

Good afternoon, Chairwoman Pena-Melnyk, and Members of the Health and Government Operations Committee:

Thank you for the opportunity to speak with you today about HB 982, the Genetic Testing Protection Act. This important piece of legislation could save the lives of future generations, potentially including my relatives and children. My name is John Knowles, my wife Teri was diagnosed with ALS in March of 2021. Her identical twin sister Mary died from ALS in 2013 and her sister Patty died from it in 2020.

When Mary was diagnosed there was no history of ALS in our family. Diagnosis was done through a process of elimination as there are no blood tests or any tests (for that matter) that confirm the diagnosis. There are, however, genetic tests that indicate a person may have a gene that is linked to ALS, but even these tests only provide a possibility.

Teri comes from a family of 7 sisters. All were married and together produced 16 children and currently a next generation of 5 children with 2 on the way, including our first grandchild. The children (including my own) are all at the time in their lives when they are marrying and adding to the family. Several of them have undergone genetic testing but most of them have not. It is sobering when the geneticist doing the testing warns you that if you carry a gene defect linked to ALS, it will likely cause you to either pay higher life insurance rates or to be denied insurance altogether. So, they suggest, if you are contemplating getting life insurance, you should get it before you get tested.

Back in 2009 when Mary was diagnosed, the prognosis was bleak and there was only one drug available to help slow the progress of ALS. Today I am happy to share there are 3 approved drugs to slow the process and that there are numerous drugs under development (and) in various stages of testing that show promise on slowing and hopefully curing the disease. We are teetering on the pinnacle of so many companies and researchers finding a cure.

Some of these treatments may one day be used to treat non-symptomatic patients who have one of the genetic defects. But without genetic testing, Maryland citizens who could get early proactive treatment won't because they've put it off due to concerns about being able to get life insurance.

Today my wife Teri is slowly getting weaker. Last year she attended these hearings but this year she is homebound. The progression of her disease is following the same path we saw in Mary and Patty. She is on three of the drugs approved to slow the disease. She is part of the new Silence ALS program that will develop experimental personalized therapies to treat patients with rare genetic forms of ALS. This may not come in time. Teri recognized early onset of the disease because she is a physical therapist who also helped care for her two sisters as ALS took away their strength and the ability for their muscles to work. After her second sister Patty was diagnosed, it was evident that it was the familial version and since Teri shared identical DNA with her twin, we knew she had the genetic defect even without genetic testing. It was a major factor in both of us retiring early to have as many years together as possible.

I mentioned earlier that some of our relatives have undergone genetic testing. They did this in order to be involved in a national study that is following relatives of patients with familial ALS to try and learn why some people develop it and others don't. With that said, they underwent testing knowing that it may have a negative impact on them (but hopefully will assist with finding a cure). For our family and others like us, passing of this legislation will take away one worry and it will provide an avenue for those who want to take genetic testing to discover if they have a gene defect to be open to being involved in studies and future treatments to prevent them from developing this debilitating disease.

As someone who has been impacted by insurance companies canceling insurance due to my wife's diagnosis, I can share that my life already has enough complications without an insurance company, that has profited from my premiums, deciding that her diagnosis should allow them to cancel our policy.

Last year one of the people against this legislation told us if this is passed, everyone with a defect will get as much insurance as they can afford. When Teri and I retired, we followed the suggestion of our financial advisor and canceled our life insurance since we did not need it to pay for our home or our burial. Not everyone is as mercenary as some people believe.

I'll close by simply saying...if you, your family, or friends have never been impacted by a diagnosis of ALS, be thankful – watching your loved one slowly

become weaker, eventually losing strength in every body muscle – is heartbreaking.

Thank you for taking the time to listen to our story and for your support for this important legislation.