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It's Legal For Some Insurers To Discriminate Based On Genes

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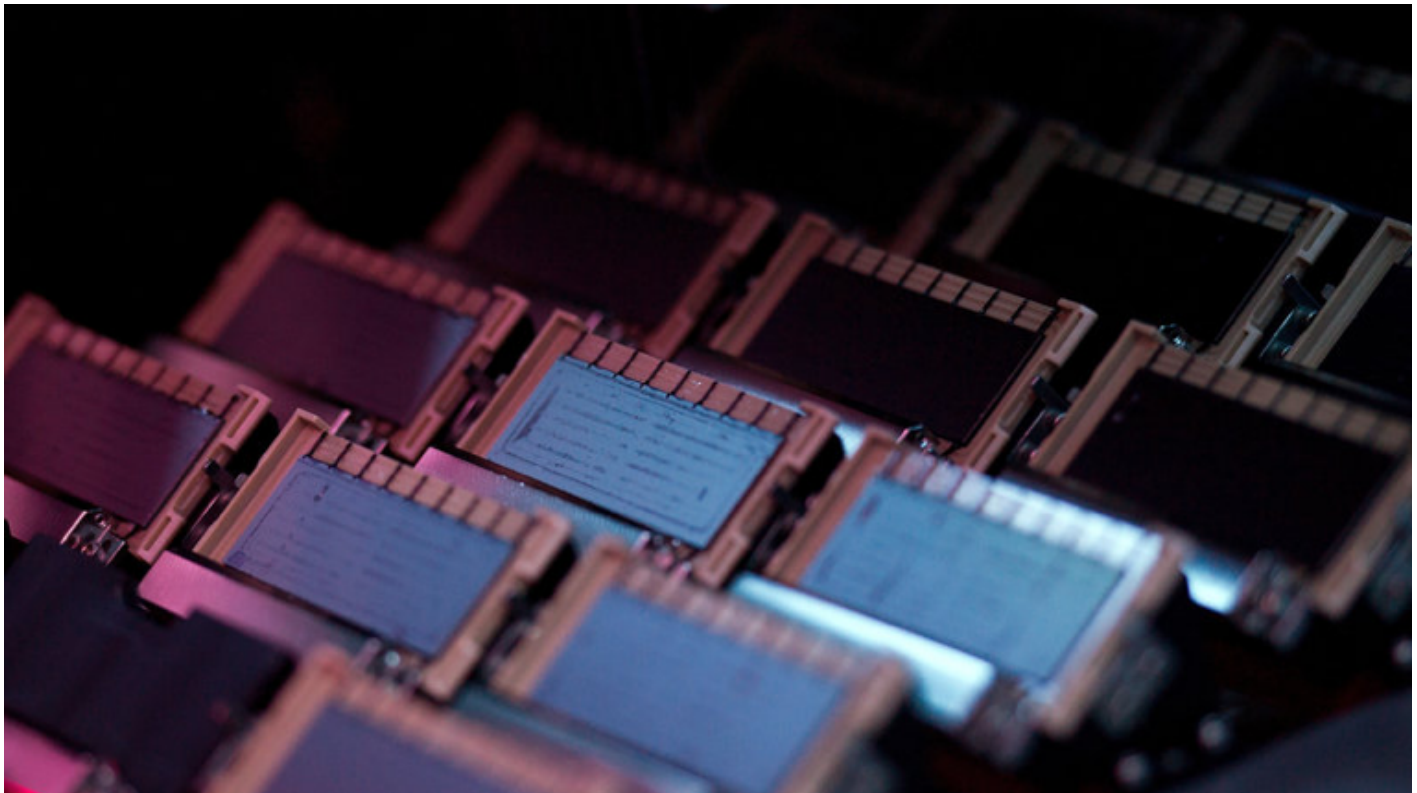
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Transcript

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Heard on All Things Considered

DAVID SCHULTZ



Slides containing DNA sit in a bay waiting to be analyzed by a genome sequencing machine.

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Getting the results of a genetic test can be a bit like opening Pandora's box. You might learn something useful or interesting, or you might learn that you're likely to develop an incurable disease later on in life.

There's a federal law that's supposed to protect people from having their own genes used against them, the Genetic Information Nondiscrimination Act, or GINA. Under GINA, it's illegal for an employer to fire someone based on his genes, and it's illegal for health insurers to raise rates or to deny coverage because of someone's genetic code.

But the law has a loophole: It only applies to health insurance. It doesn't say anything about companies that sell life insurance, disability insurance or long-term-care insurance.

"GINA was a fabulous accomplishment," says Robert Green, a researcher in the genetics department at Harvard Medical School. "It was long in coming and much needed. But I think that it was not perfect."

Green oversaw a study that examined how people react after they learn they have ApoE4, a gene associated with Alzheimer's. He found that people who discover they have the gene are five times more likely than the average person to go out and buy long-term-care insurance.

"It would be a natural thing that people might consider if they find out that they are at an increased risk for Alzheimer's disease. This is a logical outcome to getting genetic-risk information," Green says.

But when people go make that "logical" decision, there's nothing stopping the insurance companies from demanding to see the results of their genetic test. In fact, a long-term-care company could legally require someone to take a genetic test before selling him a policy.

Green says it's especially ironic that GINA does not apply to long-term-care insurance policies, since they cover the costs of nursing homes, assisted living facilities, home health aides and other things that people with Alzheimer's disease often need to use.

Rep. Louise Slaughter, a Democrat from western New York, introduced GINA in the House back in 2007. She says she fought hard for the law because she didn't think it was fair that a few wayward strands of DNA could make you essentially uninsurable.

"There were countless people in this country who were not eligible for insurance at all, simply by the way they were born," Slaughter says.

But she knows the law still has gaps that need to be closed. "And we plan to do that," she says.

If that happens, the insurance industry will have a thing or two to say about it.

Insurance works best when lots of people purchase policies but only a few actually need to use them. Selling these kinds of policies suddenly becomes unsustainable if genetic testing becomes widespread, and most — or even all — of the people who buy long-term-care policies do so knowing they're probably going to develop Alzheimer's sometime down the road.

When Green talked about his study to a room full of insurance executives a few years ago, he found out just how frightened the industry is of this scenario.

"These very mild-mannered people in the audience got very, very heated," he says.

"They were standing up and saying, 'This kind of situation is going to put us out of business.' "

A spokesman with the company Genworth, the largest seller of long-term-care policies in the U.S., said in an email to NPR that it doesn't want to lose its ability to "utilize all information." Genworth isn't restricted by the law now, and it doesn't want that to

change.