February 10, 2021

The Honorable Delores Kelley
Chair, Senate Finance Committee
Miller Senate Office Building, 3 East
11 Bladen Street
Annapolis, MD 21401

RE: <u>SENATE BILL 112 – COMMERICAL LAW – PERSONAL INFORMATION PROTECTION ACT – REVISIONS - TESTIMONY IN SUPPORT WITH AMENDMENT</u>

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 consumer's genetic data.

Senate Bill 112 (SB112), as introduced, makes several changes to the Maryland Personal Information Protection Act (MPIPA), including updating the definition of "personal information" to include genetic data. CGDP does not oppose the inclusion of genetic data in MPIPA, but it would propose a more modern definition of genetic data that better encompasses the current collection and use practices for this type of data and also takes into consideration existing federal regulation for genetic data collected for specific purposes. Below, please find a proposed definition for genetic data for the Committee's consideration:

(A)   "Genetic data" means any data, regardless of its format, that results from the analysis of a biological sample obtained from a natural person (an "individual"), and concerns information about an individual's inherited or acquired genetic characteristics, including: deoxyribonucleic acid (DNA), ribonucleic acid (RNA), genes, chromosomes, alleles and genome.

(B)   "Genetic data" does not include deidentified data. For purposes of this subparagraph, "deidentified data" means data that cannot be used to link information to a particular individual, provided that the business that possesses the deidentified data does all of the following:

(i) Takes reasonable measures to ensure that the deidentified data cannot be linked with an individual.

(ii)   Publicly commits to maintain and use the deidentified data only in deidentified form and not to attempt to reidentify the deidentified data, except that the business may attempt to reidentify the deidentified data solely for the purpose of determining whether its deidentification processes satisfy the requirements of this subparagraph, provided that the business does not use or disclose any reidentified data in this process and destroys the reidentified data upon completion of that assessment.

(iii)   Contractually obligates any recipients of the deidentified data to take reasonable measures to ensure that the deidentified data cannot be linked with an individual and to commit to maintaining and using the deidentified data only in deidentified form and not to reidentify.

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(C) *"Genetic data" does not include any data that is collected, used, maintained, and disclosed exclusively for scientific research, clinical trial, or other biomedical research conducted in compliance with applicable federal and state laws and regulations for the protection of human subjects in research, including, but not limited to, the Common Rule pursuant to Part 46 (commencing with Section 46.101) of Title 45 of the Code of Federal Regulations, United States Food and Drug Administration regulations pursuant to Parts 50 and 56 of Title 21 of the Code of Federal Regulations, the federal Family Educational Rights and Privacy Act (20 U.S.C. Sec. 1232g), or the Protection of Human Subjects in Medical Experimentation Act, Chapter 1.3 (commencing with Section 24170) of Division 20 of the Health and Safety Code.*

(D) *"Genetic data" does not include any physical biological sample.*

CGDP believes amending SB112 to include this comprehensive definition of genetic data, in place of the drafted definition of "genetic data" is more consistent with other aspects of the legislation, including provisions dealing with deidentified data and overlapping federal regulation. The proposed definition is also in keeping with the types of services that are now associated with the collection and use of genetic data, as opposed to it solely being used for health testing purposes. CGDP looks forward to working with the bill sponsor, the members of the Committee, and the Attorney General's Office to develop and implement reasonable policy for the use and protection of genetic data in Maryland.

Sincerely,

Eric Heath
Chief Privacy Officer
Ancestry

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

Steve Haro
Executive Director
Coalition for Genetic Data Protection

cc: