

February 6, 2023

The Honorable Ron Latz
Chair, Senate Judiciary Committee
Minnesota State Legislature
Minnesota Senate Office Building, Room 3105
95 University Avenue West
St. Paul, MN 55155

RE: Senate File 1138 (Klein) – Genetic Information Privacy – SUPPORT

Dear Chair Latz:

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.

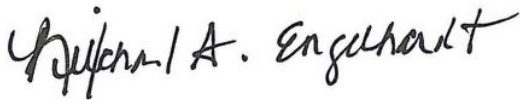
SF 1138 by Senator Klein will provide among the strongest privacy protections for consumer genetic testing services in the world. The bill ensures that Minnesota consumers are in control of their genetic data at all times, and would require all of the following:

- 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 SF 1138 by Senator Klein to ensure that consumers have all of these protections regardless which testing service they use.

Sincerely,



Ritchie Engelhardt
Head of Government Affairs
Ancestry



Jacquie Cooke
General Counsel and Privacy Officer
23andMe

cc: Sen. Matt Klein (Sponsor)
Sen. Warren Limmer, Ranking Member, Senate Judiciary Committee
Members, Senate Judiciary Committee