

COALITION FOR GENETIC DATA PROTECTION

January 27, 2021

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

RE: HOUSE BILL 218 – COMMERICAL LAW – CONSUMER PROTECTION – BIOMETRIC IDENTIFIERS AND BIOMETRIC INFORMATION PRIVACY - TESTIMONY IN SUPPORT WITH AMENDMENT

Dear Chair Davis:

The Coalition for Genetic Data Protection (CGDP) serves to provide a unified and proactive voice to advance policies that ensure the privacy and security of an individual's genetic data and enable responsible innovation. Consumer genetic testing can empower consumers to take a proactive role in their health, wellness, ethnicity, and origin in unprecedented ways – and millions of consumers have taken advantage of these opportunities. At the same time, genetic data provides unprecedented opportunities for the research community to better understand the role genetics play in our health and well-being as a human population. While we recognize the significant opportunities genetic testing and research present, we also support and advocate for reasonable and uniform privacy regulation that will ensure the responsible and ethical handling of every person's genetic data.

House Bill 218, as introduced, generally requires each “private entity” in possession of “biometric identifiers” or “biometric information” to develop a publicly available written policy establishing a retention schedule and guidelines for permanently destroying the biometric identifiers and information and sets minimum standards for such policies. The legislation creates a definition of “confidential and sensitive information” that includes “A GENETIC MARKER” and “GENETIC TESTING INFORMATION”, which essentially aligns this type of genetic data with other personal information as information that can be used to uniquely identify an individual.

CGDP believes that genetic data is very different from other types of both biometric information and personal information, in that it is not used in the same manner to directly, and often immediately, identify an individual for security or other purposes. In fact, genetic data on its own, without the addition of other personal identifying information, cannot be used to directly identify an individual. Due to the unique nature of genetic data, statutes and regulation at both the state and federal level that regulate biometric data do not expressly include genetic data in that regulation. The Maryland General Assembly has several other pieces of legislation before it in the 2021 Legislative Session that address the protection and privacy of personal information and lay out specific parameters for the use and protection of genetic data. These bills define this type of data separately and differently than general biometric data, and CGDP seeks a similar application of the standards set in HB218.

The attached amendment does not alter the proposed standards for private entity use of biometric data in Maryland, other than to remove references to genetic data. In keeping with CGDP's stated mission, it is not opposed to the reasonable regulation of genetic data collected and used by private entities, but urges the Committee to pursue privacy policy that recognizes the unique nature of genetic data and how it differs from the other biometric information that is the primary focus in HB218. CGDP looks forward to working with the bill



sponsor and the members of the Committee on HB218 and other legislation before the General Assembly that specifically addresses the use of genetic data.

Sincerely,

A handwritten signature in blue 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

cc: