FORCE

Facing Hereditary Cancer EMPOWERED

February 10, 2025

RE: Proponent of SB 476

Dear Chair Beidle, Vice-Chair Hayes and Esteemed Members of the Senate Finance Committee,

On behalf of FORCE (Facing Our Risk of Cancer Empowered), a national nonprofit organization that advocates for families facing hereditary cancers, and the Maryland constituents we represent, please vote in favor of SB 476. This legislation would ensure that individuals in Maryland with a certain personal or family history of cancer have access to guideline-recommended testing to determine if they carry an inherited genetic mutation that significantly increases their cancer risk. For those found to carry a cancer-causing mutation, it would also ensure access to the appropriate high-risk cancer screenings without the burden of cost-sharing.

There has been tremendous progress in cancer prevention, detection, and treatment over the past quarter century. Research shows that inherited genetic mutations play a major role in approximately 10% of cancers, including breast, ovarian, endometrial, prostate, pancreatic, and colorectal.[i] Major cancer organizations, genetics, and medical professional societies including the National Comprehensive Cancer Network (NCCN), American Society of Clinical Oncology (ASCO), and others have established guidelines for genetic testing and management of hereditary cancer risk.

Knowledge Saves Lives

Healthcare providers are encouraged to use evidence-based cancer risk assessment tools to collect information about a patient's personal or family cancer history annually. Adult patients with a personal or family history of cancers who meet genetic testing criteria should be provided or referred for genetic counseling and/or offered genetic testing.

Knowledge of an inherited genetic mutation is instrumental in estimating the chance of an individual developing cancer in their lifetime, predicting the risk of specific cancers, informing family members of their potential cancer risk, and determining if a patient has gene mutations that may pass increased cancer risk to their children. This knowledge also empowers patients to be more proactive with their health, managing their risk with more intensive, more frequent cancer screenings beginning at younger ages than the general population. For example, clinical guidelines recommend that individuals at high risk of breast cancer due to certain genetic mutations start screening with annual breast MRIs at age 25.

Awareness of a genetic mutation that increases the risk of certain cancers also enables potentially lifesaving, risk-reducing procedures, such as bilateral salpingo-oophorectomy (removal of the ovaries and fallopian tubes). This laparoscopic surgery is critical for women at high risk of ovarian cancer because there is no reliable screening or early detection; more than 75% of women are diagnosed with advanced-stage disease (Stage III or IV).[ii] Up to 25% of ovarian cancers are attributable to an inherited genetic mutation.

Existing Coverage
Under federal law, most health insurers are required to cover BRCA genetic counseling and testing with no cost-sharing for women currently not in cancer treatment. This coverage falls significantly short because it doesn't include:

- Men, who carry cancer-related genetic mutations in equal numbers to women, and may be at increased risk of male breast, prostate, pancreatic and colorectal cancers.
- Women currently in cancer treatment, who need genetic testing to guide their treatments and screening for other cancers.
- Testing for the dozens of genetic mutations beyond BRCA1 and BRCA2—ATM, BRIP1, CDH1, CHEK2, PALB2, etc.—known to increase cancer risk.

Similarly, the Affordable Care Act (ACA) facilitates coverage of cancer screenings with no cost-sharing for those at average risk of the disease. Screenings needed by individuals at increased risk of cancer, however, are not addressed. As a result, many of the guideline-recommended cancer screenings for high-risk individuals are not viewed as essential care by health insurers. The cost for these screenings is often applied to a person's deductible or denied altogether.

Ultimately, these patients face a dilemma: forgo the medically appropriate care or shoulder the cost of tests such as colonoscopies every 12-24 months starting at age 25—which can cost thousands of dollars (under the ACA, they are covered with no cost-sharing starting at age 45). Ultimately, this exacerbates health disparities because the least financially stable individuals can't afford the recommended interventions. It also costs the health system more money due to later-stage cancer diagnoses.

Cost for Multigene Genetic Testing
With next-generation sequencing (NGS), the technology used for genetic testing, the cost of looking for a mutation in one gene is the same as that of looking at dozens of genes so the standard practice is multigene panel testing. There is no rational reason to limit coverage with no cost-sharing to just the BRCA genes. The BRCA genes are included in multigene panels, but insurers bill the patient because the panel looks at additional genes as well. This presents an access barrier for many people. It is also a flawed approach that ignores the fact that knowledge of a genetic mutation associated with an increased risk of cancer ultimately saves lives and money because cancers can be caught earlier or prevented altogether.

Cancer and Genetic Mutation Prevalence
Cancer is the second leading cause of death in Maryland (after heart disease). Rates of breast, melanoma, stomach and prostate cancers in Maryland exceed the U.S. average; all are associated with hereditary cancer genes. Genetic testing informs appropriate interventions such as increased screening, so cancers can be prevented or caught early when they are easier and less expensive to treat.

It is estimated that 1 in 300 Americans carry a Lynch Syndrome mutation, associated with up to 80% risk of colorectal cancer and 50% risk of endometrial cancer; 1 in 400 people carry a BRCA genetic mutation, associated with up to 75% risk of breast cancer and 60% risk of ovarian cancer. Yet, there are no laws requiring genetic testing for hereditary cancer risk in Maryland. In contrast, newborn screening for 3-methylcrotonyl-CoA carboxylase deficiency, caused by inherited genetic mutations, is typically covered. This affects only 1 in 50,000 individuals; fewer than 120 infants are born with 3-MCC deficiency each year in the U.S., and some never experience any signs or symptoms of the condition.

The National Cancer Institute (NCI) predicts nearly 10,000 excess deaths in the U.S. from breast and colorectal cancer alone over the next 10 years because of pandemic-related delays in cancer screening and treatment.[iii] Enactment of this bill will inform more people about their cancer risk so they can undertake critical screening and preventive care that may mitigate some of the predicted cancer-related deaths over the next decade and beyond.

In Conclusion

Coverage of recommended genetic testing is crucial to facilitate access and inform Maryland residents about their cancer risks and help them engage in appropriate management of those risks. SB 476 will save lives and healthcare dollars. We urge you and your colleagues to support this lifesaving legislation!

Thank you for your time and consideration. Please contact me should you have any questions.

Sincerely,

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[i] National Cancer Institute, The Genetics of Cancer

[ii] *Am Fam Physician.* 2016 Jun 1;93(11):937-944

[iii] *SCIENCE*. 19 Jun 2020; Vol 368, Issue 6497, p. 1290