

**Testimony to the House Economic Matters Committee
HB 866: Commercial Law – Consumer Protection – Genetic Information Privacy
Position: Favorable**

February 25, 2022

The Honorable C. T. Wilson, Chair
House Economic Matters Committee
Room 231, House Office Building
Annapolis, Maryland 21401
Cc: Members, House Economic Matters Committee

Honorable Chair Wilson and Members of the Committee:

The Maryland Consumer Rights Coalition (MCRC) is a statewide coalition of individuals and organizations that advances economic rights and financial inclusion for Maryland consumers through research, education, direct service, and advocacy. Our 8,500 supporters include consumer advocates, practitioners, and low-income and working families throughout Maryland.

We are writing in strong support of HB 866. The bill provides common-sense guardrails to protect Marylanders' genetic data privacy. Many of these protections in HB 866 are enshrined in law for other types of data to protect consumers. HB 866 extends these protections to address modern technological advances.

Direct-to-consumer (DTC) genetic testing is widely popular. A Consumer Reports survey found that about 1 in 5 Americans has taken a DTC genetic test, and brands such as 23andMe and Ancestry are household names.¹ However, there has been increasing scrutiny surrounding how these DTC companies handle the personal and genetic data they collect, and how they share that info with third parties. Currently there are few restrictions on how companies collect, analyze, store, share, or sell our personal biometric identifiers. A privacy breach with genetic data is significantly more risky than a hacked email or lost credit card; consumers can't just close their DNA account and get a new sequence.

As the use of DTC genetic testing is becoming more widespread, so are the concerns surrounding this practice. Popular DNA testing companies like 23andMe and Ancestry.com have been investigated by the Federal Trade Commission and lawsuits have been filed in states claiming that genetic testing companies are violating state privacy acts.² Many consumers don't realize that their personal info may be shared with third-party companies and there have been complaints raised that the companies' terms of service are not always clear about their policies in such matters. HB 866 works to directly address the need for transparency between DTC testing companies and consumers.

The bill requires genetic testing companies to provide consumers with clear and complete information regarding company policies and procedures and obtain express consent from consumers before collecting, using, or disclosing the consumer's genetic data.

For all of these reasons, we support HB 866 and urge a favorable report.

Best,

Isadora Stern
Policy Associate

¹ <https://www.consumerreports.org/genetic-testing/genetic-testing-kit-read-this-before-you-buy-a7760054746/>

²

<https://www.fastcompany.com/40580364/the-ftc-is-investigating-dna-firms-like-23andme-and-ancestry-over-privacy>