23andMe Holding Co.
870 Market Street, Room 415
San Francisco, CA 94086

info@23andme.com
www.23andme.com

Statement of Joseph Selsavage
Interim Chief Executive Officer and Chief Financial Officer, 23andMe, Holding Co.
Hearing: Securing Americans' Genetic Information: Privacy and National Security Concerns Surrounding 23andMe's Bankruptcy Sale
Committee on Oversight and Government Reform
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Chairman Comer, Ranking Member Lynch, other members of the committee, thank you for the opportunity to appear before you today. My name is Joseph Selsavage, and I represent 23andMe, a mission-driven organization founded on a simple yet transformative belief: that individuals have the right to access, understand, and benefit from their own genetic information. I came to 23andMe in November 2021, when the company acquired Lemonaid Health, where I had been Chief Financial Officer since joining in 2020. As of March 23, 2025, I have been serving as the Interim Chief Executive Officer of 23andMe.

From the very beginning, 23andMe's purpose has been clear: to help people live healthier lives through direct access to their own DNA, to accelerate scientific discovery, and to contribute meaningfully to the future of personalized medicine. We recognize that with this vision comes immense responsibility—to our

customers, to public health, and to the trust we are granted by millions of individuals who have chosen to participate in something larger than themselves.

We are here today not only to answer your questions, but to reaffirm our deep commitment to data privacy and security, transparency, customer choice, data stewardship, and scientific integrity. At a time when science and technology are evolving faster than policy and public understanding, it is essential that companies like ours lead with accountability.

As we share our perspective with the Committee today, we do so with humility, with a clear view of the challenges ahead, and with an unwavering focus on our mission: to empower every person with access, understanding and the ability to benefit from their DNA, while safeguarding the principles of ethics, privacy, and security that must guide innovation in the 21st century.

Background on 23andMe

Founded in 2006, 23andMe is a personal genomics and biotechnology company that pioneered direct-to-consumer genetic testing. We are named after the 23 pairs of chromosomes in every human cell. 23andMe is a saliva-based DNA service that provides customers with information about their ancestry and important health information.

Our mission has always been to empower consumers by providing access to information about their personal genetics based on the latest science, so they can make their own informed decisions about their healthcare journey. We believe the information provided by direct-to-consumer genetic tests provides a starting point for individuals to consider various choices, including lifestyle changes that could help them reduce potential genetic health risks about which they may never have been aware through the traditional healthcare system. We have worked for 19 years to translate complex genetic science into actionable, understandable insights, empowering individuals to make informed decisions.

As one of the first and only companies to receive FDA authorization for direct-to-consumer genetic health reports, we helped democratize access to personal genomic information. Our mission is for all people to be able to *access*, *understand* and *benefit* from their DNA. We have over 13 million customers globally, many of whom have used our service to connect with family members, discover their roots, and gain insights into health risks, traits, and inherited conditions. Our services allow customers to gain DNA insights about their genetic risk for dozens of conditions like Type 2 diabetes, Alzheimer's disease, and certain cancers. They can also learn about their carrier status for inherited conditions like cystic fibrosis or Tay-Sachs disease, or wellness factors like lactose intolerance or deep-sleep tendencies. 23andMe customers have consistently reported taking positive health action after learning about their genetics through 23andMe's services. Based on surveys, 82% of customers with an actionable genetic result were previously unaware of their health risks, and after receiving their report, 86% of customers who shared results with their doctors received at least one medical recommendation, and 87.5% of those recommendations were followed.[1]

Additionally, more than 4 million customers have found they have a higher likelihood of Type 2 diabetes; more than 2.2 million customers have learned they have a higher likelihood of coronary artery disease; more than 1 million customers have found they are at high genetic risk for harmful blood clots (hereditary thrombophilia); and more than 28,000 customers have been identified as having BRCA1/BRCA2 variants which indicates up to an 85% lifetime risk for breast cancer and increased risk for ovarian and other cancers.

[1] Based on 2023 survey, designed by 23andMe Genomic Health & Sciences, of 1,076 23andMe research-consented participants with variants in *BRCA1, BRCA2, APOB, LDLR, HFE, TTR, MUTYH*.

The Registration Process

The process for our services was built to be easy for everyone over the age of 18 to complete: You order a kit from 23andMe.com or a retailer like Amazon or Walmart.com. Once you receive a kit, you create an account online and register your kit's barcode on 23andMe's website or its mobile app. After registering, you submit a saliva sample using a small tube provided in the kit. The sample is sent to a CLIA-certified laboratory using prepaid packaging. The registration process is designed to ensure a new customer's sample is connected to their account in a way that protects their privacy. The barcode number customers use to register their kit ensures the processing lab does not receive any personally identifying information and that the data is linked to the correct individual.

