Testimony of Adriana Beltrano in Support of SB 757

Uploaded by: Adriana Beltrano
Position: FAV

Testimony of Adriana Beltrano in Support of SB 757, The Genetic Testing Protection Act

Good afternoon, Chair Beidle, Vice Chair Hayes, and members of the committee. My name is Adriana Beltrano, and I am a graduate student and instructor at Johns Hopkins University, working toward earning my Master of Fine Arts in Poetry. Yesterday, I turned twenty-four.

In June of 2023, my mother was diagnosed with genetic ALS. Just one month later, I tested positive for a mutation in the SOD1 gene, which causes genetic ALS. This news was devastating for my family.

While I do not know if or when I will begin developing symptoms, I do know that there is a gene-specific treatment for this ALS-related gene—one that has shown signs of stopping disease progression in my mom.

Because I carry this gene mutation, I am not only grappling with the impact ALS has had on my mother, my family, and my own future—I also face the reality that, under current Maryland law, I can legally be denied life insurance, long-term care insurance, and disability insurance based solely on my genetic status.

Knowing my genetic status allows my doctors to monitor me for early signs of ALS, giving me the best possible chance to access treatments when they become available. But this kind of insurance discrimination discourages people from getting tested and taking proactive steps for their health.

At the same time, genetic testing is an incredibly personal and often traumatic decision. People who test positive for a genetic disease while remaining asymptomatic, or who have family members battling these diseases, are already facing unimaginable challenges. The added burden of insurance discrimination is simply unjust.

That is why I strongly support SB 757, the Genetic Testing Protection Act, and I urge you to do the same. This bill will ensure that Marylanders are not penalized for taking charge of their health. I am incredibly grateful to Senator Washington for introducing this critical legislation.

Please do not allow outdated and unfair insurance policies to stand in the way of people like me getting the medical information we need. Thank you for your time and consideration.

SB757 Testimony .pdf

Uploaded by: Alonzo Washington

Position: FAV

Alonzo T. Washington
Legislative District 22
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Finance Committee

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THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

Testimony in Support of Senate Bill 757 – Genetic Testing – Prohibition on Disability, Life, and Long–Term Care Insurance (Genetic Testing Protection Act)

The bill seeks to prohibit insurance carriers that offer life insurance, long–term care insurance, or disability insurance policies or contracts from taking certain actions relating to coverage based on whether an applicant or a policy or contract holder has requested or undergone genetic testing or the results of the genetic testing.

No one should have to choose between understanding their genetic health risks and securing their financial future. Senate Bill 757 ensures that Marylanders can seek genetic testing without fear of losing life insurance, long-term care coverage, or disability benefits. By prohibiting insurers from using genetic information to deny coverage, raise premiums, or impose restrictions, this bill upholds fairness, privacy, and the right to make informed healthcare decisions without penalty. Senate Bill 757 seeks to prohibit insurance carriers offering life insurance, long-term care insurance, or disability insurance from denying coverage, adjusting premiums, or imposing restrictions based on an individual's results of genetic testing. This bill ensures that individuals are not penalized for seeking genetic information to make informed healthcare decisions.

The pressing need for stronger protections against genetic testing discrimination in Maryland is evident as gaps in current federal laws leave individuals vulnerable to insurance-related biases. These gaps include but are not limited to:

- Federal protections against genetic discrimination exist under the Genetic Information Nondiscrimination Act of 2008 (GINA), which prohibits the use of genetic information in health insurance and employment. However, GINA does not extend these protections to life insurance, long-term care insurance, or disability insurance, leaving individuals vulnerable to discrimination in these critical areas.
- Additionally, the Health Insurance Portability and Accountability Act (HIPAA) prohibits health insurers from using genetic information to determine eligibility or benefits, but its protections do not cover life, long-term care, or disability insurance.

Effects of Gaps in Federal Laws

As genetic testing becomes more prevalent in preventive medicine, the lack of comprehensive protections creates an environment where individuals may avoid life-saving genetic testing for fear of discrimination.

State- Level Precedents

Florida enacted House Bill 1189, to prohibit life and long-term care insurers from canceling, limiting, or denying coverage or adjusting premium rates based on genetic information. California also established similar measures through the Genetic Information Privacy Act ensuring individuals retain control over their genetic information.

Senate Bill 757 is a necessary step to align Maryland with these states in safeguarding consumer rights. It protects individuals from insurance discrimination based on genetic predisposition rather than actual medical diagnoses. Insurers should base their decisions on manifested health conditions rather than potential future risks inferred from genetic data. Protecting individuals from genetic discrimination encourages participation in genetic testing, which can facilitate early detection, preventive care, and personalized treatment strategies.

By passing SB757, Maryland will ensure that its residents are not penalized for seeking knowledge about their health. This bill promotes the fairness and consumer protection needed in our insurance system.

Therefore, I respectfully request a favorable report on SB757.

Testimony of Brian Schafer on SB 757.pdf

Uploaded by: Brian Schafer

Position: FAV

Testimony of Brian Schafer – SB 757, The Genetic Testing Protection Act

Good afternoon, Chairwoman Beidle, Vice Chair Hayes and Members of the Senate Finance Committee.

Thank you for the opportunity to provide testimony in support of Senate Bill 757.

My name is Brian Schafer, and I am the proud father of seven amazing children. I live in Bel Air, Maryland. ALS has taken the lives of four members of my family—my father, sister, aunt, and grandmother.

In two of those cases, I witnessed firsthand as they gradually lost all their physical abilities before ultimately losing their lives. I watched my father struggle to continue providing for his family while barely able to lift his arms. I saw him nearly choke to death at our kitchen table because he could no longer swallow.

I watched my sister, a devoted teacher, use a microphone in her classroom so she could continue teaching for as long as possible before being forced to leave the job she loved. Eventually, her condition declined to the point where I had to feed her—something no brother should ever have to do for his sister. ALS is a cruel, horrific disease that I wouldn't wish on my worst enemy.

I have tested positive for one of the ALS-related genes. Fortunately, I have not developed the disease, but I am under close medical monitoring. If I do begin to show symptoms, early detection will be critical to accessing any available treatments. With ALS, early diagnosis and intervention can make all the difference.

Genetic testing is essential, especially for those with a family history of ALS. It is one of the only ways to have a fighting chance against this disease. Yet, under current law, if any of my children undergo genetic testing and test positive for an ALS-related gene, they could face discrimination and be denied life insurance coverage.

Because of our family history, my children are already at risk of facing higher insurance rates—regardless of whether they ever develop ALS. Denying them coverage based on a genetic test result only adds to this unfair burden.

Life insurance companies have been around for centuries. They have survived economic downturns, wars, and pandemics. Like any other successful business, they adapt to changing conditions. Passing this bill will not ruin the life insurance industry.

As I mentioned earlier, genetic testing, ongoing monitoring, and early access to new treatments are essential in the fight against ALS. Please do not let the fear of being denied life insurance deter my children—or anyone else at risk—from getting tested.

Thank you.

SUPPORT SB 757.pdf
Uploaded by: Dale Jafari
Position: FAV

NURSE PRACTITIONER
Association of Maryland

"Advocating for Nurse Practitioners since 1992"

SB 757

Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)

Position: **SUPPORT**

Dear Chair Pena-Melnyk, Vice Chair Cullison, and Members of the Committee:

On behalf of the over 800 members, the Nurse Practitioner Association of Maryland, Inc. (NPAM), and the over 8,000 Nurse Practitioners licensed to practice in Marland, I am writing to support SB 757.

My name is Dr. Dale Jafari and I have been a Nurse Practitioner in Women's Health on the rural Eastern Shore of Maryland for more than 27 years. I serve the five mid-shore communities of Talbot, Dorchester, Caroline, Queen Anne's, and Kent County including multiple communities of medically underserved populations.

