American Society of Human Genetics

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The Honorable Brenda Carter, Chair
Life Insurance & Financial Planning Committee
National Council of Insurance Legislators
C/O Will Melofchik, CEO
Via email: wmelofchik@ncoil.org

Dear Chair Carter and Distinguished Committee Members:

I am writing on behalf of the American Society of Human Genetics (ASHG), the world's largest organization for human genetics professionals. Our nearly 8,000 members—primarily based in the United States—include researchers, academics, physicians, technicians, genetic counselors, students, and others advancing the field of human genetics and genomics. ASHG's vision is that people everywhere benefit from the progress and promise of human genetics and genomics research.

ASHG has long championed the Genetic Information Nondiscrimination Act (GINA), working alongside lawmakers and patient advocates throughout the 13-year effort that culminated in the signing of the landmark protections into law in 2008. GINA's champions were visionary in foreseeing a future in which genome sequencing would be commonplace in research labs and clinics. ASHG welcomes efforts to expand the protections provided by GINA, including proposals to extend protections against genetic discrimination to additional types of insurance. As advances in genomics increasingly offer profound opportunities to improve both individual and public health, law and policy should focus on eliminating barriers that hinder the realization of this potential.

We appreciate your meaningful work in drafting NCOIL's Model Act Regarding Life Insurers' Use of Genetic Information and your consideration of consumer concerns regarding the use of genetic test results in life insurance underwriting decisions.

Individuals undergo genetic testing for a variety of reasons. Some are motivated by curiosity about their ancestry, while others pursue testing due to a family history of certain diseases or to better understand their own health risks. Millions of Americans also participate in genetic research studies—such as the NIH *All of Us* Research Program, the Healthy Oregon Project, the Healthy Nevada Project, and the Nebraska Medicine's Genetic Insights Project—contributing valuable data to advance medical knowledge and public health. Although many participate in this essential research, we know that others decline to participate due to concerns about genetic discrimination.

Importantly, genetic tests conducted as part of research are generally confidential, with results often provided directly to the participant. If an individual tests positive for a mutation thought to be associated with an increased risk of disease, they must decide whether to keep this information private or share it

with their healthcare provider, who can then document it in their medical record. Research can also uncover genetic mutations known to cause disease such as hypertrophic cardiomyopathy or breast cancer. Sharing this information and noting it in the patient's chart is essential for health insurance coverage of risk management, which may involve preventive measures such as medication, enhanced screening, or surgical intervention. It is crucial to encourage—not discourage—individuals to take proactive steps in managing their health. People should be empowered to benefit from genetic insights without fear of discrimination or penalty.

Furthermore, our understanding of genetics and its role in disease continues to evolve. Researchers often revise their understanding of how genetic mutations affect disease risk as new information emerges. For instance, historically, the *CDH1* genetic mutation was thought to confer up to an 80% risk of gastric cancer. A 2024 study, however, found the lifetime risk of gastric cancer in these mutation carriers is actually 10% or less, much lower than previous estimates.[1] Therefore, the earlier risk estimates were not supported by more accurate, updated research. Policies must ensure that individuals are not disadvantaged by outdated genetic information and can use their results confidently, without fear that evolving science will be used against them.

Another example is mutations in the *SOD1* gene, which account for about 2% of all cases of ALS. The risk of developing ALS is high for those who carry mutations in *SOD1*, but more importantly, different *SOD1* mutations have different effects on the disease. Some mutations are associated with a more rapid disease progression, while others are linked to slower progression. Many *SOD1* mutation carriers live to an advanced age without symptoms. For those with this mutation, there is hope. Qalsody is a new, innovative drug that slows disease progression and stabilizes muscle strength and respiratory function, especially when treatment is started early. Genetic testing is crucial in determining eligibility for this therapy as well as supporting informed clinical decisions, family planning, and eligibility for clinical trials.

Currently, life insurers are permitted to use genetic test results in underwriting decisions with little or no transparency, a practice that would not change under the committee's model law. This raises concerns about the accuracy and fairness of underwriting practices, especially as genetic research rapidly evolves. For example, 90% of Variants of Uncertain Significance (VUS) are ultimately reclassified as benign. As such, a VUS should never be used for any type of determination, as it is not an indication of disease risk or lack thereof. It is unclear whether and how this type of information is utilized by insurers, and this ambiguity contributes to distrust and fear of discrimination.

