



February 16, 2023

The Honorable Joseline Pena-Melnyk
Chair, House Health and Government Operations
Room 241, House Office Building
Annapolis, Maryland 21401

Dear Chairwoman Pena-Melnyk, Vice Chair Kelly, and Members of the Health and Government Operations Committee:

RE: HB 155 – The Genetic Testing Protection Act of 2023

Position: SUPPORT

My name is Neil Thakur, Ph.D. I am the Chief Mission Officer for The ALS Association and a public health scientist living in Rockville, Maryland. I am writing today in support of HB 155: The Genetic Testing Prohibition on Disability, Life, and Long-Term Care Insurance and Educational Materials (Genetic Testing Protection Act of 2023), but most importantly, in support of the 224 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 protections needed to realize the full benefits of genetic science.

In 2019, researchers from Harvard University and the University of Queensland in Australia found that 40% of diseases have a genetic component. This includes ALS. ALS is a devastating disease that progressively robs people of their ability to move, speak, eat, and 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 that either cause or increase a person's risk of developing ALS – 30 of which were discovered in the last decade alone.

It is possible that the first genetically targeted treatment for ALS will be approved this year. At least 10 other therapies targeting ALS-linked genes are being tested in clinical trials with almost a dozen more being developed preclinically. Currently, patients in Maryland are helping test six of these 10 therapies through trials conducted by scientists at Johns Hopkins like Drs. Sarah Berth, Jeffrey Rothstein and Nicholas Maragakis and researchers at the NIH Clinical Center in Bethesda.



One such study underway at Johns Hopkins goes even further. It is trying to prevent ALS from developing – or perhaps delay the onset of the disease – in people with mutations in a gene known as *SOD1* who have no ALS symptoms. *SOD1* was the first gene discovered to be linked to ALS. Imagine if we establish this proof of concept – we could stop ALS before it starts in genetically at-risk individuals and save the economic, societal, and personal costs incurred after the diagnosis of this terrible disease.

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.

The Genetic Testing Protection Act will help allay this fear of discrimination by putting protections in place for accessing life, long-term care, 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 the 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,

Neil Thakur, Ph.D.
Chief Mission Officer
The ALS Association
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