

March 3, 2023

The Honorable Kesha Ram Hinsdale  
Chair, Senate Committee on Economic Development, Housing, and General Affairs  
Vermont General Assembly  
State Capitol Building  
115 State Street  
Montpelier, Vermont 05633

**RE: Senate Bill 49 (Lyons) – Genetic Data Privacy – SUPPORT IF AMENDED**

Dear Chair and Members of the Senate Committee on Economic Development, Housing and General Affairs:

Over the past decade, Vermonters 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.

S.49 by Senator Lyons will provide among the strongest privacy protections for consumer genetic testing services in the world. The bill ensures that Vermont 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 provides 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 upon request.
- Genetic testing companies must provide clear and complete information about their privacy practices and protocols.

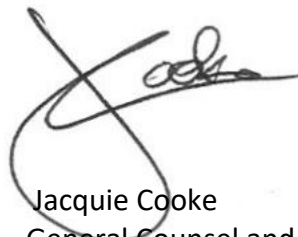
Attached, we are proposing two amendments that we feel will strengthen the bill. The first is at the request of the Vermont Public Interest Research Group (VPIRG) and makes it clear that a consumer must provide an answer to an unambiguous question when we obtain their consent for the items above. The second clarifies that the attorney general has the sole authority to enforce the provisions in the bill. Our companies allow our consumers to download their genetic data, which consumers can then choose to share with others, including by uploading their data to a third party platform for further interpretation. Any apparent violations of the statute related to the consumer's genetic data would be best investigated through the attorney general's office to ensure that the entity who actually violated the statute is brought to account.

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 Vermont General Assembly to pass S.49 by Senator Lyons, with amendments, to ensure that consumers have all of these protections regardless of which testing service they use.

Sincerely,



Ritchie Engelhardt  
Head of Government Affairs  
*Ancestry*



Jacquie Cooke  
General Counsel and Privacy Officer  
*23andMe*

cc: Sen. Virginia Lyons (Sponsor)  
Members, Senate Economic Development, Housing, and General Affairs Committee

## **PROPOSED AMENDMENTS**

On Page 1, insert at the end of line 18:

*Express consent means an affirmative authorization by the consumer granting permission in response to a statement of the nature of the data collection, use, maintenance, or disclosure for which express consent is sought in plain and prominent language that an ordinary consumer would notice and understand. Express consent shall not be inferred from inaction.*

On page 6, strike lines 11-13 and replace with:

*(d) The Attorney General and State's Attorney shall have sole and full authority to investigate potential violations of this subchapter and to enforce, prosecute, obtain, and impose remedies for a violation of this subchapter or any rules or regulations made pursuant to this chapter as the Attorney General and State's Attorney have under chapter 63 of this title. The Attorney General may refer the matter to the State's Attorney in an appropriate case. The Superior Courts shall have jurisdiction over any enforcement matter brought by the Attorney General or a State's Attorney under this subsection.*