

SB0142_FAV_MedChi_Genetic Testing Protection Act o

Uploaded by: Danna Kauffman

Position: FAV



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TO: The Honorable Pamela Beidle, Chair
Members, Senate Finance Committee
The Honorable Katherine Klausmeier

FROM: Danna L. Kauffman
Pamela Metz Kasemeyer
J. Steven Wise
Andrew G. Vetter
Christine K. Krone
410-244-7000

James L. Madara, MD (AMA)
Wes Cleveland (AMA)

DATE: January 31, 2024

RE: **SUPPORT** – Senate Bill 142 – *Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2024)*

The American Medical Association (AMA) and the Maryland State Medical Society (MedChi), the largest physician organization in Maryland, **support** Senate Bill 142. Senate Bill 142 prohibits carriers that offer life insurance, long-term care insurance, and disability insurance policies or contracts from taking certain coverage actions (e.g., denying, limiting, rejecting, increasing rates, etc.) based on whether an applicant or policy or contract holder has requested or undergone genetic testing or the results of the genetic testing.

The increasingly common use of genetic information, both inside and outside of the clinical setting, combined with the negative impact of the fear of genetic discrimination on patient care, make it essential that robust and comprehensive protections against genetic discrimination be enacted. Senate Bill 142 provides such protections in non-health insurance markets and, if enacted, would be a national model for other states to follow.

Genomic-based technologies are becoming an increasingly routine part of medical care. Every newborn, for example, undergoes a panel of genetic tests at birth to detect inherited conditions that are vitally important to treat early in life. Several clinical guidelines now include genetic testing, and the safe and effective use of many drugs requires knowledge of the patient's genotype. Genetic tests are available for risk assessment, diagnosis, and/or management of thousands of diseases. Moreover, whole-genome sequencing is gaining traction as a useful clinical tool. Genomic data is also increasingly common in non-clinical applications. Direct-to-consumer genetic testing companies analyze customers' DNA to reveal information about both medical and non-medical traits, and genealogy services analyze customers' DNA samples to deliver information on genetic ethnicity. With more frequent use of technologies that involve

analysis of patients' genomic information, the potential for misuse and discrimination grows.

Genetic discrimination and fears thereof negatively impact patient care. Knowing that their genetic information may have financial repercussions in insurance markets, some patients avoid seeking genetic counseling or refuse to undergo genetic testing, resulting in serious health implications for individuals for whom genetic testing could be beneficial. Given the rapid advancement of genomic testing available to inform diagnostic and therapeutic decision-making across a wide and growing spectrum of diseases, forgoing genetic testing when appropriate impedes optimal patient care. Even among those who do undergo genetic testing, many withhold test results from their physicians or request that genetic information be withheld from the medical record. This lack of information can have detrimental effects on future care of the patient as treating physicians unfamiliar with the patient will have no record of genetic test results. Moreover, fears of discrimination hinder the open and honest patient-physician communication that is essential in the patient-physician relationship.

The Genetic Information Nondiscrimination Act (GINA), passed by Congress in 2008, is intended to protect individuals from genetic discrimination by health insurers and employers. While GINA has afforded important protections, it left unaddressed a number of areas in which individuals may experience genetic discrimination, including in areas of disability, long-term care, and life insurance. Senate Bill 142 addresses the shortcomings of GINA by extending protections against genetic discrimination with respect to disability, long-term care, and life insurance.

Therefore, enactment of Senate Bill 142 will provide needed protection to patients who are vulnerable to genetic discrimination, help foster patient trust and engagement in cutting-edge genomic based care, and make Maryland a leader in protecting patients from genetic discrimination. The AMA and MedChi urge a favorable vote.

AMA contact:

On behalf of James L. Madara, MD
CEO and Executive Vice President, AMA
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Engle-testimony-SB0142-2024-01-31.pdf

Uploaded by: Ellen Engle

Position: FAV

Good afternoon. Thank you for the opportunity to be here. My name is Ellen Engle. I am a resident of Montgomery County and a life-long Maryland resident. I am also an ovarian cancer patient/survivor and a volunteer Advocate Leader with the Ovarian Cancer Research Alliance. I am here today to urge you to pass the Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024) (SB0142).

For those who may not be familiar with ovarian cancer, it is the deadliest of the gynecologic cancers, and one of the deadliest overall. There is no screening mechanism for ovarian cancer. As a result, 85% of cases are diagnosed at late stages. The available treatments have a low success rate, leading to an overall 5-year survival rate of only 42%.

