2025_Genetic Testing_Written Testimony_SGK.pdf
Uploaded by: Angelica Katz
Position: FAV

Written Testimony Supporting SB 476
Submitted to the Finance Committee
2-12-2025
By Susan G. Komen

Chair Beidle, Vice Chair Hayes and Members of the Committee, thank you for the opportunity to provide testimony in support of SB 476, which relates to coverage of genetic testing for inherited cancer mutations and the recommended screenings based on the results of that testing. My name is Angelica and I am the Regional Manager for State Policy and Advocacy at Susan G. Komen®.

Komen is the world's leading nonprofit breast cancer organization representing the millions of people who have been diagnosed with breast cancer. Komen has an unmatched, comprehensive 360-degree approach to fighting this disease across all fronts—we advocate for patients, drive research breakthroughs, improve access to high quality care, offer direct patient support and empower people with trustworthy information. Komen is committed to supporting those affected by breast cancer today, while tirelessly searching for tomorrow's cures. We advocate on behalf of the estimated 6,270 people in Maryland will be diagnosed with breast cancer and the 830 who will die from the disease in 2025 alone.

Genetic testing can provide important information to breast cancer patients, their family members and their medical providers. Not only do the results from genetic testing help individuals and their family members understand their inherited risk of breast cancer, but they can be a catalyst for patients to access targeted prevention and treatment strategies.

Germline testing is a type of test that looks for inherited mutations that have been present in every cell of the body since birth. These tests use blood, saliva or cheek cells.

Approximately 5-10 percent of breast cancer is inherited, and the lifetime risk of breast cancer is increased 20-49 precent for women with risk gene mutations and 50 percent or higher for women with high-risk gene mutations. Identification of inherited cancer risk can help guide decisions regarding recommended screenings for the early detection of cancer, personalized cancer treatments and risk-reducing medical treatments. Individuals with an inherited mutation often require additional imaging based on their inherited mutation and lifetime risk.

In the past, genetic testing for inherited breast cancer mutations only checked for mutations in BRCA 1 and BRCA 2 genes. Now, it's common to be tested for multiple other moderate to high-risk gene mutations in a practice called panel testing or multi-gene testing. Studies have shown an estimated 83 percent of eligible patients that underwent multi-gene panel testing had changes to their medical management, including modifications in imaging follow-up and chemotherapy strategy.

It is critical that patients with a personal or family history of breast cancer have equitable access to genetic testing and medically recommended screenings in accordance with evidence based, clinical practice guidelines. According to a 2020 American Association for Cancer Research Report, 65 percent of young white women with breast cancer were offered genetic testing, whereas only 36 percent of young Black women with breast cancer were offered this same testing. Additional studies show that under resourced patients were more likely to utilize genetic testing following a cancer diagnosis and less likely following a family history of cancer, resulting in a missed opportunity for mutation detection and cancer prevention for these patients.

By eliminating the cost barrier to genetic testing and evidence-based screenings, all patients will have access to critical information regarding their lifetime cancer risk and ensure they have access to medically recommended early detection and cancer surveillance.

As committed partners in the fight against breast cancer, we know how deeply important it is for all cancer patients to have fair and equitable access to the genetic testing services that may save their lives. As such, we support SB 476 and urge you to pass this critical legislation.

Thank you for your consideration.

Support SB 476 NPAM letterhead.pdf
Uploaded by: Dale Jafari
Position: FAV

NURSE PRACTITIONER
Association of Maryland

"Advocating for Nurse Practitioners since 1992"

Health Insurance - Genetic Testing and Cancer Imaging – Required Coverage and Prohibited Cost-Sharing

Position: **SUPPORT**

Dear Chair Beidle, Vice Chair Hayes, and Members of the Committee:

On behalf of the over 800 members, the Nurse Practitioner Association of Maryland, Inc. (NPAM), and the over 8,000 Nurse Practitioners licensed to practice in Marland, I am writing to support SB 407.

