

Support Strong Protections for Genetic Data in Minnesota

Over the past decade, Minnesotans have taken a strong interest in direct-to-consumer genetic testing products. These services can provide consumers with insights to their health, wellness, and family history based on genetic data extracted from a saliva sample they provide to private companies like Ancestry and 23andMe.

These companies, recognizing the sensitive nature of their consumers' genetic data, have carefully considered the privacy and data protection issues incumbent with direct-to-consumer genetic testing services. They support having safeguards in place that ensure consumers are aware of their privacy practices, have control over their data, and have the opportunity to provide separate express consent before their data is shared.

The Future of Privacy Forum, working with leading consumer privacy advocates, key policy makers in DC, and Ancestry, 23andMe and Helix, among other genetic testing companies, promulgated the *Privacy Best Practices for Direct-to-Consumer Genetic Testing Services* in 2018. When states began to discuss codifying privacy protections for consumer genetic data shortly after, the *Best Practices* were translated into model state legislation. Six states have passed that bill so far: Arizona, California, Kentucky, Maryland, Utah, and Wyoming – with more states joining the list every year.

If enacted in Minnesota, this bill will provide among the strongest privacy protections for consumer genetic testing services in the world. The bill ensures that the consumer is in control of their genetic data at all times, and would require all of the following:

- Separate express consent before DNA is extracted from a biological sample and analyzed.
- Separate express consent before a biological sample is stored.
- Separate express consent for genetic data to be used for research purposes.
- Separate express consent for genetic data to be shared with a third party.
- Separate express consent for genetic data to be used for marketing purposes.
- Genetic testing companies may not share genetic data with employers or providers of insurance for any reason without written consent (and neither Ancestry nor 23andMe provide genetic data to these entities at all).
- Genetic testing companies must provide consumers with a means to delete their genetic data from their database and close their accounts without unnecessary steps.
- Genetic testing companies must delete a consumer's biological sample within 30 days of a request.
- Genetic testing companies must provide clear and complete information about their privacy practices and protocols.

We are proud of the work we have undertaken to provide customers with straightforward privacy policies that empower them to control how their genetic data is used. We urge the Minnesota legislature to pass this bill to ensure that consumers have all of these protections regardless which testing service they use.

FREQUENTLY ASKED QUESTIONS

Why Do We Need This Bill if the Companies Are Already Providing These Protections?

Not every provider of genetic testing services or analysis is signatory to the *Best Practices*. In recent years, startup operations have entered the market claiming they can provide additional insights to consumers if they download their genetic data files from Ancestry or 23andMe and share them with those companies.

Unfortunately, many of these companies do not provide the privacy protections described above. The most common example of this is companies using genetic data for marketing purposes without the consumer's consent, *except where prohibited by state law*. Without this bill, companies are free to use genetic data for marketing and can even sell a consumer's genetic data to third parties without consent.

How is Genetic Data Different from Biometric Data?

Biometric data and genetic data are different types of data and should be regulated separately. Biometric data in its various uses (fingerprints, facial images, physical gait, etc.) can be used to *immediately* authenticate an individual – often without their knowledge or consent. Biometric data is often collected incidentally when a consumer uses a product or service for another primary purpose. Genetic data, on the other hand, requires a biological sample from the individual. Our companies, as noted above, go to great lengths to ensure that the consumer understands how their data will be used and provides consent to all uses of their genetic data.

Do You Allow Law Enforcement to Use Your Database to Solve Cold Cases?

We do not share customer data with law enforcement unless we receive a legally valid request such as a search warrant or written court order. Upon receipt of an inquiry from law enforcement, we use all practical legal measures to challenge such requests in order to protect our collective customers' privacy. In addition, our companies voluntarily publish transparency reports that are available on our public websites and detail the number of valid law enforcement requests we receive, and whether or not customer data has been disclosed.

Our consumers may download their raw genetic data files from our respective services and upload it to other sites that offer additional analysis or features. One of these sites, GEDMatch, allows users to upload their genetic data from any testing service. This allows them to search for genetic relatives that may have used a different testing company. GEDMatch allows users to *opt-in* to participate in law enforcement investigations. Nearly all of the high-profile cases solved using forensic genealogy, such as the Golden State Killer, used GEDMatch to construct the family tree of the unknown assailant. Neither Ancestry nor 23andMe allow any third-party uploads to our service, and we direct law enforcement to GEDMatch when they wish to engage in such an investigation.

Is Ancestry Owned by the Church of Jesus Christ and Latter Day Saints?

No. The two men who started Ancestry in 1983 were members of the Church, but the LDS Church has never had an ownership interest directly in Ancestry. They operate their own genealogy service, FamilySearch. Ancestry is currently owned by private equity

Further Reading

To learn more about the Future of Privacy Forum's *Best Practices* and our Coalition, please visit <http://www.geneticdataprotection.com>.