In order to guide the appropriate health screening procedures and intervals, we screen every new patient for personal and family history that may indicate they have an increased risk for specific cancers. Those patients who are recommended for genetic testing due to provocative or personal health history are protected from having the results of that testing impact their access to health insurance coverage or exclusions through the 2008 federal Genetic Information Discrimination in Employment (GINA). SB 757 will reach beyond the prohibition of healthcare services by health insurance plans based on known genetic risk to extend to life ins, long term care insurance, and disability. These are currently exempt from GINA.

I am personally impacted by this as a Women's Health provider. I recommend to my patients who are considering genetic testing for a deleterious mutation that they must consider that the results of genetic testing could result in a positive result indicating increased risk for certain cancers. Once they have that information, they must disclose the positive result if they apply in the future for life insurance, long term care insurance, or disability insurance. Such disclosure may result in an unfavorable decision regarding underwriting of those policies. If the patient already has such policies in place BEFORE undergoing genetic testing, consideration must be given to the risk that they will not be covered for an outcome related to the known positive genetic predisposition. SB 757 will protect my patients, your constituents, to be denied payouts for a death or disability related to an as yet unidentified genetic mutation. This Bill protects the patient from insurance prejudice or denial of coverage.

The Nurse Practitioner Association of Maryland is in full support of SB 757. It is our hope that the Bill is given a favorable report so that our patients may have access to care despite a potential deleterious genetic mutation.

Should you have any questions, please feel free to contact me or our government relations consultant, Sarah Peters, at speters@hbstrategies.us.

Sincerely,

S.Dale G Jafari

S. Dale G. Jafari
S. Dale G. Jafari, DNP, FNP-BC, FAANP
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Nurse Practitioner Association of Maryland, Inc.

SB757 Genetic Testing LOS Final.pdf

Uploaded by: Irnise Williams
Position: FAV

CAROLYN A. QUATTROCKI
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Deputy Attorney General

ZENITA WICKHAM HURLEY
Chief, Equity, Policy, and Engagement

STATE OF MARYLAND
OFFICE OF THE ATTORNEY GENERAL
CONSUMER PROTECTION DIVISION
HEALTH EDUCATION AND ADVOCACY UNIT

ANTHONY G. BROWN
Attorney General

WILLIAM D. GRUHN
Division Chief

PETER V. BERNS
General Counsel

CHRISTIAN E. BARRERA
Chief Operating Officer

IRNISE F. WILLIAMS
Assistant Attorney General

February 24, 2025

TO: The Honorable Pamela Beidle, Chair
Senate Finance Committee

FROM: Hanna Abrams, Assistant Attorney General
Consumer Protection Division

Irnise F. Williams, Deputy Director
Health Education and Advocacy Unit

RE: Senate Bill 757- Genetic Testing - Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)- **SUPPORT**

The Consumer Protection Division (CPD) of the Office of the Attorney General and the Division's Health Education and Advocacy Unit (HEAU) support Senate Bill 757. This bill extends the protections of current law at Ins. Article § 27-909, which prohibits an insurer, nonprofit health plan, or health maintenance organization from using a genetic test, genetic information, or a request for genetic services to affect a health insurance policy or contract. This bill extends these prohibitions to issuers of life, disability, or long-term care coverage so the issuer may not deny or limit coverage under these contracts or policies based on genetic tests, information, or services.

We share the advocates' concerns that, if consumers fear being denied insurance based on the results of genetic testing, consumers will instead forego the testing. Genetic testing may be relevant to an individual's healthcare or lifestyle decisions and may be used to trace ancestry. Genetic testing is also critical to research into curing or treating diseases or developing therapeutic medicines. However, just as Maryland and the federal Genetic Information Nondiscrimination Act (GINA) prohibit denying health insurance to individuals based on genetic testing, these genetic tests should not also be used to deny an individual the ability to obtain disability, life, and long-term care insurance.

Maryland is not alone in offering its residents consumer protections for genetic testing. Florida passed a law for policies starting or renewing after January 1, 2021, which states insurers (including life, disability, and long-term care insurers), in the absence of a diagnosis of a condition related to genetic information, cannot require or ask for genetic information or use genetic test results to deny, limit, or cancel coverage or set different premiums based on genetic information. https://laws.flrules.org/2020/159 (Florida does allow a life or long-term care insurer to consider a diagnosis in the medical record, even if the diagnosis was made with the results from a genetic test.)

We note that the definition of "genetic information" in HB 1007 covers information not obtained for diagnostic and therapeutic purposes at a time when the individual was asymptomatic for the disease. There are two definitions for "genetic information" found within the Insurance Article. *Compare* Ins. Art. § 27-909(a)(3) *with* § 18-120(a)(2)(i). We recommend adopting the definition proposed in HB 1007 which conforms to that found in § 18-120 of the Insurance Article because the purpose of § 18-120 of the Insurance Article is to prohibit long-term insurance carriers from discriminating based on genetic information, the same type of protections sought in this bill. In contrast, the purpose of § 27-909 of the Article is to require health insurance coverage, rather than to prohibit discrimination.

The CPD and HEAU believe that Senate Bill 757 would help to protect Maryland citizens from discrimination based upon the results of genetic testing.

We urge a favorable report.

cc: The Honorable Alonzo T. Washington

2025 MOTA SB 757 Senate Side.pdf

Uploaded by: Jennifer Navabi

Position: FAV

Maryland Occupational Therapy Association

PO Box 36401, Towson, Maryland 21286 ♦ mota-members.com

Committee:	**Senate Finance Committee**
Bill Number:	**Senate Bill 757**
Title:	**Genetic Testing - Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)**
Hearing Date:	**February 26, 2025**
Position:	**Support**

The Maryland Occupational Therapy Association (MOTA) supports Senate Bill 757 – *Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection)*. This bill will prohibit life insurance, long-term care insurance, and disability insurance carriers from denying or limiting coverage based on whether the applicant has undergone genetic testing and prohibiting these types of insurance carriers from canceling a policyholder for undergoing a genetic test. The bill also prohibits carriers from using a genetic test or the results of a genetic test in a way that would limit, deny, cancel or increase an individual's insurance coverage.

MOTA wants to remove barriers to people obtaining disability and long-term care insurance. Such coverage is essential in supporting individuals to live as independently as possible. Maryland law already prohibits health insurance using genetic testing to discriminate against enrollees. This prohibition should be extended to other types of insurance.

We ask for a favorable report. If we can provide any further information, please contact Michael Paddy at mpaddy@policypartners.net.

2025 TCC SB 757 Senate Side.pdf

Uploaded by: Jennifer Navabi

Position: FAV

THE COORDINATING CENTER
YOUR HEALTH. YOUR JOURNEY. OUR PRIORITY.

Committee:	**Senate Finance Committee**
Bill Number:	**Senate Bill 757 – Genetic Testing - Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)**
Hearing Date:	**February 26, 2025**
Position:	**Support**

The Coordinating Center supports *Senate Bill 757 – Genetic Testing - Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)*. The bill prohibits carriers that offer life insurance, long-term care insurance, and disability insurance policies or contracts from discriminating against individuals based on genetic tests.

The Coordinating Center, a Maryland statewide nonprofit care coordination organization for people living with disabilities and complex medical needs, supports this legislation because an individual's decision about whether to seek genetic testing should not be based on fear of discrimination by insurance carriers. If someone is afraid of discrimination from a life, long-term care, or disability insurer, they may forgo genetic testing. Decisions about genetic testing should be made by individuals, in consultation with their providers and not based around the concern of not qualifying for an insurance product, months or years later. Maryland has already made the policy decision to prohibit health insurance carriers from engaging in this practice and The Coordinating Center believes that the prohibition should now be extended to disability, life and long-term care insurance carriers.

We ask for a favorable report. If we can provide any additional information that is helpful, please contact Robyn Elliott at relliott@policypartners.net.

