

Testimony of Brian Schafer – HB 1007, The Genetic Testing Protection Act

Good afternoon, Chairwoman and Members of the Finance Committee.

Thank you for the opportunity to provide testimony in support of House Bill 1007.

My name is Brian Schafer, and I am the proud father of seven amazing children. I live in Bel Air, Maryland. ALS has taken the lives of four members of my family—my father, sister, aunt, and grandmother.

In two of those cases, I witnessed firsthand as they gradually lost all their physical abilities before ultimately losing their lives. I watched my father struggle to continue providing for his family while barely able to lift his arms. I saw him nearly choke to death at our kitchen table because he could no longer swallow.

I watched my sister, a devoted teacher, use a microphone in her classroom so she could continue teaching for as long as possible before being forced to leave the job she loved. Eventually, her condition declined to the point where I had to feed her—something no brother should ever have to do for his sister. ALS is a cruel, horrific disease that I wouldn't wish on my worst enemy.

I have tested positive for one of the ALS-related genes. Fortunately, I have not developed the disease, but I am under close medical monitoring. If I do begin to show symptoms, early detection will be critical to accessing any available treatments. With ALS, early diagnosis and intervention can make all the difference.

Genetic testing is essential, especially for those with a family history of ALS. It is one of the only ways to have a fighting chance against this disease. Yet, under current law, if any of my children undergo genetic testing and test positive for an ALS-related gene, they could face discrimination and be denied life insurance coverage.

Because of our family history, my children are already at risk of facing higher insurance rates—regardless of whether they ever develop ALS. Denying them coverage based on a genetic test result only adds to this unfair burden.

Life insurance companies have been around for centuries. They have survived economic downturns, wars, and pandemics. Like any other successful business, they adapt to changing conditions. Passing this bill will not ruin the life insurance industry.

As I mentioned earlier, genetic testing, ongoing monitoring, and early access to new treatments are essential in the fight against ALS. Please do not let the fear of being denied life insurance deter my children—or anyone else at risk—from getting tested.

Thank you.