

Banning Genetic Discrimination in Life Insurance — Time to Follow Florida’s Lead

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On July 1, 2020, Florida became the first state to prohibit life insurance companies from using genetic information, defined as the results of predictive genetic tests, in underwriting unless the information is accompanied by a diagnosis of a medi-

cal condition. This policy is important because the federal Genetic Information Nondiscrimination Act (GINA) applies only to employment and health insurance. Life insurance is regulated by states, and no other state has enacted such bold legislation, in

part because of highly effective lobbying by insurance companies. The new law represents a long-awaited opportunity and highlights the important role of physicians in shaping policies that promote health.

Several other states have con-

sidered legislation prohibiting genetic discrimination in underwriting for life insurance policies, and some have enacted protections that are less robust than those in Florida. For example, Arizona prohibits genetic discrimination in life insurance unless there is actuarial justification for use of the genetic information; California prohibits genetic discrimination against unaffected carriers of genes for recessive disorders in any insurance policy; and Vermont prohibits life insurance companies from requiring genetic testing as a condition of applying for insurance, but insurers may use the results of clinical genetic tests in underwriting decisions.

There have been very few documented examples of underwriting on the basis of results of predictive genetic tests. But because there has been little legal protection against such underwriting, consent forms for medical care and research routinely warn about the possibility of discrimination by life insurance companies. After receiving such warnings, many people who may be at risk for various genetic conditions are reluctant to undergo clinically indicated genetic testing or to participate in genetic research. In one study, 25% of people who declined to participate in genomic-sequencing research cited fear of discrimination by life insurance companies as their primary reason.¹ In addition, people who obtain clinically actionable results from a direct-to-consumer or other consumer-facing genetic-testing laboratory may be reluctant to inform their physician because they are worried that results from follow-up testing or genetic-risk information placed in their medical records will be accessi-

ble by life insurance companies. The new law in Florida will allow residents there to undergo genetic testing without fear of the financial consequences of predictive test results.

Life insurance companies have long been concerned that potential customers who receive genetic information through clinical or consumer-facing genetic-testing platforms will engage in adverse selection — the tendency of people with undisclosed information about their own health to expand their insurance coverage beyond the amount they would otherwise obtain. Life insurers have insisted on preserving their right to decide to require applicants to submit genetic test results or to obtain access to genetic information in applicants' health records, and they have argued that limiting this right would have dire financial consequences for their business. But many other countries, including Australia, Canada, France, Germany, South Korea, and the United Kingdom, already restrict the use of predictive genetic test results by life insurers.² We are unaware of any evidence that prohibitive laws or industry-wide moratoriums have threatened the viability of life insurance companies or resulted in reduced availability of life insurance to consumers in these countries.

The effect on underwriting has been minimal probably because genetic test results are valuable in the life insurance context only in relation to a small number of genetic conditions and under limited circumstances, such as in cases of lethal, adult-onset disorders with high penetrance and no documented family history. Traditional underwriting criteria, such as age, current health sta-

tus, personal and family medical history, lifestyle, environmental exposures, and amount of coverage sought relative to income, are sufficient for underwriting for the vast majority of policies.

The limited utility of commonly used genetic tests for underwriting contrasts with the substantial health benefits that may accrue if people at risk for genetic disorders aren't deterred from undergoing genetic testing. For many conditions, including some types of cancer and heart disease, early detection using genetic testing, followed by surveillance and intervention, can substantially improve health outcomes.³ What's more, gene therapy and other emerging treatment methods will soon have the potential to substantially extend the lives of people with genetic disorders. Delaying a molecular diagnosis because of a patient's concerns about genetic discrimination is therefore likely to lead to poorer health outcomes.

Fear of discrimination by life insurance companies has been an important obstacle to progress in the use of genetic technologies in medicine and medical research. Florida's legislative breakthrough creates important opportunities for physicians to advocate for similar bills in their own states, including by working with professional organizations and patient groups.

We further believe that physicians who serve as medical directors of life insurance companies have an ethical duty to advocate for antidiscrimination policies. Even though such physicians may not be engaged in direct patient care, they retain their professional responsibility to follow the principles of medical ethics. Chapter

10 of the American Medical Association's Code of Ethics, which addresses the ethical obligations of physicians in nonclinical roles, states that "when physicians use the knowledge and values they gained through medical training and practice in roles that affect the care and well-being of individual patients or groups of patients, they are functioning within the sphere of their profession."⁴ When it comes to consumer-facing policies that can influence health, therefore, physicians working for life insurance companies are obligated to uphold the ethical values of the medical profession.

The ethical obligation to avert harms to life insurance applicants does not mean that physicians

need to endorse fundamental changes in the way life insurance is underwritten. Life insurance companies could still use an applicant's current health information and family health history, both of which might contain genetic information. Rather, the ethical and policy imperative is for physicians to oppose practices, including underwriting by life insurance companies, that discourage people from undergoing potentially beneficial genetic testing.⁵

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