SB757_ALSA_Dave.pdf

Uploaded by: Kuldip Dave

Position: FAV

February 24, 2025

Senator Pamela Beidle
Chair, Finance Committee
3 East Miller Senate Office Building
11 Bladen Street
Annapolis, MD 21401

The Honorable Chair Beidle, Vice Chair Hayes, and Members of the Finance Committee

RE: SB 757 – Genetic Testing Protection Act

Position: SUPPORT

My name is Kuldip Dave, Ph.D., and I am Senior Vice President for Research at the ALS Association. I am writing today in support of SB 757: Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act), but most importantly, in support of the more than 200 families with ALS we currently serve in the state of Maryland as well as the tens of thousands more affected by the disease across the country.

Probably one of the greatest scientific achievements of our time has been mapping the human genome, a project led in Maryland. Now, the state and this Committee have the opportunity to lead the way in advancing medicine yet again through the Genetic Testing Protection Act, which if passed, will provide the safeguards needed to realize the full potential of the genetic discoveries made over the last two decades.

Genetic Basis of ALS and New Opportunities for Treatment

In 2019, researchers from Harvard University and the University of Queensland in Australia estimated that 40% of diseases have a genetic component.[1] This includes ALS. Amyotrophic lateral sclerosis, or ALS, is a devastating neurodegenerative disease that affects nerve cells in the brain and spinal cord. Over the course of the disease, people progressively lose the ability to move, to speak, and eventually, to breathe. Few treatment options exist, so the disease is always fatal, usually within five years of diagnosis.

We estimate that roughly 10–15% of ALS is driven by gene mutations that are either passed down in families or occur randomly during development. So far, researchers have identified more than 40 genes linked to ALS. One of these genes is *SOD1*. Mutations in the *SOD1* gene are the second-most common cause of familial, or inherited forms, of ALS. The most prevalent *SOD1* gene mutations in North America are associated with younger age of onset and shorter survival.

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[1] Lakhani, C.M. et al. Repurposing large health insurance claims data to estimate genetic and environmental contributions in 560 phenotypes, *Nature Genetics* (2019).

In 2023, families devastated by *SOD1*-ALS were given new hope when the Food and Drug Administration approved the first genetically targeted ALS treatment. Tofersen, now known as Qalsody®, was developed to specifically target the RNA produced from mutated *SOD1* genes to stop the production of toxic SOD1 proteins that cause ALS.

In the phase 3 VALOR trial, Qalsody was shown to reduce levels of mutated SOD1 proteins in cerebral spinal fluid by 35% as early as eight weeks after participants began receiving the therapy.[2] By 12–16 weeks, Qalsody reduced bloodstream levels of neurofilament light chain (NfL), a biomarker of neuron damage and neurodegeneration, by 50%.

More recent peer-reviewed real-world data have confirmed that treatment with Qalsody decreases NfL levels and has disease-modifying activity.[3,4] Evidence is also emerging that treatment with Qalsody not only has the potential to stabilize the disease but also to restore lost function—something many in the neurodegenerative field never considered possible.

A study published last month in *The Annals of Clinical and Translational Neurology* reported on seven people with *SOD1*-ALS treated with Qalsody at Washington University in St. Louis from November 2021 to February 2024.[5] All participants showed either stabilization or slight improvement in function, as measured by the ALS Functional Rating Scale-Revised (ALSFRS-R).

The researchers estimated that the participants progressed an estimated 52% slower than expected following treatment with Qalsody. In addition, muscle strength improved for five of the study participants. Participants also gained, on average, a little more than five points on the functional independence measure motor score, a "notable improvement in functional independence," according to the researchers.

This study builds on growing evidence from Europe, where long-term studies in Italy[6] and Germany[7] have also shown stabilization and improvement among people with *SOD1*-ALS treated with Qalsody.

Until now, the prevailing hypothesis in the neurodegenerative field has been that disease-modifying therapies would either slow down or stop further progression. Qalsody, however, has shown that improvement in function (recovery) is possible. The fact that these data were

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[2] Miller, T.M. et al., Trial of Antisense Oligonucleotide Tofersen for SOD1 ALS, *N Engl J Med* (2022).

[3] Meyer, T. et al., Neurofilament light-chain response during therapy with antisense oligonucleotide tofersen in SOD1-related ALS: Treatment experience in clinical practice, *Muscle Nerve* (2023).

[4] Wiesenfarth, M. et al. Effects of tofersen treatment in patients with SOD1-ALS in a "real-world" setting – a 12-month multicenter cohort study from the German early access program, *EClinicalMedicine* (2024).

[5] Smith, S.A. et al., Tofersen treatment leads to sustained stabilization of disease in SOD1 ALS in a "real-world" setting, *Ann Clin Transl Neurol* (2025).

[6] Sabatelli, M. et al., Long-term treatment of SOD1 ALS with tofersen: a multicentre experience in 17 patients, *J Neurol* (2024).

[7] Meyer, T. et al. Clinical and patient-reported outcomes and neurofilament response during tofersen treatment in SOD1-related ALS—A multicenter observational study over 18 months, *Muscle Nerve* (2024).

collected during standard of care treatment in real-world settings should further validate that the functional recovery is not just a characteristic of a tightly controlled double-blind trial but is real and significant.

Increasing Importance of Genetic Testing for ALS

Qalsody is the only ALS treatment, to date, to demonstrate results like these. However, because of its targeted nature, only people with a *SOD1* mutation can benefit, necessitating more routine integration of genetic testing into ALS clinical management. According to evidence-based consensus guidelines published in 2023 in the *Annals of Clinical and Translational Neurology*, everyone living with ALS should be offered genetic counseling and testing.[8]

The role of genetic testing and counseling will only become more vital moving forward as at least 10 other therapies targeting ALS-linked genes are being tested in clinical trials, and almost a dozen more are being developed preclinically.

Genetic testing results not only have implications for people living with ALS but also for their family members. Having a first-degree relative test positive for an ALS-linked mutation significantly increases a family member's risk of developing the disease. It also potentially paves the way for prevention.

In a study being conducted at Johns Hopkins, Dr. Nicholas Maragakis and colleagues are trying to see if Qalsody can delay the onset of ALS—or perhaps even prevent the disease from developing all together—in people with a *SOD1* mutation who have no ALS symptoms. Not everyone with a *SOD1* mutation will develop ALS in their lifetime, but what if we could stop the disease before it starts in those individuals who would eventually be affected—like using cholesterol levels in blood and treatment with cholesterol-reducing drugs to prevent heart disease? Imagine the economic, societal, and personal costs that would be saved.

Threat of Genetic Discrimination Holds Back Progress—And Harms Marylanders

Despite the tremendous benefits Qalsody and other genetically targeted drugs in development could provide to individuals and the entire ALS community, few people with ALS and their family members know their genetic status. Fear of their genetic information being used against them is one reason why they don't get tested.

In the fall of 2024, we surveyed more than 775 people with ALS and their proxies about genetic testing and counseling through our ALS Focus™ Survey Program. Twenty-two percent (22%) of participants had not received genetic testing for ALS, and another 5% didn't know if they had been tested. Within this group, two out of three said they were unlikely to get tested in the future. When asked why, 20% said they felt they would lose their long-term care, disability, or life insurance if the results were positive. Over a quarter (27%) thought their families would lose

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[8] Roggenbuck, J. et al. Evidence-based consensus guidelines for ALS genetic testing and counseling, *Ann Clin Transl Neurol* (2023).

those same benefits if the results were positive. And another 12% preferred not to even answer these questions, which also raises concerns about fear of discrimination.

Thus, the threat of genetic discrimination creates a serious dilemma for Marylanders—risk their physical health because they don't know their genetic status or risk their financial health because they do.

The Genetic Testing Protection Act will help allay this fear by putting protections in place for accessing life and disability insurance by people who have undergone genetic testing, requested genetic testing, or received genetic test results. Such protections will not only benefit those living in this state, but through the amazing science being done in Maryland, bring life-changing new genetic therapies to everyone who needs them faster.

For all these reasons, I respectfully request your support for the Genetic Testing Protection Act. Thank you to Senator Washington for introducing this legislation and to the members of the Finance Committee for your time and consideration.

