

COALITION FOR GENETIC DATA PROTECTION

May 18, 2022

The Honorable Jim Marshall
Chair, House Consumer Affairs Committee
Pennsylvania House of Representatives
Capitol Building, 501 North Third Street
Harrisburg, PA 17120

RE: House Bill 2202 (Mercuri) – REQUEST AMENDMENTS

Dear Chair Marshall:

On behalf of The Coalition for Genetic Data Protection¹, a national coalition of the leading consumer genetic testing companies including 23andMe and Ancestry – we are writing to request amendments on House Bill 2202.

Our companies continue to carefully consider the privacy and data protection issues incumbent with direct-to-consumer genetic testing services and we continue to support having safeguards in place that ensure consumers are aware of our privacy practices, have control over their data, and have the opportunity to provide affirmative consent before their data is shared.

We worked with the Future of Privacy Forum, a leading privacy think tank in Washington, DC, to develop the *Privacy Best Practices for Consumer Genetic Testing Services* in 2018. Our companies immediately adopted those *Best Practices*. As states have begun considering legislation to regulate the direct-to-consumer genetic testing industry, we have worked with legislators to translate the *Best Practices* into legislation. So far, three states – Arizona, California, and Utah – have passed laws based on the *Best Practices*, which we supported. Those bills ensure that the consumer is in control of their genetic data at all times, and 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 scientific research purposes.
- Separate express consent for genetic data to be shared with a third party.

¹ <https://geneticdataprotection.com/>



- Separate express consent for genetic data to be used for marketing purposes.
- Genetic testing companies to not share genetic data with employers or providers of insurance for any reason.
- Genetic testing companies to provide consumers with a means to delete their genetic data from their database and close their accounts without unnecessary steps.
- Genetic testing companies to destroy a consumer's biological sample within 30 days of a request.
- Genetic testing companies to provide clear and complete information about their privacy practices and protocols.

In considering HB 2202, we are not opposed to privacy protections for genetic data in Pennsylvania. However, we strongly believe that biometric information and genetic data should be regulated separately. Biometric data in its various uses (fingerprints, facial images, physical gait, etc.) can be used to *immediately* identify an individual – often without their knowledge or consent. Genetic data, on the other hand, requires a biological sample from the individual and 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.

This is fundamentally different than the scenarios that HB 2202 seeks to regulate. While we charge a fee for our service in exchange for a product that a consumer requests, in most instances the consumer data regulated by HB 2202 is collected incidentally to the service a consumer is using – be it social media, online shopping, or other interactions with a business. In those instances, it makes sense that a consumer is afforded rights regarding how a business collects, retains, uses, or shares their data.

Our companies provide consumers with far greater control over their genetic data than what is contemplated in HB 2202. Our consumers need to have confidence that we are treating their genetic data with the utmost care or their will opt to not use our services. We would be amenable to Pennsylvania adopting legislation based on our *Best Practices*, and Sen. John Gordner has circulated a colleague letter detailing a bill he plans to introduce that would do just that.

The amendments enumerated below would refine the definition of biometric information to exclude DNA and genetic data. Given that uses for these types of data is different, we feel the correct approach is to regulate them separately. So far, no state that has passed a biometric information privacy act has included DNA in their definition.

Our companies are proud of the work we have undertaken to provide our customers with straightforward privacy policies that empower them to control how their genetic data is used. We have had productive discussions with Rep. Mercuri and



hope that you are amenable to the proposed amendments. We are additionally committed to working with Sen. Gordner on his proposed bill.

Thank you for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Eric Heath".

Eric Heath
Chief Privacy Officer
Ancestry

A handwritten signature in black ink that reads "Jacquie Cooke Haggarty".

Jacquie Cooke Haggarty
General Counsel & Privacy Officer
23andMe

cc: Representative Rob Mercuri
Senator John Gordner
Members, House Consumer Affairs Committee

Requested Amendments

On Page 2, Lines 1-2, Strike: "deoxyribonucleic acid (DNA) information"

On Page 2, Line 4, insert after "demographic data": ", human biological sample used for valid scientific testing or screening"