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The Honorable Brenda Carter, Chair
Life Insurance & Financial Planning Committee
National Council of Insurance Legislators
c/o Will Melofchik, CEO

Dear Chair Carter and Committee Members:

Thank you so much for your careful consideration of the NCOIL Model Act Regarding Life Insurers' Use of Genetic Information. I have been working on and researching issues of genetic privacy and discrimination, particularly in the context of insurance, for over fifteen years and I applaud the committee for taking up this important issue. While use of genetic information by life insurers has been a concern since the advent of the Human Genome Project, we are currently in an era with great public attention to this issue, so the time is ripe for model legislation. A model law would be particularly helpful in this space since family members—who share genetic information in common—may have different protections depending on where they live in the country. This patchwork creates inconsistencies and challenges, and a model law could go a long way towards addressing these problems.¹

While a model law can be beneficial to provide more consistent regulation across the U.S., I believe that changes to the current language can better help to address the discrimination concerns of the public. I believe that the committee has made positive changes in the October draft by expanding section 4B to include coverage or pricing. Overall, I would encourage the committee to reconsider the language suggested by Alex Meixner, VP of State Policy and the ALS Association. As Mr. Meixner noted in his presentation in July, Section 4C calling for written consent to access medical information, including genetic information, does not provide meaningful protection in the context of life insurance. Life insurance companies will simply not consider applications from customers who do not give consent. For example, one medical release consent document includes language stating that "I further understand that if I refuse to sign this authorization, the Company may not be able to process my application..."² While notice and consent for sharing of medical information is always a helpful baseline, these provisions do not provide meaningful individual control without additional statutory language, such as that suggested by Mr. Meixner.

¹ Jarrod O. Anderson, Anna C.F. Lewis, & Anya E.R. Prince, The problems with patchwork: state approaches to regulating insurer use of genetic information, 22 DePaul J. Health Care L. 1 (2021); Genetic Privacy in the U.S.: Insurance and Law Enforcement Use, www.geneticprivacy.lib.uiowa.edu.

² <https://hinermangroup.com/wp-content/uploads/2009/05/hipaa-authorizationlog.pdf>

In addition, I believe that the definition of genetic information would benefit from broader language. The current model act defines genetic information as genetic testing to detect variants or mutations “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*” (emphases added). Thus, through the definition, genetic test results only count as genetic information under the act if they are linked to a disease or disorder. This language mirrors many state laws that similarly constrain genetic testing definitions.³ However, advancements in genetic testing call for a broader definition of genetic information to ensure sufficient protection. First, researchers are identifying genetic variants that are protective against disease. The model act definition only envisions genetic results that cause or increase risk of disease: It does not encompass variants that protect against or lower risk of disease. Additionally, new genetic tests, called polygenic scores, are being developed to identify genetic associations with social and behavioral traits, such as risk tolerance, smoking and drinking behaviors, and educational attainment.⁴ Scholars have noted how life insurers may be particularly interested in incorporating polygenic scores for medical traits into underwriting,⁵ and it is foreseeable that some polygenic scores for non-medical traits could be associated with life insurer risk.⁶ Given these and other advances in genetic testing, it is best to have a broad definition of genetic test. For example, the Genetic Information Nondiscrimination Act (GINA) defines genetic test to be “an analysis of human DNA, RNA, chromosomes, proteins, or metabolites, that detects genotypes, mutations, or chromosomal changes.”⁷ This language more appropriately encompasses the range of genetic test results relevant to the life insurance industry.

Beyond these suggestions, the crux of the model act lies in Section 4A. The current draft reads: “A life insurance provider shall not cancel insurance coverage for an individual or a family member of an individual based on solely on the individual’s or family member’s genetic information.” This provision prioritizes the long-standing position of the life insurance industry that insurers need to have the same information about risk as an applicant to properly assess premiums and balance risk pools. In this way, the provision as written codifies existing life insurance practices, thus not altering the status quo in how insurers utilize genetic information. I believe there are several important arguments for why stronger protections, such as those provided for in Florida, which bans life insurer use of genetic information, are warranted in this model law. For example, in his testimony, Mr. Meixner suggested the following language: “A life insurance provider shall not deny, cancel, limit, or establish differentials in premium rates for an individual or their family member based in whole or in part on the individual’s or their family member’s genetic information.”⁸

³ Kayte Spector-Bagdady, et al., Analysis of state laws on informed consent for clinical genetic testing in the era of genomic sequencing, 178 *Amer. J. Med. Genetics Part C* 81 (2018).

⁴ Courtney Canter, et al., Scanning the Horizon of Sociogenomics: An Assessment of the Development and Growth of Polygenic Scores for Social Traits, *American Journal of Bioethics Empirical* 1 (2025).

⁵ Richard Karlsson Linnér & Philipp D. Koellinger, Genetic Risk Scores in Life Insurance Underwriting, 81 *J. HEALTH ECON.* 1 (2022).

⁶ Shawneequa Callier & Anya E.R. Prince, The Legal Uncertainties of Sociogenomic Polygenic Scores, 38 *Harvard J L & Tech* 553 (2024).

⁷ 29 CFR § 1635.3(f).

⁸ Alex Meixner Testimony for NCOIL, July 2025.

1. There is little real-world evidence of adverse selection in the case of bans on use of genetic information

Adverse selection is an important concern of the insurance industry, however, when bans on the use of genetic information have been implemented, there is little evidence of resulting increased premiums. For example, in 2020, Florida became the first state in the U.S. to bar the use of genetic information in life insurance underwriting. Since then, there has been no indication of impact on premiums. The ACLI and others in the insurance field note that five years is too short of a period to observe potential impacts. However, there are other jurisdictions that have had longer-standing limits on use of genetic information and there has similarly been no evidence of market destabilization. Most notably, the United Kingdom has had a policy in place restricting life insurer use of genetic information for over twenty-five years—a much longer time span to observe market effects. Canada’s policy barring life insurers from considering genetic information has also been in place since 2017.

