COALITION FOR GENETIC DATA PROTECTION • •

March 16, 2022

The Honorable Delores Kelley Chair, Senate Finance Committee Miller Senate Office Building, 3 East 1 Bladen Street Annapolis, MD 21401

RE: <u>SENATE BILL 643 – COMMERCIAL LAW – MARYLAND PERSONAL INFORMATION</u> PROTECTION ACT – REVISIONS – SUPPORT WITH AMENDMENTS

Dear Chair Kelley 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 to support Senate Bill 643 with amendments. Over the past several years, we have carefully considered the privacy and data protection issues incumbent with direct-to-consumer genetic testing services and agree with the bill sponsor and the proposed legislation that the genetic data held by our companies should be treated in the same manner as other personal information in the unlikely event of a data breach.

CGDP fully supports SB643 with an amendment to modernize the definition of "genetic information" included in the bill as introduced. The definition in the proposed legislation is from the 2008 federal "Genetic Information Nondisclosure Act" or GINA. That definition is outdated, limited in how it envisions genetic data is collected and used on behalf of modern consumers, and tailored specifically to anti-discrimination protections. The CGDP proposes the following definition be amended into the bill instead:

(III) Genetic Data means any data, regardless of its format, that results from analysis of a biological sample of an individual, or from another source enabling equivalent information to be obtained, and concerns genetic material.

 Genetic material includes, but is not limited to, deoxyribonucleic acids (DNA), ribonucleic acids (RNA), genes chromosomes, alleles, genomes, alterations or modifications to DNA or RNA, single nucleotide polymorphisms (SNPs), uninterpreted data that results from analysis of the biological sample or other sources, and any information extrapolated, derived, or inferred therefrom.

The proposed replacement definition better encapsulates all forms of genetic data, more accurately reflects the way genetic data is collected, held and used by modern direct-to-consumer genetic testing services, and is consistent with the definitions used in data breach statutes in other states, including California. The CDGP believes that, with the inclusion of the suggested definition, SB643 would ensure that consumers' genetic data is subject to the secure and protective treatment required for other forms of personal information under the existing Maryland Personal Information Protection Act.



We take this opportunity to thank the bill sponsors and the Office of the Attorney General for working with us on amendments that significantly address our definitional concerns. We continue to work with the OAG to determine exactly how an entity that maintains genetic data, as defined in the bill, in a deidentified manner will comply with the provisions of the bill that require us to determine the number of impacted Maryland residents impacted by a breach. Deidentified data, by definition, means that we do not know whom the genetic data belongs to and, therefore, are unable to determine their state of residence. We appreciate the ongoing discussion on this point and look forward to additional guidance from the Consumer Protection Division on the best manner to comply.

The CGDP respectfully requests the Committee's favorable consideration of House Bill 962 with the suggested definitional amendment and clarification.

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