Sincerely,

Kuldip Dave, Ph.D.
Senior Vice President, Research
The ALS Association
Kuldip.Dave@als.org

Lindsay Jack_MD GTPA_Finance_Written Testimony_202

Uploaded by: Lindsay Jack

Position: FAV

ALS
ASSOCIATION

February 26, 2025

Senator Pamela Beidle
Chair, Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

The Honorable Chair Beidle, Vice Chair Hayes, and Members of the Senate Finance Committee:

RE: SB 757 – The Genetic Testing Protection Act of 2025

Position: SUPPORT

My name is Lindsay Jack, and I am the Managing Director of Advocacy at the ALS Association. I am writing today in strong support of SB 757: The Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2025).

This critical piece of legislation will ensure that individuals can seek genetic testing without fear of discrimination by life, long-term care, or disability insurers. The benefits of this bill far outweigh any concerns, as it promotes preventive healthcare, protects individuals from unfair insurance practices, and strengthens trust in medical research.

It is not our intention for this legislation to negatively impact the life insurance market. We want people to get genetic testing *and* life insurance - but affordably.

Why This Legislation is Essential

1. Encourages Preventive Healthcare & Early Intervention

Genetic testing empowers individuals to take proactive steps to mitigate health risks. Without protections, fear of discrimination discourages people from undergoing potentially life-saving testing. Genetic testing and genetic counseling are crucial to family members that have ALS, as it helps to inform prevention, future treatment options, innovative breakthroughs for this devastating disease, and important life decisions.

Despite the progress that has been made for the ALS community, there have been multiple studies and real-life examples that show that the fear of genetic information being used against them is one reason people say they do not get tested. Thus, the threat of genetic discrimination creates a serious dilemma for Marylanders — risk their physical health because they do not know their genetic status or risk their financial health because they do.

2. Protects Consumers from Unjust Discrimination

A genetic predisposition does not equate to a medical diagnosis; basing insurance decisions on genetic probabilities is inherently unfair. This bill ensures that policyholders are judged based on their actual health conditions, not genetic potential.

3. Fosters Public Trust in Medical Research

Many individuals avoid genetic testing due to insurance concerns. Ensuring protections encourages participation in medical studies, leading to better treatment options and healthcare advancements.

4. Maintains Fair Insurance Practices Without Undue Burden

The bill does not prohibit insurers from considering actual medical diagnoses. Additionally, our bill does not prevent insurers from accessing an individual's medical record as part of an application exam. It only ensures that individuals are not penalized solely for their genetic predispositions.

In some cases, genetic test results can prevent a patient from getting a life insurance policy. There are also times that patients are offered coverage at an extremely high premium. That is what our bill addresses: avoiding discrimination as it concerns issuance & price protection. An important distinction is that a genetic test indicates potential health risks – it is not a diagnostic exam and should not be treated as such by life insurers.

5. Aligns with Existing Ethical and Legal Standards
Similar protections exist under the Genetic Information Nondiscrimination Act (GINA) and the Affordable Care Act (ACA) for health insurance. Expanding these protections to life, long-term care, and disability insurance is the logical next step.

6. Reduces Long-Term Healthcare Costs
Early detection through genetic testing can help prevent costly late-stage treatments. Insurers ultimately benefit from healthier policyholders who engage in preventive care.

Addressing Potential Concerns

Concern: Insurance Risk Assessment & Pricing
Insurers claim that genetic data is essential for accurate risk assessment, yet they can still evaluate medical diagnoses and family history. A similar bill passed in Florida in 2020 and took effect in 2021. Nearly five years later, there is no evidence of adverse outcomes from this legislation or any impact on life insurance premiums. In fact, Florida's life insurance market remains strong, ranking among the top states for life insurance sales.

For well over 125 years, life insurers and applicants *did not* have genetic testing information, and their business has managed to flourish. Life insurers claim that they will never require a patient to receive a genetic test to obtain a policy, but we don't have any law in place to support that. Medical records for the purpose of medical underwriting have been used for decades. It's unfair for insurers to base issuance and pricing decisions on private and personal genetic information and it is completely unnecessary for the sustainability of their business.

Concern: Adverse Selection (High-Risk Individuals Seeking More Coverage)
People already make insurance decisions based on family history; this bill ensures fairness in that process. A genetic predisposition does not guarantee the development of a condition, making it an unreliable sole factor for pricing.

Conclusion

The Genetic Testing Protection Act will help allay this fear by putting protections in place for accessing life and disability insurance by people who have undergone genetic testing, requested genetic testing, or received genetic test results. Such protections will not only benefit those living in this state, but through the amazing science being done in Maryland, bring life-changing new genetic therapies to everyone who needs them faster.

For all these reasons, I respectfully request your support for The Genetic Testing Protection Act. Thank you to Senator Washington for introducing this legislation and to the members of the Senate Finance Committee for your time and consideration.

Sincerely,

Lindsay Jack

Lindsay Jack
Managing Director, Advocacy
The ALS Association

SB757_GTPA_LOS.pdf
Uploaded by: Lisa Peabody
Position: FAV

FORCE
Facing Hereditary Cancer EMPOWERED

February 24, 2025

RE: Please support MD SB 757

Dear Chairwoman Beidle, Vice-Chairman Hays and Esteemed Members of the Finance Committee,

On behalf of FORCE (Facing Our Risk of Cancer Empowered), a national nonprofit organization that advocates for families facing hereditary cancers, and the Maryland constituents we represent, please support SB 757.

The majority of our constituents carry an inherited genetic mutation that increases their risk of cancers including breast, ovarian, prostate, pancreatic and colorectal cancer.

The predisposition to hereditary cancers is passed down through families. Parents who carry a mutation have a 50% chance of passing that mutation on to their children. Hereditary cancers often occur at younger ages. Members of our community also face a greater risk of recurrence and additional primary cancers. Accordingly, national medical guidelines recommend that high-risk individuals undergo more intensive, more frequent cancer screenings starting at younger ages than the general population.

For example, Lynch Syndrome affects approximately 1 in 300 Americans. Associated with five gene mutations (MLH1, MSH2, MSH6, EPCAM and PMS2), Lynch Syndrome causes up to 80% risk of colorectal cancer and 50% risk of endometrial cancer. While these are disquieting numbers, the good news is that these cancers can be prevented or detected at an early stage through evidence-based interventions.

For instance, the National Comprehensive Cancer Network (NCCN) and similar medical society guidelines recommend that individuals with MLH1 and similar mutations begin screening colonoscopy every one to two years between the ages of 20 and 25. If polyps are found, they are removed, which eliminates the chance for the growths to become cancerous.

Similarly, endometrial cancer can often be caught early based on symptom awareness. Regular screening with transvaginal ultrasound and endometrial biopsies, or hysterectomy after completion of childbearing are also options for those at increased risk.

These evidence-based interventions empower high-risk individuals to take control of their health, detecting cancer earlier when it is easier to treat, or preventing it altogether.

We don’t know why most people get cancer. However, an estimated 10% of Americans carry an inherited genetic mutation that increases their cancer risk. Advances in genetics have made it possible to identify these individuals—and to intervene as appropriate. These are the ideal candidates for prevention and early detection, so why are we penalizing this population?

The Genetic Information and Nondiscrimination Act, a federal law known as GINA, applies to health insurance and employment but falls short of providing comprehensive protections. The fear of being denied or charged significantly higher rates for life, disability and long-term care insurance is real. Many members of our community have experienced this discrimination. Some people refuse genetic testing even though it is medically indicated due to concern that it will impact their ability to get insurance. This doesn't mean they don't have a genetic predisposition to disease; it means they are deliberately choosing to be uninformed for fear of insurance repercussions.

Nearly every human has a predisposition to some disease or ailment—cancer, heart disease, dementia, diabetes, arthritis, etc. In this era of personalized and precision medicine, we should be rewarding people for being educated and proactive with their health. Individuals with knowledge of their predisposition to disease are empowered to take measures to mitigate that risk.

