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Judicial Proceedings Committee

Joint Committees

Children, Youth, and Families

Ending Homelessness



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THE SENATE OF MARYLAND
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**Testimony Regarding SB 766:
Maryland Genetic Information Privacy Act
Before the Finance Committee
March 9, 2022**

Good afternoon Chair Kelley, members of the Finance Committee,

Over the last decade, we have seen the rise of popular direct-to-consumer genetic testing services like 23 and Me, Ancestry.com, and GEDmatch, to name a few, which allow consumers to access and use their own genetic data in unprecedented ways. Direct-to-consumer genetic testing services allow anyone to submit a sample of their DNA to learn a variety of things about their genetic makeup and ancestry. These services can match the DNA of the individual against publicly available DNA profiles.¹ Recently, due to the cutting-edge combination of DNA and genetic genealogy, some public genealogy databases have also been used to help solve criminal cases. Detectives have searched with relative ease for distant relatives of an unknown suspect by analyzing the DNA submitted voluntarily to these databases.² We addressed this use last year when we passed SB 187. However, SB 766 addresses the other side of the coin, possible civil misuse of one's genetic material.

As genetic testing services have become more prevalent in the marketplace, so has the need for up-to-date consumer protections for their unique, personal genetic material utilized to provide these services. SB 766 intends to provide consumers protections which they do not currently have, and thereby put them in control of their genetic data at all times.

SB 766 regulates direct-to-consumer genetic testing companies that use consumers' genetic data by requiring them to provide consumers with "clear and complete information" about their policies and procedures for collecting, using, or disclosing genetic data prior to the consumer sharing their DNA. Those policies and procedures must be publically available and placed in a prominent place on the companies' website.³

SB 766 also notes that these companies must, prior to collecting, using, or disclosing genetic data, obtain a consumer's consent. That consent must describe the uses of how a consumer's genetic data will be used and specify who will have access to genetic testing results and how the genetic

¹Study of Familial DNA Searching Policies and Practices: Case Study Brief Series. Department of Justice's Office of Justice Programs.

² *Id.*

³ CL 14-4403.

data may be shared, as well as the consumer's express consent for transferring or disclosing their genetic data to an unaffiliated third party. The direct-to-consumer genetic testing company must also disclose any use of the consumer's genetic data beyond what was the consumer's primary purpose of engaging its marketed services, among other kinds of consent.⁴

SB 766 also requires that direct-to-consumer genetic testing companies establish legal policies and processes for releasing to law enforcement or other government entities genetic data, without the consumer's express written consent.⁵

Companies must also develop, implement and maintain a comprehensive security program to protect a consumer's genetic data as well as a process for the consumer to access their account, delete their account and genetic data, and request the destruction of their biological sample.⁶

If a direct-to-consumer genetic testing company violates any of these requirements, SB 766 provides consumers with the ability to hold them accountable for an unfair, abusive or deceptive trade practice. It also expressly allows a consumer to pursue any other legal remedy provided by law. For the aforementioned reasons, I ask that SB 766 be reported out favorably.

⁴ CL 14-4404.

⁵ CL 14-4405.

⁶ CL 14-4406.