

## MEMORANDUM

To: Senate Commerce Committee  
From: Samuel D. Zurier  
Subject: Genetic Information Privacy (S-2203)  
Date: April 14, 2026

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A September 27, 2024 Atlantic Magazine article (Exhibit A) sounded the alarm concerning the financial problems at 23andMe, the company that collects genetic information from customers to allow them to connect with unknown family members and helped police catch criminals. The article noted that the company's database of genetic information could become a valuable asset in the event of a bankruptcy. The article noted that a buyer could use that information in a way that 23andMe customers did not intend. It also noted a law passed in California to provide their residents with additional genetic privacy rights, including the right to delete their data ahead of a sale.

On March 23, 2025, 23andMe announced that it was filing for bankruptcy (Exhibit B). After that announcement, the company, which had been the object of a major data breach in 2023, was flooded with requests from customers to delete their genetic data (Exhibit C). In December, 2025, the bankruptcy court approved the company's acquisition by a nonprofit research organization (Exhibit D). This fortuitous outcome avoided the risk of a "free and clear" purchase by a for-profit company. A Rhode Island Current article (Exhibit E) notes that 14 states have enacted legislation to protect consumers' privacy, but that Rhode Islanders remain unprotected.

Bill S-2203 is based on the California law. It requires companies collecting customers' genetic data to (1) obtain express consent concerning the specific permitted uses of their genetic data, (2) ensure that the company and any others who receive the data take reasonable measures to protect the privacy of the customers who provide the data and (3) develop clear practices and procedures to ensure compliance with these two basic requirements.

# **EXHIBIT    A**

More From Being Human

Explore This Series

HEALTH

# Remember That DNA You Gave 23andMe?


The company is in trouble, and anyone who has spit into one of its test tubes should be concerned.

By Kristen V. Brown



Illustration by Akshita Chandra / The Atlantic. Source: Getty.

SEPTEMBER 27, 2024

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23andMe is not doing well. Its stock is on the verge of being delisted. It shut down its in-house drug-development unit last month, only the latest in several rounds of layoffs. Last week, the entire board of directors quit, save for Anne Wojcicki, a co-founder and the company's CEO. Amid this downward spiral, Wojcicki has said she'll consider selling 23andMe—which means the DNA of 23andMe's 15 million customers would be up for sale, too.

23andMe's trove of genetic data might be its most valuable asset. For about two decades now, since human-genome analysis became quick and common, the A's, C's, G's, and T's of DNA have allowed long-lost relatives to connect, revealed family secrets, and helped police catch serial killers. Some people's genomes contain clues to what's making them sick, or even, occasionally, how their disease should be treated. For most of us, though, consumer tests don't have much to offer beyond a snapshot of our ancestors' roots and confirmation of the traits we already know about. (Yes, 23andMe, my eyes *are* blue.) 23andMe is floundering in part because it hasn't managed to prove the value of collecting all that sensitive, personal information. And potential buyers may have very different ideas about how to use the company's DNA data to raise the company's bottom line. This should concern anyone who has used the service.

## ADVERTISEMENT

DNA might contain health information, but unlike a doctor's office, 23andMe is not bound by the health-privacy law HIPAA. And the company's privacy policies make clear that in the event of a merger or an acquisition, customer information is a salable asset. 23andMe promises to ask its customers' permission before using their data for research or targeted advertising, but that doesn't mean the next boss will do the same. It says so right there in the fine print: The company reserves the right to update its policies at any time. A spokesperson acknowledged to me this week that the company can't fully guarantee the sanctity of customer data, but said in a statement that "any scenario which impacts our customers' data would need to be carefully considered. We take the privacy and trust of our customers very seriously, and would strive to maintain commitments outlined in our Privacy Statement."

Certain parties might take an obvious interest in the secrets of Americans' genomes. Insurers, for example, would probably like to know about any genetic predispositions that might make you more expensive to them. In the United States, a 2008 law called the Genetic Information Nondiscrimination Act protects against discrimination by employers and health insurers on the basis of genetic data, but gaps in it exempt providers of life, disability, and long-term-care insurance from such restrictions. That means that if you have, say, a genetic marker that can be correlated with a heart condition, a life insurer could find that out and legally deny you a policy—even if you never actually develop that condition. Law-enforcement agencies rely on DNA data to solve many difficult cases, and although 23andMe says it requires a warrant to share

data, some other companies have granted broad access to police. You don't have to commit a crime to be affected: Because we share large chunks of our genome with relatives, your DNA could be used to implicate a close family member or even a third cousin whom you've never met. Information about your ethnicity can also be sensitive, and that's encoded in your genome, too. That's all part of why, in 2020, the U.S. military advised its personnel against using consumer tests.

Read: Big Pharma would like your DNA

Spelling out all the potential consequences of an unknown party accessing your DNA is impossible, because scientists' understanding of the genome is still evolving. Imagine drugmakers trolling your genome to find out what ailments you're at risk for and then targeting you with ads for drugs to treat them. "There's a lot of ways that this data might be misused or used in a way that the consumers couldn't anticipate when they first bought 23andMe," Suzanne Bernstein, counsel at the Electronic Privacy Information Center, told me. And unlike a password that can be changed after it leaks, once your DNA is out in the wild, it's out there for good.

Some states, such as California, give consumers additional genetic-privacy rights and might allow DNA data to be deleted ahead of a sale. The 23andMe

## RECOMMENDED READING

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spokesperson told me that “customers have the ability to download their data and delete their personal accounts.” Companies are also required to notify customers of any changes to terms of service and give them a chance to opt out, though typically such changes take effect automatically after a certain amount of time, whether or not you’ve read through the fine print.

Consumers have assumed this risk without getting much in return. When the first draft of the human genome was unveiled, it was billed as a panacea, hiding within its code secrets that would

help each and every one of us unlock a personalized health plan. But most diseases, it turns out, can’t be pinned on a single gene. And most people have a boring genome, free of red-flag mutations, which means DNA data just aren’t that useful to them—at least not in this form. And if a DNA test reveals elevated risk for a more common health condition, such as diabetes and heart disease, you probably already know the interventions: eating well, exercising often, getting a solid eight hours of sleep. (To an insurer, though, even a modicum of risk might make someone an unattractive candidate for coverage.) That’s likely a big part of why 23andMe’s sales have slipped. There are only so many people who want to know about their Swedish ancestry, and that, it turns out, is consumer DNA testing’s biggest sell.



What’s Lost When Black Children Are Socialized Into a White World



DANI MCCLAIN



America Has a Drinking Problem



KATE JULIAN



How Fancy Water Bottles Became a 21st-Century Status Symbol



AMANDA MULL

### Read: DNA tests are uncovering the true prevalence of incest

Wojcicki has pulled 23andMe back from the brink before, after the Food and Drug Administration ordered the company to stop selling its health tests in 2013 until they could be proved safe and effective. In recent months, Wojcicki has explored a variety of options to save the company, including splitting it to separate the cash-burning drug business from the consumer side. Wojcicki has still expressed interest in trying to take the company private herself, but the board rejected her initial offer. 23andMe has until November 4 to raise its shares to at least \$1, or be delisted. As that date approaches, a sale looks more and more likely—whether to Wojcicki or someone else.

The risk of DNA data being misused has existed since DNA tests first became available. When customers opt in to participate in drug-development research, third parties already get access to their de-identified DNA data, which can in some cases be linked back to people's identities after all. Plus, 23andMe has failed to protect its customers' information in the past—it just agreed to pay \$30 million to settle a lawsuit resulting from an October 2023 data breach. But for nearly two decades, the company had an incentive to keep its customers' data private: 23andMe is a consumer-facing business, and to sell kits, it also needed to win trust. Whoever buys the company's data may not operate under the same constraints.

## ABOUT THE AUTHOR

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**Kristen V. Brown**

 Follow

Kristen V. Brown is a staff writer at *The Atlantic*.

# **EXHIBIT B**



[March 19, 2025](#)

### \$12B in LA Wildfire Insurer Payouts & State Farm's 22% Emergency...

Insurer Payouts for LA Wild res Top \$12B  
California Insurance Commissioner  
Ricardo Lara (D) announced that insurers  
have now paid out over \$12 billion in  
claims from the largest of the Los Angeles  
wild res...

[March 19, 2025](#)

### Google's Response to App Store Age-Verification on Legisla on,...

Google Weighs in on Social Media Age  
Verification Days after Utah passed a  
first-in-the-nation law ( SB 142 ) requiring app  
stores to verify the age of users, Google  
nally weighed in publicly on the...

## State Lawmakers Find Success with Genetic Privacy

June 17, 2022 (6 min read)



With Americans spending so much of their time online - [over 1,300 hours a year on social media alone](#) - state lawmakers have increasingly focused on consumer data privacy in recent years. Much of their efforts have been channeled into comprehensive data privacy legislation. But they've actually had more success with measures specifically targeting the privacy of consumer genetic information collected by testing companies like 23andMe and Ancestry.com.

## High Passage-Rate Issue in Growing Regulatory Area

In 2021, consumer data privacy legislation was introduced in 38 states, up from 30 in 2020 and 25 in 2019, [according to the National Conference of State Legislatures](#).

Comprehensive data privacy bills - which have been coming in increasing numbers since the passage of the California Consumer Privacy Act (CCPA) in 2018 - were introduced last year in 25 states, two of which, Colorado [[SB 190 \(2021\)](#)] and Virginia [[HB 2307 \(2020\)](#)], enacted them.



delete personal information collected by businesses.”

Bills dealing specifically with the protection of consumer genetic information were introduced in only nine states last year. But they were enacted in seven of them, making genetic privacy bills the type of consumer data privacy legislation with the highest passage rate among the dozen categories tracked by NCSL.

One of the seven genetic privacy enactments last year was California’s Genetic Information Privacy Act ([SB 41](#)), signed by Gov. Gavin Newsom (D) in October. The law, which took effect in January, requires genetic testing companies to notify customers of their privacy policies and obtain customers’ consent before using their genetic data or sharing it with a third party.

The law also requires companies to provide an easy way for customers to opt-out of that consent authorization; prohibits companies from using deceptive practices to lure customers into providing consent, such as by employing popups; prohibits companies from disclosing customers’ data to insurers or the customers’ employers; and requires companies to provide customers a simple method of closing their accounts and having their DNA data deleted from the companies’ databases and their samples destroyed, which the companies must do within 30 days of receiving customer requests.

## DNA Companies Say They Welcome Regulation

Ancestry and 23andMe welcomed the law’s passage, according to a [report at the time by Wired](#).

“We think it’s very important for all consumers in California to be afforded the confidence that when they choose to participate in direct-to-consumer genetic testing that their data will be used and shared as



Arizona and Utah enacted similar laws earlier in the year, [HB 2069 \(2021\)](#) and [SB 227 \(2021\)](#), respectively, addressing customer notification of privacy policies, customer consent for data use, and data deletion.

Supporters of the legislation say it's needed because existing privacy laws don't cover home DNA testing. The federal Health Insurance Portability and Accountability Act, better known as HIPAA, only protects genetic tests ordered by doctors, not those purchased from companies like 23andMe and Ancestry. When HIPAA was enacted in 1996, home genetic tests didn't even exist. Now nearly 20 percent of Americans have used one, [according to a national survey by Consumer Reports in 2020](#).

"This is really coming about because so much has changed in the marketplace and the technology," Lee Tien, a senior staff attorney for the Electronic Frontier Foundation, a San Francisco-based nonprofit digital rights group, told Wired.

## Consumer Data Privacy Legislative Trends Continue

The recent trends in consumer data privacy legislation appear to be continuing this year. Five months into 2022 [at least 34 states have introduced or considered consumer data privacy bills](#), just four shy of the total for the entirety of 2021.

Comprehensive data privacy legislation has been considered in 25 states, matching last year's total. Two of those states have enacted bills: Utah ([SB 227](#)) and Virginia ([HB 381](#), [HB 714/SB 534](#)), although in the latter case the enactments were merely amendments to the comprehensive data privacy law the state passed last year [[HB 2307 \(2020\)](#)]/[SB 1392 \(2020\)](#)].



All three bills require genetic testing companies to provide clear notice of their privacy policies; obtain customers' consent before collecting, using, or disclosing their genetic data; maintain a comprehensive data security program; and allow customers to access their data and have their account and data deleted and their DNA sample destroyed.

The three bills would also prohibit testing companies from disclosing a customer's genetic data to insurers or the customer's employer without their consent and require a "valid legal process" for disclosing a customer's data to law enforcement.

The Kentucky and Maryland bills go a step further. The former restricts law enforcement's use of DNA records voluntarily submitted to eliminate suspects. The latter requires testing companies to provide users "explicit notice" that the service might be used by law enforcement to investigate crimes, an acknowledgment of the fact that [genealogy databases have been used in hundreds of criminal investigations](#), including the one that led to the identification of the Golden State Killer in 2018.