My name is Dale Jafari. I am President of the Nurse Practitioner Association of Maryland and I have been a Nurse Practitioner in the State of Maryland for more than 27 years. I serve the five mid-shore communities of Talbot, Dorchester, Caroline, Queen Anne's, and Kent County. This is a rural area with multiple communities of medically underserved populations.

We support SB 407 for the significant improvement in access to specific healthcare modalities related to genetic predisposition for identified cancer-causing mutations. This Bill strikes a personal note for me in my Women's Health practice. Breast cancer rates on the Eastern Shore of Maryland and Delaware are amongst the highest in the country for reasons that are poorly understood. The care we render to the women we serve is targeted at early identification and, where possible, prevention of the development of breast cancer, ovarian cancer, colon cancer and other related cancers that may be genetically predisposed. We use standardized risk assessment tools in our practice to stratify our patients into the high risk we already have to the highest risk for those with a genetic mutation. We use a scoring tool called the Tyer Cuzick breast cancer assessment software to calculate multiple personal and family factors that relate to genetic predisposition resulting in a lifetime percentage of risk for the development of such cancers. A score of 20% or more is considered higher risk and triggers our high-risk breast protocol. This enhanced screening makes it more likely that we will identify a developing breast cancer at the earliest possible interval where 5-year disease-free breast cancer survival rates may exceed 95%. We follow the evidence-based practices set forth by the National Cancer Compendium in staggering breast imaging with mammogram and breast MRI at 6 mos. intervals and we see these patients for a clinical breast exam every 6 mos. rather than once a year. Those who are identified with a genetic mutation can be offered prophylactic mastectomy or chemoprophylaxis with tamoxifen to reduce the risk for cancer development. In so doing, these high-risk individuals may be spared from developing life-threatening breast cancer and will continue to actively participate in the lives of their family members as well as to continue as productive members of society. The benefit of risk identification by genetic testing is not limited to breast cancer as colon cancer screening frequency and techniques can also be modified for those identified with a genetic

The Nurse Practitioner Association of Maryland, Inc.
5372 Iron Pen Pl Columbia MD 21044
Office: 443-367-0277 Fax: 410-772-7915
www.npamonline.org NPAM@npedu.com

condition such as Lynch syndrome. Identification of Lynch syndrome tells me to step up my surveillance for uterine cancer risk as there is a co-association with this condition.

The Nurse Practitioner Association of Maryland is in full support of SB 476. Not for me; but for the many patients in our population who are not aware that they may be at high risk for a genetically predisposed cancer and have not yet been offered the opportunity to reduce their risk. I ask for a favorable vote for your constituents whose concerns may be allayed by a negative genetic test result. I ask for the removal of barriers to such testing and follow up so that insurers cannot deny our patients access to these potentially life and health preserving measures. Thank you for your consideration.

Sincerely,

S. Dale G. Jafari
S. Dale G. Jafari, DNP, FNP-BC, FAANP
dalegjafari@gmail.com
Nurse Practitioner Association of Maryland, Inc.

Support SB 476 NPAM letterhead.pdf
Uploaded by: Dale Jafari
Position: FAV

NURSE PRACTITIONER
Association of Maryland

"Advocating for Nurse Practitioners since 1992"

Health Insurance - Genetic Testing and Cancer Imaging – Required Coverage and Prohibited Cost-Sharing

Position: **SUPPORT**

Dear Chair Beidle, Vice Chair Hayes, and Members of the Committee:

On behalf of the over 800 members, the Nurse Practitioner Association of Maryland, Inc. (NPAM), and the over 8,000 Nurse Practitioners licensed to practice in Marland, I am writing to support SB 407.

My name is Dale Jafari. I am President of the Nurse Practitioner Association of Maryland and I have been a Nurse Practitioner in the State of Maryland for more than 27 years. I serve the five mid-shore communities of Talbot, Dorchester, Caroline, Queen Anne's, and Kent County. This is a rural area with multiple communities of medically underserved populations.