2. Assumptions regarding insurance-purchasing behavior following genetic testing are not always grounded in best evidence or people’s lived experiences

Absent real-world evidence of adverse selection, economists and insurers must rely on modeling to predict the outcome of a potential ban on insurer use of genetic information. Actuarial modeling of the impact of loss of genetic information for life insurers ranges from increases of a fraction of 1% to a 12% increase in premiums.⁹ This modeling rests largely on assumptions regarding the insurance purchasing behavior following a genetic test result.¹⁰ The study that predicted impacts of 12% premium increase assumed that 75% of people with a positive genetic test result would take out life insurance policies ten-times the average.¹¹ Existing evidence, life insurance practices, and practical realities do not support this high of an assumption.¹² “Overall, the variance in the literature suggests no widespread agreement on the impact of genetic tests on insurance purchasing behavior and, therefore, anti-selection and that any evidence that there is an impact is based on studies with small sample sizes and focused on diseases with high penetrance and few preventive measures.”¹³ This lack of strong evidence of strategic insurance purchasing following a genetic test supports the conclusion that a ban on insurer use of genetic information has a low risk of leading to wide-spread adverse selection.

⁹ Angus Macdonald and F. Yu, “The Impact of Genetics on Insurance: Conclusions from the ‘Bottom-up’ Modelling Programme,” *ASTIN Bulletin* 41 (2011): 343-376; Ron Howard, Report to Canadian Institute of Actuaries Research Committee, Genetic Testing Model: If Underwriters Had No Access to Known Results, Document 214082 (July 10, 2014).

¹⁰ M. Lombardo, “The Impact of Genetic Testing on Life Insurance Mortality,” Society of Actuaries, 2018.

¹¹ M. Lombardo, “The Impact of Genetic Testing on Life Insurance Mortality,” Society of Actuaries, 2018.

¹² Dexter Golinghorst et al., Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective, 50 *J.L.Med. Ethics* 139 (2022).

¹³ Dexter Golinghorst et al., Anti-selection & Genetic Testing in Insurance: An Interdisciplinary Perspective, 50 *J.L.Med. Ethics* 139 (2022).

3. There is real-world evidence of people opting out of genetic testing and research for fear of genetic discrimination

While the evidence on economic impact on the insurance industry is difficult to measure and speculative, there have been empirical studies that document that individuals fail to get recommended genetic testing or participate in genetic research due to concerns of genetic discrimination. Systematic reviews show that fear of genetic discrimination is a commonly measured concern, especially in the context of insurance.¹⁴ Studies have shown that some individuals do not undertake genetic testing because of these concerns—a decision which can risk lives and essential medical research.¹⁵ For example, in one large-scale genomics study across multiple sites, 13% of individuals who declined to participate in the study cited discrimination concerns.¹⁶ In a time where advances in genomics hold the promise to improve individual and population health, law and policy should prioritize removing barriers to realizing this promise.

4. The codification of the status quo will not address consumers' concerns and therefore is unlikely to quell future advocacy and legislative action

A major goal of a model act is to provide consistency across states; another is to provide stability. If adopted as written, my concern is that this model act will not quell consistent advocacy efforts for stronger protections because it does not adequately address consumers' concerns. History has shown that laws requiring life insurers to have actuarial justification for use of genetic information do not stop additional efforts to shore up anti-discrimination protections. This is true both in the United States and abroad.¹⁷ For example, at least nine states currently have actuarial justification laws related to genetic information. In the past four years alone, bills have been introduced in a third of these states in attempts to strengthen the laws.

5. While a ban on life insurer use of genetic information is the best way to address public fear of genetic discrimination, other policy options are available to balance insurance industry and public concerns.

For the reasons listed above, I believe that a ban on life insurer use of genetic information is a reasonable policy option to consider in order to encourage genetic testing and advances in research. However, there are multiple policy options that have been implemented in other countries that adopt a middle-ground approach between a full ban and the current approach of Section 4(A). For example, multiple international jurisdictions have adopted a monetary threshold which would allow insurers to use genetic information, but only for life insurance policies of high monetary value. This type of policy option minimizes the risk of adverse selection to the insurance industry given the varying existing impact models discussed above.

¹⁴ Annet Wauters and Ine Van Hoyweghen. "Global trends on fears and concerns of genetic discrimination: a systematic literature review." 61 *JOURNAL OF HUMAN GENETICS* 275 (2016).

¹⁵ Mark A. Rothstein, "Time to end the use of genetic test results in life insurance underwriting." 46 *The Journal of Law, Medicine & Ethics* 794 (2018).

¹⁶ Laura M. Amendola, et al. "Why patients decline genomic sequencing studies: experiences from the CSER consortium." 27 *JOURNAL OF GENETIC COUNSELING* 1220 (2018).

¹⁷ Anya E.R. Prince, Political economy, stakeholder voices, and saliency: lessons from international policies regulating insurer use of genetic information, 5 *J. L. Biosciences* 461 (2018).

While the evidence suggests that it is unlikely for large numbers of individuals to try to game the system purchasing exorbitant insurance policies following a positive genetic test, a monetary cap would insulate the life insurance industry from this risk while address many of the anti-discrimination concerns of the public.

Overall, I argue that stronger protections should be substituted into Section 4(A) to better reflect current evidence regarding the balance between the concerns of the insurance industry and the public, but that at the very least, compromise policy options should be strongly considered.

Regards,

A handwritten signature in black ink, appearing to read 'AP', is positioned below the text 'Regards,'.

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