



Facing Hereditary Cancer EMPOWERED

February 13, 2024

RE: SUPPORT HB 982 – The Genetic Testing Protection Act of 2024

Dear Chairwoman Pena-Melnyk, Vice Chair Cullison and esteemed members of the House Health Government and Operations Committee,

We appreciate the opportunity to comment on House Bill 982, 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 HB982.

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 80% risk of colorectal cancer and 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.

The National Comprehensive Cancer Network (NCCN) and other 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.

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.

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. 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 empowered to take measures to mitigate that risk.

People diagnosed with cancer and other diseases often face significant out-of-pocket costs for their healthcare. In fact, medical debt has become a leading cause of personal bankruptcy. If an individual is unable to get disability or long-term care insurance, ultimately the state ends up paying for their care.

The insurers state that individuals should simply secure a policy before undergoing genetic testing. Unfortunately, this is not feasible for many people. Genetic testing for a hereditary cancer mutation is often recommended for young adults, ages 18-25, so they can begin the appropriate cancer screenings. Students and people early in their careers are not in a position to purchase life insurance. In addition, insurers require access to the applicant's or insured's medical records. Some members of our community report that their insurance policies were canceled, or premiums significantly increased and coverage was reduced after testing positive for a mutation.

With this legislation, we have the opportunity to right a wrong. More than a dozen states have enacted laws that extend 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 HB982 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,



Lisa Schlager
Vice President, Public Policy
PH: 301-961-4956
Email: lisas@facingourrisk.org