



February 15, 2024

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 982 – 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 HB 982: 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 Delegate Kipke for introducing this legislation and to the members of the House Health and Government Operations 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