With no way to effectively screen for ovarian cancer, the latest recommendations are to try to prevent it, if possible. However, what steps a woman should take to do so is dependent on knowing one's genetic risk. A woman who has a BRCA mutation is encouraged to complete child-bearing by the age of 30, and to then have a preventive double mastectomy, complete hysterectomy, and salpingo-oophorectomy (removal of ovaries and fallopian tubes). A woman who does not have a BRCA mutation is encouraged to have her fallopian tubes removed if she is done with child-bearing and is having any other pelvic surgery. The only way to know into which category you personally fall (and therefore what actions to take) is to be tested. Knowledge is power, and gaining that knowledge is the only way for women to be empowered to take the appropriate recommended action.

However, many women are currently hesitant to get tested for fear that they will be discriminated against. They worry that insurance companies will deny them a policy, drop them from a current policy, or raise their rates so high that they will no longer be able to afford it. Even worse, they worry that their employer will find a way to fire them to avoid having to pay excessive rates if the insurance company finds out they have an employee with a known genetic risk. As long as these can and do happen, women will continue to eschew testing in order to keep their insurance, their jobs, and their incomes safe, but at the cost of not being able to take the necessary steps to protect their health, and potentially the health of their daughters, granddaughters, and future generations.

I strongly urge you to pass SB0142 and empower the women of Maryland to take the necessary steps to protect their health without jeopardizing their livelihoods or financial security. Thank you.

SB142_GeneticTesting_KennedyKrieger_support.pdf

Uploaded by: Emily Arneson

Position: FAV



DATE: January 31, 2024 **COMMITTEE:** Senate Finance
BILL NO: Senate Bill 142
BILL TITLE: Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2024)
POSITION: Support

Kennedy Krieger Institute supports Senate Bill 142 - Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023).

Bill Summary:

Senate Bill 142 prohibits life insurance, long-term care insurance and disability insurance policies from denying or limiting coverage based on genetic test results.

Background:

Kennedy Krieger Institute is an internationally recognized institution dedicated to improving the lives of children and adults with developmental disabilities and disorders of the brain, spinal cord and musculoskeletal system. The Institute serves over 27,000 patients per year, a significant portion of whom have a genetic basis for their disability. Kennedy Krieger currently employs seven certified genetic counselors, two board-certified medical geneticists, and numerous other physician specialists who utilize genetic testing in their care of their patients.

Rationale:

The rapid growth of medical genetics has affected virtually all areas of medicine. Over the past decade, advances in genomic technology and research have elucidated the genetic basis of a vast array of health conditions including neurodevelopmental disorders. Research has also identified promising pathways to targeted therapeutics. Genetic counselors are vital to translating these discoveries into clinical care and attaining the goal of precision medicine. Identifying the genetic etiology of a patient's medical or neurodevelopmental disorder. It is a standard of care for patients with neurodevelopmental disorders to have genetic testing to identify the etiology of their condition. Results of genetic testing frequently impacts medical management, prognostication, treatment, and family counseling.

Unfortunately, a barrier to uptake of genetic testing is patient/family concern about the risk of genetic discrimination. The federal Genetic Information Nondiscrimination Act (GINA) offers protections against genetic discrimination by employers and health insurance companies, but not other types of insurance. At Kennedy Krieger, we often hear from patients and families we serve that they are hesitant to proceed with genetic testing for fear that doing so would prevent them from qualifying for life, long-term care, or disability insurance in the future. Some ultimately decline genetic testing out of this concern, which negatively impacts their care. Without a genetic diagnosis, patients may not have access to disease-modifying therapeutics, clinical trial participation, and/or medically necessary treatments. Senate Bill 142 covers a critical gap in GINA, by providing protections against genetic discrimination by life, disability, and long-term care insurance. Senate Bill 142 will give patients and families affected by genetic conditions peace of mind when opting to undergo genetic testing, ultimately improving outcomes and access to treatments.

Kennedy Krieger Institute requests a favorable report on Senate Bill 142.

