

## Genetic Discrimination Is Coming for Us All

By Kristen V. Brown, *The Atlantic*, November 12, 2024

*Insurers are refusing to cover Americans whose DNA reveals health risks. It's perfectly legal.*

The news came four years ago, at the end of a casual phone call. Bill's family had always thought it was a freak coincidence that his father and grandfather both had ALS (amyotrophic lateral sclerosis). But at the end of a catch-up, Bill's brother revealed that he had a diagnosis too. The familial trend, it turned out, was linked to a genetic mutation. That meant Bill might also be at risk for the disease.

An ALS specialist ordered Bill a DNA test. While he waited for results, he applied for long-term-care insurance. If he ever developed ALS, Bill told me, he wanted to ensure that the care he would need as his nerve cells died and muscles atrophied wouldn't strain the family finances. When Bill found out he had the mutation, he shared the news with his insurance agent, who dealt him another blow: "I don't expect you to be approved," he remembers her saying.

Bill doesn't *have* ALS. He's a healthy 60-year-old man. A recent study of mutations like his suggests that his genetics increase his chances of developing ALS by about 25 percent, on average. Most ALS cases aren't genetic at all. And yet, Bill felt like he was being treated as if he was already sick. [...]

What happened to Bill, and to dozens of other people whose experiences have been documented by disease advocates and on social media, is perfectly legal. Gaps in the United States' genetic-nondiscrimination law mean that life, long-term-care, and disability insurers can obligate their customers to disclose genetic risk factors for disease and deny them coverage (or hike prices) based on the resulting information. It doesn't matter whether those customers found out about their mutations from a doctor-ordered test or a 23andMe<sup>1</sup> kit.

For decades, researchers have feared that people might be targeted over their DNA, but they weren't sure how often it was happening. Now at least a handful of Americans are experiencing what they argue is a form of discrimination. [...]

When scientists were mapping the immense complexity of the human genome around the turn of the 21st century, many thought that most diseases would eventually be traced to individual genes. Consequently, researchers worried that people might, for example, get fired because of their genetics; around the same time, a federal research lab was sued by its employees for conducting genetic tests for sickle-cell disease on prospective hires without their explicit consent. In 2008, the Genetic Information Nondiscrimination Act (GINA) was signed into law, ensuring that employers couldn't decide to hire or fire you, and health insurers couldn't decide whether to issue a policy, based on DNA. But lawmakers carved out a host of exceptions. Insurers offering life, long-term-care, or disability insurance *could* take DNA into account. Too many high-risk people in an insurance pool, they argued, could raise prices for everyone. Those exceptions are why an insurer was able to deny Bill a long-term-care policy.

Cases like Bill's are exactly what critics of the consumer-genetic-testing industry feared when millions of people began spitting into test tubes. These cases have never been tallied up or well documented. But I found plenty of examples. [...] Kelly Kashmer, a 42-year-old South Carolina resident, told me she was denied life insurance in 2013 after learning that she had a harmful version of the BRCA2 gene. [...]

Studies have shown that people seek out additional insurance when they have increased genetic odds of becoming ill or dying. [...] But many also avoid seeking out potentially lifesaving health information. Concerns about discrimination are one of the most cited reasons that people avoid taking DNA tests.

For some genetically linked diseases, such as ALS and Huntington's disease, knowing you have a harmful mutation does not enable you to prevent the potential onset of disease. Sometimes, though, knowing about a mutation can decrease odds of severe illness or death. BRCA mutations, for example, give someone as much as an 85 percent chance of developing breast cancer, but evidence shows that testing women for the mutations has helped reduce the rate of cancer deaths by encouraging screenings and prophylactic surgeries that could catch or prevent disease. Kelly Kashmer told me that her first screening after she discovered her BRCA2 mutation revealed that she already had breast cancer; had she not sought a genetic test, she may have gotten a policy [...]. She's now been cancer-free for 11 years, but she said she hasn't bothered to apply for a policy again. [...]

---

<sup>1</sup> 23andMe is an American personal genomics and biotechnology company best known for providing a direct-to-consumer genetic testing service in which customers provide a saliva sample that is laboratory analysed to generate reports relating to the customer's ancestry and genetic predispositions to health-related topics.