

COALITION FOR GENETIC DATA PROTECTION

February 25, 2022

The Honorable CT Wilson
Chair, House Economic Matters Committee
House Office Building, Room 230
6 Bladen Street
Annapolis, MD 21401

RE: HOUSE BILL 866 – COMMERCIAL LAW – CONSUMER PROTECTION – GENETIC INFORMATION PRIVACY

Dear Chair Wilson and Members of the Committee

On behalf of the Coalition for Genetic Data Protection (CGDP), a national coalition of the leading consumer genetic testing companies including 23andMe and Ancestry, we are writing in strong support for House Bill 866. By passing HB866, Maryland would join California, Arizona and Utah in enacting comprehensive privacy protections for consumer genetic data.

Over the past several years, we have carefully considered the privacy and data protection issues incumbent with direct-to-consumer genetic testing services and we support having safeguards in place to 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 – regardless of which genetic testing service they use.

If enacted, HB866 will provide among the strongest privacy protections for consumer genetic testing services in the world. The bill ensure 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 the biological sample and analyzed;
- Separate express consent before a biological sample is stored;
- Separate express consent for genetic data 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 to not share genetic data with employers or providers of insurance for any reason;
- Genetic testing companies to provide consumer with a means to delete their genetic data from their database and close their accounts without unnecessary steps.
- Genetic testing companies to delete 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.



We 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 take this opportunity to thank and commend Delegate Qi for her leadership on this important issue and urge the Committee's favorable consideration of House Bill 866.

Sincerely,

A handwritten signature in black ink, appearing to read "Eric Heath".

Eric Heath
Chief Privacy Officer
Ancestry

A handwritten signature in black ink, appearing to read "Jacquie Haggarty".

Jacquie Haggarty
VP, Deputy General Counsel & Privacy Officer
23andMe

A handwritten signature in black ink, appearing to read "Steve Haro".

Steve Haro
Executive Director
Coalition for Genetic Data Protection