SB 142 - CPD Written Testimony - SUPPORT.pdf

Uploaded by: Hanna Abrams

Position: FAV

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WILLIAM D. GRUHN
Chief
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January 31, 2024

TO: The Honorable Pamela Beidle, Chair
Finance Committee

FROM: Hanna Abrams, Assistant Attorney General
Consumer Protection Division

Heather Forsyth, Deputy Director
Health Education and Advocacy Unit

RE: Senate Bill 142 – Genetic Testing – Prohibitions on Disability, Life, and
Long-Term Care Insurance (Genetic Testing Protection Act of 2024)
(SUPPORT)

The Consumer Protection Division of the Office of the Attorney General and the Division's Health Education and Advocacy Unit (HEAU) support Senate Bill 142, sponsored by Senator Klausmeier. Senate Bill 142 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 health care 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 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 SB 142 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 SB 142 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 Consumer Protection Division and HEAU believe that Senate Bill 142 would help to protect Maryland citizens from discrimination based upon the results of genetic testing and respectfully requests that the Senate Finance Committee return a favorable report on Senate Bill 142.

cc: The Honorable Katherine Klausmeier
Members, Finance Committee

The GTPA Coalition Written Testimony.pdf

Uploaded by: Jenna Sublett

Position: FAV

The GTPA Coalition

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

January 31, 2024

The Honorable Chairwoman Beidle, Vice Chairwoman Klausmeier, and Members of the Finance Committee

RE: SB 142 – The Genetic Testing Protection Act of 2024

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 and Educational Materials (Genetic Testing Protection Act of 2024).

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 4 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 or 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

TRIG
CANCER®

FORCE
Facing Hereditary Cancer EMPOWERED

 American Kidney Fund®
FIGHTING ON ALL FRONTS

Susan G.
Komen®

OCRA
ovarian cancer
research alliance


NPAM
NURSE PRACTITIONER
Association of Maryland

PTEN
Hamartoma
Tumor
Syndrome
Foundation


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GENETIC
COUNSELORS


THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

LI-FRAUMENI SYNDROME

LFSA
ASSOCIATION

John Knowles GTPA Testimony 2024 Final.pdf

Uploaded by: John Knowles

Position: FAV

Good afternoon, Chairwoman Beidle and Members of the Finance Committee:

Thank you for the opportunity to speak with you today about SB 142, the Genetic Testing Protection Act. This important piece of legislation could save the lives of future generations, potentially including my relatives and children. My name is John Knowles, my wife Teri was diagnosed with ALS in March of 2021. Her identical twin sister Mary died from ALS in 2013 and her sister Patty died from it in 2020.

When Mary was diagnosed there was no history of ALS in our family. Diagnosis was done through a process of elimination as there are no blood tests or any tests (for that matter) that confirm the diagnosis. There are, however, genetic tests that indicate a person may have a gene that is linked to ALS, but even these tests only provide a possibility.

Teri comes from a family of 7 sisters. All were married and together produced 16 children and currently a next generation of 5 children with 2 on the way, including our first grandchild. The children (including my own) are all at the time in their lives when they are marrying and adding to the family. Several of them have undergone genetic testing but most of them have not. It is sobering when the geneticist doing the testing warns you that if you carry a gene defect linked to ALS, it will likely cause you to either pay higher life insurance rates or to be denied insurance altogether. So, they suggest, if you are contemplating getting life insurance, you should get it before you get tested.

Back in 2009 when Mary was diagnosed, the prognosis was bleak and there was only one drug available to help slow the progress of ALS. Today I am happy to share there are 3 approved drugs to slow the process and that there are numerous drugs under development (and) in various stages of testing that show promise on slowing and hopefully curing the disease. We are teetering on the pinnacle of so many companies and researchers finding a cure.

Some of these treatments may one day be used to treat non-symptomatic patients who have one of the genetic defects. But without genetic testing, Maryland citizens who could get early proactive treatment won't because they've put it off due to concerns about being able to get life insurance.

Today my wife Teri is slowly getting weaker. Last year she attended these hearings but this year she is homebound. The progression of her disease is following the same path we saw in Mary and Patty. She is on three of the drugs approved to slow the disease. She is part of the new Silence ALS program that will develop experimental personalized therapies to treat patients with rare genetic forms of ALS. This may not come in time. Teri recognized early onset of the disease because she is a physical therapist who also helped care for her two sisters as ALS took away their strength and the ability for their muscles to work. After her second sister Patty was diagnosed, it was evident that it was the familial version and since Teri shared identical DNA with her twin, we knew she had the genetic defect even without genetic testing. It was a major factor in both of us retiring early to have as many years together as possible.