The insurers assert that individuals should simply secure a policy before undergoing genetic testing. Unfortunately, this is not feasible for many people. Genetic testing for a hereditary cancer mutation is often recommended for young adults, ages 18-25, so they can begin the appropriate cancer screenings. Students and people early in their careers are not in a position to purchase life insurance. In addition, insurers require access to the applicant's or insured's medical records. Some members of our community report that their insurance policies were canceled, or premiums significantly increased and coverage was reduced after testing positive for a mutation.

With this legislation, we have the opportunity to right a wrong. More than a dozen states have enacted laws that extend GINA protections. Florida, one of the most conservative states in the country, passed a model anti-genetic discrimination law in 2020. Maryland should follow suit and prohibit insurers from canceling, limiting, increasing the premium, or denying coverage based on genetic information.

In summary, we strongly support SB 757 and urge you to endorse this legislation, ensuring that all Maryland residents have equal access to the insurance they need.

Thank you for your consideration,

Lisa S Peabody

Lisa Peabody
Advocacy Manager
FORCE: Facing Our Risk of Cancer Empowered
Ph: 202-381-1357

SB757_LisaSchlager_FAV

Uploaded by: Lisa Schlager

Position: FAV

February 26, 2025
RE: SB 757 – The Genetic Testing Protection Act
Position: SUPPORT

Thank you for the opportunity to comment on Senate Bill 757. My name is Lisa Schlager, and I am the Vice President of Public Policy for FORCE, a national nonprofit that advocates for people facing hereditary cancers. Comments on behalf of our broader community have been submitted by my colleague, Lisa Peabody.

Today, I am writing to share my personal perspective as an individual affected by the issue under consideration—genetic discrimination. In 1999, I was recently married and looking forward to starting a family. A relative shared that she had been diagnosed with a genetic mutation that increases the risk of cancer. I was encouraged to pursue genetic testing. I chose to do this through a research study because information on these mutations was still evolving, and I wanted to contribute to the science.

Ultimately, I learned that I carry a BRCA1 genetic mutation. Children have a 50% chance of inheriting a mutation from a parent with the mutation. Passed down from my father, this mutation causes a high risk of breast and ovarian cancer, as well as increased risk of pancreatic and prostate cancers. Upon receiving my results from the genetic counselor, I was warned not to let my healthcare providers put information about the mutation in my medical chart because it was still legal for a health insurer to drop your policy if you were deemed to be too risky or expensive. I was also told that I could be denied life or other types of insurance.

The advice to refrain from noting the mutation in my medical chart simply wasn't feasible. Medical guidelines for those with certain mutations recommend more intensive, more frequent cancer screenings starting at younger ages than the general population. Women with BRCA mutations are supposed to start breast screening at age 25. Information about my mutation was necessary to justify insurance coverage of mammograms and breast MRIs, alternating every six months. Later, information about the mutation served as justification for my risk-reducing salpingo-oophorectomy—guideline-recommended removal of ovaries and fallopian tubes after I had children—and a prophylactic mastectomy after precancerous cells were found in my breast.

I was fortunate because genetic mutations weren't on the insurers' radar yet. I was able to get a term life insurance policy and had no issues with my health insurance (perhaps because I was on a group health plan through my husband's employer). In time, the Genetic Information Nondiscrimination Act (GINA) passed, and the Affordable Care Act followed shortly thereafter. These laws alleviated concerns about health insurance coverage, but discrimination in life, long-term care, and disability insurance is still legal at the federal level.

I am evidence that "knowledge is power." Information about my genetic predisposition to cancer has enabled me to be proactive with my health. My risk of breast and ovarian cancer is now lower than that of the general population. Currently, I undergo annual pancreatic cancer screenings to catch the disease at the earliest stages should it occur. With information about a genetic mutation, cancer and other diseases can be prevented or detected earlier when they are easier to treat.

However, a lot has changed since I first learned about my mutation. Life, long-term care and disability insurers are using information about an individual's genetic mutation (or a mutation in their family) to deny policies or increase rates to an exorbitant level. My brother is the primary breadwinner in his family. He refuses to undergo genetic testing for fear that he will be denied additional insurance should he need it. Not knowing if you have a mutation doesn't mean you aren't at risk. But like many Americans, he is fearful that this information will be used against him.

Since young women with mutations should start breast cancer screening at age 25, many have genetic testing around this age. My 24-year-old daughter will be getting tested for the mutation this spring. "Get insurance before you test" is the advice given. Let's be honest: most people in their early to mid-20s are just starting their careers, few are married, and even fewer have children. They are not yet in a position to invest in life, long-term care, or disability insurance.

A representative from New York Life testified at the recent House hearing on the companion bill for SB 757. He stated that they don't make underwriting decisions based solely on an individual's genetic mutation. This is not what we hear from people around the country. The following are just a few of the many accounts we've received:

> Thank you for your recent request for life insurance… We have completed your underwriting review. After careful consideration, we regret that we are not able to approve your request for coverage.
>
> Our action was based on:
>
> - Your medical history of positive BRCA mutation

> I recently applied for life insurance, and after a completely healthy assessment, the cost for coverage that our rep quoted me QUADRUPLED, simply because of my BRCA1 genetic predisposition.

> I was denied life insurance when my husband tried switching. I'm stuck with his employer's plan that we had before my genetic testing. They lowered my payout and upped premiums when they got word, without notifying us.

The use of genetics and genomics in medicine and health is rapidly growing. It facilitates personalized screening, prevention, and treatments. Maryland medical institutions such as Johns Hopkins are leading the way in using genetic information to improve health. **Awareness and evidence-based interventions empower people to be proactive with their health, to reduce their risk.** Why are we penalizing them?

The insurance industry claims that it needs information about genetic mutations for effective risk calculation in underwriting. Insurers didn't have access to this information in the past; they did just fine by basing their decisions on personal and family health history. A genetic mutation is not a guarantee that the individual will get the disease. Likewise, a person without knowledge of a mutation is still at risk.

In the case of long-term care or disability insurance, if an individual gets sick and can no longer work, who ends up supporting them? Who pays for their care if they lack insurance? Ultimately, these people turn to Medicaid and other state or federal programs for assistance. Wouldn't it be preferable for the insurance industry to address this need?

In 2020, Florida passed a law banning the use of genetic information. The law stipulates that insurers cannot deny coverage, limit, or cancel insurance coverage, or set different premiums based on genetic information or DNA. Since passage of that law, Florida's insurance marketplace has remained just as robust as ever, with rates increasing only 2% (far less than the rate of inflation).

Maryland has a chance to be a leader, to close a glaring gap in federal law. Please protect my children, my family members and my fellow Marylanders from genetic discrimination. Prohibit insurers from considering genetic information in their coverage decisions; personal and family health history should suffice. I urge you to endorse SB 757, ensuring that all Maryland residents have access to the insurance they need.

Thank you for your time and consideration,

Lisa Schlager

Lisa Schlager
Chevy Chase, MD
lisas@facingourrisk.org

MD Testimony_GTPA_2025_Melanie Lendnal_SB757.pdf

Uploaded by: Melanie Lendnal
Position: FAV

February 26, 2025

Senator Pamela Beidle
Chair, Senate Finance Committee
3 East Miller Senate Office Building
Annapolis, Maryland 21401

The Honorable Chair Beidle, Vice Chair Hayes, and Members of the Senate Finance Committee:

RE: SB 757 – Genetic Testing Protection Act
Position: SUPPORT

Thank you for giving me the opportunity to provide input to you today about Senate Bill 757.

My name is Melanie Lendnal, and I am submitting this testimony as a resident of Montgomery County, Maryland, and someone with a long family history of breast cancer.

Numerous studies have demonstrated that fear of discrimination by insurers is one of the primary reasons people choose not to get a genetic test. Two years ago, I shared with members of this committee that I was one of those people.

Every single woman on my mother's side of my family, going back to my great, great grandmother has been diagnosed with the breast cancer, including most recently my mother.

And while my doctors have encouraged and countless researchers have literally begged me to undergo genetic testing for their studies, I have refused.