Another measure that is similar to the Kentucky, Maryland, and Wyoming bills has been passed by state lawmakers and awaits gubernatorial action in Hawaii ([SB 2032](#)), according to [State Net's legislative tracking system](#).

The bills actually [share much of the same language because it was developed at the Council of State Governments' Annual Meeting in September of last year](#) and included in the organization's annual shared state legislation volume, which is circulated among state lawmakers and staff.

Genetic privacy bills are still pending in three states. But the bills in two of those states - New Jersey [AB 525](#) and Pennsylvania [HB 2283](#),



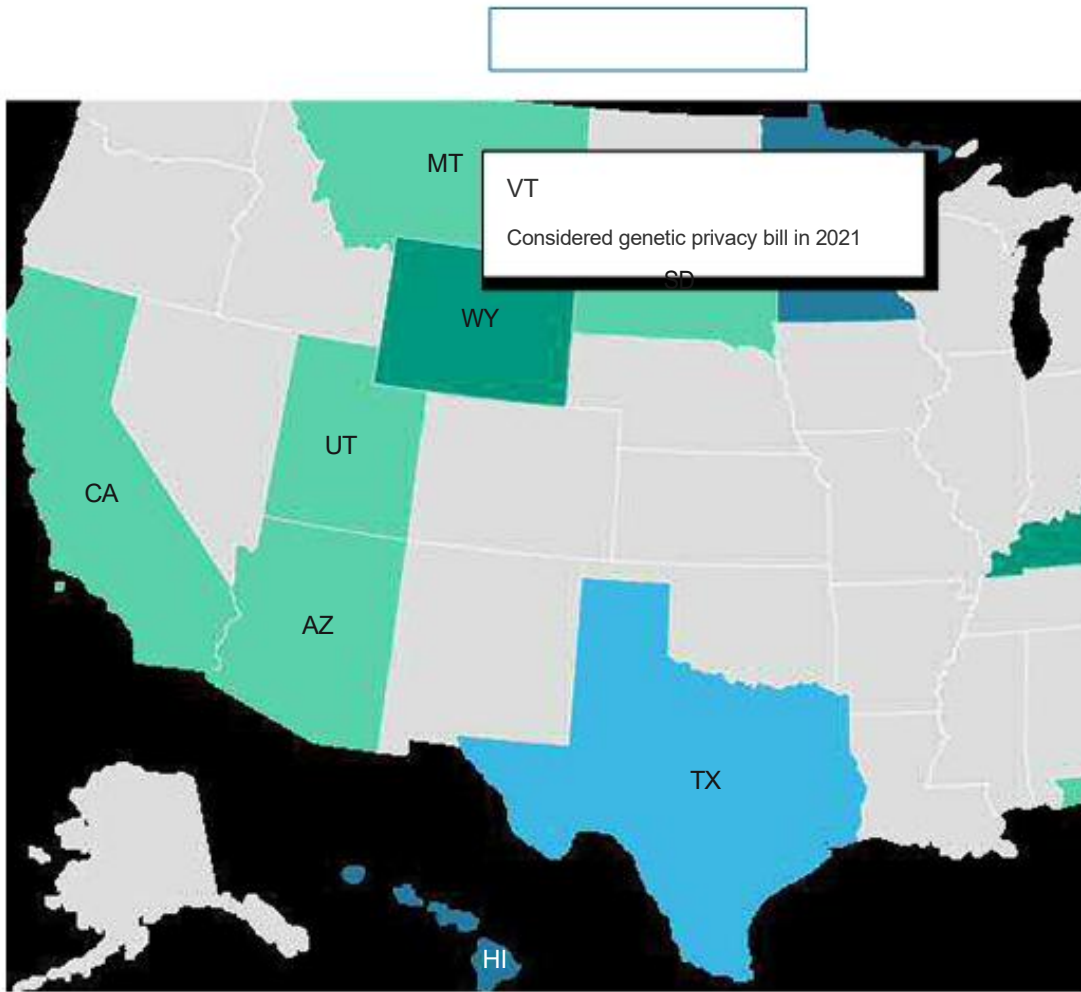
The third bill is pending carry over to next year's session in Virginia ([SB 419](#)), which adjourned the first year of its two-year session cycle in March. And a genetic privacy measure has failed in Minnesota ([SB 2817](#)).

Still, genetic privacy bills have now been enacted or are near enactment in half of the states where they've been considered so far this year. The continuing success of such measures - and their relatively easy lift in comparison to comprehensive data privacy legislation - are likely to keep them coming as lawmakers pursue greater protection of consumers' online privacy.

