

BRIAN E. FROSH
Attorney General

WILLIAM D. GRUHN
Chief
Consumer Protection Division

ELIZABETH F. HARRIS
Chief Deputy Attorney General

CAROLYN QUATTROCKI
Deputy Attorney General



STATE OF MARYLAND
OFFICE OF THE ATTORNEY GENERAL
CONSUMER PROTECTION DIVISION

February 25, 2022

TO: The Honorable C.T. Wilson, Chair
Economic Matters Committee

FROM: Hanna Abrams, Assistant Attorney General

RE: House Bill 259 – Genetic Information Privacy – SUPPORT WITH
AMENDMENTS

The Consumer Protection Division of the Office of the Attorney General (the “Division”) supports House Bill 866 (“HB 866”), sponsored by Delegate Qi, with the amendments outlined below. HB 866 requires direct-to-consumer genetic testing (“DTC-GT”) companies to provide consumers with information about the collection, use, and sharing of genetic data, as well as obtain consumer consent for these activities. HB 866 addresses the important issue of genetic privacy, and with the Division’s proposed amendments, will provide consumers with necessary protections.

Genetic information constitutes the most sensitive and personal of information: it uniquely identifies an individual, reveals their propensity to develop certain diseases, and exposes genetically related family members. Given the sensitive nature of genetic information, however, there are growing privacy concerns regarding DTC-GT company data practices. Traditional genetic testing is administered through healthcare providers who are extensively regulated, but DTC-GT companies market directly to consumers and currently are subjected to very little state or federal regulation. DTC-GT companies can use, sell, or disseminate the genetic information they have gathered with few limitations. For example, 23andMe collected the genetic information of its customers, and in July 2018, sold access to this information to the drug company GlaxoSmithKline (GSK) for \$300 million.¹

- **Scope:** Section 14-4402 carves out all education institutions, whether public, private, nonprofit, or for-profit, as well as any entity owned or operated by these institutions from the scope of HB 866.² If the intent of this language is to permit academic research, this exemption is ill-conceived and overbroad. One of the hallmarks of for-profit educational

¹ Press Release, *GSK and 23andMe Sign Agreement to Leverage Genetic Insights for the Development of Novel Medicines*, Jul. 25, 2018; Jamie Ducharme, *A Major Drug Company Now Has Access to 23andMe’s Genetic Data. Should You Be Concerned*, TIME (July 26, 2018), <http://time.com/5349896/23andme-glaxo-smith-kline/> [<https://perma.cc/BU23-DE6S>].

² § 14-4402(2) excludes institutions of higher education as defined by Education Article § 10-101. Subsection (h) of this article defines this as “an institution of postsecondary education that generally limits enrollment to graduates of secondary schools, and awards degrees at either the associate, baccalaureate, or graduate level” and expressly includes “public, private nonprofit, and for-profit institutions of higher education.”

institutions is the lack of academic research.³ There is therefore no need to craft an exemption encompassing for-profit educational institutions. Moreover, to the extent that research is conducted by entities covered by the Health Insurance Portability and Accountability Act of 1996 (HIPAA) or their business associates, they are already exempted.⁴ The Division recommends eliminating subsection 2 and 3.⁵

- **Amend Definition of Genetic Data:** Genetic data is personal data relating to inherited or acquired genetic characteristics of a person and their family members acquired through DNA or RNA analysis. The definition of “genetic data” should be modified to include information extrapolated, derived, or inferred from the genetic analysis.⁶
- **Remove or Further Limit the Exemption for De-identified Data:** Section 14-4401(g)(3) excludes de-identified data from the definition of genetic data entirely, a blanket exclusion that is overbroad. To de-identify data, a DTC-GT supposedly removes identifying details from the data. But once the DTC-GT engages in this de-identification process, consumers will no longer be able to control the data’s use or require its deletion, and DTC-GT companies will be able to sell it or use it in any way it chooses. If the data were truly anonymized and unable to be traced back to the consumer the exemption might be justifiable, but the problem with permitting this exclusion is that study after study has shown that de-identification is a misnomer—*de-identified data can be re-identified*.⁷

Numerous studies have demonstrated that it is possible to re-identify data that has been de-identified according to current regulatory standards set forth in HIPAA, using limited information such as birth year and state of residency or through information publicly available through the Internet.⁸ This has led the American Medical Association to conclude

³ Kinser, Kevin. “Faculty at Private For-Profit Universities: The University of Phoenix as a New Model?” Private Higher Education, pp. 273-276 (2005), available at https://www.prophe.org/cache/0633066_p13_14_Kinser.pdf.

⁴ § 14-4402(1).

⁵ At the very least, subsection 2 should be amended to read: “a public or private nonprofit institution of higher education as defined in § 10-101 of the Education Article[,]” and subsection 3 should be eliminated entirely. § 14-4402(3) excludes from the application of HB 866 any “entity owned or operated by an institution of higher education, as defined in § 10-101 of the Education Article.”

⁶ For example, the California Genetic Information Privacy Act defines “genetic data” as “any data, regardless of its format, that results from the analysis of a biological sample from a consumer, or from another element 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 the analysis of the biological sample, and any information extrapolated, derived, or inferred therefrom.” Section 56.18(b)(7) of the California Civil Code (Chapter 2.6. Genetic Privacy).

⁷ Exec. Office of the President, *Big Data: Seizing Opportunities, Preserving Values*, 8 (2014) (discussing re-identification), at 51 (discussing harms including financial loss, intrusion into private life, reputational damage and societal harms).

⁸ See, e.g., Melissa Gymrek, *Identifying Personal Genomes by Surname Inference*, 339 SCI. 321, 321 (2013); Jeantine E. Lunshof et al., *From Genetic Privacy to Open Consent*, 9 Nature Revs. Genetics 406, 406 (2008) (“Developments in both medical informatics and bioinformatics show that the guarantee of absolute privacy and confidentiality is not a promise that medical and scientific researchers can deliver any longer.”); Amy L. McGuire & Richard A. Gibbs, *No Longer De-Identified*, 312 Science 370, 370 (2006).

that “[i]n terms of privacy, increasingly it has been recognized that genetic data *cannot* be de-identified . . . A DNA profile alone may be adequate to identify most individuals even in the absence of other identifying information, including individuals that have not previously participated in genetic testing.”⁹ Even if the data can be adequately de-identified with today’s technology, there is no guarantee that it will not be re-identifiable in the future because “de-identification is a moving-target—data that could not be linked back to an individual at the time of its release could become identifiable over time, as new datasets and new re-identification techniques become available.”¹⁰

- Section 14-4405(d) prohibits DTC-GT companies from disclosing a consumer’s genetic information to entities offering health insurance, life insurance, or long-term care insurance absent consent.¹¹ These are important prohibitions, but absent from the list is disability insurance. The Division recommends entities offering disability insurance be added to the prohibited disclosures.

Accordingly, the Consumer Protection Division respectfully requests a favorable report on HB 866 with the amendments described herein.

Cc: Members, Economic Matters Committee
The Honorable Lily Qi

⁹ American Medical Association Board of Trustees Report 12, Resolution 207-A-19, Nov. 2021 (emphasis added). A 2018 publication in the leading academic journal *Science* indicated that “a genetic database needs to cover only 2% of the target population to provide a third-cousin match to nearly any person.”

¹⁰ *A Practical Path toward Genetic Privacy*, Future on Privacy Forum, Apr. 2020, available at https://fpf.org/wp-content/uploads/2020/04/APracticalPathTowardGeneticPrivacy_April2020.pdf

¹¹ § 14-4405(d).