I am a mom, and more than anything else I need to know that if anything ever happens to me my two young daughters will be okay. I need to know that whatever insurance I choose to purchase now or in the future will not be out of reach financially.

But decisions can have consequences. One of those is my inability to present this testimony to you in person since just last month I was diagnosed with breast cancer and underwent a bilateral mastectomy. I am still recovering.

This did not have to happen since there are now medical interventions available for those who test positive for genetic breast cancer and so many other genetic diseases. I, along with every other resident of this state should not have had to choose between physical health and financial health. Passing this legislation will ensure no one else is forced to make these difficult decisions again.

I respectfully ask for a favorable report for Senate Bill 757. Thank you for time and for your careful consideration of this important matter.

Sincerely,

Melanie Lendnal

Melanie Lendnal
9521 Hemswell Place
Potomac, Maryland 20854
Melanie.lendnal@gmail.com

SB757.Geneticbill.pdf
Uploaded by: Nicole Lollo
Position: FAV

NURSE PRACTITIONER
Association of Maryland

"Advocating for NPs since 1992"

Bill: Senate Bill 757
Position: SUPPORT

The Genetic Testing Protection Act is a crucial safeguard to ensure that Marylanders are not unjustly denied disability, life, or long-term care insurance based on their genetic information. Genetic testing holds immense potential to improve healthcare by identifying risks early and guiding treatment decisions. However, without strong confidentiality protections, this valuable tool can be "weaponized" leading to discrimination, denial of coverage, and financial hardship for individuals with inherited conditions. By prohibiting insurers from using genetic test results to determine eligibility, rates, or benefits, this legislation empowers patients to make informed healthcare choices without fear of unjust consequences.

As a nurse practitioner, I care for patients who carry hereditary gene mutations linked to life-threatening diseases. While medical advancements offer treatments to slow disease progression, many patients hesitate to undergo genetic testing, fearing that a positive result will render them uninsurable. Without legal protections, they are forced to choose between knowledge that could save their lives and the ability to secure essential coverage.

These are not hypothetical concerns, they are real stories from real people. A 53-year-old patient in my clinic recently tested positive for transthyretin amyloidosis with peripheral neuropathy and cardiac involvement, having inherited the Leu58H variant from her father. She pursued genetic testing in hopes of accessing life-saving treatment, only to later discover she was denied life insurance due to her newly classified pre-existing condition. Cases like hers underscore the urgent need for SB 757.

Genetic testing should be a pathway to better health, not a barrier to financial security. I urge you to support this critical legislation to protect Marylanders from discrimination and ensure that genetic advancements serve to enhance rather than limit access to care.

I respectfully request that you **SUPPORT – SB 757 Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protecting Act).**

Sincerely,
Nicole Lollo
Nicole Lollo, MS, AGPCNP-BC
Past President, Nurse Practitioner Association of Maryland

The GTPA Coalition Written Testimony - Finance.pdf

Uploaded by: Patrick Hogan

Position: FAV

The GTPA Coalition

A group of organizations working together to end discrimination for individuals receiving genetic tests.

February 26, 2025

The Honorable Chair Beidle, Vice Chair Hayes, and Members of the Finance Committee

RE: SB 757 – Genetic Testing Protection Act

Position: SUPPORT

We, the undersigned, represent hundreds of thousands of Marylanders who have genetic disorders. We have come together and are writing in strong support of the Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act).

The Genetic Information Nondiscrimination Act (GINA) prevents health insurers and employers from discriminating against an individual, based on their genetic information. Unfortunately, this federal legislation did not extend to 3 types of insurances: Life, Long-Term Care, or Disability Insurance.

Currently 13 states have an extension of GINA, or a GINA 2.0, adding protections for Life, Long-Term Care, or Disability Insurance. There are also several states that have introduced legislation similar to our bill this year. In 2020, Florida passed House Bill 1189, which prohibited life insurers and long-term care insurers from discriminating an individual based on genetic tests. In 2008, Maryland passed HB29 that prevented Long-Term Care insurers from discriminating based on genetic information. We have not seen adverse effects on premiums due to the passage of that legislation. Our goal in Maryland is to bring Life Insurance and Disability insurance up to the same standard to prohibit those insurers from canceling, limiting, increasing the premium, or denying coverage based on genetic information.

Our intention for this legislation is to avoid discrimination that our patients, advocates, and their families *have* experienced. Genetic tests are helpful information for individuals as they make life decisions for themselves and/or their families. They should not be treated differently, discriminated against, or delay receiving a genetic test because they fear insurers will deny coverage or increase rates due to their genetics.

We thank you for your time and ask that you support this legislation with a favorable report.

Signed,

ALS Association

Triage Cancer

FORCE Facing Hereditary Cancer EMPOWERED

American Kidney Fund FIGHTING ON ALL FRONTS

Ovarian Cancer Research Alliance

BREM Foundation to Defeat Breast Cancer DETECT EARLY. SAVE LIVES.

EveryLife Foundation for Rare Diseases

Susan G. Komen

American Cancer Society Cancer Action Network

Immune Deficiency Foundation

PTEN World

PTEN Hamartoma Tumor Syndrome Foundation

Maryland & DC society of Genetic Counselors

The Michael J. Fox Foundation for Parkinson's Research

End the Legacy Genetic ALS & FTD

NPAM Nurse Practitioner Association of Maryland

Li-Fraumeni Syndrome LFSA Association

Carle_Written Testimony Language_SB 757.pdf

Uploaded by: Rebecca Carle
Position: FAV

Subject: Testimony in Support of SB 757 – Protecting Genetic Privacy
Hearing: February 26, 2025

Dear Chair Beidle, Vice Chair Hayes, and Members of the Finance Committee,

My name is Rebecca Carle, and I am a constituent and an advocate with the Ovarian Cancer Research Alliance (OCRA). I strongly support SB 757, which would protect Marylanders from genetic discrimination in life, disability, and long-term care insurance. As someone who has a genetic mutation and as an advocate for individuals and families affected by ovarian and other gynecologic cancers, I know firsthand how vital genetic testing can be in saving lives.

Genetic testing provides critical information that empowers individuals to make informed medical decisions, yet the fear of discrimination prevents many from accessing these potentially life-saving tests. This is particularly true for those at risk for hereditary cancers like ovarian cancer, where early detection and preventive care can mean the difference between life and death. No one should have to choose between protecting their health and securing their financial future.

While the federal Genetic Information Nondiscrimination Act (GINA) prohibits genetic discrimination in health insurance, **there is currently no such protection for life, disability, and long-term care insurance**. This gap in the law disproportionately impacts those with a family history of cancer and other hereditary conditions. SB 757 would ensure that Marylanders can undergo genetic testing without fear of financial repercussions, fostering a healthcare environment that prioritizes prevention and early intervention.

In my 20s, testing positive for the BRCA mutation empowered me to take control of my health and make informed, preventive decisions. Now, in my 30s, with a family to consider, it's deeply unreasonable that this crucial health information could jeopardize my family's financial future. **Those of us who choose to be proactive about our health—ensuring we remain healthy, contributing members of society—should not be penalized for taking responsible, preventive action.** It's time to remove the barriers that punish individuals for prioritizing their well-being.

I urge this committee to support SB 757 and protect the privacy and well-being of Marylanders seeking to take proactive steps in managing their health. Thank you for your time and consideration.

Sincerely,
Rebecca Carle
Rebecca Carle
Baltimore, Maryland
Ovarian Cancer Research Alliance

SB 0757 favorable Genetic testing Dixon.pdf

Uploaded by: Shannan Dixon

Position: FAV

UNIVERSITY of MARYLAND
SCHOOL OF MEDICINE

Master's of Genetic Counseling Program

685 W. Baltimore Street
MSTF 3-014
Baltimore, MD 21201
410 706 4713

http://medschool.umaryland.edu/mgc/

February 20, 2025

Senator Pamela Beidle

RE: SB 0757 – Genetic Testing Protection Act

Position: SUPPORT

On behalf of the University of Maryland School of Medicine, thank you for the opportunity to support SB0757 Genetic Testing- Prohibition on Disability, Life and Long-Term Care Insurance (Genetic Testing Protection Act). I am the director of the Master's in Genetic Counseling Training Program, a genetic counselor and an Assistant Professor in the Department of Pediatrics.

