




# Long-awaited progress in addressing genetic discrimination in the United States

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The US federal Genetic Information Nondiscrimination Act (GINA) protects individuals against much health insurance and employment genetic discrimination, but by design does not protect in other realms. Individuals with certain genetic test results, such as women who test positive for pathogenic variants in hereditary breast and ovarian cancer genes like *BRCA1* and *BRCA2*, may struggle to get life insurance. More generally, life, disability, and long-term care insurers have broad discretion over how to use genetic information from applicants.<sup>1</sup> But, as of 1 July 2020, this is no longer the case in Florida—representing a significant shift in existing antidiscrimination protections.

GINA passed in 2008 and set a federal floor for antidiscrimination protections, but states are free to develop broader protections, and there has been a steady stream of attempts to do so. Since GINA's passage, there have been 187 legislative efforts across 43 states to address some aspect of genetic discrimination, 58 of which were enacted and 15 of which are pending (bills discussed in this commentary are available in the National Human Genome Research Institute's Genome Statute and Legislation Database,<sup>2</sup> numbers are from 21 July 2020 and exclude duplicates). These efforts, which cover discrimination in employment, health insurance, and other lines of insurance, show no signs of abating. Continued growth in the genetic testing industry means that persistent state legislative efforts in combating genetic discrimination could impact ever more individuals.

From the perspective of the genetics and medical communities, the lack of broad genetic antidiscrimination protections may hinder scientific research and have negative impacts on patient care.<sup>3</sup> For example, individuals enrolling in research are told during informed consent that although GINA protects against most health insurance and employment discrimination, no such protection exists for life, long-term care, and disability insurance. This can cause individuals to decline participation in research.<sup>4</sup> Broad participation in genomics research, as in the federal All Of Us Research

Program, relies on participants trusting that genomic information will not be used against them in the future. While nonhealth insurers are not widely considering genetic information, it is clear that they are interested in maintaining the ability to do so because they are worried about better risk prediction through genetics.

The United States is one of the only developed countries without robust genetic antidiscrimination protections for nonhealth insurance. While some states do have laws that regulate the use of genetic information beyond health insurance, most offer relatively weak protections and do not bar insurer use of genetic test results across the board. No state prior to Florida barred life insurers from using genetic information, making Florida the first state to prohibit the use of genetic information in life, long-term care, and disability insurance (the bill covers disability insurance as a form of health insurance under existing protections after it removed a previous exception). Strategies employed by other countries include moratoria, outright bans, and other policy mechanisms such as a monetary cap.<sup>5,6</sup> In the United States, since the passage of GINA, there have been 22 legislative efforts across 12 states to bolster protections in nonhealth insurance, with four currently pending in Delaware, Connecticut, Alabama, and Vermont. Of the total introduced since GINA, only three, in Maryland, Maine, and Illinois, have been enacted, and these bills were reframed such that they do not offer much by way of protection. For example, in 2019, bills in both Illinois and Maine were changed to mandate only that direct-to-consumer companies require an individual's consent before sharing results with insurers. This reframing reflects the explicit strategy of the American Council of Life Insurers, a lobby group for the nearly \$1 trillion US life insurance industry.<sup>7</sup> Despite this, concerns about genetic discrimination in nonhealth insurance resonate across the partisan divide: of all the states that have introduced bills to target this discrimination, four legislatures were controlled by

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Democrats, three by Republicans, and five were split (as measured after the 2016 election).

Insurers see restrictions on use of genetic test results as challenging the basis of their business model: the ability to offer products at prices that reflect risk. Their concern is that restrictions on this ability will lead to people who are at higher risk buying more insurance, necessitating higher consumer prices or potentially an unsustainable business model. Projections of the actual financial impact on insurers, and subsequently policyholder premiums, if they were to be blocked from using genetic information, are divergent.<sup>8,9</sup> In the case of the Florida law, the life insurance lobby was not able to make the case that the effects would be large, as legislative summaries of the bill simply noted that the fiscal impact to the industry was currently “unknown.”

As the persistent legislative efforts indicate, the stakes are also high for individuals: the ability to find out medically important information about their genetic predispositions, and to not have this information used against them. There is precedent for legislators restricting insurance companies from using certain risk factors in their underwriting decisions. For example, in many states life insurers are not allowed to use race or whether someone has been a victim of intimate partner violence, even if these attributes are predictive of mortality.

Florida legislators have been persistent in attempts to enact broader protections: the 2020 legislative session was the fourth attempt at legislation calling for a ban on genetic discrimination in at least life insurance and long-term care insurance. In 2020, the bill as introduced was passed 117 to 1 in the House (HB 1189). In a familiar move, the Senate Banking and Insurance Committee substituted the language of the bill with a version that would have offered minimal protections. But, in a twist to the tale, the Senate Judiciary Committee made a further substitution, this time back to the original bill. They included an amendment to allow use of a genetic test result for insurance underwriting if it was used to make a medical diagnosis. The amended bill passed in the Senate 35 to 3. The bill took effect on 1 July 2020 and will apply to policies issued or renewed in Florida from 1 January 2021.

While the Florida bill marks a significant advance in genetic antidiscrimination protections, several lingering questions remain regarding the legislation and its potential impact. First, there is ambiguity concerning the exception carved out for medical diagnoses made on the basis of genetic information. The intention of the legislators was clearly to protect predispositional genetic information, while allowing use of current medical conditions, much like in GINA. Yet the examples of both Lynch syndrome and hereditary breast and ovarian cancer syndrome, in which the syndrome may be diagnosed by family history and supported by genetic test results, and which increase the risk that an individual later receives a cancer diagnosis, show the overlap between the categories of predispositional testing and diagnostic testing.

Second, a potential consequence of the bill is that individuals may not be able to use beneficial genetic information to their advantage. For example, a woman with a strong family history of breast cancer could share the negative results of a *BRCA1/2* test in the hope that a life insurer would not charge her more for her family history. Data from Australia indicate life insurers do sometimes use genetic information in this manner.<sup>10</sup> This option could be foreclosed under the new Florida bill. In the bill that Illinois legislators originally considered in 2019, this possibility was explicitly considered and exempted from the prohibition on use of genetic test results. The use of beneficial genetic information is hence a point of policy debate that other legislators should be aware of.

Third, the Florida law does not apply just to residents of Florida, but to anyone physically located in the state buying insurance from an agent properly licensed and appointed in Florida. The passage of this law, offering the first strong protections against genetic discrimination in life and long-term care insurance in the country, thus opens up the possibility of “insurance tourism.” For an individual with a pathogenic genetic test result wanting to purchase a large life insurance policy, a trip to Florida might be a financially sound decision, and one that could increase the financial impact on the insurance industry in Florida.

While states vary in the strength of legislation and the scope of possible protections, the sheer number of attempts to strengthen anti-genetic discrimination protections testifies to the persistent, bipartisan relevance of this issue. Many stakeholders care about genetic privacy and increased protection of genetic information, from the public, to the medical, genetic, and research community, to advocacy groups.<sup>5</sup> The success of Florida’s legislature, in the face of strong resistance from the life insurance industry, could mark the beginning of a new chapter for these types of efforts and could serve as a model for future state or federal efforts. For those who support enhanced protections against genetic discrimination, the time is ripe for further progress.

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