I mentioned earlier that some of our relatives have undergone genetic testing. They did this in order to be involved in a national study that is following relatives of patients with familial ALS to try and learn why some people develop it and others don't. With that said, they underwent testing knowing that it may have a negative impact on them (but hopefully will assist with finding a cure). For our family and others like us, passing of this legislation will take away one worry and it will provide an avenue for those who want to take genetic testing to discover if they have a gene defect to be open to being involved in studies and future treatments to prevent them from developing this debilitating disease.

As someone who has been impacted by insurance companies canceling insurance due to my wife's diagnosis, I can share that my life already has enough complications without an insurance company, that has profited from my premiums, deciding that her diagnosis should allow them to cancel our policy.

Last year one of the people against this legislation told us if this is passed, everyone with a defect will get as much insurance as they can afford. When Teri and I retired, we followed the suggestion of our financial advisor and canceled our life insurance since we did not need it to pay for our home or our burial. Not everyone is as mercenary as some people believe.

I'll close by simply saying...if you, your family, or friends have never been impacted by a diagnosis of ALS, be thankful – watching your loved one slowly

become weaker, eventually losing strength in every body muscle – is heartbreaking.

Thank you for taking the time to listen to our story and for your support for this important legislation.

Kuldip-Dave_ALS-Association_GTPA-Testimony_013024.

Uploaded by: Kuldip Dave

Position: FAV

January 30, 2024

The Honorable Pamela Beidle
Chair, Senate Finance
Room 3 East Wing, Miller Senate Office Building,
11 Bladen Street, Annapolis, MD 21401-1991

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

RE: SB 142 – The Genetic Testing Protection Act of 2024

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 142: The Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024), but most importantly, in support of the more than 220 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.

One of the greatest scientific achievements of our time was mapping the human genome, a project that was 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 benefits of genetic science.

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. ALS is a devastating neurodegenerative disease that progressively robs people of their ability to move, speak, eat, and eventually breathe. There is no way to stop or reverse this deterioration once it starts, meaning that most people only live for 2–5 years after being diagnosed.

Although there is still no cure, we are living in an era of unprecedented change in ALS care catalyzed by the knowledge we've gained about the genetic underpinnings of the disease. 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*, which is the second-most common cause of familial ALS. The most prevalent *SOD1* gene mutations in North America are associated with younger age of onset and shorter survival.

¹ Lakhani, C.M., Tierney, B.T., Manrai, A.K. *et al.* Repurposing large health insurance claims data to estimate genetic and environmental contributions in 560 phenotypes. *Nat Genet* **51**, 327–334 (2019).
<https://doi.org/10.1038/s41588-018-0313-7>

Last year, families devastated by *SOD1*-ALS were given new hope when the Food and Drug Administration approved the first genetically targeted treatment for ALS. 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. Because of this, only people with a *SOD1* mutation can benefit from taking this drug, thereby underscoring the importance of genetic testing for people living with ALS.

Increasing Importance of Genetic Testing for ALS

With the approval of tofersen, at least 10 other therapies targeting ALS-linked genes being tested in clinical trials, and almost a dozen more being developed preclinically, genetic testing is being recognized as a vital part of ALS clinical management. According to new evidence-based consensus guidelines published last year in the *Annals of Clinical and Translational Neurology*, everyone living with ALS should be offered genetic counseling and testing.²

Genetic testing results not only have implications for people living with ALS but also 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 tofersen 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 this research could provide to individuals and the entire ALS community, it is difficult and time-consuming to recruit participants because 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 people say they don't get tested.

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.

² Roggenbuck, J., Eubank, B.H.F., Wright, J. *et al.* Evidence-based consensus guidelines for ALS genetic testing and counseling. *Ann Clin Transl Neurol* **11**, 2074-2091 (2023). <https://doi.org/10.1002/acn3.51895>

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 Klausmeier for introducing this legislation and to the members of the Senate Finance Committee for your time and consideration.

Sincerely,

Kuldip Dave, Ph.D.
Senior Vice President, Research
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Lindsay Gill_MD GTPA_Written Testimony_2024.pdf

Uploaded by: Lindsay Gill

Position: FAV



January 30, 2024

The Honorable Pamela Beidle
Chair, Senate Finance
Room 3 East Wing, Miller Senate Office Building,
11 Bladen Street, Annapolis, MD 21401-1991

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

RE: SB 142 – The Genetic Testing Protection Act of 2024

Position: SUPPORT

My name is Lindsay Gill and I am the Managing Director of Advocacy at the ALS Association. I am writing today in support of SB 142: The Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024).