This bill will help to ensure that all Marylanders receive timely preventative care. With recent advances in genomic technologies, genetic testing has emerged as a vital tool to provide patients, their families, and their providers with valuable information to personalize their healthcare. Genetic testing reduces the need for unnecessary tests and procedures by providing more precise information about a patient's specific health risks. Early detection and prevention can lead to significant cost savings in the long term as well as improved outcomes for the patient.

Maryland SB0757 is a crucial step in ensuring genetic privacy and protecting individuals from discrimination by disability, life, and long-term care insurance providers. Advances in genetic testing allow individuals to assess their risk for various medical conditions, but using this information to determine insurance eligibility or premiums may discourage people from seeking potentially life-saving testing. Without legal protections, individuals could face higher rates or even denial of coverage based on genetic predispositions rather than actual medical conditions. This bill upholds the principle that genetic information should remain private and not be used as a tool for financial discrimination.

Furthermore, SB0757 promotes fairness and equity by preventing insurance companies from disproportionately targeting individuals based on factors beyond their control. Genetic predisposition does not guarantee the development of a disease, and using such information to determine insurance coverage reinforces systemic inequalities in healthcare and financial security. By prohibiting the use of genetic data in insurance decisions, Maryland ensures that individuals are judged based on their actual health status rather than predictive genetics. This legislation fosters a more inclusive and just healthcare system, empowering individuals to pursue genetic testing without fear of negative consequences.

Until life insurance, long term care, and disability insurances have the data to use genetic information to accurately assess risk, both as a risk factor and a mitigating factor, Marylanders need the statutory protections afforded by SB0757. This is the only way to ensure that all Marylanders can comfortably choose to receive life-saving genetic information. At the University of Maryland School of Medicine, we are dedicated to providing the best medical care to our patients and their families. Therefore, we urge a favorable report on SB0757.

Sincerely,

Shannan M Dixon

Shannan M. Dixon, MS, PhD, LCGC
Assistant Professor
Department of Pediatrics
Director, Master's in Genetic Counseling Program
University of Maryland School of Medicine
685 W. Baltimore St.
MSTF 314
Baltimore, MD 21201
sdelany@som.umaryland.edu

SB757_NFB_FAV

Uploaded by: Sharon Maneki
Position: FAV

Favorable SB757/HB1007: Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)

Date: February 20, 2025

From: National Federation of the Blind of Maryland
15 Charles Plaza, #3002

President@nfbmd.org

To: Finance Committee

The members of the National Federation of the Blind of Maryland urge the Senate Finance Committee to definitely vote in favor of Sb757/HB1007. This bill prohibits discrimination in genetic testing and services by life insurance, long term care insurance and disability insurance.

There are some causes of blindness that have a genetic component such as Retinitis Pigmentosa and Leber Congenital Amaurosis. Prohibiting discrimination by insurance is the right thing to do. Insurance companies can either deny coverage altogether or force the customer to pay a higher price. Using genetic testing in this way is both unfair and unjust.

Please vote yes on SB757 and HB1007. Since genetic testing is becoming more prominent it is necessary for this bill to become law.

FORCE Testimony SB 0757 Stefani Read - Google Docs

Uploaded by: Stefani Read
Position: FAV

SB 0757 - FAV
Written Testimony

To whom it may concern:

My name is Stefani Read currently residing in Westminster, Maryland and I volunteer as both a Peer Navigator and Patient Advocate Leader with FORCE.

FORCE (Facing Our Risk of Cancer Empowered) is a national nonprofit organization dedicated to empowering the millions of individuals and families facing hereditary cancers. Its community includes people with BRCA, ATM, PALB2, CHEK2, PTEN, or other inherited gene mutations and those diagnosed with Lynch syndrome. We accomplish this through education, support, advocacy and research efforts. Visit FORCE's website at www.facingourrisk.org for more information about our mission and hereditary cancers.

I am writing to you today to ask you to support HB 1007. Research shows that inherited genetic mutations play a major role in approximately 10-15% of cancers, including breast, ovarian, prostate, pancreatic, and colorectal cancers. While the BRCA1 and BRCA2 mutations may be the most well-known, there are dozens of other hereditary genetic mutations that increase cancer risk. As the saying goes, knowledge is power - and we are worried that folks with identified mutations may be discriminated against by insurers.

As the saying goes, knowledge is power - and we are worried that folks with identified mutations are being discriminated against by insurers. I am personally familiar with the reality of this discrimination as I am BRCA1+ myself. I learned of my genetic mutation after losing family members to cancer and watching others fight their battles up to this very day. While completing the genetic testing process, I was openly warned many times that my positive status could impact my ability to find insurance coverage, particularly for life insurance. I even had to sign a paper attesting that I had been told about this risk due to the severity of the possibility of being denied coverage.

Although folks like me may be at higher risk of cancer, we do not deserve to be denied or overcharged for care. The reality is that this discrimination exists to such a degree that it is used as a cautionary block for those seeking testing. The warnings of denied coverage given pre-genetic testing may scare patients away from getting the information about their mutation that could save their lives.

With your help passing SB 0757 we can help all Marylanders like me live longer, healthier, and hopefully cancer-free lives. I thank you for your support and I am always available to discuss this further.

Thank you for your time,

Stefani Read

Patient Advocate Leader, FORCE
797 Mountain View Drive
Westminster, MD 21157

SB 757 - LOS - UMMS.pdf

Uploaded by: Will Tilburg
Position: FAV

UNIVERSITY of MARYLAND
MEDICAL SYSTEM

Senate Bill 757 – Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)

POSITION: Support
February 26, 2025
Senate Finance Committee

The University of Maryland Medical System ("UMMS") respectfully submits this letter of support to Senate Bill 757 – Genetic Testing – Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act).

UMMS provides primary, urgent, emergency and specialty care at 12 hospitals and more than 150 medical facilities across the state. The UMMS network includes academic, community and specialty hospitals that together provide 25% of all hospital-based care in Maryland. Our acute care and specialty hospitals are located in 13 counties and Baltimore City, and serve urban, suburban and rural communities.

The University of Maryland Medical Center's Neuromuscular Program provides specialty comprehensive-specialist care for patients with amyotrophic lateral sclerosis ("ALS", or "Lou Gehrig's disease"), muscle disease, myasthenia gravis, and peripheral neuropathy. The hospital also houses an interdisciplinary ALS Clinic, managed in partnership with the ALS Association and the Muscular Dystrophy Association. Here, patients can meet with doctors, nurses, therapists and nutritionists, who collaborate to address medical issues, treat symptoms and provide resources and referrals for ongoing care. Additionally, ALS patients have access to augmentative alternative communication (AAC) devices that assists patients connect with their families and care providers.

Since 2019, UMMS has counseled hundreds of patients who have taken genetic testing panels for the purposes of diagnosis and screening for these diseases. UMMS and its neuromuscular specialists support this bill to protect the rights of patients to be informed of their genetic risks, while also protecting them against unheeded discrimination to obtain reasonable insurance policies. Patients are increasingly undergoing genetic testing due to improved affordability and increasing awareness and information regarding genetic diseases. Asymptomatic patients should not have these results be used against them when determining their eligibility for various

UNIVERSITY OF MARYLAND MEDICAL SYSTEM
University of Maryland Medical Center • University of Maryland Medical Center Midtown Campus •
University of Maryland Rehabilitation and Orthopaedic Institute • University of Maryland Baltimore Washington Medical Center •
University of Maryland Shore Regional Health – University of Maryland Shore Medical Center at Easton -
University of Maryland Shore Medical Center at Chestertown - University of Maryland Shore Medical Center at Dorchester –
University of Maryland Shore Emergency Center at Queenstown •
University of Maryland Charles Regional Medical Center • University of Maryland St. Joseph Medical Center •
University of Maryland Upper Chesapeake Health System – University of Maryland Upper Chesapeake Medical Center -
University of Maryland Harford Memorial Hospital •
University of Maryland Capital Region Health – University of Maryland Bowie Health Center –
Mt. Washington Pediatric Hospital

insurance policies. Even if a patient does carry a genetic mutation, it is not a guarantee that they will become disabled or have their lifespan shortened from the disease. Therefore, this information should not be used against the patient in a policy analysis performed by an insurance carrier.