-- By KOREY CLARK

## Genetic Privacy Continues to Be Active Issue in Statehouses

So far this year, at least eight states have considered legislation dealing with the privacy of consumer genetic information collected by testing companies like 23andMe and Ancestry.com, according to [analysis by the National Conference of State Legislatures](#) and State Net. Two of those states, Kentucky and Wyoming, have enacted measures. In 2021 genetic privacy bills were considered in nine states, seven of which enacted them.



Source: National Conference of State Legislatures, State Net • [Get the data](#) • Created with [Datawrapper](#)

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# **EXHIBIT C**



## **23andMe Initiates Voluntary Chapter 11 Process to Maximize Stakeholder Value Through Court-Supervised Sale Process**

March 24, 2025

Intends to use Proceedings to Conduct a Value-Maximizing Sale Process and Resolve Liabilities

Company Expects to Continue Business Operations in the Ordinary Course During Proceedings; Secures Commitment for Approximately \$35 Million in DIP Financing to Support Ongoing Operations

No Changes to Customer Data Management and Access; Company Remains Committed to Transparency Around Customer Data Privacy; Any Buyer will be Required to Comply with Applicable Law with Respect to Treatment of Customer Data

Company Announces Board and Leadership Changes to Support Restructuring and Sale Process

SAN FRANCISCO, March 23, 2025 (GLOBE NEWSWIRE) -- 23andMe Holding Co. ("23andMe" or the "Company") (Nasdaq: ME), a leading human genetics and biotechnology company, today announced that it has initiated voluntary Chapter 11 proceedings in the U.S. Bankruptcy Court for the Eastern District of Missouri (the "Court") to facilitate a sale process to maximize the value of its business. The Company intends to continue operating its business in the ordinary course throughout the sale process. There are no changes to the way the Company stores, manages, or protects customer data.

"After a thorough evaluation of strategic alternatives, we have determined that a court-supervised sale process is the best path forward to maximize the value of the business," said Mark Jensen, Chair and member of the Special Committee of the Board of Directors. "We expect the court-supervised process will advance our efforts to address the operational and financial challenges we face, including further cost reductions and the resolution of legal and leasehold liabilities. We believe in the value of our people and our assets and hope that this process allows our mission of helping people access, understand and benefit from the human genome to live on for the benefit of customers and patients."

Jensen continued, "We want to thank our employees for their dedication to 23andMe's mission. We are committed to supporting them as we move through the process. In addition, we are committed to continuing to safeguard customer data and being transparent about the management of user data going forward, and data privacy will be an important consideration in any potential transaction."

23andMe is seeking authorization from the Court to commence a process to sell substantially all of its assets through a chapter 11 plan or pursuant to Section 363 of the U.S. Bankruptcy Code. If approved by the Court, the Company, with the assistance of an independent investment banker, would actively solicit qualified bids over a 45-day process. If multiple qualified bids are submitted during the Court-supervised sale process, the Company plans to conduct an auction to maximize the value of its assets. Any buyer will be required to comply with applicable law with respect to the treatment of customer data and any transaction will be subject to customary regulatory approvals, including, as applicable, approvals under the Hart-Scott-Rodino Act and the Committee on Foreign Investment in the United States.

The Company has filed customary motions with the Court seeking a variety of "first-day" relief, including the authority to pay employee wages and benefits and compensate certain vendors and suppliers on a go-forward basis. 23andMe has also filed a motion with the Court seeking approval to reject numerous contracts, including the real estate leases in Sunnyvale and San Francisco, to reduce 23andMe's ongoing operating expenses. The Company expects to receive Court approval for these requests.

In addition, 23andMe intends to use the proceedings to resolve all outstanding legal liabilities stemming from the previously disclosed October 2023 cyber incident.

23andMe has received a commitment for debtor-in-possession ("DIP") financing of up to \$35 million from JMB Capital Partners. Upon Court approval, the additional liquidity from the DIP financing, combined with cash generated from the Company's ongoing operations, is expected to support the business during these proceedings.

The commencement of the proceedings follows the rejection by the Special Committee of the final non-binding acquisition proposal made by Anne Wojcicki and certain of her affiliates on March 10, 2025. Ms. Wojcicki's proposal was included in an amended Schedule 13D filing made by Ms. Wojcicki and such affiliates with the Securities and Exchange Commission on March 11, 2025.

