

S.247 - PROHIBITING GENETIC DISCRIMINATION IN VERMONT

Proposal. An act relating to prohibiting discrimination based on genetic information. This bill proposes to prohibit discrimination based on an individual's genetic information in relation to all insurance coverage, including life insurance, and the provision of social and medical services.

What is genetic discrimination?

Genetic discrimination occurs when people are treated differently because they have a gene mutation that causes or increases the risk of an inherited disorder. Fear of discrimination is a common concern among people considering genetic testing.

What is genetic testing?

Genetic testing is a type of medical test that identifies changes in chromosomes, genes, or proteins. The results of a genetic test can confirm or rule out a suspected genetic condition or help determine a person's chance of developing or passing on a genetic disorder. Genetic testing is voluntary. Because testing has benefits as well as limitations and risks, the decision about whether to be tested is a personal and complex one.

Genetic information offers therapeutic opportunities in clinical health care.

Using knowledge of a person's health risks and diagnosis to guide their healthcare is not new. The use of genetic information for targeted interventions and therapies, like cancer drugs specifically formulated to attack disease based on genetic information of the patient and their condition, is new and research in this area is producing exciting results. The applications for the use of genetic information to inform primary care and to expand opportunities in disease treatment are also new and growing rapidly.

Commercialization of genetic information increases opportunities for discrimination.

Testing for health and heritage information is a prolific and growing commercial industry. The information collected is continually analyzed as new technologies emerge or additional genetic information is added to the "system."

What kind of genetic discrimination is currently prohibited?

Several laws at the federal and state levels help protect people against genetic discrimination. In particular, a federal law called the Genetic Information Nondiscrimination Act (GINA) is designed to protect people from this form of discrimination. GINA prohibits genetic discrimination in health insurance and makes it illegal for health insurance providers to use or require genetic information to make decisions about a person's insurance eligibility or coverage. GINA also prohibits discrimination in employment and makes it illegal for employers to use a person's genetic information when making decisions about hiring, promotion, and several other terms of employment.

Vermont currently has laws in place that generally protect against genetic discrimination in health insurance with limited protections in other lines of insurance. **8 VSA §4724 (7)(D), 8 VSA §4724(22)**. Vermont also has laws in place that generally protect individuals from being forced to undergo genetic testing and laws that prevent employers or labor organizations from using genetic information for discriminatory purposes. **18 VSA §9331 et seq.**

Are there gaps in the law?

GINA and other laws do not protect people from genetic discrimination in all circumstances. For example, neither GINA nor Vermont law protect against genetic discrimination in forms of insurance other than health insurance, such as life insurance.

How many states currently prohibit life insurance companies from using genetic information in underwriting? A handful of states - Arizona, California and Montana - offer limited protections against the use of genetic information in underwriting. Florida law offers the strongest protections. Florida law prohibits 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 medical condition.

Why is it important to prohibit life insurance companies from using genetic information in underwriting?

- 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. In addition, gene therapy and other emerging treatment methods may have the potential to extend the lives of people with genetic disorders.
- Fear of discrimination by life insurance companies has been an important obstacle to progress in the use of genetic technology in medicine. In one study, 28% of people who decline to participate in genetic testing cited fear of discrimination in insurance as their primary concern.¹ A majority of respondents in a study about breast cancer genetic tests expressed reluctance to participate in research if the results could be disclosed to insurers.²
- Delaying a diagnosis because a patient is concerned about discrimination can lead to poorer health outcomes.

If life insurance companies cannot use genetic information in underwriting, what information can they use? Life insurance companies traditionally use a wide variety of underwriting criteria to write policies and determine rates, including, age, current health status, personal and family medical history, lifestyle, environmental exposures, other demographic information.

Will prohibiting discrimination have an adverse impact on life insurance companies? Life insurance companies have expressed concern that potential customers who receive genetic information through clinical or direct-to-consumer genetic testing will engage in “adverse selection.” This means the potential for people with undisclosed information about their own health to expand their life insurance coverage beyond the amount they would otherwise obtain, thereby creating more or unfair risk to the insurance company. Life insurance companies have warned that this could have dire financial consequences. However, a number of other countries, including, Australia, Canada, France, Germany, South Korea and the United Kingdom, already restrict the use of predictive genetic tests by life insurers³ and we are not aware of any evidence that these restrictive laws have reduced availability of life insurance or threatened the financial viability of life insurance companies.

¹ Robinson, J. O. et al. Participants and study decliners’ perspectives about the risks of participating in a clinical trial of whole genome sequencing. *J. Empir. Res. Hum. Res. Ethics* 11, 21–30 (2016).

² Dalpé, G. et al. Breast cancer risk estimation and personal insurance: a qualitative study presenting perspectives from Canadian patients and decision makers. *Front. Genet.* 8, 128 (2017).

³ Otlowski, M., Taylor, S. & Bombard, Y. Genetic discrimination: international perspectives. *Annu. Rev. Genom. Hum. Genet.* 13, 433–454 (2012).