



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:

On behalf of all people living with ALS, including the 224 families we currently serve in Maryland, **we respectfully request your support for House Bill 155: the Genetic Testing Protection Act of 2023.** If passed, life insurance, long-term care insurance, and disability insurance companies operating in the state would not be able to charge higher premiums or refuse to insure a patient that has undergone genetic testing, requested genetic testing, or because of the results of a genetic test.

Amyotrophic lateral sclerosis (ALS), also commonly known as “Lou Gehrig's disease,” is a fatal progressive neurodegenerative disease that slowly robs a person’s ability to walk, talk, eat, and eventually breathe. There is no cure, and we do not know what causes ALS.

The ALS Association is the largest philanthropic funder of ALS research in the world. The Association funds global research collaborations, assists people with ALS and their families through its nationwide network of chapters and certified clinical care centers, and advocates for better public policies for people with ALS. The ALS Association builds hope and enhances quality of life while urgently searching for new treatments and a cure.

At The ALS Association, our goal is to make ALS a livable disease by 2030. Genetic testing is a critical component to understanding the disease, treating the disease, and hopefully preventing the disease.

We do know that at least 10-15% of people with ALS have familial ALS, meaning they have a specific gene mutation that is hereditary. This specific population is unique, and we are seeing clinical trials for gene therapies to treat familial ALS across the country, including here in Maryland at Johns Hopkins. We also know that the more people participate in genetic testing, the more companies are incentivized to invest in gene therapy trials for a variety of rare diseases.

Under federal law, the Genetic Information Nondiscrimination Act (GINA), health insurers are prohibited from using information learned through genetic testing – such as a gene mutations linked to ALS – to deny coverage or engage in price discrimination. Employees are likewise protected from being fired based on genetic tests. But life insurance, long-term care insurance, and disability insurance companies are not covered under GINA.

HB 155 will allay the fear of discrimination that Marylanders may feel when trying to obtain these types of plans. This bill will put protections in place to increase access and affordability of



these plans. Genetic testing and genetic counseling are crucial to people living with ALS and it helps to inform earlier diagnosis, treatment, and important life decisions.

The ALS Association thanks Delegate Kipke for introducing this legislation. Thank you for your time and your consideration. For all these reasons, we respectfully request your support for HB 155.

Sincerely,

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