We support SB 407 for the significant improvement in access to specific healthcare modalities related to genetic predisposition for identified cancer-causing mutations. This Bill strikes a personal note for me in my Women's Health practice. Breast cancer rates on the Eastern Shore of Maryland and Delaware are amongst the highest in the country for reasons that are poorly understood. The care we render to the women we serve is targeted at early identification and, where possible, prevention of the development of breast cancer, ovarian cancer, colon cancer and other related cancers that may be genetically predisposed. We use standardized risk assessment tools in our practice to stratify our patients into the high risk we already have to the highest risk for those with a genetic mutation. We use a scoring tool called the Tyer Cuzick breast cancer assessment software to calculate multiple personal and family factors that relate to genetic predisposition resulting in a lifetime percentage of risk for the development of such cancers. A score of 20% or more is considered higher risk and triggers our high-risk breast protocol. This enhanced screening makes it more likely that we will identify a developing breast cancer at the earliest possible interval where 5-year disease-free breast cancer survival rates may exceed 95%. We follow the evidence-based practices set forth by the National Cancer Compendium in staggering breast imaging with mammogram and breast MRI at 6 mos. intervals and we see these patients for a clinical breast exam every 6 mos. rather than once a year. Those who are identified with a genetic mutation can be offered prophylactic mastectomy or chemoprophylaxis with tamoxifen to reduce the risk for cancer development. In so doing, these high-risk individuals may be spared from developing life-threatening breast cancer and will continue to actively participate in the lives of their family members as well as to continue as productive members of society. The benefit of risk identification by genetic testing is not limited to breast cancer as colon cancer screening frequency and techniques can also be modified for those identified with a genetic

The Nurse Practitioner Association of Maryland, Inc.
5372 Iron Pen Pl Columbia MD 21044
Office: 443-367-0277 Fax: 410-772-7915
www.npamonline.org NPAM@npedu.com

condition such as Lynch syndrome. Identification of Lynch syndrome tells me to step up my surveillance for uterine cancer risk as there is a co-association with this condition.

The Nurse Practitioner Association of Maryland is in full support of SB 476. Not for me; but for the many patients in our population who are not aware that they may be at high risk for a genetically predisposed cancer and have not yet been offered the opportunity to reduce their risk. I ask for a favorable vote for your constituents whose concerns may be allayed by a negative genetic test result. I ask for the removal of barriers to such testing and follow up so that insurers cannot deny our patients access to these potentially life and health preserving measures. Thank you for your consideration.

Sincerely,

S. Dale G. Jafari
S. Dale G. Jafari, DNP, FNP-BC, FAANP
dalegjafari@gmail.com
Nurse Practitioner Association of Maryland, Inc.

SB476_DeborahRColeman_FAV
Uploaded by: Deborah Renee Coleman
Position: FAV

Written Testimony Supporting SB0476

Submitted to the Senate Finance Committee

February 18, 2025

Senator Pamela Beidle, Senator Antonio Hayes, and members of the Senate Finance Committee, thank you for the opportunity to provide testimony in support of SB0476, which eliminates the patient out-of-pocket costs for multi-gene panel testing for inherited gene mutations and evidence-based screenings. My name is Deborah Renee Coleman, and I am a resident of Montgomery County Maryland.

As a two-time cancer survivor, it is essential that I lend my voice in support of this lifesaving legislation. My divine mandate is to help others, so they prayerfully never receive a cancer diagnosis, or to ensure they have access to the best care if they do.

I was diagnosed with early-stage breast cancer in 2012 at the age of 37. In 2020, I was diagnosed with a rare gastrointestinal cancer at the age of 45.

By way of background, my maternal grandmother Cynthia Tate was diagnosed with breast cancer when she was in her forties. By the grace of God, she survived her bout with breast cancer and lived cancer-free until just shy of her ninety-fifth birthday. Her daughter, my maternal aunt Lorraine Bragg-Tate was diagnosed with pancreatic cancer, which took her life at the age of 57. My paternal grandfather Theodore Roosevelt Coleman was diagnosed with colon cancer when he was in his eighties. Thankfully, he did not succumb to cancer.

