

REPORT \ SCIENCE \ US & WORLD \

# The US has laws against genetic discrimination, but people still fear it

*And that's a problem for geneticists*

By [Arielle Duhaime-Ross](#) | Jan 29, 2015, 12:33pm EST



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Genetic discrimination hasn't yet become a problem in the US. Since the Genetic Information Nondiscrimination Act (GINA) was signed into law in 2008, very few

GINA-related charges have been made. That doesn't mean that Americans aren't worried that this sort of discrimination might arise in their own lives, however, according to a [perspective piece](#) published yesterday in the *New England Journal of Medicine*.

GINA was signed into law almost seven years ago to prevent health insurance companies and employers from discriminating against individuals based on family history of illness or results from genetic testing. For example, the law prevents an employer from firing an employee because they have a family history of cancer. But GINA hasn't been invoked very often since 2008. In 2013, for instance, the US only had 333 GINA-related charges of employment discrimination, compared with 90,000 charges relating to other areas of discrimination. Moreover, most of those charges were added following an investigation relating to an Americans with Disabilities Act claim.

"GINA has sent a powerful message throughout society that we won't tolerate genetic discrimination," says Robert Green, a geneticist at Brigham and Women's Hospital and co-author of the perspective piece. "And I'm guessing that these companies realize that they might get tremendous public push-back if they were to do this."

## **333 GINA-RELATED CHARGES OF EMPLOYMENT DISCRIMINATION IN 2013**

But the small number of charges may also be a sign that Americans aren't aware that GINA exists. An online survey of 1,479 individuals performed in 2014 by Green and his colleagues showed that 79 percent of respondents didn't know what GINA was or what protection it offered. And people who did know about GINA didn't fully comprehend it. What's even more striking, however, is that 30 percent of participants said that they became more worried about genetic discrimination after reading about

GINA. "We noticed how present in the minds of our participants concerns about genetic discrimination were — particularly by employers and insurance," Green says.

## **"GINA WAS ATTEMPTING TO REASSURE THE PUBLIC."**

This fear is a big problem for researchers because some people refuse to participate in studies as a result, Green says. In order to implement genetic data in a research project, participants have to be willing to tolerate genetic information being

included in their medical records and discussed with their doctors. This practice comes with an "omnipresent concern about genetic discrimination," Green says. And yet, this sort of fear is exactly what GINA was trying to avoid in the first place. "What was fascinating to me was that the very language of GINA was attempting to reassure the public, so that they could take advantage of the fruits of genomic research," Green says.

The fact that GINA doesn't cover genetic discrimination relating to life insurance, long-term care insurance or disability insurance may be the reason for continued fear in the US. Yet Green says that he hasn't seen many insurance companies request genetic test results. "I'm not aware of any recent incidents where anybody has been denied insurance on the basis of genetic testing," he says.

This could still happen, of course. A 2010 study found that people who learn that they have a higher than average risk of developing Alzheimer's disease are more likely to buy long-term care insurance. Once insurance companies clue into this, they may start increasing their long-term care insurance prices based on genetic risk factors — a change that would be perfectly legal under GINA.

## **AS GENETIC MEDICINE BECOMES THE**

# ***NORM, THE TERM "GENETIC DISCRIMINATION" MAY BECOME OBSOLETE***

That is one possible future, Green says. But even that might not last very long. Genomic science is moving quickly, and it's bound to become more present in our lives. Eventually it may help us personalize medicine and tailor our diets and exercise regimens. Once that happens, the term "genetic discrimination" may become obsolete, the researchers write — genetic-based medicine will simply become all medicine, and any form of medical discrimination will be outlawed by extension.

In the meantime, however, researchers and government officials should try to find a way to overcome the public's fears. "We've had so many stories and narratives of people losing health insurance that this is sort of an existential concern that permeates our society now," Green says. If we want people to take full advantage of the medical knowledge we've gained recently, we have to overcome the "absolute fear of genetic discrimination," he says. And like many other fear-based issues, education might be the only way forward.

- SOURCE: [New England Journal of Medicine](#)