

GENETIC INFORMATION ▶ PRIVACY ACT (H.639)



Todd Daloz, Assistant Attorney General
March 26, 2026 - Senate Economic Development, House & General Affairs

Importance of Protecting Consumer Genetic Data

- ▶ Privacy in the Digital Age presents a host of challenges:
 - ▶ Permanency
 - ▶ Duplication
 - ▶ Transferability
- ▶ Genetic data is our most sensitive data
 - ▶ **“Genetic data is not just data about people—*it is people*. Our genome is our unique individual source code. It cannot be changed, and thus it is immutable.”**

- Prof. Richards, *Report of Consumer Privacy Ombudsman*, Case No. 25-40976-357 (E.D. Mo. 2025) at 43-44

23andMe Data Breach

- ▶ October 2023 - 23andMe reported data breach as a result of cyber attack.
- ▶ While nation-wide roughly 14,000 accounts were breached, because of linking DNA-related relatives, nearly 7 million users' information was compromised.

23andMe Bankruptcy

- ▶ March 2025 - 23andMe sought bankruptcy protection
- ▶ The AGO issued a consumer alert
 - ▶ Provided steps for consumers to delete account—a multi-step process
 - ▶ Company faced technical challenges
 - ▶ States intervened

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Consumer Alert: Protect Your Data from the 23andMe Bankruptcy

Vermonters can demand that 23andMe delete their data

MONTPELIER, Vt. – Attorney General Charity Clark today issued a consumer alert to help Vermonters protect their personal data in the wake of 23andMe’s bankruptcy recent filing.

On Monday, 23andMe [announced](#) that they had filed for bankruptcy. 23andMe is a direct-to-consumer genetic testing company that collects and analyzes genetic information and health data for consumers. The company announced that it “intends to continue operating its business in the ordinary course through the sale process” and that “[t]here are no changes to the way [it] stores, manages, or protects customer data.” However, the bankruptcy and 23andMe’s plan to “sell substantially all of [its] assets” raises the risk that 23andMe may attempt to sell Vermonters’ personal data and other private information in the bankruptcy process. Attorney General Clark is notifying Vermonters of actions they can take to make sure that 23andMe deletes their personal data rather than selling it.

23andMe Bankruptcy

Case 25-40976 Doc 687 Filed 06/09/25 Entered 06/09/25 15:42:46 Main Document
Pg 6 of 22

UNITED STATES BANKRUPTCY COURT
EASTERN DISTRICT OF MISSOURI
ST. LOUIS DIVISION

23ANDME HOLDING CO., *et al.*,¹

Debtors.

§
§ Chapter 11
§ Case No. 25-40976-357
§
§ (Jointly Administered)
§
§ **Response Deadline:** June 17, 2025
§ **Hearing Date:** June 17, 2025
§ **Hearing Time:** 9:00 AM CT
§ **Hearing Location:**
§ Thomas F. Eagleton U.S. Courthouse
§ 111 S. 10th Street
§ Courtroom 5 North
§ St. Louis, MO 63102
§
§ **Relates to Docket Nos. 30, 125, & 420**

THE STATES' OBJECTION TO THE DEBTORS' PROPOSED SALE OF
CUSTOMERS' ASSETS

(Relates to Docket Nos. 30, 125, & 420)

11. In reality, this “Customer Data” comprises an unprecedented compilation of highly sensitive and immutable personal data of consumers: a human being’s permanent and everlasting genetic identity (their genome) coupled with their phenotype data – how their genome is manifest physically and mentally – together with sensitive personal information, including the individual’s birth sex and gender, their family tree, and contact information.

12. Virtually all of this “Customer Data” is immutable. *If stolen or misused, it cannot be changed or replaced.* Furthermore, this data is exclusively personal and unique in representing that customer’s identity – something that no other human being who ever existed or will exist in the future (absent abuse of currently illegal cloning technologies) will match.