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. Our bill does not prevent insurers from accessing an individual's medical record as part of an application exam.

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.

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.

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 Klausmeier for introducing this legislation and to the members of the Senate Finance Committee for your time and consideration.

Sincerely,

A handwritten signature in cursive script that reads "Lindsay Gill".

Lindsay Gill
Managing Director, Advocacy
The ALS Association
Lindsay.Gill@als.org

SB142_Comments_Written.pdf

Uploaded by: Lisa Schlager

Position: FAV



Facing Hereditary Cancer EMPOWERED

January 30, 2024

RE: SUPPORT SB 142 – The Genetic Testing Protection Act of 2024

Chairman Lam and Esteemed members of the Senate Finance Committee,

We appreciate the opportunity to comment on Senate Bill 142, which would ensure that Maryland residents are protected from genetic discrimination in life, long-term care and disability insurance.

FORCE is a national nonprofit that advocates for people facing hereditary cancers. The majority of our constituents carry an inherited genetic mutation that increases their risk of cancers including breast, ovarian, prostate, pancreatic and colorectal cancer. Our organization and the Maryland residents we serve strongly support SB142.

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.

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 poster children 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 it that 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 the 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. People with knowledge of their predisposition to disease are empowered to take measures to mitigate that risk.

The insurers state 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 SB142 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 Schlager
Vice President, Public Policy
PH: 301-961-4956
Email: lisas@facingourrisk.org

MGA2024 -SB142-FAV-MDAC.pdf

Uploaded by: Liz Zogby

Position: FAV



Senate Education, Energy, and the Environment Committee
SB 142: Genetic Testing Protection Act of 2024
January 30, 2024
Position: Support

The Maryland Down Syndrome Advocacy Coalition (MDAC) is a coalition of the five Down syndrome organizations in Maryland as well as individuals with Down syndrome and their family members who have come together to advocate for improved quality of life for all individuals with Down syndrome throughout the state of Maryland. MDAC works in coalition with other disability and advocacy organizations across the state and supports many legislative and policy efforts.

MDAC supports SB 142, which would prohibit insurance carriers that offer, issue, or deliver life insurance policies from rejecting, denying, or limiting a life insurance, long-term care insurance, or disability insurance policy or contract based on genetic information. Currently, individuals with Down syndrome are routinely denied the opportunity to purchase life insurance, based on their genetic variation irrespective of age, health or medical history, or other factors.

Down syndrome is “one of the most common genetic variations and occurs in approximately one in every 700 live births in the United States. For most people, each cell in the body has 23 pairs of chromosomes. One chromosome in each pair comes from the mother and the other comes from the father. But sometimes, during cell division, an extra copy of the 21st chromosome is present.”¹ There are three types of Down syndrome: Trisomy 21 (i.e., three copies of the chromosome 21), translocation Down syndrome (i.e., part or all of a third copy of chromosome 21 is attached to a different chromosome), and mosaic Down syndrome (i.e., some cells have three copies of chromosome 21 and some have two copies).

Due largely to medical advances and shifts in societal attitudes, the life expectancy of individuals with Down syndrome has increased significantly in recent decades, with the majority living upwards of 60 or 70.² In the United States, an increasing number of adults with Down syndrome live independently, or with limited assistance from family members or the state. Some students who have Down syndrome can graduate from high school, and some attend post-secondary education.³ To deny life insurance solely on the basis of their chromosomal difference is unjust. For these reasons, MDAC believes SB142 would positively impact our community and is pleased to support it.

Respectfully submitted,

Liz Zogby
Maryland Down Syndrome Advocacy Coalition
katzogby@gmail.com, 443-691-1755

¹ National Down Syndrome Congress, “What is Down syndrome?” <https://www.ndscenter.org/programs-resources/what-is-down-syndrome/>

² Ibid.

³ Global Down Syndrome Foundation, “Misconceptions vs. Reality” <https://www.globaldownsyndrome.org/about-down-syndrome/misconceptions-vs-reality/>

2024 MOTA SB 142 Senate Side.pdf

Uploaded by: Michael Paddy

Position: FAV



Maryland Occupational Therapy Association

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

Committee:	Senate Finance Committee
Bill Number:	Senate Bill 142
Title:	Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024)
Hearing Date:	January 31, 2024
Position:	Support

The Maryland Occupational Therapy Association (MOTA) supports Senate Bill 142 – *Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024)*. 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 people being able 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.