Additional information regarding 23andMe's Chapter 11 filing, proceedings and claims process will be available at <https://restructuring.ra.kroll.com/23andMe>. Questions about the claims process should be directed to the Company's claims agent, Kroll, at [23andMeInfo@ra.kroll.com](mailto:23andMeInfo@ra.kroll.com) or by calling (888) 367-7556.

### **Board and Leadership Changes to Support Restructuring and Sale Process**

23andMe also announced that Anne Wojcicki is resigning from her role as Chief Executive Officer, effective immediately, by mutual agreement between Ms. Wojcicki and the Special Committee. Ms. Wojcicki will continue to serve as a member of 23andMe's Board. The Board has appointed Joe Selsavage, Chief Financial and Accounting Officer, to the additional role of Interim Chief Executive Officer and Matt Kvarda, a Managing Director at Alvarez & Marsal, as Chief Restructuring Officer. In addition, Thomas Walper, a former Partner in the Financial Restructuring Practice at Munger, Tolles & Olson LLP, was appointed to 23andMe's Board and the Special Committee as an independent director. Mr. Jensen has been appointed Chair of the Board.

### **Advisors**

Paul, Weiss, Rifkind, Wharton & Garrison LLP and Morgan, Lewis & Bockius LLP are serving as legal counsel to 23andMe and Alvarez & Marsal North

America, LLC as restructuring advisor. Moelis & Company LLC is serving as investment banker and Goodwin Procter LLP is serving as legal advisor to the Special Committee of 23andMe's Board of Directors. ReeveMark and Scale are serving as communications advisors to the Company.

#### **About 23andMe**

23andMe is a genetics-led consumer healthcare and biotechnology company empowering a healthier future. For more information, please visit [www.23andme.com](http://www.23andme.com).

#### **Forward-Looking Statements**

This press release contains forward-looking statements within the meaning of Section 27A of the Securities Act of 1933, as amended, and Section 21E of the Securities Exchange Act of 1934, as amended. All statements, other than statements of historical fact, included or incorporated in this press release are forward-looking statements. The words "believes," "anticipates," "estimates," "plans," "expects," "intends," "may," "could," "should," "potential," "likely," "projects," "predicts," "continue," "will," "schedule," and "would" or, in each case, their negative or other variations or comparable terminology, are intended to identify forward-looking statements, although not all forward-looking statements contain these identifying words. These forward-looking statements are predictions based on 23andMe's current expectations and projections about future events and various assumptions. 23andMe cannot guarantee that it will actually achieve the plans, intentions, or expectations disclosed in its forward-looking statements and you should not place undue reliance on 23andMe's forward-looking statements. These forward-looking statements involve a number of risks, uncertainties (many of which are beyond the control of 23andMe), or other assumptions that may cause actual results or performance to differ materially from those expressed or implied by these forward-looking statements, which could include the following: risks and uncertainties relating to the Company's Chapter 11 case (the "Chapter 11 case"), including but not limited to, the Company's ability to obtain bankruptcy court approval with respect to motions in the Chapter 11 case, the effects of the Chapter 11 case on the Company and on the interests of various constituents, bankruptcy court rulings in the Chapter 11 case and the outcome of the Chapter 11 case in general, the Company's plans to pursue a structured sale of its assets pursuant to a competitive auction and sale process pursuant to a Chapter 11 plan or under Section 363 of the Bankruptcy Code, the length of time the Company will operate under the Chapter 11 case, risks associated with any third-party motions in the Chapter 11 case, the potential adverse effects of the Chapter 11 case on the Company's liquidity or results of operations and increased legal and other professional costs necessary to execute the Company's reorganization; whether the Company will emerge, in whole or in part, from the Chapter 11 case as a going concern, trading price and volatility of the Company's Class A Common Stock, and the ability of the Company to remain listed on The NASDAQ Capital Market. The forward-looking statements contained herein are also subject generally to other risks and uncertainties that are described from time to time in the Company's filings with the Securities and Exchange Commission, including under Item 1A, "Risk Factors" in the Company's most recent Annual Report on Form 10-K, as filed with the Securities and Exchange Commission, and as revised and updated by our Quarterly Reports on Form 10-Q and Current Reports on Form 8-K. The statements made herein are made as of the date of this press release and, except as may be required by law, 23andMe undertakes no obligation to update them, whether as a result of new information, developments, or otherwise.