23andMe Bankruptcy

UNITED STATES BANKRUPTCY COURT
EASTERN DISTRICT OF MISSOURI

In re:)
23ANDME HOLDING CO., *et al.*,) Case No. 25-40976-357
Debtors.) Chapter 11
) Jointly Administered
) Related to Docs. 527, 574, and 575
)
)
)

REPORT OF CONSUMER PRIVACY OMBUDSMAN

June 11, 2025

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Case 25-40976 Doc 718 Filed 06/11/25 Entered 06/11/25 22:45:11 Main Document
Pg 46 of 211

contains the most personal aspects of their identity,” and was passed due to Americans’

“legitimate fears about how this deeply private information will be used.”¹⁶⁹ The CPO notes

that, in the aftermath of the 2023 23andMe data breach, media reports suggested that hackers had

posted an initial data sample on the dark web, boasting that they had data on a million people of

Ashkenazi Jewish heritage.¹⁷⁰ Moreover, the Pentagon has warned service members not to use

DTC genetic testing companies like 23andMe because of the risk that it “could expose personal

and genetic information, and potentially create unintended security consequences and increased

risk to the joint force and mission.”¹⁷¹

23andMe Bankruptcy - States' Objections

- ▶ States sought to prevent sale of 23andMe assets, including genetic material and genetic data
- ▶ Argued that transfer of company was equivalent to the unauthorized sale of genetic data
- ▶ Objected to sale without safeguards on transfer of data

23andMe Bankruptcy - States' Action

- ▶ States began negotiating with alternative potential buyer
- ▶ Through negotiations, States established an agreement that would protect consumer data and consumer genetic material
- ▶ Reached a voluntary agreement between potential buyer and the States

23andMe Bankruptcy - Outcome

- ▶ Court rejected States' objections to free transfer of consumer genetic data as part of transfer of 23andMe
- ▶ Permitted sale to potential buyer
- ▶ States' negotiated agreement still protects consumer data
- ▶ Vermont continues to have an interest in remaining company assets as bankruptcy continues
 - ▶ No damages for individual consumers

How H.639 Responds to these risks - Informed Consumers

- ▶ Greater consumer information (§ 2421b(a)(1)):
 - ▶ Summary of privacy practices - *in plain language*
 - ▶ Prominent and accessible privacy notice, including data collection practices and data security and deletion practices
 - ▶ Notice about lawful data sharing - deidentified data for research purposes under federal law

How H.639 Responds to these risks - Engaged Consumers

- ▶ Consumer consent (§ 2421b(a)(2) & (c)):
 - ▶ Express consent for collection and storage of data & sample
 - ▶ Express consent for use *beyond* primary purpose of genetic testing
 - ▶ Express consent for transfer
 - ▶ Simple process to revoke consent

11 (2) obtain a consumer's express consent for the collection, use, and
12 disclosure of the consumer's genetic data, including, at a minimum, separate
13 and express consent for each of the following:
14 (A) the use of the genetic data collected through the genetic testing
15 product or service offered to the consumer, including:
16 (i) who has access to genetic data;
17 (ii) how genetic data may be shared; and
18 (iii) the specific purposes for which the data will be collected,
19 used, and disclosed;

How H.639 Responds to these risks - Data Security

- ▶ Greater data protection (§ 2421b(d) & (e)):
 - ▶ Reasonable practices to prevent unauthorized access
 - ▶ Enable a consumer to both access data AND delete account and data
 - ▶ Prohibit service providers from combining consumer genetic data with other, separately obtained data

H.639 - Discrimination & Non-disclosure

- ▶ Similar to federal law (GINA), § 2421b(f) prohibits discrimination based on consumer's exercise of rights:
 - ▶ Denying services or goods
 - ▶ Charging different prices (including discounts or incentives)
 - ▶ Providing different level or quality of goods or services
- ▶ DTC cannot disclose consumer's information to insurance companies or employers (§ 2421b(g))
 - ▶ Does not regulate life insurance companies

H.639 - Enforcement

- ▶ Violation of Genetic Information Privacy Act is violation of Consumer Protection Act (Tit. 9, Ch. 63)
- ▶ AGO enforcement
- ▶ Similar to Act 63 (2025), Age-Appropriate Design Code
- ▶ Core information about us as humans
- ▶ Cannot be changed