After a sample arrives at the lab, it takes roughly 4 to 6 weeks to process, and customers can find up-to-date information by logging into their 23andMe account. Once the DNA is processed, customers receive reports through our secure online platform.

There are four types of services we offer today:

1. Ancestry Service: Our Ancestry Service is the most comprehensive ancestry breakdown available with 80+ personalized reports, ancestry composition across 4000+ geographic regions, ancestry percentages (to the 0.1%), 30+ trait reports and has the ability to upgrade to the health services at any time.

   Our Ancestry Service helps customers understand who they are, where their DNA comes from and their family story. It breaks down their ethnic background, shows their genetic ancestry by region, and traces their maternal and paternal lineage. If they choose to participate in the DNA

Relatives features, customers can connect with other customers with whom they share DNA - their genetic relatives.

2. Health & Ancestry Service: Our Health & Ancestry service includes everything in the Ancestry Service, plus 150+ personalized reports which include FDA-authorized reports. This service is FSA/HSA eligible. Report examples include: increased risk for conditions like Type 2 diabetes, late-onset Alzheimer's disease, and BRCA1- and BRCA2-related cancers.

3. 23andMe+ Premium Service: An annual subscription service includes everything in our Health & Ancestry Service. This service includes advanced, premium features, reports and tools for ancestry and health related data. This service is FSA/HSA eligible.

   23andMe+ Premium offers everything from our Health + Ancestry kit as well as more than 40 additional health predisposition reports on common conditions (e.g. heart health) based on polygenic risk scores (PRS), pharmacogenetics reports that help customers learn how they may process certain medications. Premium offers ongoing access to new reports as they are developed.

4. 23andMe+ Total Health: Our most advanced service providing next generation sequencing genetic reports and includes blood testing and access to genetics-based clinical care. This service is FSA/HSA eligible. This service covers 200x more hereditary disease-causing variants than our personal genome service reports (50,000+ variants in Total Health exome sequencing compared to 250 in Carrier Status and Genetic Health Risk reports). It is an annual subscription. Total Health gets its name from adding essential bloodwork and genetics trained clinician discussions to the service, to get an advanced, integrated understanding of your health risks.

Providing health data to our customers is something we take very seriously at 23andMe. We implemented educational and comprehension-based tutorials before providing access to specific reports. Customers must specifically opt in to receiving reports for Parkinson's and Alzheimer's. These explicit opt-ins are in addition to the initial company consents, meaning customers cannot access or view these reports until they take this action. We also have educational tutorials for BRCA, HOXB13 (hereditary prostate cancer), and MUTYH (hereditary colorectal cancer) cancer reports, as well as for general carrier status, genetic health risks, and pharmacogenetic report categories that customers *must view before* accessing those categories of reports.

Customer Stories

We have many powerful customer stories that highlight the profound impact genetic insights can have on people's lives—often uncovering health risks, prompting critical medical action, and enabling proactive decisions that change the course of individuals' futures Below are a few examples that customers have shared with us.

At 31, Casey didn't expect his health reports to reveal anything significant—but they did. He discovered he carried two copies of a variant linked to hereditary hemochromatosis, a condition that can lead to dangerous iron overload. Follow-up bloodwork and imaging confirmed elevated iron levels and mild liver toxicity. Thanks to early detection, Casey is now under specialist care and undergoing regular phlebotomy to manage the condition.

Ashley, a 33-year-old mother, discovered she had a BRCA1 variant through her genetic health report. Despite her young age and no known family history, Ashley insisted on further screenings—requests that were initially dismissed. Her persistence paid off: she was diagnosed with stage two triple negative breast

cancer, a fast-moving form closely tied to BRCA1. Her doctors told her that without early detection, it might have been found much later, when treatment options would be more limited.

Similarly, Gina was unaware of her Ashkenazi Jewish ancestry or any breast cancer history. But her 23andMe report revealed a BRCA1 variant, prompting her to consult with medical experts and eventually undergo a prophylactic double mastectomy and hysterectomy. Navigating this during the height of the COVID-19 pandemic, Gina faced her journey with courage—and now uses her experience to advocate for others through her blog and speaking engagements.