2024 TCC SB 142 Senate Side.pdf

Uploaded by: Michael Paddy

Position: FAV



THE COORDINATING CENTER
INSPIRED SOLUTIONS

Committee: Senate Finance Committee

Bill Number: Senate Bill 142 - Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024)

Hearing Date: January 31, 2024

Position: Support

The Coordinating Center supports Senate Bill 142 - Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024). 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 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.

01.31.24 MD Testimony S.B. 142.pdf

Uploaded by: Zach Hardy

Position: FAV



Wednesday, January 31, 2024
Maryland Senate Finance Committee
S.B. 142 – Genetic Testing Protection Act of 2024 (SUPPORT)

Chair Beidle, Vice Chair Klausmeier, and members of the Senate Finance Committee - on behalf of The Michael J. Fox Foundation for Parkinson's Research (MJFF), I write in support of **S.B. 142**, which would 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.

Founded in 2000, MJFF has been singularly dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today. To date, MJFF has funded nearly \$2 billion in global Parkinson's research.

The Genetic Information Nondiscrimination Act (GINA) is a federal law that prohibits health insurers from using information learned through genetic testing, such as a gene mutation linked to neurological disorders, to deny coverage or engage in price discrimination. GINA protections, however, do not apply to life insurance, long-term care insurance, and disability insurance policies.

Currently, there are 13 states that have an extension of GINA, otherwise known as GINA 2.0, which expands protections to include life insurance, long-term care, or disability insurance. In 2008, Maryland passed H.B. 29, which prevented long-term care insurers from discriminating based on genetic information. The goal of the Genetic Testing Protection Act of 2024 is to bring life insurance and disability insurance up to the same standard and prohibit those insurers from canceling, limiting, increasing premiums, or denying coverage based on genetic information.

There are estimated to be more than 1 million Americans currently living with Parkinson's disease, with about 90,000 more diagnosed each year.¹ According to the Centers for Disease Control and Prevention, Parkinson's disease is the second most common and the fastest-growing neurological disorder worldwide.

MJFF recognizes that genetic testing can help identify changes in our DNA that may be linked to Parkinson's disease. A person's decision to learn their genetic status is a personal decision, but the results may help them make proactive health care choices and advance science closer to cures. Currently, genetic testing for Parkinson's disease is primarily for research, and not care. MJFF, however, is opposed to any genetic information being used to penalize patients seeking specific insurance coverages, including life insurance, long-term care insurance, and disability insurance.

¹ "New Study Shows the Incidence of Parkinson's in the U.S. Is Nearly 50 Percent Higher than Previous Estimates." The Michael J. Fox Foundation for Parkinson's Research | Parkinson's Disease, 15 Dec. 2022, <https://www.michaeljfox.org/news/new-study-shows-incidence-parkinsons-us-nearly-50-percent-higher-previous-estimates>.

For these reasons, MJFF strongly supports **S.B. 142**. I urge this committee to favorably vote on this important piece of legislation and look forward to seeing it move forward. If you have any questions, please do not hesitate to contact me at zhardy@michaeljfox.org or 202-638-4101, ext. 225.

Sincerely,

A handwritten signature in black ink, appearing to read "Z Hardy". The signature is stylized with a large, sweeping initial "Z" and a cursive "Hardy".

Zach Hardy
State Government Relations Officer

DOCS-#234150-v1-SB_142_Genetic_Testing_Opposed.pdf

Uploaded by: Matthew Celentano

Position: UNF



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

January 31, 2024

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

**Senate Bill 142 – Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance
(Genetic Testing Protection Act of 2024)**

Dear Chairman Griffith,

The League of Life and Health Insurers of Maryland, Inc. respectfully **opposes** *Senate Bill 142 – Genetic Testing – Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2023)* 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 SB 142 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 SB 142 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 SB 142 has the potential to upset the market in such a fashion that Marylanders that 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 142 an unfavorable report.

Very truly yours,

A handwritten signature in black ink, appearing to read "Matthew Celentano", with a long horizontal flourish extending to the right.

