



ATTORNEY GENERAL WILLIAM TONG
STATE OF CONNECTICUT

Testimony in Support of H.B. No. 5128
An Act Concerning Direct to Consumer Genetic Testing
General Law Committee
Wednesday, February 18, 2026

Chairman Maroney, Chairman Lemar, Ranking Member Cicarella, Ranking Member Rutigliano, and distinguished members of the General Law Committee, thank you for the opportunity to submit testimony in support of House Bill No. 5128, *An Act Concerning Direct to Consumer Genetic Testing*.

This bill addresses a concerning gap in Connecticut's current law that puts the most sensitive data of every resident at risk, their DNA. DNA is what determines our biological characteristics – our eye color, aspects of our personality, height, even our predisposition for certain diseases. The key to who we are, who our ancestors were, and who we will be is found in our DNA. By its very nature DNA is inherently identifiable – every piece of DNA can be tracked back to the person from whom it came. Each person's genes are unique and immutable – they cannot be changed.

In recent decades, an entire industry has developed around collecting people's DNA and sharing insights with them (and with others) that can only be determined through analysis of genetic code. One company in particular, 23andMe, was wildly successful – gathering the DNA of over 15 million people to reveal the secrets found within their genes. People discovered new relatives, countries of origin, and even their predisposition for diseases. 23andMe also sold this information to pharmaceutical companies and others and used it in their own attempts to develop drugs, harnessing this unique data to fight rare and devastating diseases.

However, the great promise of this technology also presents great risk. A threat actor targeted 23andMe, stealing records including genetic information derived from over six million people. The Attorney General's Office began an investigation immediately, eventually serving as co-leaders of a multistate group of 43 states. As part of our investigation, we learned about the potential uses and misuses of genetic data. The threat actor used this genetic data to spread fear, offering lists for sale of 23andMe users based on their genetic ancestry, targeting people of Jewish and Chinese descent. In many cases, these leaks disclosed genetic ancestry data of users along with the name and location they had entered in their 23andMe profile. Another threat actor leaked more data, claiming to expose the genetic ancestry information of celebrities and world leaders. One hacker had created an application that would block visitors to websites based on their race or ethnic origin. A post on the dark web claimed that the threat actors had downloaded raw genetic data from 23andMe, including excel spreadsheets containing people's entire genetic code.

We led this investigation for more than two years, pursuing the company even after they filed for bankruptcy. 23andMe owners were selling the DNA of their users to the highest bidder, but we discovered that under Connecticut law such a transfer could take place without informing their users, and without asking their users for consent for a transfer of their genetic data to what would potentially be a completely different entity. Due to this lacuna in Connecticut law, a company can also collect DNA from consumers for one purpose and then use it for a completely different purpose, without notice or consent for this new use. We believe that Connecticut must implement protections for DNA, including



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notice and consent requirements for any transfer or sale of that data and for any uses that were not communicated and consented to at time of collection.

At least 27 states have genetic privacy laws in place. They vary, from civil rights and healthcare-focused laws to a newer wave of legislation that focuses specifically on direct-to-consumer genetic testing companies like 23andMe. Many state laws require separate express consent for new uses of genetic data that were not communicated to the individual at time of collection. All of these laws give people rights over their genetic data and require consent for disclosure.

House Bill No. 5128 is the product of an extensive review of genetic privacy laws in other states. We believe that we have consolidated the best of these laws into the provisions in the bill before you, which will provide strong legal protections for the DNA of Connecticut residents. The bill grants Connecticut residents exclusive control over their biological material, their DNA, and the results of any analysis of their DNA. Under the bill, companies that collect the DNA of Connecticut residents must obtain their express consent for any use of their data that was not previously communicated and consented to at time of collection, and they also must obtain express consent prior to any sale or transfer of their DNA. Drawing on our experience in 23andMe, the bill also requires that companies that collect DNA impose reasonable security measures to protect consumers' biological samples and genetic data from unauthorized access or disclosure.

The bill also protects Connecticut residents from the use of their DNA for marketing or targeted advertising – the use of immutable, unchangeable genetic characteristics for marketing purposes is a grave consumer protection concern. Such a practice would undermine individual autonomy and independent market participation by consumers. In addition, the bill protects Connecticut residents from the use of their DNA by insurance companies, bolstering pre-existing federal protections against the use of DNA by health insurers. Violations under this bill would be deemed a violation of the Connecticut Unfair Trade Practices Act (CUTPA).

DNA that has been stolen, misappropriated, or exposed in a data breach is not like any other type of personal information. It is not just information associated with you to create an identity like a Social Security number – it *is you*. You cannot change your DNA. DNA is immutable. It is inherently identifiable. DNA reveals secrets about you that even you do not know, and as technology advances the potential for misuse of genetic information will only proliferate. We ask today that you act to impose much-needed safeguards on genetic data that are currently lacking under Connecticut law.

For these reasons, the Office of the Attorney General recommends that the Committee favorably report H.B. No. 5128.

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