Congress of the United States

Washington, DC 20515

June 12, 2025

Anne Wojcicki Founder TTAM Research Institute 171 Main Street Suite 259 Los Altos, CA 94022

CC: Privacy Ombudsman, Washington University School of Law Professor Neil Richards

Dear Ms. Wojcicki,

In May 2025, Regeneron Pharmaceuticals and TTAM Research Institute announced bids in the Chapter 11 bankruptcy auction of 23andMe Holding Co.¹ We write to ensure that the 15 million consumers who entrusted 23andMe with their sensitive genetic data will be protected from abuse and exploitation during and after this sale. We are seeking assurances that your company will adopt the broadest possible interpretation of previous policies and continue to put new safeguards in place.

Genetic data, which 23andMe helped make accessible to millions of Americans, provides myriad benefits for medical research, genealogical research, and individuals and families seeking to understand their personal histories.² However, genetic data is highly sensitive and its inclusion in a commercial bankruptcy proceeding presents enormous and unprecedented privacy risks for millions of consumers.

We've already seen the harms of genetic data usage by bad actors. In 2023, millions of accounts were compromised in a data breach that impacted nearly 50% of 23andMe's customers.³ Over the course of five months, hackers exposed the personal data of seven million customers, including a leak targeting hundreds of thousands of Ashkenazi Jews based on the ancestry profiles that genetic data enabled.⁴

There is also extensive evidence that many allegedly anonymized databases are less safe than they appear and can still be used to identify specific individuals, threatening the civil rights and privacy of those included. According to privacy groups, "genetic data cannot truly be de-identified," as the government, law enforcement,

4 NBC News, "23andMe user data targeting Ashkenazi Jews leaked online," October 7, 2023, https://www.nbcnews.com/news/us-news/23andme-user-data-targeting-ashkenazi-jews-leaked-online-rcna119324.

¹ Reuters, "23andMe seeks new bids after \$305 million offer from its co-founder," June 4, 2025, https://www.reuters.com/sustainability/boards-policy-regulation/23andme-seeks-new-bids-after-305-million-offer-its-co-founder-2025-06-04/.

² Wall Street Journal, "23andMe Is Bankrupt. Here's What You Need to Know About Your Genetic Data." March 25, 2025, <u>https://www.wsj.com/tech/biotech/23-and-me-bankruptcy-genetic-data-what-happens-625794fc</u>.

³ New York Times, "23andMe Just Filed for Bankruptcy. You Should Delete Your Data Now." March 25, 2025, <u>https://www.nytimes.com/wirecutter/reviews/23andme-data-bankrupt/</u>.

and private companies have the ability to re-identify and de-anonymize this data.⁵ Even more alarmingly, this data can identify family members, raising the risk for individuals who were not customers of 23andMe or TTAM. Unlike breaches of mutable identifiers, the leak of genetic data presents a threat to victims potentially in perpetuity.

As Members of the Energy & Commerce Committee and other concerned offices, we are seeking further information on how potential owners will protect consumers and their families in and after this sale. Given the need for all interested parties to review the safety and privacy of this sale, we ask that you provide written responses to the following questions no later than Thursday, June 26, 2025 outlining TTAM Research Institute's privacy policies if the company were to acquire 23andMe Holding Co.:

- 1. 23andMe's existing policy gives customers the right to delete their data and withdraw their consent for its use in medical research. Will TTAM Research Institute continue to provide consumers with these options?
 - a. Several state Attorneys General, including New York Attorney General Letitia James, warned consumers to delete or limit their information following 23andMe's bankruptcy announcement ahead of the sale.⁶ However, 23andMe's system has repeatedly crashed and prevented customers from successfully deleting their data.⁷ Under the current timeline, the new owner will finalize its ownership of 23andMe within months.⁸ What steps will your company take to ensure any customer seeking to delete their information can do so prior to the company's sale?
- 2. If your bid is chosen, does TTAM Research Institute intend to proactively notify all 23andMe customers regarding the sale and their right to delete their data or withdraw consent for its use in medical research prior to the ownership change? If yes:
 - a. Please outline what steps TTAM Research Institute would take to inform 23andMe customers about the sale and their rights to access, limit, and delete their data.
 - b. 23andMe has been in operation for nearly two decades, and genetic data provides insight not only into the customer but their entire family tree. Please outline what steps TTAM Research Institute would take to contact the family members of customers and what data rights your company will offer those family members?
- 3. 23andMe's existing policy prevents the sharing of genetic data with law enforcement without a warrant. Will TTAM Research Institute commit to continuing these protections in privacy policies in regards to law enforcement?

⁵ Electric Frontier Foundation, "A Sale of 23andMe's Data Would Be Bad for Privacy. Here's What Customers Can Do." October 9, 2024, <u>https://www.eff.org/deeplinks/2024/10/sale-23andmes-data-would-be-bad-privacy-heres-what-customers-can-do</u>.

⁶ BBC, "23andMe users struggle to delete their highly sensitive data," March 26, 2025, <u>https://www.bbc.com/news/articles/cddy8d632620</u>.

⁷ BBC, "23andMe users struggle to delete their highly sensitive data," March 26, 2025, <u>https://www.bbc.com/news/articles/cddy8d63262o</u>.

⁸ Fortune, "23andMe says it won permission from a judge to sell customers' medical and ancestry data. Here's how to delete yours," March 28, 2025, <u>https://fortune.com/2025/03/28/23andme-bankruptcy-chapter-11-genetic-data-medical-ancestry-dna-silicon-valley-delete/</u>.

- 4. DNA and biometric data is <u>regularly</u> used to target and track immigrants through the government-run database Combined DNA Index System (CODIS).⁹ Please outline TTAM Research Institute's policies regarding data sharing with immigration enforcement.
- 5. Does TTAM Research Institute currently use artificial intelligence and if so, does the company ever place personal identifiable information (like DNA) into data sets used to train models? Will TTAM Research Institute commit to ensuring that no 23andMe former customers' data will be included in such models?
- 6. Will TTAM Research Institute continue 23andMe's research partnerships with pharmaceutical companies or academic institutions?
 - a. If so, will all such partnerships be re-reviewed to ensure compliance with renewed consent and privacy obligations?
- 7. Will TTAM Research Institute publicly disclose a full list of all third parties who currently have access to 23andMe data? What steps will your company take to ensure transparency of third-party access in the future?
- 8. Will TTAM Research Institute support federal legislation to strengthen consumer genetic privacy rights?

Sincerely,

Alexandria Ocasio-Cortez Member of Congress

Debbie Dingell Member of Congress

Stephen F. Lynch Member of Congress

Jan Schakowsky Member of Congress

Lori Trahan Member of Congress

Kweisi Mfume Member of Congress

9 The Record, "Homeland Security has collected DNA data from 1.5 million immigrants in four years, researchers find," May 21, 2024, <u>https://therecord.media/homeland-security-collected-dna-millions-immigrants</u>.

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