I do not have a complete family history, but I am aware of three other paternal relatives who were diagnosed with cancer. All these third-degree relatives are cousins. One cousin was diagnosed with stage four cancer as a young woman. The other two cousins are sisters, both of whom were diagnosed with breast cancer in their later years. The elder of the two sisters recently completed treatment. Thankfully, all three of my cousins are survivors.

I do not know whether my relatives had access to genetic testing. Fortunately, I did. I received genetic testing after my breast cancer diagnosis in 2012 and again in 2014, 2016, and 2021. The genetic tests in 2012 and 2014 looked for mutations in the BRCA1 and BRCA2 breast cancer genes. No mutation was detected in either instance. The genetic tests in 2016 and 2021 looked for mutations in multiple genes. The test in 2021 evaluated 84 genes. All my genetic test results were considered negative. However, the additional findings for the genetic tests in 2016 and 2021 were interpreted as variants of uncertain significance (VUS), meaning there was **insufficient data at the time to determine if the variants in the specific genes analyzed caused an increased cancer risk.** Please note the following excerpts from these results:

2012

The classification and interpretation of all variants identified in this assay ***reflects the current state of scientific understanding*** *at the time this report was issued. In some instances,* ***the classification and interpretation of such variants may change as new scientific information becomes available.***

2021

This test did not identify any pathogenic variants, but includes at least one result that is not completely understood at this time. Please note that ***the classification of variants may change over time as a result of new variant interpretation guidelines and/or new information.***

I do not know how many of you have been directly or indirectly impacted by cancer. We can all agree that, when faced with this life-or-death scenario, you want access to all available resources. Regardless of the results, genetic testing represents exactly that namely, access to potentially lifesaving information.

My genetic testing was critical in providing me with vital information about my genetic makeup. It also provided peace of mind knowing that I did not carry any genetic mutations, despite my family history. I did not have to change my medical care and for that, I am grateful. I know others who were not as fortunate.

For anyone with a personal or family history of cancer, genetic testing is critical in determining whether they carry any gene mutations and can help them take the appropriate steps to manage their future health. This bill will ensure that genetic testing is available to all Marylanders, as medically necessary.

Genetic testing is a way for patients to have access to their genetic makeup and not only take healthcare into their own hands, but also ensure they have the best options available to manage their medical care.

For these reasons, I strongly urge you to support SB0476 and vote to pass this legislation.

Thank you for your consideration.

SB476_ONS_FAV
Uploaded by: Eleni Valanos
Position: FAV

Oncology Nursing Society
Support. Synergy. Strength.

To:	Chair Biedle, Vice Chair Hayes, and members of the Senate Finance Committee
From:	Oncology Nursing Society
Date:	February 12, 2025
RE:	Support SB476 – Genetic Test Cost Sharing

On behalf of the Oncology Nursing Society (ONS) and the 758 oncology nurse members in the state of Maryland, I am writing to express our strong support for **Maryland S476,** which would require coverage of multigene panel genetic testing and follow up cancer screenings with no patient cost-sharing. This policy change would greatly help detect the potential for cancer early and eliminate any associated out-of-pocket cost burdens for patients who may have an increased risk of developing cancer.

The ability to identify individuals who are at increased risk for developing cancer because of an inherited altered (mutated) cancer predisposition gene is possible through cancer predisposition genetic testing. Since the mapping of the human genome in 2003, genetic testing has rapidly evolved from single-gene tests to more complex profiles that measure multiple genes. It's now part of standard care for many types of cancer. The knowledge, through genetic testing, that a patient has an increased risk for cancer would open the door for additional risk-reducing intervention therapies and diagnostics – improving health outcomes. As an example, if a patient was found to have a genetic variant for breast cancer, a clinician would be able to recommend mammography imaging or MRI screenings at an earlier age than the general population, thus improving their long-term outcomes for early detection.

