

## **The ALS Association – DC/MD/VA Chapter Testimony in Favor of SB 910**

I am Matt Salomon, the Government Relations Manager for The ALS Association – DC/MD/VA Chapter and I am here in support of S.B. 910

Amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease, is a fatal progressive neurodegenerative disease that steals the patient's ability to walk, talk, eat, and eventually breathe by attacking nerve cells in the brain and spinal cord, causing loss of muscle control. It is a devastating disease affecting thousands of families across the United States.

Our Chapter estimates ALS currently affects roughly 400 Marylanders at any given time. The World Health Organization expects a 69% increase in ALS diagnoses over the next 20 years. And for unknown reasons, military veterans are nearly twice as likely to be diagnosed with ALS than the general public.

The cost of caring for an ALS patient can exceed \$250,000 a year out of pocket, causing many families to easily blow through retirement accounts and college savings funds. It is one of the most expensive diseases in existence, rivaling Alzheimer's disease. We estimate ALS is costing roughly 400 Maryland families living with ALS, their insurance companies, and taxpayers, a total close to \$100 million per year to care for their loved ones.

This leads me to the importance of passing S.B. 910. We have seen an uptick in investment in innovative and groundbreaking research to find a cure for ALS, thanks in large part to the Ice Bucket Challenge, a viral social media campaign in 2014. But compared to other diseases, like breast cancer, funding pales in comparison. A large part of the problem is that the private sector doesn't have a big incentive to fund the basic research and the expensive early stage clinical trials that can lead to a cure because it is risky. S.B 910 is an innovative way to fill the incentive gap and get companies more involved in this research space.

Finding a cure for this dreadful disease will not only end a tremendous and unacceptable amount of human suffering but will save families and taxpayers billions of dollars in the long run.

Diseases, like ALS, shouldn't have to rely on a once in a lifetime viral social media campaign to fund basic research. I sincerely hope you can join us as an ally in the fight to end ALS and other rare diseases that don't get nearly enough attention or investment.

ALS is not an incurable disease, it's an underfunded one.

Thank you for your time.