

HB155

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My name is Dr. Sarah Berth, and I am a physician and Assistant Professor in Neuromuscular Medicine at Johns Hopkins Hospital. I see ALS patients in our ALS Multidisciplinary Clinic which is one of the largest in the nation, I am a member of our ALS Clinical Trials Unit, and I also research genetic causes of ALS. ALS is a relentless and fatal neurodegenerative disease robbing patients of their ability to move, speak, swallow, and breath. Mortality for this disease is still within 2-5 years of symptom onset and there is no cure. 10-15% of ALS is inherited, meaning that these patients have a genetic mutation causing ALS. Over 40 mutations have been found that cause ALS, and I expect that more will continue to be discovered.

The treatment landscape is rapidly changing for our patients with genetic causes of ALS. There is now a pipeline of drugs being developed to target the specific genes that cause ALS, which offers tremendous impact to our patients. In fact, one of these such drugs will be undergoing FDA review shortly. These genetic treatments hold great promise that they can provide the possibility of extending life or even halting the progression of the disease. Because of this, expedient genetic testing is absolutely necessary so these patients can be directed to and receive the appropriate treatment in a timely manner before they develop profound disability. This HB155 bill is important because it would help to protect patients and prevent them from having to delay or even forego genetic testing due to concerns about the ability to receive life insurance, long term care or disability insurance. Because of this, as a physician I am strongly in support of House Bill 155 and believe this bill would provide important protections for people with ALS, among many other people who suffer from genetic disease.