Most consumers pursue life insurance to ensure their families' financial security, not to manipulate the system. If there are concerns, one option to consider is policy size caps. Before completely banning the use of genetic information in life insurance underwriting, countries such as Australia and the United Kingdom experimented with excluding genetic test results from policies below certain thresholds (e.g., $500,000), which helped balance consumer protection with insurer risk management.

As you continue your efforts to craft model legislation, please consider the information provided above and review the following suggestions, which we hope will improve protection from genetic discrimination.

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[1] Germline CDH1 Variants and Lifetime Cancer Risk. *JAMA*. 2024 Sep 3;332(9):722-729. doi: 10.1001/jama.2024.10852. PMID: 38873722; PMCID: PMC11372503. https://pubmed.ncbi.nlm.nih.gov/38873722/

SECTION A

Current draft language

(A) A life insurance provider shall not cancel insurance coverage for an individual or a family member of an individual based solely on the individual's or family member's genetic information.

Suggested language

(A) A life insurance provider shall not *deny,* cancel, *limit, or establish differentials in premium rates* for an individual or a family member of an individual based ~~solely~~ *in whole or in part* on the individual's or family member's genetic test information.

SECTION B

Current draft language

(B) A life insurance provider shall not request or require an individual to whom the insurer provides life insurance coverage, or an individual who applies for life insurance coverage, to undergo genetic testing, including complete genomic sequencing, ~~take a genetic test~~ as a precondition of ~~insurability~~ coverage or pricing~~, and shall not require the complete genome sequencing of an individual's DNA~~.

Suggested language

(B) A life insurance provider shall not request, ~~or~~ require*, encourage or coerce* an individual to whom the insurer provides life insurance coverage, or an individual who applies for life insurance coverage, to undergo genetic testing, including complete genomic sequencing, as a precondition of *coverage, renewal, or pricing.*

SECTION C

Current draft language

(C) A life insurance provider shall not access, use, retain, or disclose sensitive medical information, including the genetic data of an individual, without first obtaining the individual's signed, written consent.

Suggested language

(C) A life insurance provider shall not access, ~~use,~~ retain, or disclose sensitive medical information, including the genetic data of an individual, without first obtaining the individual's *prior, express, written and informed consent. Such consent must be separate from any general authorization to release medical records. An insurer shall not deny, cancel, increase pricing, refuse to issue or renew a life insurance policy because an individual declines to provide such consent.*

SECTION D

Current draft language

(D) This section does not prevent a life insurance provider from requesting~~,~~ ~~or~~ obtaining, or using existing health information for underwriting, including genetic information contained within an individual's medical record.

Suggested language

(D) This section does not prevent a life insurance provider from requesting or obtaining existing health information for underwriting, including *family history of disease* or genetic information already contained within an individual's medical record*, provided that the insurer complies with all other applicable state and federal privacy laws and the individual has provided appropriate consent. Nothing in this section prohibits an insurer from considering a family history of disease or medical diagnosis included in an individual's medical record, even if a diagnosis was made based on the results of a genetic test, if prior express consent is obtained from the individual.*

In summary, we appreciate your efforts to address consumer concerns as you develop the Model Act Regarding Life Insurers' Use of Genetic Information. ASHG supports policies that ensure that an individual's genetic information cannot be used against them and has long supported the establishment of strong protections against genetic discrimination. Given our evolving understanding of the role genetics plays in disease risk and development, and the importance of incentivizing the U.S. population to contribute to science and take a more proactive approach to their health, consideration of genetic test results should be prohibited from use in life insurance coverage, renewal, and pricing decisions. The financial stability and solvency of the life insurance industry have historically been solid without access to genetic information. Personal and family health history of disease is sufficient and should remain the standard for policy underwriting.

Thank you for your consideration. Please reach out to Karina Miller, PhD, Associate Director of Advocacy and Public Affairs (Kmiller@ashg.org) at ASHG if you have any questions or would like further clarification.

Sincerely,

Susan A. Slaugenhaupt, PhD

ASHG President