

April 2, 2026

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

**RE: House Bill 639 (Scheu) – Genetic Information Privacy – House Amendments**

Dear Chair Clarkson -

In advance of my testimony to your committee today, I wanted to provide written comments regarding a few amendments that the House adopted for H.639 that may need further scrutiny in the Senate.

**Biometric Data**

The House inserted a broad definition of biometric data in the bill and then applied all the bill's provisions to this new definition. While we support the regulation of biometric data, we believe the rules regarding biometric data should apply equally to companies. As this appears in a bill that solely applies to companies that offer direct-to-consumer genetic testing, Ancestry would face a different level of scrutiny and a different level of statutory penalty for alleged violations on our family history site solely by virtue of the fact that we offer a genetic testing product.

One of our most significant competitors - FamilySearch - does not offer DNA testing. They do have similar content on their family history service. By regulating biometric data in a genetic privacy bill - Vermont would be the first state to establish a bill that treats competitors differently for how they handle the exact same kinds of data.

In the introduced version, the references to biometric data were exclusively focused on the collection and storage of biological samples. That is the correct focus in a genetic privacy bill.

***We urge the committee to strike the definition of biometric data from the bill and replace all references to 'biometric data' with 'biological sample'.***

**Additionally, we recommend qualifying Section (12)(B)(i) on Page 21 by adding, "unless otherwise made publicly available by the consumer to whom the information pertains" before the final period.** This would conform the treatment of biological samples to genetic data and ensure that companies are not penalized for using publicly available research datasets and samples for valid scientific research. We understand that Rep. Monique Priestley plans to address the regulation of biometric data in her comprehensive privacy bill. That is the correct vehicle for this definition and regulation as it would apply to every company that holds that type of data in an equitable manner.

## Deletion of Genetic Data Held by Third Parties

The House amendments introduce a requirement that companies notify service providers and any third-parties with whom they have shared genetic data of deletion requests that are received from customers. These entities then must delete the data from their systems without exception.

There are two unique cases where this may not be possible or advisable. Laboratories who act as service providers to sequence genetic data are subject to the Clinical Laboratory and Improvement Act of 1988 (CLIA) and must retain a sample of specimens in order to validate the assays the laboratory is running.

Additionally, for consumers who have opted in to participate in research, their informed consent explains that they may withdraw participation from future research, but any samples or information included in a research dataset that has commenced or completed will not be deleted. This aligns with both the Common Rule and FDA guidelines for human subject research and ensures that the integrity of controlled-variable research is not compromised.

**We recommend adding to Section (d)(1)(C) the same qualification that appears in Section (d)(1)(B)(ii), while adding an additional exception for in-progress or completed research : *“except for genetic data that is required to be retained by the company to comply with applicable legal and regulatory requirements; or genetic data that is included in a research project that the consumer previously provided informed consent and for which the research has already commenced or completed.”***

## Private Right of Action

**We recommend removing Section 2421c(a) on p.14 which references a private right of action and ask that enforcement be within the authority of the Attorney General.**

We appreciate the opportunity to engage on H.639. Please let me know if there is any other information we can provide to assist the committee in its deliberations. I am happy to testify again by Zoom next week if that would facilitate the committee's work.

Sincerely,



Ritchie Engelhardt  
Head of Government Affairs, Ancestry

cc: Members, Senate Committee on Economic Development, Housing and General Affairs