Dana's story further illustrates how genetic knowledge can uncover critical connections. Though she had a family history of pancreatic cancer, she didn't know it was linked to the BRCA gene—or that her Ashkenazi Jewish heritage meant a 1 in 40 chance of carrying the mutation. Just four months after reviewing her reports, she confirmed her BRCA status through additional testing and underwent preventive surgeries that dramatically reduced her risks for both breast and ovarian cancer.

As a 57-year-old adoptee, Laura lacked access to her biological health history. Genetic testing revealed a heightened risk for nonalcoholic fatty liver disease (NAFLD), particularly among women with her genetic profile. After experiencing chronic symptoms, she worked with her physician to confirm the condition and is now taking active steps—including working with a nutritionist and exercising regularly—to manage it before it progresses.

Rebecca learned she carries one copy of the APOE ε4 gene, associated with an increased risk for late-onset Alzheimer's disease. Motivated by this information, she enrolled in clinical trials and began treatment with Leqembi®, just before its FDA approval. Her sister, who shares the same genetic variant, now joins her for biweekly infusion therapy—an example of how these insights can benefit entire families.

Andrew's experience shows how genetic insights can become urgently relevant. After learning he carried a variant in the F2 gene associated with blood clots, his father suddenly collapsed due to massive clots in his heart and lungs. Andrew shared his results with doctors, who confirmed his father also carries the variant. This diagnosis has since helped guide preventative care for both of them.

These are only some of the many, hundreds of stories that illustrate the power of genetic testing. These individuals have not only taken control of their own health but have also paved the way for others to do the same (https://www.23andme.com/stories/).

Powering Research and Scientific Publications

The value of personal genomics goes beyond the insights people learn about themselves. Customers who submit their DNA for analysis also have the option to allow their data to be shared for research purposes—and over 80% choose to consent to research. Since 2010, 23andMe has published 293 papers (https://www.23andme.com/publications/).

Consent is a central tenet of 23andMe's Research program. We have separate research consents, beyond our processing sensitive data consent, Privacy Statement, and terms of service, that customers must review and agree to if they want to participate in our Research program. These consent documents are subject to the review and oversight of our external and independent Institutional Review Board (IRB), which ensures that the risks and benefits of participation in research are properly presented to the potential participant so they can make an informed decision about participation.

Customers who affirmatively consent contribute to more than 230 studies on topics that range from Parkinson's disease to lupus to asthma and more. We collaborate with biotech companies, advocacy organizations and universities to bring customers opportunities to participate in research. Participants can spend anywhere from five to 50 minutes—the choice is theirs—answering online survey questions

that enable researchers to combine their genetic information with millions of other data points to help drive scientific and medical discoveries.

23andMe has received grants from the U.S. National Institutes of Health to fund research and data voluntarily provided by 23andMe's customers has led to the identification of hundreds of new genetic associations, including associations with Parkinson's disease, depression, and skin cancer. We collaborate with some of the best and brightest talent in the world of genetics research—including researchers at the University of Chicago, Stanford University and the Broad Institute, as well as the Lupus Research Institute, the Michael J. Fox Foundation and Sickle Cell 101, among others—and our findings are regularly published in leading peer-reviewed scientific journals, such as *Science*, *Nature*, and the *New England Journal of Medicine*. In addition to working with partners that focus on drug development, 23andMe previously conducted its own research to try to identify new therapies for both common and rare diseases.

Our commitment is to responsibly harness the power of DNA to benefit human health and advance scientific understanding.

How We Ensure Customer Data is Protected and Their Preferences Honored

Our customers can make their own choices about how their data is used and whether 23andMe retains their information. Customers' data is not shared for research purposes unless the customer affirmatively consents—and we remove all identifying information before genetic data is shared unless specifically consented for limited purposes. Any customer who affirmatively consents to participate in our Research program can easily opt out at ANY time through their account settings—and always has been able to do so. Customers are also free to delete their accounts and all the information we retain at any time.

From the beginning, privacy and empowerment have been central to 23andMe's business. Our systems ensure that genetic data is stored separately from personal identifiers; and users control their

information—including having the ability to decide whether to participate in research, share information with DNA matches, or download their raw data.

We have a strong security program that includes encryption, access controls and regular audits. We comply with applicable regulatory requirements.

We follow strict security protocols and privacy principles, including:

- **Explicit Consent:** We never share individual-level data without the user's consent.
- **Transparency:** We clearly communicate how data is used and give customers control over their data sharing preferences.
- **Data Storage:** All research data is stored separately from any identifying information to protect customer privacy.
- **Security Standards:** We use industry-standard encryption, access controls, and monitoring systems to protect data.