Matthew Celentano
Executive Director

cc: Members, Senate Finance Committee

SB 142 - ACLI Letter of Opposition.pdf

Uploaded by: Vincent Ryan

Position: UNF

January 31, 2024

The Honorable Pam Beidle
Chair
Senate Finance Committee
Maryland State Senate
Miller Senate Office Building, 2 East Wing
11 Bladen St
Annapolis, MD 21401

Re: **Senate Bill 142 – Genetic Testing Protection Act of 2024**

Dear Madam Chair:

I write on behalf of the American Council of Life Insurers (“ACLI”) to express our opposition to Senate Bill 142 (“SB 142”) that is currently before the Senate Finance Committee. For the reasons outlined below, we respectfully ask that this bill be reported unfavorably from this Committee.

The American Council of Life Insurers is the leading trade association driving public policy and advocacy on behalf of the life insurance industry. Ninety million American families rely on the life insurance industry for financial protection and retirement security. ACLI’s member companies are dedicated to protecting consumers’ financial wellbeing through life insurance, annuities, retirement plans, long-term care insurance, disability income insurance, reinsurance, and dental, vision and other supplemental benefits. ACLI’s 290 member companies represent 94 percent of industry assets in the United States.

Each day, life insurers pay out \$12.9 million in life insurance and annuities to Maryland families and businesses, helping Maryland families secure the things that matter most through all stages of life. Our mission is to financially protect families by embracing opportunities to issue coverage to as many consumers as possible.

With respect to SB 142, 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.

An unintended consequence of SB 142 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.

ACLI 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 SB 142 would result in higher prices and fewer choices for Maryland consumers.

Thank you for your time, and please do not hesitate to contact me with questions.

Sincerely,

A handwritten signature in black ink that reads "Vincent J. Ryan" followed by a horizontal line.

Vincent J. Ryan
American Council of Life Insurers
Regional Vice President—State Relations
202-624-2452
vincentryan@acli.com

SB0142 - MIA - LOI - FINAL.pdf

Uploaded by: Kathleen Birrane

Position: INFO

WES MOORE
Governor

ARUNA MILLER
Lt. Governor



KATHLEEN A. BIRrane
Commissioner

TAMMY R. J. LONGAN
Acting Deputy Commissioner

200 St. Paul Place, Suite 2700, Baltimore, Maryland 21202
Direct Dial: 410-468-2215 Fax: 410-468-2204
Email: david.cooney@maryland.gov
1-800-492-6116 TTY: 1-800-735-2258
www.insurance.maryland.gov

Date: January 31, 2024

Bill # / Title: Senate Bill 142 – Genetic Testing - Prohibitions on Disability, Life, and Long-Term Care Insurance (Genetic Testing Protection Act of 2024)

Committee: Senate Finance Committee

Position: Letter of Information (LOI)

The Maryland Insurance Administration (MIA) appreciates the opportunity to provide the Committee with information regarding Senate Bill 142.

If enacted, Senate Bill 142 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. Specifically, under a new § 27-909.1 of the Insurance Article,¹ 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.

Section 27-909 currently imposes many of the same prohibitions on insurers, non-profit health service plans, and HMOs, but expressly exempts life insurance, LTC insurance, and disability insurance from those prohibitions. In 2009, the Maryland General Assembly asked the MIA to convene a Workgroup on Genetic Testing to explore the use of genetic information and genetic testing in disability insurance and life insurance. The MIA issued a report in December, 2009 to summarize the findings and recommendations of the Workgroup. Although some of the information in the report is outdated due to recent advancements in medicine and genetic research, many of the issues examined by the Workgroup remain relevant to the discussion of Senate Bill 142, including providing the background and rationale for why § 27-909 of the Insurance Article currently exempts life insurance, LTC insurance, and disability insurance from the prohibitions on the use of genetic testing and genetic information. A copy of the complete report is attached to this letter of information.

¹ All statutory references herein are to the Insurance Article, Maryland Annotated Code.

