February 18, 2026

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:

On behalf of the National Society of Genetic Counselors (NSGC), we appreciate the opportunity to comment on the National Council of Insurance Legislators' (NCOIL) proposed *Model Act Regarding Life Insurers' Use of Genetic Information*. NSGC commends the Committee for its thoughtful engagement on this complex and timely issue and for its efforts to provide states with guidance that addresses consumer concerns while preserving access to affordable life insurance.

Protecting patient privacy, safeguarding against genetic discrimination, and removing systemic barriers to genetic testing for healthcare or research purposes are priorities for NSGC and its members. We appreciate NCOIL's recognition of these concerns and respectfully offer the following comments to help strengthen the proposed model legislation in a manner that reflects current scientific understanding and promotes responsible use of genetic information.

About NSGC

Founded in 1979, NSGC is the professional society and leading voice for genetic counselors, representing over 5,000 members nationwide. Genetic counselors are healthcare professionals with specialized graduate training in medical genetics and counseling who help individuals and families understand genetic testing results in the context of personal and family history, evolving scientific evidence, and available medical interventions. Genetic counselors practice across a wide range of specialties, including oncology, cardiology, neurology, prenatal care, pediatrics, and via telehealth, and contribute to research, education, industry, and public health initiatives. NSGC's mission is to advance education, research, and public policy to ensure equitable access to high-quality genetic services.

General Comments on the Model Act

NSGC believes that public policy should encourage, rather than discourage, individuals to pursue genetic testing and participate in genetic research. Individuals undergo genetic testing for various reasons, including curiosity about their ancestry, assessment of inherited disease risk, to inform clinical decision-making, and participation in research that advances medical knowledge. Regardless of the motivation, genetic testing - whether clinical or research-based - offers individuals the opportunity to benefit their personal health and contribute to broader public health goals. Yet, while millions of Americans undergo genetic testing and contribute to genetic research initiatives, apprehension about genetic discrimination remains a common, persistent deterrent for many individuals.

Decisions about whether to pursue genetic testing—particularly in the healthcare context—are often complex and deeply personal and should not be further complicated by concerns about how

genetic information may be used outside of clinical care. No person should forego, or feel the need to forgo, medical care, genetic testing, or participation in clinical trials and/or research studies out of fear that genetic information may be used against them or their family members. Policies that allow individuals to benefit from genetic insights without fear of discrimination are therefore essential to supporting proactive health management and maintaining public trust.

While many states have enacted laws addressing the use of genetic information, protections remain inconsistent across jurisdictions, particularly with respect to life insurance. A well-crafted model law could provide greater clarity and consistency across states, helping to address consumer concerns and reduce the burden placed on healthcare providers, including genetic counselors, who are frequently asked to explain the non-clinical implications of genetic testing. However, NSGC is concerned that, as currently drafted, the proposed model legislation would continue to permit life insurers to use genetic test results in underwriting decisions with little transparency or meaningful limitation. This raises concerns about the accuracy and fairness of underwriting practices, particularly given the rapid pace of change in genetic science and clinical interpretation.

The Evolving Nature of Genetic Information

Our understanding of genetics and its role in disease is ever evolving. As of 2023, over 175,000 genetic tests are available on the market, with approximately 10 new tests introduced daily.[1, 2] Genetic variants historically believed to confer very high disease risk have, in some cases, been shown to carry substantially lower risk as additional data become available. In other cases, the development of new therapies and interventions has significantly altered clinical outcomes for individuals with known genetic mutations.

Because genetic test results require expert interpretation within a clinical context and scientific understanding continues to rapidly evolve, there is significant concern about whether life insurers can reasonably keep pace with the field without additional guardrails around the use of such complex information. Variants of uncertain significance (VUS), which represent a substantial proportion of genetic test findings, are not clinically predictive, and approximately 90% are ultimately reclassified as benign. Even experts in genetics must continually reassess how new variants, reclassifications, and emerging interventions affect disease risk. Further, a lack of transparency regarding how genetic information could or would be used by life insurers, and whether such use is scientifically appropriate, may exacerbate public apprehension and fears of discrimination.

