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## Protecting Patients from Genetic Discrimination

Despite laws meant to protect US citizens from insurance discrimination due to their DNA, some still fear such judgment, while others claim they have experienced it.

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“We haven’t had much to offer, other than to write letters of support saying the child has an extremely low risk of an event,” Sanatani told *The Scientist*. “All we can do, really, is advocate for our patients. I’m not confident about how successful we are.”

How often do parents discover that a genetic screening result has rendered their children uninsurable, or subject to prohibitively high insurance premiums? Sanatani resolved to find out. In a January 24 study in *Circulation: Cardiovascular Genetics*, Sanatani and colleagues conducted informal interviews of 202 people across North America who had either a SADS diagnosis (which, in 73 percent of cases, involved a genetic screen) or an affected family member. Despite its limitations—the survey did not ask when the alleged acts of insurance discrimination occurred, for instance—the self-reported results shed some anecdotal light on what Sanatani said he had been observing in his medical practice.

Thirty-nine percent of the respondents with a SADS diagnosis or an affected family member reported an increase in their existing insurance premiums. Just more than half said they applied for insurance only after receiving the diagnosis; 60 percent of these respondents indicated that they were rejected by insurers.

Before initiating the study, “a lot of families came to us with the notion that having their kids tested would impact their health coverage, but whenever we went to the literature to see if we could substantiate this or refute this, we couldn’t find much,” Sanatani told *The Scientist*. Yet, after examining the data, the team concluded that “a large percentage of the respondents had experienced some form of insurance rejection,” he said, “with most of them being rejected on the basis of the diagnosis.”

The results were surprising because, according to the researchers, most of the survey respondents were from the United States, where the 2008 [Genetic Information Nondiscrimination Act](#) (GINA) should have protected them.

Under GINA, it is illegal for employers to discriminate against employees or job applicants based on genetic information and, crucially, it is illegal for health insurers to factor genetic information into decisions about insurance eligibility or premiums. In other words, since 2008, it has been against US law for health insurers to reject an applicant or raise premiums due to the applicant's DNA.

By most accounts, GINA works. In a 2015 article in the *New England Journal of Medicine*, medical geneticist [Robert Green](#) of Harvard analyzed the impacts of GINA seven years after the law's passage. He noted that virtually no cases of genetic insurance discrimination had been reported since GINA—although, without any significant record of such discrimination prior to 2008, he concluded that it was impossible to measure whether the lack of discrimination was because of GINA or because genetic discrimination had not been an issue in the first place.

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Under the Affordable Care Act (ACA), enacted in 2010, the possibility of genetic insurance discrimination became even less likely. GINA did not cover manifest disease, which meant that a patient who had already been diagnosed with cancer, for instance, would not have been protected by GINA. But the ACA [filled that gap](#), by preventing insurers from increasing premiums or denying coverage based on pre-existing conditions.

“What was nice about ACA is that it kind of covered the spectrum from genetic risk to manifest disease,” Green said. “GINA, for all its importance, did not.”

The ACA and GINA together should have protected Sanatani’s patients from discrimination since 2010.

“This paper did not document genetic discrimination so much as they documented the very routine practice of underwriting based upon pre-existing medical conditions,” Green said. “Most of the respondents had a diagnosis of SADS, meaning they had syncope, fainting, or at least clear-cut EKG abnormalities. That is what insurance does when they underwrite.”

“At this moment in time,” he added, “I don’t think any insurance companies are actively discriminating or underwriting on the basis of genetic testing.”

Sanatani offered two possible explanations for the apparent anomaly his team reported. First, the survey was preliminary—based on interviews and self-reporting—and therefore could not definitively identify genetic discrimination. He also noted that the alleged discriminatory incidents may have preceded GINA and/or the ACA.

But he believes it’s possible that patients with rare conditions, such as SADS, are slipping through the cracks—being denied insurance or offered only elevated premiums due to the results of their genetic data, but not reporting the discrimination. People with “these uncommon conditions really need a champion,” he said. “There’s a certain complacency and trust. We often just sort of assume things are working fine because we haven’t heard any noise.”

Whether Sanatani’s patients indeed faced genetic discrimination aside, the notion that GINA may not protect some people—especially with the Trump administration bearing down on the ACA, which is colloquially known as “Obamacare”—has spurred some to push for stronger protections.

“I think people overestimate the protection power of GINA,” [Arthur Caplan](#), a bioethicist at New York University, told *The Scientist*. And the legislation lacks teeth without the added protection of the ACA, he noted. “Certainly, under GINA, it’s hard to discriminate,” said Caplan. “But, that said, it will be harder to protect you given the imminent demise of Obamacare.”

Caplan said he suspects some US citizens may face health insurance discrimination despite GINA and the ACA. “Not in huge numbers,” he said. “I think you’ll find it’s hard to track this . . . I’m not sure that



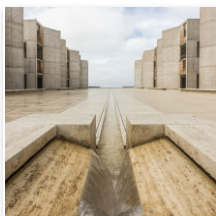
said. Nonetheless, “a lot of people don’t understand GINA, and when you do explain it to them they’re not reassured.”

Sanatani said that most forms of discrimination based on genetic data, whether in health insurance or otherwise, is not only unethical—it’s unscientific. In the case of SADS, for instance, studies have not demonstrated that genetic results are causally linked to adverse outcomes. “Genetic testing is being applied quite broadly without us necessarily understanding the implications clinically,” he told *The Scientist*. Even so, “genetics is an incredibly powerful tool and we don’t want to deprive ourselves of it,” he said. “We don’t need to do less genetic testing. We need to do a lot more learning.”

### Keywords:

discrimination, genetics, insurance

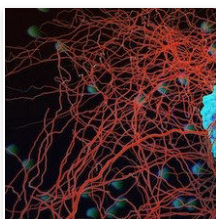
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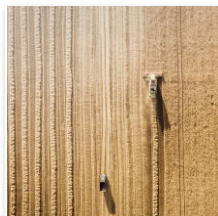
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