

February 20, 2025

Delegate Joseline A. Pena-Melnyk  
Chair, Health and Government Operations  
Room 241, House Office Building  
Annapolis, Maryland 21401

The Honorable Chair Pena-Melnyk, Vice Chair Cullison, and Members of the Health and Government Operations Committee:

**RE: HB 1007 – 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 HB 1007: 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 Delegate Wells for introducing this legislation and to the members of the House Health and Government Operations Committee for your time and consideration.

Sincerely,

*Lindsay Jack*

Lindsay Jack  
Managing Director, Advocacy  
The ALS Association