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## **ACLU OF RI POSITION: SUPPORT**

### **TESTIMONY ON 26-H 7639, RELATING TO COMMERCIAL LAW--GENERAL REGULATORY PROVISIONS -- GENETIC INFORMATION PRIVACY ACT March 10, 2026**

The ACLU of Rhode Island support this bill, which would require direct-to-consumer genetic testing companies, like 23andMe and AncestryDNA+, to provide a user with information regarding the company's policies and procedures for the collection, use, maintenance, and disclosure of genetic data. The bill would also require these companies to obtain a consumer's express consent for collection, use, or disclosure of this data.

In an age where technology evolves daily, privacy concerns are more pressing than ever. Companies collect vast amounts of personal data, highlighting the urgent need for protective measures. Specifically in this context, users send their DNA samples to a company that retains that sample and any subsequent data from testing the sample. Genetic data offers sensitive personal insights into a person, from their potential health risks to their food preferences to their ancestral origins. This data's potential extends across areas like medical research, marketing, and even predicting traits of future generations.

In response, this bill establishes strict guidelines on how genetic data should be handled by these companies, as well as requiring service providers -- like mail carriers or the company that actually conducts the testing on these samples -- to ensure the security of this data and prohibit them from retaining this data. It would also prohibit the use of genetic data for third-party marketing, such as targeted advertising, and restricts sharing this data with entities involved in health or life insurance decisions.

These proposed protections are especially crucial following 23andMe's bankruptcy filing last year, and their privacy policies which allowed the data to be sold to other companies.<sup>1</sup> This is on the heels of a 2023 data breach, where hackers exposed the personal data of more than 7 million customers over the course of 5 months.<sup>2</sup> Passage of this legislation will preserve the legitimate use of these services while protecting the individual privacy rights of all Rhode Islanders. For these reasons, we support passage of this bill.

Thank you for considering our views.

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<sup>1</sup> <https://www.reuters.com/business/healthcare-pharmaceuticals/ftc-concerned-about-privacy-protections-23andme-bankruptcy-2025-03-31/>

<sup>2</sup> <https://www.reuters.com/technology/cybersecurity/23andme-settles-data-breach-lawsuit-30-million-2024-09-13/>