However—despite our best efforts—we know that no system is infallible.

In October 2023, we learned that a threat actor accessed individual 23andMe.com accounts through a process called *credential stuffing*. This is the automated injection of stolen username and password pairs ("credentials") into website login forms to fraudulently gain access to user accounts. The threat actor was able to access approximately 14,000 user accounts in instances where usernames and passwords that customers used on the 23andMe website were the same as those used on other websites that had been previously compromised and then made available online. Using this access to the credential stuffed accounts, the threat actor was able to access limited customer profile information for over 6 million users, which the customers had chosen to share with other genetic relatives when they decided to participate in 23andMe's DNA Relatives feature.

Upon discovery of the security incident, we took immediate action. We disabled impacted accounts and temporarily disabled the "DNA Relatives" feature. We forced password resets for all users. We engaged leading cybersecurity firms to conduct a full forensic investigation. We notified law enforcement, regulators and affected customers, in compliance with applicable laws. And we enhanced login security by implementing mandatory two-factor verification for all accounts.

We acknowledge the seriousness of the security incident and the anxiety it caused our customers, which we deeply regret. We are committed to continued transparency, security, and maintaining trust among customers.

Process Going Forward

23andMe's bankruptcy was driven by a variety of factors including the aforementioned security incident, macroeconomic headwinds affecting biotech companies, and a strategic reassessment of our operational model. Due to these circumstances, the company made the difficult decision to voluntarily file for Chapter 11 bankruptcy protection in March of this year to facilitate a sale, with the aim of maximizing the value of the business for its stakeholders.

During this process we continued to operate as usual. There has been no disruption to any service or offering we provide. Customers have been able to continue to purchase kits, access to data remained has unchanged, and we have continued offering and fulfilling subscriptions. We have made no changes to how we store, manage or protect customer data. We've made no changes to our privacy policies or to how customers can manage their preferences. Customers have been able to delete their data at any time, and no changes to our data deletion policy were made.

Throughout the sale process, we have sought to secure a partner that shares our commitment to customer data privacy and that will continue our mission to help people access, understand and benefit from knowledge about the human genome. We are requiring that any buyer agree to comply with existing 23andMe privacy policies and applicable law with respect to the treatment of customer data.

We also have stipulated that no bids would be accepted from entities based in or with controlling investments from countries of concern, such as China, Cuba, Iran, North Korea, Russia or Venezuela, which would have raised concerns around customer privacy and national security.

In addition, we asked the court to appoint an independent Customer Data Representative (CDR) to serve as an independent third party, reviewing whether any proposed transaction complied with our privacy policies and applicable data privacy laws and maintained customer data security. We made this request proactively and before any other party, including our regulators, made a similar request.

23andMe, the Official Committee of Unsecured Creditors (UCC), the U.S. Trustee, and 32 state attorneys general ultimately agreed to the appointment of a disinterested Consumer Privacy Ombudsman (CPO) with privacy and cybersecurity credentials to conduct an examination and present a report to the bankruptcy court, evaluating a potential bidder's privacy and security program and assessing the impact of any potential sale on the protection of consumer data.

As Congress is aware, we have run a successful sale process and are presently down to two bidders—biotech company Regeneron and the nonprofit medical research organization TTAM Research Institute. Both are American enterprises. Pursuant to a bankruptcy court order, and with the agreement of the parties, there will be a subsequent round of bidding prior to the sale hearing, which is currently set for June 17, 2025. Because this process is ongoing, I am unable to speak to the merits of either bid or the ongoing sale process.

As we proceed, I would like to make two points:

- First and foremost, privacy and data security remain one of our top priorities. We remain committed to protecting sensitive customer data. We require anyone bidding for 23andMe to agree to comply with our privacy policies and all applicable privacy laws.

- Second, there have been no changes to customer access to accounts, genetic reports, or any stored data and no change to customers' ability to control their accounts, including the ability to delete their data.

In closing, we recognize the vital importance of protecting every individual's right to access and control their own genetic information. Empowering people with knowledge about their DNA is not only a matter of personal autonomy—it is a gateway to proactive and personalized health, informed decision-making, and greater engagement in scientific progress. At 23andMe, we believe that when consumers are trusted with their own data, they become partners in advancing healthcare, not just patients of it.

I appreciate the opportunity to testify before the committee today and welcome your questions.