For these reasons, the University of Maryland Medical System supports SB 757, and respectfully requests a ***favorable*** report on the bill.

For more information, please contact:
Will Tilburg, VP, Government and Regulatory Affairs
University of Maryland Medical System
William.tilburg@umm.edu

DOCS-#238933-v1-SB_757_Genetic_Testing_OPPOSED_Lea

Uploaded by: Matthew Celentano

Position: UNF

The League of Life
and Health Insurers
of Maryland

15 School Street, Suite 200
Annapolis, Maryland 21401
410-269-1554

February 26, 2025

The Honorable Pam Beidle
Chair, Senate Finance Committee
3 East
Miller Senate Office Building
Annapolis, MD 21401

Senate Bill 757 – Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)

Dear Chair Beidle,

The League of Life and Health Insurers of Maryland, Inc. respectfully opposes **Senate Bill 757 – Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act)** and urges the committee to give the bill an unfavorable report.

It is critical to understand that underwriting is a fundamental principle that keeps insurance affordable. A life insurer has only one opportunity to evaluate risk before a policy is issued and remains in place for *decades* or more. Once a policy is in place, an insurer cannot cancel it or raise premiums because of subsequent health information or test results. Proper risk classification ensures the solvency of insurers and their ability to pay claims for all policyholders. For this reason, it is very important that life insurers have access to accurate and complete information about an applicant's health, including their full medical record, which may include genetic information and family medical history. It is also important to note that no life insurance company would ever request that a potential beneficiary take a genetic test. These are also voluntary products Marylanders choose to purchase.

Although genetic testing is relatively new, underwriting based on family history is a long-standing practice in Maryland and in all other states. **No other state prohibits underwriting based on family medical history**.

An unintended consequence of Senate Bill 757 could be adverse selection, which occurs when an applicant has information—such as genetic information—that increases their risk, but they do not disclose that information to the insurer. This results in the insurer assigning the applicant to a lower risk pool than it would if it had all relevant information. Adverse selection may lead to increased premiums for *all* risk classes and decreased availability of coverage. To avoid adverse selection, there must be a level playing field of information between the applicant and the insurer.

Advances in genetic science are improving health care in America, by giving doctors a better picture of their patients' true medical conditions. These advances improve doctors' ability to treat their patients; they also empower consumers to better control their health and their lives overall. To the extent that genetic testing provides the opportunity for a patient to undergo preventive or ongoing medical care to address a previously unknown condition, insurers may incorporate these results into their underwriting to benefit policyholders.

League members are committed to a robust and competitive insurance market that offers a variety of products that are affordable and meet consumers' insurance needs. Life insurance companies have been able to provide affordable coverage because applicants have shared with consent their complete medical records. It only makes sense that if a life insurance company is going to make a long-term promise, it knows an applicant's true health condition.

Maryland consumers have long benefitted from the accuracy, transparency, and confidentiality in the underwriting process. Prohibitions such as those contained in Senate Bill 757 would result in higher prices and fewer choices for Maryland consumers.

Maryland has a robust marketplace that enables competition and affordable options. Life insurance continues to be the most utilized retirement security approach, and Senate Bill 757 has the potential to upset the market in such a fashion that Marylanders rely on their affordable life insurance product for long term financial peace of mind for themselves and their families might find more limited choice of products.

For these reasons, the League urges the committee to give Senate Bill 757 an unfavorable report.

Very truly yours,

Matthew Celentano
Executive Director

cc: Members, Senate Finance Committee

SB 757 - MIA - LOI.pdf
Uploaded by: Marie Grant
Position: INFO

WES MOORE
Governor

ARUNA MILLER
Lt. Governor

Maryland
INSURANCE ADMINISTRATION

MARIE GRANT
Acting Commissioner

JOY Y. HATCHETTE
Deputy Commissioner

DAVID COONEY
Associate Commissioner
Life and Health Unit

200 St. Paul Place, Suite 2700, Baltimore, Maryland 21202
Direct Dial: 410-468-2471 Fax: 410-468-2020
1-800-492-6116 TTY: 1-800-735-2258
www.insurance.maryland.gov

Date:	**February 26, 2025**
Bill # / Title:	**Senate Bill 757 - Genetic Testing - Health Insurance - Preventive Services - Enforcement Authority**
Committee:	**Senate Finance Committee**
Position:	**Letter of Information**

The Maryland Insurance Administration (MIA) appreciates the opportunity to provide information regarding Senate Bill 757.

If enacted, Senate Bill 757 will place certain prohibitions on the use of genetic information and genetic testing by carriers offering life insurance, long-term care (LTC) insurance, and disability insurance. Carriers issuing these products would not be permitted to: 1) deny or limit coverage based solely on whether an applicant or policyholder has undergone genetic testing; 2) prohibit a policyholder from undergoing genetic testing; or 3) use a genetic test, the results of a genetic test, genetic information, or a request for genetic services to affect a life insurance, LTC insurance or disability insurance policy in any way, including rejecting, denying, limiting, cancelling, refusing to renew, or increasing the rates.

In 2009, the MIA convened a workgroup on genetic testing in life and disability income (DI) insurance which recommended that the General Assembly amend Maryland statutes to permit insurers to use genetic information when underwriting life and DI insurance, but prohibit insurers from requiring an applicant to undergo a genetic test. To date, the statutes concerning this have not been amended.

Senate Bill 757 is different from previous introductions of similar legislation in that it strikes “inherited characteristics” from the definition of “genetic information,” and clarifies the definition does not include family medical history. The bill adds that carriers may consider an enrollee’s medical diagnosis even if it is based on a genetic test.

The MIA understands that there are concerns from the insurance industry about the impact of this legislation on the pricing and fairness in rating for these products that could result should this legislation pass.

From a technical perspective, the MIA notes that the bill conflicts with the terms of § 18-120 of the Insurance Article. Section 18-120 includes certain prohibitions related to genetic tests and genetic information for LTC insurance that are not wholly consistent with new § 27-909.1, but, importantly, permits the use of genetic tests by carriers of LTC insurance to deny or limit coverage, or change the rate for insurance so long as "the use is based on sound actuarial principles." An amendment would be necessary to either § 18-120 or § 27-909.1 to resolve this conflict.

Another technical issue is that there are different definitions of the terms "genetic information," "genetic services," and "genetic test" in three different state laws that all address genetic information. The inconsistencies between the definitions could contribute to a somewhat confusing regulatory scheme, since the same terms would encompass slightly different types of tests, services, and information, depending on the insurance product. Consistency in definitions across all three statutes would be preferable.

In addition, a minor issue arises from the confusion the proposed bill language creates as to the limitation of the carriers to whom the bill applies. The bill includes a definition of "insurance carriers" and then indicates that it "applies only to life insurance, long-term care insurance, and disability insurance policies or contracts" and prohibits certain actions by "insurance carriers that offer, issue, or deliver a life insurance, long-term care insurance, or disability insurance policy." A more logical way to limit the scope of the bill is to simply indicate that the term "carrier" means an insurance carrier that offers, issues, or delivers a life insurance, long-term care insurance, or disability insurance policy.

Finally, while Section 2 of the bill indicates that the Act takes effect on October 1, 2025, the bill is missing the standard applicability effective date clause, which would indicate that the bill applies to policies and contracts issued, delivered, or renewed in the State on or after a specified date.

Thank you for the opportunity to provide this letter of information. The MIA is available to provide additional information and assistance to the Committee.