

## Life insurance companies deny coverage to those with cancer genes like BRCA

Many women who've been diagnosed with breast cancer get tested for cancer genes like BRCA 1 and 2. Even after those tests, women can still get healthcare because of Federal legislation barring health insurers from discriminating on a genetic basis. However, the same can not be said of life insurance and men and women who have taken genetic tests for a variety of reasons are being denied coverage.

Fast Company tells the story of a healthy young woman who now [can't get life insurance](#) because of a BRCA test:

Jennifer Marie [not her real name] should be an ideal candidate for life insurance: She's 36, gainfully employed, and has no current medical issues. But on September 15 last year, Jennifer Marie's application for life insurance was denied.

"Unfortunately after carefully reviewing your application, we regret that we are unable to provide you with coverage because of your positive BRCA 1 gene," the letter reads. In the U.S., about one in 400 women have a BRCA 1 or 2 gene, which is associated with increased risk of breast and ovarian cancer.

The [Genetic Information Nondiscrimination Act](#) (GINA) protects citizens from genetic discrimination. In 2008 when it passed, the law was already woefully behind the times and under powered. GINA's protections are limited to just two instances: employment and health insurance. Jennifer Marie's story illustrates the emerging dilemma of people who want to know about their genetic risk for disease, but who also want to purchase life insurance to financially assist their families after death. And it shows how unprepared we are for all the potential commercial and administrative uses of our genetic information.

Life insurance companies don't require people to get genetic tests when they're applying for coverage. But companies have started to ask if potential clients have used genetic testing and what those results were. Failing to disclose those tests can result in a rejected application. But as Jennifer found out, the results of the tests can also be cause for rejection. Insurance companies have always asked about family health histories to help evaluate who to cover.

Studies do show people are more likely to apply for long term care and life insurance after genetic testing reveals that they carry disease risk genes. Boston-based geneticist Robert Green found that people who found out they have the Alzheimers-related APOE gene variant are five times more likely to purchase long-term care insurance. That could sway the pool of potential insurance purchasers to be a sicker lot, and undermine how insurers balance their pools with more healthy participants who rarely make a claim in order to stay profitable. Green writes in the [New England Journal of Medicine](#):

Thus far, we have collectively decided that it is inequitable to discriminate against employees or in the pricing of health insurance but more acceptable to discriminate for products such as life, disability, and long-term care insurance. In defending the right to such discriminatory

underwriting, insurers have claimed that if applicants have relevant information that isn't available to insurers, such as robust genetic risk information, low-risk consumers will drop out of the mix and higher-risk consumers will disproportionately purchase coverage, forcing companies to raise prices and causing a "death spiral" of adverse selection.

Right now both patient advocates and researchers want to see GINA expanded to include the long-term care and life insurance industries. Patients groups like [Genetic Alliance](#) want discrimination by insurers based on genetic tests results to be illegal. Research groups worry that people are forgoing testing and subsequent research opportunities because of fear of discrimination. Nearly 25 percent of people who declined to be in a research study that would link their health records to their genetic data said no specifically for this reason. And some even worried that their positive genetic results might trail their children and keep them from qualifying for insurance. Christina Farr writes at [Fast Company](#):

Dave\*, a father from Washington, D.C., who agreed to speak on the condition of anonymity, recently learned that his sister has the BRCA gene. His doctor suggested that he get a genetic test, as men with harmful BRCA mutations have an increased risk of prostate cancer. Dave, who says he's heard copious "horror stories" of people being denied life insurance, ultimately decided against the test.

"On the one hand, I know that there is something I could do that could help prolong my life," he says. "But I'm terrified that my insurance company will find out if I get a positive result." If a life insurance company uncovered that a patient withheld valuable information, they might make a case for "guilt by omission."

The gaps in GINA aren't limited to insurance woes. Housing, education and employment are also vulnerable. California middle schooler Colman Chadam was asked to leave his classroom because he had a genetic mutation that causes the respiratory disease cystic fibrosis. Even though he had never developed the disease, school administrators moved him because there were two other children with CF in his school. Kids with CF are generally separated because they are so highly susceptible to infections. Chadam's parents sued the school for genetic discrimination, something [Sarah Zhang at WIRED](#) thinks we'll be hearing a lot more about:

Get used to those two words together, because they're likely to become a lot more common. With DNA tests now cheap and readily available, the number of people getting tests has gone way up—along with the potential for discrimination based on the results. When Colman's school tried to transfer him based on his genetic status, the lawsuit alleges, the district violated the Americans With Disabilities Act and Colman's First Amendment right to privacy. "This is the test case," says the Chadam's lawyer, Stephen Jaffe.

Some states, including California, have tried to bump up GINA protections by passing state legislation. California's law expands to include housing, mortgage lending and business owners denying services to people based on genetics. Vermont and Massachusetts have similar laws but none include life or long term care insurance.

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