As the Committee considers SB 142, for context, the MIA notes that there are important differences between the three types of insurance impacted by Senate Bill 142 and the products (primarily health insurance products) that are currently subject to the prohibitions under § 27-909 of the Insurance Article. Life insurance, LTC insurance, and disability insurance are products intended to be of long duration that remain in force with guaranteed renewals as long as premium is paid. For these types of insurance, insurers have only one opportunity to evaluate and price a risk that is being insured for decades to come because, *once issued, premium cannot be adjusted based on changes in the health or risk profile of the individual insured.*²

Given that, for these three types of long-duration insurance products, the applicant's health status, as well as their individual and family health history, are not only permissible considerations during underwriting, but are often critical considerations in deciding whether to insure the applicant and, if so, what to charge for that insurance.³ From the standpoint of fiscal responsibility and solvency, it is imperative that carriers price these products correctly at the outset to assure that the amount of premium collected over the life of the policy (and all policies in the aggregate) will be sufficient to cover the claims that are typically made decades after the policies were issued. That requires carriers to consider life expectancy, longevity and an individual's mortality or morbidity risk based on relevant predictive information – which includes information about the individual's health status, health history, family history and, where it exists, genetic information and genetic testing results.

In the current Maryland market, to the MIA's knowledge, no authorized carrier requires or requests applicants to undergo genetic testing as part of the underwriting process. However, where medical underwriting occurs, to the extent results for genetic testing exist in the medical record, carriers writing in the Maryland market do consider this information if it is relevant to their underwriting standards. Doing so actually allows insurers to be more precise and inclusive in underwriting. For conditions with a genetic component, the results of genetic testing may improve an applicant's risk profile. For example, for certain conditions, there may be only a small number of cases where the condition is inherited, while the majority of cases develop without a genetic cause. If such a condition is part of the applicant's family history, a genetic test result showing the absence of gene is a favorable underwriting consideration that helps the consumer in the underwriting process. Consequently, while the MIA appreciates that one of the goals of Senate Bill 142 appears to be to protect individuals with genetic conditions from adverse underwriting decisions, the MIA is concerned that prohibiting insurers from considering the results of genetic tests is more likely to be detrimental to individuals, particularly those who may have a family history of diseases that have both genetic and non-genetic risk factors. Additionally, since life, LTC, and disability insurers would still be permitted to underwrite individuals based on information in the medical record that does not

² For these products, changes in rates can only be made with respect to an entire class based on the underwriting and loss performance of that entire class. This excludes individual life insurance contracts where premiums cannot exceed the maximum in the policy. Typically, the premiums charged at issue may start out lower than increase up to the maximum rates in later years. Accurate underwriting and pricing of individuals according to accurate loss assumptions helps avoid class based rate changes.

³ Not all policies in these lines of business are medically underwritten. For example, group life insurance products offered through employers and in place during the term of employment typically do not require medical underwriting for certain levels of coverage.

have a genetic component, Senate Bill 142 could be viewed as discriminating against those who have diseases that lack a genetic cause.

The MIA also notes that if life insurers, LTC insurers, and disability insurers can no longer consider genetic information or testing results, insurers will likely respond by raising premium rates overall, and by making underwriting standards more stringent for health conditions that lack a genetic cause. Genetic information and testing results, where available, allow insurers that issue long-duration policies where the risk is priced based on long term predictions of life and health status to be more precise in their underwriting and pricing. Insurers have expressed concern about the impact of being unable to identify or price coverage for someone who receives genetic test results and, based on concerns about those results, applies for coverage. Where genetic information and test results already exist within the medical records, prohibiting an insurer from utilizing that data when it is directly relevant to underwriting criteria makes loss predictions less accurate both with respect to the individual being underwritten and, ultimately, with respect to the class as a whole; while carriers cannot change an individual's premium after issuance of these kind of policies, if losses for the class of individuals is higher than projected, the rates can be changed for the class, leading to premium increases for all individuals. Ultimately, removing the current ability of carriers that issue these products blunts the instruments used to underwrite and price equitably and is likely to result in more declinations and higher pricing as a substitute for more precise loss assessment.

At present, the MIA is not able to assist the Committee to quantify the potential impact on rates, because, to the MIA's knowledge, only one state, Florida, has passed legislation that imposes similar (but not quite as broad) prohibitions as those contained in Senate Bill 142 on the life, LTC and disability market. That legislation, which was enacted in 2020, is too new to assess. We note, however, that legislation in Florida is pending that would narrow the prohibitions and allow for consideration of existing genetic information and test results in an applicant's medical records.

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.

Additionally, while the bill defines the terms "genetic test," "genetic services," and "genetic information," there are minor discrepancies between the definitions for these terms in new § 27-909.1, and the corresponding definitions for these terms in existing §§ 18-120 and 27-909. . 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.

Finally, while Section 2 of the bill indicates that the Act takes effect on October 1, 2024, 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.