

ACS CAN SUPPORTS

S1208/A7451 and S5415-A/A2083-A: Preventing Genetic Information Discrimination

ACS CAN urges passage of S1208/A7451 and S5415-A/A2083-A to prevent genetic information discrimination. **S1208/A7451** will prevent genetic testing results from being shared by anyone other than patients and health care providers and that health insurance companies may only receive information on the fact that a genetic test was done but not the findings of the test. **S5415-A/A2083-A** prohibits medical, life, accident, health, disability, or long-term health insurance plans from conditioning insurance rates, renewals, or any other coverage on the agreement of an individual to undergo genetic testing.

Certain variations or mutations in the genetic code can either cause disease or make the development of a disease highly likely. For example, mutations in the BRCA1 and BRCA2 genes are associated with a predisposition towards developing breast, cervical, and prostate cancers.

Advances in genetic testing capabilities have allowed people to identify these variations in their own genetic code. While this information can help individuals mitigate the onset of disease or better plan for the management of a condition (e.g. starting mammograms at an earlier age or elective mastectomy), this same information could be used by insurers to discriminate against such individuals through denial of coverage or charging higher premiums.

In 2008, the Genetic Information Nondiscrimination Act (GINA), a bill supported by ACS CAN, was passed, barring discrimination in health insurance and employment based on genetic information.¹

However, discrimination in long-term care, disability or life insurance based on genetic information is still legal. There have been documented cases of such discrimination against individuals who possess a certain genetic variation, such as the BRCA1 mutation, or who have a family history of a genetic disease, such as Huntington's disease, even though the individuals in question are perfectly healthy.^{2 3}

Concerningly, there is evidence that the fear of genetic discrimination in life, long-term, and disability insurance is leading individuals to forgo needed cancer screenings or decline participation in clinical trials involving genetic sequencing.^{4 5 6}

A recent survey of patients about perceptions of genetic discrimination showed that over two-thirds of respondents reported being either somewhat or very worried about life insurance companies using their genetic information to set rates.⁷

These concerns may decrease the willingness of patients to undergo recommended and potentially lifesaving screenings. A different survey of individuals who had undergone or were considering undergoing genetic testing for hereditary breast and ovarian cancer markers found that "52.2, 33.6, and 34.2 percent were worried about life insurance discrimination, disability insurance, and access to long term care, respectively."⁸

Fear of discrimination may also impact the willingness of individuals to enroll in clinical trials that involve genetic sequencing. A 2016 paper describes how, in an ongoing study involving whole genome sequencing, 28 percent of those who declined to participate in the study said that a fear of insurance discrimination was their primary reason for not participating.⁹

Similarly, a 2019 analysis of parental interest in newborn genetic sequencing found that, among those who declined to have their babies screened after attending an enrollment session, 41% cited concerns about privacy and insurability.¹⁰

These findings indicate that the fear of genetic discrimination in life, long-term, and disability insurance poses a barrier to care for many who could benefit from genetic sequencing.

At least seven states have issued regulations curtailing the use of genetic information by life, long-term, and/or disability insurers. However, most Americans remain vulnerable to genetic discrimination and the barriers it may pose to needed cancer screenings and clinical trial participation.

ACS CAN Supports S1208/A7451 and S5415-A/A2083-A

ACS CAN is concerned that individuals are forgoing recommended genetic screenings due to the fear of discrimination in medical, life, accident, health, disability, or long-term health insurance plans. ACS CAN urges passage of S1208/A7451 and S5415-A/A2083-A to prevent discrimination in insurance based on genetic information.

¹ Genetic Information Nondiscrimination Act (GINA). National Human Genome Research Institute. Accessed March 18, 2021. <https://www.genome.gov/genetics-glossary/Genetic-Information-Nondiscrimination-Act>

² Farr C. If You Want Life Insurance, Think Twice Before Getting a Genetic Test. Fast Company. Published February 17, 2016. Accessed March 18, 2021. https://www.fastcompany.com/3055710/if-you-want-life-insurance-think-twice-before-getting-genetic-testing?utm_source=mailchimp&utm_medium=email&utm_campaign=fast-company-daily-newsletter&position=8&partner=newsletter&campaign_date=02172016

³ Erwin C, Williams JK, Juhl AR, et al. Perception, experience, and response to genetic discrimination in Huntington disease: The international RESPOND-HD study. *Am J Med Genet.* 2010;9999B:n/a-n/a. doi:10.1002/ajmg.b.31079

⁴ Parkman AA, Foland J, Anderson B, et al. Public Awareness of Genetic Nondiscrimination Laws in Four States and Perceived Importance of Life Insurance Protections. *J Genet Counsel.* 2015;24(3):512-521. doi:10.1007/s10897-014-9771-y

⁵ Allain DC, Friedman S, Senter L. Consumer awareness and attitudes about insurance discrimination post enactment of the Genetic Information Nondiscrimination Act. *Familial Cancer.* 2012;11(4):637-644. doi:10.1007/s10689-012-9564-0

⁶ Robinson JO, Carroll TM, Feuerman LZ, et al. Participants and Study Decliners' Perspectives About the Risks of Participating in a Clinical Trial of Whole Genome Sequencing. *Journal of Empirical Research on Human Research Ethics.* 2016;11(1):21-30. doi:10.1177/1556264615624078

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¹⁰ Genetti CA, Schwartz TS, et al. Parental interest in genomic sequencing of newborns: enrollment experience from the BabySeq Project. *Genet Med.* 2019;21(3):622-630. doi:10.1038/s41436-018-0105-6