By offering coverage of this type of precision oncology and eliminating copays, **Maryland S476** will lead to improved outcomes, lower costs, and fewer side effects for Maryland patients.

Thank you for your attention to this important matter and encourage you to support Maryland HB830/S476. Should you require any further information or wish to discuss our support, please feel free to contact healthpolicy@ons.org

###

ONS is a professional association that represents the over 100,000 oncology nurses in the United States and is the professional home to more than 35,000 members. ONS is committed to promoting excellence in oncology nursing and the transformation of cancer care. Since 1975, ONS has provided a professional community for oncology nurses, developed evidence-based education programs and treatment information, and advocated for patient care, all in an effort to improve the quality of life and outcomes for patients with cancer and their families.

Testimony.pdf
Uploaded by: Elliott Wack
Position: FAV

Elliott Wack
2/10/2025

Testimony

My name is Elliott Wack, and I live in Catonsville, Maryland. Last year, a close friend of mine had a stroke and was admitted to the hospital. Because seemingly healthy twenty-six-year-olds don't typically have strokes, I was terrified. She lost vision in both eyes for nearly a month; CT scans revealed tumors in her thyroid and lymph nodes, more in her lungs. She has stage IV thyroid cancer.

My friend is going through chemotherapy now. Her hair is thinning, and her skin is sallow. She teaches elementary school special education, and she used to juggle the chaos of her life with ease, but now her eyes are listless when she talks to me. I never expected to see that expression on her face.

When I was in high school, my grandfather was also diagnosed with cancer. His health declined rapidly, and two years after his diagnosis, he was dead. I wondered if better testing or earlier screening might have prolonged his life. Now, I wonder if it might have helped my friend

Please pass this bill. It will save the lives of your neighbors, your friends, your teachers, and your constituents.

2025 MOTA SB 476 Senate Side.pdf
Uploaded by: Jennifer Navabi
Position: FAV

Maryland Occupational Therapy Association

PO Box 36401, Towson, Maryland 21286 ♦ mota-members.com

Committee: **Senate Finance Committee**

Bill Number: **Senate Bill 476**

Title: **Health Insurance - Genetic Testing and Cancer Imaging - Required Coverage and Prohibited Cost-Sharing**

Hearing Date: **February 12, 2025**

Position: **Support**

The Maryland Occupational Therapy Association (MOTA) supports *Senate Bill 476 – Health Insurance - Genetic Testing and Cancer Imaging - Required Coverage and Prohibited Cost-Sharing*. The bill will require insurers, nonprofit health service plans, and health maintenance organizations to provide coverage for genetic testing to identify whether individuals who may have an increased risk of developing cancer if the testing is recommended by a health care professional and consistent with evidence-based, clinical practice guidelines. If the testing shows an increased risk, follow–up evidence–based cancer imaging is required.

Genetic testing is a successful means of early cancer detection, but it is often cost prohibitive for a patient because most insurance policies will not cover it. MOTA supports this bill because early detection is key, and this bill will make it more affordable for people to receive this potentially life-saving genetic testing.

We ask for a favorable report. If we can provide any further information, please contact Michael Paddy at mpaddy@policypartners.net.

ACSCAN_FAV_SB476.pdf
Uploaded by: Lance Kilpatrick
Position: FAV

Memorandum In Support of SB 476 – Senator Beidle

Senate Finance Committee

February 12, 2025

American Cancer Society Cancer Action Network is the nonprofit nonpartisan advocacy affiliate of the American Cancer Society. ACS CAN empowers cancer patients, survivors, their families and other experts on the disease, amplifying their voices and public policy matters that are relevant to the cancer community at all levels of government. We support evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. On behalf of our constituents, many of whom have been personally affected by cancer, we stand in strong support of SB 476.

In the past two decades, our understanding of human genes and of the genetic basis of disease has grown dramatically. Many, if not most, diseases have their roots in our genes. Genes - through the proteins they encode - determine how efficiently we process foods, how effectively we detoxify poisons, and how vigorously we respond to infections.