#### **Contact Information**

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# **EXHIBIT D**

# CYBER REPORT

## CYBER REPORT

# 23andMe bankruptcy: With America's DNA put on sale, market panic gets a new twist

PUBLISHED SUN, MAR 30 2025•9:54 AM EDT UPDATED SUN, MAR 30 2025•11:39 AM EDT

Kevin Williams

WATCH LIVE

## KEY POINTS

The bankruptcy of consumer genetics testing company 23andMe last week led to widespread fears about the DNA of millions of Americans going on sale to the highest bidder.

23andMe has 15 million customers and with calls for users to delete their data, traffic to its website surged 526% on the day of its bankruptcy filing.

Some experts say putting genetic information on sale is both a data disaster and national security disaster, but others say the 23andMe panic represents a small part of a much bigger health information problem.



Signage at 23andMe headquarters in Sunnyvale, California, U.S., on Wednesday, Jan. 27, 2021.

David Paul Morris | Bloomberg | Getty Images

DNA testing has become a valuable tool for hobbyists and novice genealogists. For some, learning they are the 10th cousin of Paul Revere or the 15th great nephew four times removed of the last King of Prussia is worth the perceived risk of sharing a DNA sample. But what happens when the company harvesting the DNA goes bankrupt?

That was the question posed to millions of Americans last week when 23andMe, the company that popularized consumer genetic testing and had early backing from Google, [led for bankruptcy](#), leading to a wave of calls for Americans to [delete their DNA](#) from the company's database.

While it's not 100 percent clear if the "delete your DNA" calls were warranted, privacy experts are alarmed, and Americans who had taken the genetic test took the advice to heart.

According to data from online traffic analysis company Similarweb, on March 24, the day of the bankruptcy announcement, 23andMe received 1.5 million visits to its website, a 526% increase from one day prior. According to Similarweb, 376,000 visits were made to help pages specifically related to deleting data, and 30,000 were made to the customer care page for account closure. The next day, that figure rose to 1.7 million visits, and traffic to the delete data help page about 480,000.

Margaret Hu, professor of law and director of the Digital Democracy Lab at William & Mary Law School, thinks Americans made the right move. “This development is a disaster for data privacy,” said Hu. In her view, the 23andMe bankruptcy should serve as a warning as to why the federal government needs strong data protection laws.

In some states, Hu noted, the government is taking an active role in counseling consumers. The California Attorney General’s Office is [urging Californians](#) to delete their data and have 23andMe destroy saliva samples. But Hu says that is not enough, and such guidance should be provided to all U.S. citizens.

The potential national security implications of 23andMe’s data falling into the wrong hands are not new. In fact, the Pentagon had previously warned military personnel that these DNA kits could pose a risk to national security.

Exposing DNA collected from consumers is not a new issue for 23andMe, either. In 2023, almost 7 million people who took the genetic test were already exposed [in a major 23andMe data breach](#). The company signed an agreement that involved a \$30 million settlement and a promise of three years’ worth of security monitoring.

But Hu says the bankruptcy does make the company, and its data, especially vulnerable now.

## Drug research and genetic testing data

One of the things notable about the consumer mindset in the early years of the popularization of genetic testing was that [a majority of users opted into sharing their DNA](#) for research purposes, as much as 80% in the years when 23andMe was growing rapidly. Then, as the market for consumer sale of the popular DNA test kits reached saturation sooner than many expected, 23andMe focused more on research and development partnerships with drug companies as a way to diversify its revenue.

Currently, when 23andMe sells genetic data to other research companies, most is used at an aggregate level, as part of millions of data points being analyzed as a whole. The company also strips out identifying data from the genetic data, and no registration information (like a name or email) is included. Data researchers do need, such as date of birth, is stored separately from genetic data, and shared with randomly assigned IDs.

Hu is among the experts concerned these practices could change under 23andMe or any new buyer. “In a time of financial vulnerability, companies such as pharmaceutical companies might

see an opportunity to exploit the research benefits of the genetic data,” Hu said, adding that they might try to renegotiate prior contracts to extract more data from the company. “Will the next company that buys 23andMe do that?” Hu said of its privacy policies.

In recent days, 23andMe has said it will try to find a buyer who shares its privacy values.

23andMe did not respond to a request for comment.



Anne Wojcicki, 23andMe Co-Founder & CEO pushes the button, remotely ringing the NASDAQ opening bell at the headquarters of DNA tech company 23andMe in Sunnyvale, California, U.S., June 17, 2021.

