



Facing Hereditary Cancer EMPOWERED

February 16, 2023

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

Position: SUPPORT

Esteemed members of the House Health and Government Operations Committee,

We appreciate the opportunity to comment on House Bill 155, which would ensure that Maryland residents are protected from genetic discrimination in life, long-term care and disability insurance.

FORCE is a national nonprofit that advocates for people facing hereditary cancers. The majority of our constituents carry an inherited genetic mutation that increases their risk of cancers including breast, ovarian, prostate, pancreatic and colorectal cancer. Our organization and the Maryland residents we serve strongly support HB155.

The predisposition to hereditary cancers is passed down through families. Parents who carry a mutation have a 50% chance of passing that mutation on to their children. Hereditary cancers often occur at younger ages. Members of our community also face a greater risk of recurrence and additional primary cancers. Accordingly, national medical guidelines recommend that high-risk individuals undergo more intensive, more frequent cancer screenings starting at younger ages than the general population.

For example, Lynch Syndrome affects approximately 1 in 300 Americans. Associated with five gene mutations (MLH1, MSH2, MSH6, EPCAM and PMS2) Lynch Syndrome causes up to a 60% risk of colorectal cancer and a 50% risk of endometrial cancer. While these are disquieting numbers, the good news is that these cancers can be prevented or detected at an early stage through evidence-based interventions.

National Comprehensive Cancer Network (NCCN) and similar medical society guidelines recommend that individuals with MLH1 and similar mutations begin screening colonoscopy every one to two years between the ages of 20 and 25. If polyps are found, they are removed, which eliminates the chance for the growths to become cancerous.

Similarly, endometrial cancer can often be caught early based on symptom awareness. Regular screening with transvaginal ultrasound and endometrial biopsies, or hysterectomy after completion of childbearing are also options for those at increased risk.

These evidence-based interventions empower high-risk individuals to take control of their health, detecting cancer earlier when it is easier to treat, or preventing it altogether.

The truth is, we don't know why most people get cancer. However, an estimated 10% of Americans carry an inherited genetic mutation that increases their cancer risk. Advances in genetics have made it possible to identify these individuals—and to intervene as appropriate. These are the poster children for prevention and early detection, so why are we penalizing this population?

The Genetic Information and Nondiscrimination Act, a federal law known as GINA, applies to health insurance and employment but falls short of providing comprehensive protections. The fear of being denied or charged significantly higher rates for life, disability and long-term care insurance is real. Many members of our community have experienced this discrimination. In fact, some people refuse genetic testing even though it is medically indicated due to concern it that will impact their ability to get insurance. This doesn't mean they don't have a genetic predisposition to disease; it means they are deliberately choosing to be uninformed for fear of the insurance repercussions.

Nearly every human has a predisposition to some disease or ailment—cancer, heart disease, dementia, diabetes, arthritis, etc. In this era of personalized and precision medicine, we should be rewarding people for being educated and proactive with their health. People with knowledge of their predisposition to disease are able to take measures to mitigate that risk.

With this legislation, we have the opportunity to right a wrong. More than a dozen states have enacted some sort of law that extends GINA protections. Florida, one of the most conservative states in the country, passed a model anti-genetic discrimination law in 2020. Maryland should follow suit and prohibit insurers from canceling, limiting, increasing the premium, or denying coverage based on genetic information.

In summary, we strongly support HB155 and urge you to endorse this legislation, ensuring that all Maryland residents have equal access to the insurance they need.

Thank you for your consideration,

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