

February 16, 2023

RE: HB 155 – The Genetic Testing Protection Act of 2023

Position: SUPPORT

Please note that I am submitting the below comments on behalf of an individual who wishes to remain anonymous due to concerns about genetic discrimination.

~ Lisa Schlager

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Members of the House Health and Government Operations Committee,

Thank you for the opportunity to submit testimony in support of House Bill 155, the Genetic Testing and Protection Act of 2023.

I respectfully ask that you think back to when you were 31, or what you hope your life will be like at that age – personally, professionally, and medically.

I am 31 and have a PTEN syndrome known as Cowden syndrome. When my mother was 31, and purchasing life insurance, she did not know that she had up to an 85% lifetime risk of breast cancer because she did not know about Cowden syndrome. Only three years after she purchased her policy, she passed away from breast cancer. My father buried his soulmate and became a single father at age 31. I was an infant, and my brother was four.

Thankfully, the life insurance payout was more than needed to support our young family. My family, when I have one, likely will not be as fortunate.

As the field of genetics grew, I was eventually diagnosed with Cowden syndrome. Everyone has health risks but knowing about mine set me on a very different path. Knowledge of my genetic predisposition has provided me and my healthcare team with the ability to be very proactive. At age 31, I have already survived three cancers and prevented a fourth.

There are a number of well-known hereditary cancer mutations and syndromes, but it is believed that Cowden syndrome is very underdiagnosed in part because many people have few signs of it until they have terminal cancer.

Despite the medical advances of the past three decades, and the value of the information genetic testing provides, our society still allows genetic discrimination. Understandably, this pressures people to postpone care and to remain unaware of their health risks.

I respectfully request that the committee prioritize Marylanders' lives by deciding to support the Genetic Testing and Protection Act of 2023. Thank you for your time and consideration.