Peter DaSilva | Reuters

Over the years since 23andMe’s founding in 2006, many customers were willing to send in a swab to learn more about their family history. Lansing, Michigan resident Elaine Brockhaus, 70, and her family were excited to learn more about their lineage when they submitted samples of their DNA to 23andMe. But with the company now teetering in bankruptcy and privacy experts concerned about what happens to the millions of people with DNA samples stored, Brockhaus says the whole thing has “caused a bit of a ruckus in my family.”

“We enjoyed some aspects of 23&Me,” Brockhaus said. “They continually refined and updated our heritage as more people joined, and they were better able to pinpoint genetically related groups,” Brockhaus said. She was able to learn more about health risk factors that were present or not present in her past.

Now, her family has come full circle in the 23andMe experience: some members were initially reluctant to go along, and now, Brockhaus says, everyone has deleted their accounts.

## A unique company collapse, but everyday cyber risks

But Brockhaus continues to view 23andMe within a larger consumer health market where the risks are not new, and health information is being shared in all sorts of environments where security issues could arise. “Anyone sending ColoGuard or receiving medical results through the mail is taking a risk of exposure,” Brockhaus said. “Our very identities can be stolen with a few keystrokes. Of course, this does not mean that we should throw up our hands and agree to be victims, but unless we want to dig holes out back and live in them we have to be vigilant, proactive, but not panicked,” she added.

Jon Clay, vice president of threat intelligence at cybersecurity firm Trend Micro, says consumers of 23andMe do need to view the bankruptcy as a threat. In any sale process, if the data is not transferred and guarded in the most secure manner possible, “it is at risk of being used by malicious actors for a number of nefarious purposes,” he said.

Clay thinks 23andMe’s data is incredibly valuable to cybercriminals — not just because it’s permanent and personally identifiable, but also because it can be exploited for identity theft, blackmail, or even medical fraud.

“Cybercriminals can use it to target consumers with convincing scams and social engineering tactics, such as fraudulently claiming someone is a blood relative to another person or to send deceptive messages about their potential health risks,” Clay said. “Organizations who go bankrupt should ensure the security and privacy of their customer’s data is critical, and any sharing or selling of data to others should not be done,” he added.

But other experts say the lesson of 23andMe is less about the company’s collapse and the threat to privacy that created than serving as a reminder about the everyday cyber hazards related to personal information.

“When people start talking about personal data, they forget where their data is already sitting,” says Rob Lee, chief of research and head of faculty at SANS Institute, which specializes in helping businesses with information security and cyber issues. Whether it’s sending a blood sample into a private lab or getting rid of a laptop to upgrade to a new one, “your digital footprints are being left out there for people to find,” Lee said. “People don’t understand the scope, so there is a larger discussion out there, specifically around where does data go?”

With DNA information, there are certain basic legal factors people should weigh before swabbing themselves and sending the sample in.

According to Lynn Sessions, an expert on healthcare privacy and digital assets and partner at the law firm BakerHostetler, the federal law that covers patient information privacy, HIPAA, does not apply to this situation, and 23andMe would not be considered a HIPAA-covered entity, or business associate of one. But there are state laws that apply to genetic information that would be in play, [such as in California.](#)

Meredith Schnur, a managing director and cybersecurity leader at insurance company Marsh, thinks the risk from 23andMe's bankruptcy for people who sent in their swabs is relatively low. "It doesn't cause any additional consternation or heartburn," Schnur said. "I just don't think it opens up any additional risk that doesn't already exist," she said, adding that many people's information is "already out there."

Last week, a 23andMe co-founder, Linda Avey, [blasted the company's leadership.](#) "Without continued consumer-focused product development, and without governance, 23andMe lost its way, and society missed a key opportunity in furthering the idea of personalized health," Avey wrote in a social media post. "There are many cautionary tales buried in the 23andMe story," Avey said.

The bankruptcy itself is the issue that is now hard for consumers to ignore, and until the sale process is completed, the questions will remain.

"When you're in bankruptcy, data privacy values are not what you're really thinking about. You're thinking about selling your company to the highest bidder," Hu said. That highest bidder, Hu says might take the genetic data and consumer profile data and link them together when selling it to others.

And that initial sale which includes the DNA of millions of people may only be the first of many transactions.

"It might sell it off, piece by piece, indiscriminately. And the buyer of that data might be a foreign adversary," Hu said. "That is why this is not just a data privacy disaster. It's also a national security disaster."

# **EXHIBIT E**

