, and local law enforcement agencies, to obtain the explicit consent of an individual before sharing their genetic information with any other public sector entity.
- Requiring that clinical labs, commercial direct-to-consumer DNA testing companies, and other companies who collect or store genetic information, to annually disclose to the Department of Health and Human Services (HHS) any requests by public sector entities for the genetic information of any individual and to further disclose if they obtained consent from that individual before complying with that data request.
- Requiring that any clinical lab that has access to the genetic information of U.S. citizens, as part of obtaining its Clinical Laboratory Improvement Amendments (CLIA) certification, disclose to HHS on a quarterly basis whether it has provided services to any company or entity with ties to foreign adversaries.
- Requiring the approval of the Committee on Foreign Investment in the United States (CFIUS) for any merger or acquisition that involves a company whose operations significantly involve providing genetic services or that collects genetic information of U.S. citizens.
- Restricting the use of any National Institutes of Health (NIH) funding for genetic services or the collection of the genetic information of U.S. citizens by any company or entity with ties to foreign adversaries unless licensed by HHS to ensure that legitimate research benefits are being served.

IN ADDITION TO THE LEGISLATIVE INITIATIVES OUTLINED ABOVE, THE BIDEN ADMINISTRATION SHOULD TAKE THE FOLLOWING STEPS TO PROTECT INDIVIDUALS' GENETIC DATA:

- Directing NIH to convene a roundtable that includes consumer groups, privacy and data security experts, and the biomedical research community to develop a robust consumer education campaign about the importance of protecting genetic information.
- Developing and implementing additional export controls so that the U.S. government can monitor the transfer of U.S. genetic information to entities with ties to foreign adversaries, including the immediate Entity List designation of all companies and subsidiaries that are known to be involved in the management and administration of the China National GeneBank.
- Prohibiting commercial direct-to-consumer DNA testing companies from sharing genetic information with entities with ties to Chinese government without prior U.S. government approval.
- Working with the Federal Trade Commission (FTC) to take legal action against any company that violates consumers' genetic privacy rights or does not implement sufficient measures to secure genetic data records.
- Ensuring HHS enforces the Health Insurance Portability and Accountability Act (HIPAA) to protect individuals' genetic data records. This includes adhering to the national standards of protection and using appropriate safeguards to keep individuals' genetic data records private and limiting and conditioning the uses and disclosure of this information without the respective individual's authorization.

FOR ACTIONS THAT PRIVATE INDUSTRY CAN TAKE UNILATERALLY, NCL URGES THE FOLLOWING EFFORTS:

- Creating a forum with consumer groups, health care institutions, the biomedical research community, the genetic services industry, and relevant federal agencies to discuss how privacy and data security measures can be updated to account for the advances in the uses and applications of genomic data.
- Developing an "Ask the Question" campaign to encourage consumers to ask, "where is my DNA being sent for testing and what happens to my DNA sample?" before they agree to a DNA test or send their DNA sample to a direct-to-consumer genetic testing company.