

Congress of the United States

Washington, DC 20515

June 12, 2025

Leonard S. Schleifer
Chief Executive Officer
Regeneron Pharmaceuticals Inc.
777 Old Saw Mill River Rd.
Tarrytown, NY, 10591

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

Dear Mr. Schleifer,

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. While we applaud Regeneron Pharmaceutical's commitments to upholding 23andMe's consumer privacy policies,² 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.³ 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.⁴ 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.⁵

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.

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 Regeneron Pharmaceuticals, press release, May 19, 2025, <https://newsroom.regeneron.com/news-releases/news-release-details/regeneron-enters-asset-purchase-agreement-acquire-23andme-256>.

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

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

5 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>.

According to privacy groups, “genetic data cannot truly be de-identified,” as the government, law enforcement, and private companies have the ability to re-identify and de-anonymize this data.⁶ Even more alarmingly, this data can identify family members, raising the risk for individuals who were not customers of 23andMe or Regeneron. 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 Regeneron Pharmaceuticals’ 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 Regeneron Pharmaceuticals 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.⁷ However, 23andMe’s system has repeatedly crashed and prevented customers from successfully deleting their data.⁸ Under the current timeline, the new owner will finalize its ownership of 23andMe within months.⁹ What steps will Regeneron Pharmaceuticals 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 Regeneron Pharmaceuticals 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 you 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 you 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 Regeneron Pharmaceuticals commit to continuing these protections in privacy policies in regards to law enforcement?

⁶ Electric Frontier Foundation, “A Sale of 23andMe’s Data Would Be Bad for Privacy. Here’s What Customers Can Do.” October 9, 2024, <https://www.eff.org/deeplinks/2024/10/sale-23andmes-data-would-be-bad-privacy-heres-what-customers-can-do>.

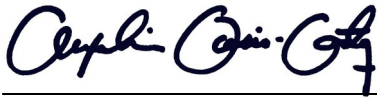
⁷ BBC, “23andMe users struggle to delete their highly sensitive data,” March 26, 2025, <https://www.bbc.com/news/articles/cddy8d63262o>.

⁸ BBC, “23andMe users struggle to delete their highly sensitive data,” March 26, 2025, <https://www.bbc.com/news/articles/cddy8d63262o>.

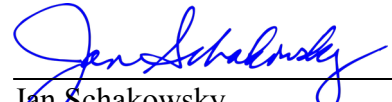
⁹ Fortune, “23andMe says it won permission from a judge to sell customers’ medical and ancestry data. Here’s how to delete yours,” March 28, 2025, <https://fortune.com/2025/03/28/23andme-bankruptcy-chapter-11-genetic-data-medical-ancestry-dna-silicon-valley-delete/>.

4. DNA and biometric data is regularly used to target and track immigrants through the government-run database Combined DNA Index System (CODIS).¹⁰ Please outline Regeneron Pharmaceuticals' policies regarding data sharing with immigration enforcement.
5. Does Regeneron Pharmaceuticals 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 the company commit to ensuring that no 23andMe former customers' data will be included in such models?
6. Will Regeneron Pharmaceuticals 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 Regeneron Pharmaceuticals 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 Regeneron Pharmaceuticals support federal legislation to strengthen consumer genetic privacy rights?

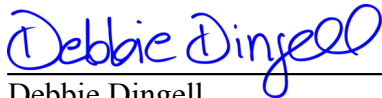
Sincerely,



Alexandria Ocasio-Cortez
Member of Congress



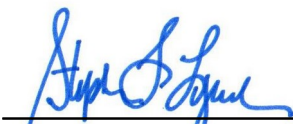
Jan Schakowsky
Member of Congress



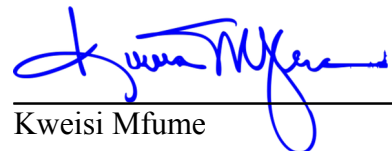
Debbie Dingell
Member of Congress



Lori Trahan
Member of Congress




Stephen F. Lynch
Member of Congress




Kweisi Mfume
Member of Congress


¹⁰ The Record, "Homeland Security has collected DNA data from 1.5 million immigrants in four years, researchers find," May 21, 2024, <https://therecord.media/homeland-security-collected-dna-millions-immigrants>.




Jasmine Crockett
Member of Congress




Eleanor Holmes Norton
Member of Congress




Ro Khanna
Member of Congress



Ayanna Pressley
Member of Congress



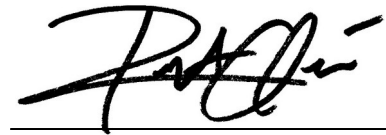
Rashida Tlaib
Member of Congress




Summer L. Lee
Member of Congress




Yassamin Ansari
Member of Congress




Robert Garcia
Member of Congress



Kevin Mullin
Member of Congress




Shontel M. Brown
Member of Congress



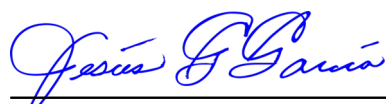
Brendan F. Boyle
Member of Congress



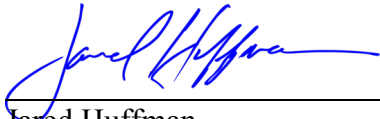
Maxwell Alejandro Frost
Member of Congress



Pramila Jayapal
Member of Congress



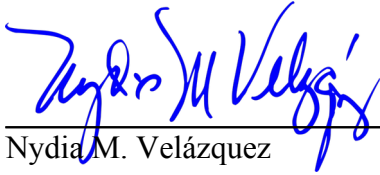
Jesús G. "Chuy" García
Member of Congress

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Jared Huffman
Member of Congress

A handwritten signature in blue ink, appearing to read "James P. McGovern", written over a horizontal line.

James P. McGovern
Member of Congress

A handwritten signature in blue ink, appearing to read "Nydia M. Velázquez", written over a horizontal line.

Nydia M. Velázquez
Member of Congress