

To: House Committee on Commerce & Economic Development
From: Jessa Barnard, Executive Director, Vermont Medical Society
Date: April 18, 2022
RE: Support for S. 247, Prohibiting Genetic Discrimination

The Vermont Medical Society is the largest physician membership organization in the state, representing over 2400 physicians, physician assistants and medical students across specialties and geographic locations. The mission of the Vermont Medical Society is to optimize the health of all Vermonters and the health care environment in which Vermont physicians and physician assistants practice medicine.

VMS is reaching out today on behalf of our members to ask that your Committee support S. 247, prohibiting the use of a person's genetic information in insurance underwriting, specifically life, disability and long-term care insurance.

Allowing the practice of genetic discrimination in insurance scares people away from genetic testing for both research and clinical purposes. According to a 2020 New England Journal of Medicine (NEJM) article,¹ 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. In addition, people who obtain testing results from a 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 accessible by life insurance companies

Genetic testing is merely predictive and not diagnostic. The NEJM article goes on to clarify that the effect on life insurance underwriting in countries like Australia, Canada, France, Germany, South Korea and the UK that ban the use of predictive genetic test results by life insurers 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. Instead, traditional underwriting criteria, including current health information and family health history, are sufficient.

In 2021, the American Medical Association adopted a policy to “advocate for extending the consumer protections of the Genetic Information Non-Discrimination Act (GINA) of 2008 by adding long-term care, disability insurance, and life insurance to the Act.”² VMS supports this statement by the AMA and asks that you support S. 247, which would put these protections in place in Vermont law.

If I can provide any further information or answer questions please contact me at jbarnard@vtmd.org or 802-917-1460.

¹ <https://www.nejm.org/doi/full/10.1056/NEJMp2024123>

² See Consumer Genetic Testing and Privacy, policy D-315.970, available at: <https://policysearch.ama-assn.org/policyfinder/detail/Consumer%20Genetic%20Testing%20and%20Privacy%20D-315.970?uri=%2FAMADoc%2Fdirectives.xml-D-315.970.xml>