

Testimony of Adriana Beltrano in Support of SB 757, The Genetic Testing Protection Act

Good afternoon, Chair Beidle, Vice Chair Hayes, and members of the committee. My name is Adriana Beltrano, and I am a graduate student and instructor at Johns Hopkins University, working toward earning my Master of Fine Arts in Poetry. Yesterday, I turned twenty-four.

In June of 2023, my mother was diagnosed with genetic ALS. Just one month later, I tested positive for a mutation in the SOD1 gene, which causes genetic ALS. This news was devastating for my family.

While I do not know if or when I will begin developing symptoms, I do know that there is a gene-specific treatment for this ALS-related gene—one that has shown signs of stopping disease progression in my mom.

Because I carry this gene mutation, I am not only grappling with the impact ALS has had on my mother, my family, and my own future—I also face the reality that, under current Maryland law, I can legally be denied life insurance, long-term care insurance, and disability insurance based solely on my genetic status.

Knowing my genetic status allows my doctors to monitor me for early signs of ALS, giving me the best possible chance to access treatments when they become available. But this kind of insurance discrimination discourages people from getting tested and taking proactive steps for their health.

At the same time, genetic testing is an incredibly personal and often traumatic decision. People who test positive for a genetic disease while remaining asymptomatic, or who have family members battling these diseases, are already facing unimaginable challenges. The added burden of insurance discrimination is simply unjust.

That is why I strongly support SB 757, the Genetic Testing Protection Act, and I urge you to do the same. This bill will ensure that Marylanders are not penalized for taking charge of their health. I am incredibly grateful to Senator Washington for introducing this critical legislation.

Please do not allow outdated and unfair insurance policies to stand in the way of people like me getting the medical information we need. Thank you for your time and consideration.