

## OPINION

# There's No 'Reset Password' for Your DNA | Opinion

**SALLY GREENBERG**, EXECUTIVE DIRECTOR, NATIONAL CONSUMERS LEAGUE

ON 8/10/22 AT 8:00 AM EDT



OPINION

DNA

DNA TESTING

PRIVACY

DATA

**T**he battle over reproductive rights thrust the importance of our fundamental right to privacy back into the center of everyday life. From menstrual cycle tracking apps, to [Google](#) searches for abortion services, our relationship with the privacy of our personal information shifted underneath our feet. That's why our fight for genetic privacy is so vital.

Think about it. When a consumer signs up to do a genetic test, she may do so to discover her ethnic heritage, find a distant family member, or learn the chances she may one day be at risk for a hereditary disease. What she likely does not expect is that data may be accessible by some of the world's most repressive regimes, used in warrantless law enforcement searches, or commercialized by pharmaceutical companies. Unfortunately, that is exactly what can happen to consumers' genetic data today.

Unlike other unique identifiers, such as a Social Security number or login credentials, our genome cannot be changed—even if it's compromised. The consequences of this

discrimination, to [social surveillance](#) and political targeting.

**SUBSCRIBE NOW FROM JUST \$1 PER MONTH >**

Today there is no comprehensive federal privacy regulation that requires private corporations to follow clear rules to protect millions of DNA sequences voluntarily provided by consumers. These genomic testing entities often have partnerships with third parties who can and do sell the data to other partners. This allows law enforcement agencies or even repressive foreign governments like China to access millions of Americans' genetic information. That policy gap, combined with a [record rise](#) in data breaches, leaves enormous troves of consumers' genetic code at risk.

Take the BGI Group, a genetic sequencing company that manages the China National Gene Bank that has been linked to the Chinese military. Last October, the Biden administration's counterintelligence lead warned [The New York Times](#) about BGI's contracts and partnerships with health institutions across the U.S., stating that as a result Americans' DNA data could be "transferred to the Chinese government." A [Reuters](#) investigation found that the company surreptitiously scraped the DNA data of pregnant women from pre-natal test kits and added them to the China Gene Bank.

Access to genetic data should be tightly controlled, with a transparent and verifiable system of regulations in place to determine who may utilize such information and for what purposes.



A staff member tests a DNA sample.

**ROSLAN RAHMAN/AFP VIA GETTY IMAGES**

### **[SIGN UP FOR NEWSWEEK'S DAILY HEADLINES >](#)**

While there have been voluntary efforts to develop such protections, the results have been inconsistent.

#### **READ MORE**

- [U.S. Children Carry a Double Burden for Gun Violence and Policy Gaps](#)
- [Retirees Are Inflation's Hidden Victims. Here's How to Protect Them](#)
- [Republicans Better Watch Out for the Suburbs in Abortion Battle](#)
- [Stop the Spread—Why the Monkeypox Outbreak Must Be Contained](#)

and protected by statute. That's why my organization, the National Consumers League, is fighting for a set of [Genetic Privacy Rights](#) and released a [Policy Framework](#) detailing steps that [Congress](#), the Biden administration, and industry can take to protect these rights.

A bipartisan initiative, led by Senators Ron Wyden (D-Ore.) and Sheldon Whitehouse (D-R.I.) and supported by Senator [Marco Rubio](#) (R-Fla.), called the [Protecting Americans' Data from Foreign Surveillance Act](#), would be a strong step forward. The bill empowers the Biden administration to create clear safeguards for sensitive personal information, like genetic data. The White House is [reportedly](#) working on an Executive Order with similar goals.

While we applaud this news, it should be just the beginning, not the end of a federal genetic privacy protection regime. It might come as a shock to consumers that most of us can already be identified via DNA databases. Nevertheless, genetic data remains one of the most sensitive, and least protected, types of personal information out there. The future path must both police corporate behavior when handling our genetic data while also protecting that data from foreign adversaries.

Considering the near-irreversible nature of genetic record access, this is an issue that simply cannot wait.

*Sally Greenberg joined the National Consumers League as executive director on Oct. 1, 2007. The League's focus is on five key priority areas: fraud, child labor, LifeSmarts, health care, especially the safe use of medications and medication adherence, and food safety and nutrition. Sally has testified numerous times before Congress on consumer protection issues, including on product safety, fraud, excessive fees on car rentals, consumer rip-offs in calling cards and in support of protections for farmworker children.*

*The views expressed in this article are the writer's own.*

**REQUEST REPRINT & LICENSING, SUBMIT CORRECTION OR VIEW EDITORIAL GUIDELINES**