Strengthening the Model to Protect Consumers

In light of the concerns described above, prohibiting the use of genetic information by life insurers for policies below certain monetary thresholds—an approach that has been adopted in other countries—is one policy option that warrants consideration.

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[1] *Concert Genetics. The Definitive Guide to Genetic Testing for Health Plans, Part II*, version 1.1, Concert Genetics, Sept. 2022, www.concert.co/wp-content/uploads/2022/09/Part-II_Concert-Genetics_Definitive-Guide-to-Genetic-Testing_v1.1_6Sept2022.pdf

[2] Phillips, Kathryn A., Patricia A. Deverka, Gillian W. Hooker, and Michael P. Douglas. "Genetic Test Availability and Spending: Where Are We Now? Where Are We Going?" *Health Affairs*, vol. 37, no. 5, May 2018, pp. 710–716. *Health Affairs*, doi:10.1377/hlthaff.2017.1427.

However, if the Committee determines that a full prohibition is not appropriate, NSGC recommends that the Committee consider several targeted adjustments. The model legislation should be strengthened to more clearly protect against genetic discrimination and to tighten guardrails around how genetic information may be used—prohibiting its use not only in decisions to cancel policies, but also to deny coverage, limit benefits, or establish differential premium rates. The legislation should also increase transparency regarding when genetic information is used by expressly prohibiting life insurers from requesting, encouraging, or coercing individuals to provide genetic information they do not wish to disclose. In addition, it should require prior, express, written, and informed consent—separate from general medical record authorizations—before genetic information is accessed or used, and should protect individuals from discrimination based on a refusal to provide such consent.

Finally, the model's current definition of genetic information may not adequately capture the breadth of modern genetic testing or anticipate emerging technologies and advances in our understanding of clinically actionable genetic information. A broader, more durable definition—such as one aligned with the Genetic Information Nondiscrimination Act (GINA)—would help ensure that statutory protections keep pace with scientific advances, reduce ambiguity in application, and provide clearer guidance to both consumers and insurers as new forms of genetic information continue to emerge.

NSGC believes these adjustments would help empower individuals to pursue genetic testing without fear that test results will later be used to their detriment, while supporting informed healthcare decision-making and broader public health objectives.

Suggested Revisions to the Model Act

As the Committee continues its work, NSGC respectfully recommends the following revisions, which would improve the model's effectiveness in protecting consumers from genetic discrimination while preserving fairness in life insurance underwriting.

SECTION 3A

Current draft language

(A) "Genetic information" means information derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder or syndrome, or are associated with a statistically increased risk of developing a disease, disorder or syndrome, that is asymptomatic at the time of testing. The testing does not include either routine physical examinations or chemical, blood or urine analysis unless conducted purposefully to obtain genetic information or questions regarding family history.

Suggested language

(A) "Genetic information" means information derived from *an analysis of human DNA, RNA, chromosomes, proteins, or metabolites that detects genotypes, mutations, or chromosomal changes* ~~derived from genetic testing to determine the presence or absence of variations or mutations, including carrier status, in an individual's genetic material or genes that are scientifically or medically believed to cause a disease, disorder or syndrome, or are associated~~

~~with a statistically increased risk of developing a disease, disorder or syndrome, that is asymptomatic at the time of testing. The testing does not include either routine physical examinations or chemical, blood or urine analysis unless conducted purposefully to obtain genetic information or questions regarding family history~~.

SECTION 4A
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 4B
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 4C
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 4D
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.*

Conclusion
NSGC appreciates the Committee's efforts to address consumer concerns related to life insurers' use of genetic information. Given the evolving nature of genetic science and the importance of encouraging individuals to pursue genetic testing and participate in research without fear of discrimination, NSGC believes the proposed model legislation should be strengthened as outlined above. These revisions would help ensure that genetic information is interpreted and used responsibly, promote consistency across states, and support informed decision-making by patients and healthcare providers.

We appreciate the opportunity to serve as a resource to NCOIL on this and related issues.

Sincerely,

Carrie Haverty, MS, CGC NSGC President
National Society of Genetic Counselors