The identification of disease-related genes has led to an increase in the number of available genetic tests that detect disease or an individual's risk of disease. Gene tests are available for many disorders, including Tay-Sachs disease and cystic fibrosis. Tests are also available to detect predispositions to Alzheimer's disease, colon cancer, breast cancer, and other conditions.

As the number of available genetic tests increases, the use and interpretation of those tests and the information they generate will require a basic understanding of how genetic principles apply to different health problems such as cancer. Results from these tests can lead to profound, life-changing decisions, such as whether to undergo prophylactic mastectomy, get more frequent cancer screenings, or take a particular drug or dosage of a drug.

SB 476 would require insurers, nonprofit health service plans and HMOs to provide coverage for genetic testing for individuals who may have an increased risk of developing cancer. In addition, it would prohibit them from imposing a copayment, coinsurance or deductible requirement on the coverage. This would be contingent on the genetic testing being recommended by a health care professional and consistent with evidence-based, clinical practice guidelines.

SB 476 furthers the acknowledgement and development of precision, personalized medicine. ACS CAN thanks the Chair and committee for the opportunity to testify and urges a favorable report of SB 476.

Lance Kilpatrick, Government Relations Dir. | lance.kilpatrick@cancer.org | fightcancer.org | 410-547-2143

MD SB476_Multigene Test & Multicancer Screen_LOS.p
Uploaded by: Lisa Peabody
Position: FAV

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,

Lisa S. Peabody
Advocacy Manager
FORCE: Facing Our Risk of Cancer Empowered
Ph: 202-381-1357

---

[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

SB476_WomensCaucus_FAV
Uploaded by: Maryland Women's Caucus
Position: FAV

WOMEN LEGISLATORS OF MARYLAND

THE MARYLAND GENERAL ASSEMBLY

February 10, 2025

To: Senator Pamela Beidle, Chair
Senator Antonio Hayes, Vice Chair
Finance Committee

The Maryland Women's Caucus is proud to express our unanimous support for SB476: Health Insurance - Genetic Testing and Cancer Imaging - Required Coverage and Prohibited Cost-Sharing. This critical legislation is a necessary step in ensuring that Marylanders—particularly women—have access to essential, evidence-based cancer prevention and early detection services without financial barriers.

As you are aware, cancer remains one of the leading causes of death among women, with breast and ovarian cancers posing significant risks. Many women have a genetic predisposition to these and other cancers, yet the high cost of genetic testing and follow-up imaging often prevents them from obtaining the proactive care they need. By requiring insurance providers to cover genetic testing for individuals with an increased risk of developing cancer and ensuring access to necessary follow-up imaging without burdensome copayments, coinsurance, or deductibles, SB476 removes a major financial obstacle to life-saving early detection and prevention.

Ensuring that women have access to timely and affordable cancer screening is essential to improving health outcomes and reducing mortality rates. Too often, women—particularly those from low-income and underserved communities—delay or forgo critical screenings due to cost concerns. This legislation will help close the gap in health disparities, empower women to take charge of their health, and ultimately save lives.

For these reasons, the Maryland Women's Caucus strongly urges the Finance Committee to issue a favorable report for SB476. By passing this legislation, Maryland will take a significant step toward prioritizing preventive health care, supporting women's health, and reducing cancer-related deaths across the state.

Thank you for your time and consideration. We appreciate your continued dedication to improving the lives of Marylanders.

Letter for SB476.pdf
Uploaded by: Mike McKay
Position: FAV

MIKE MCKAY
Legislative District 1
Garrett, Allegany, and Washington Counties

Judicial Proceedings Committee
Executive Nominations Committee

Joint Committees
Administrative, Executive, and Legislative Review
Children, Youth, and Families
Program Open Space and Agricultural Land Preservation

THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

Annapolis Office
James Senate Office Building
11 Bladen Street, Room 416
Annapolis, Maryland 21401
410-841-3565 · 301-858-3565
800-492-7122 *Ext.* 3565
Mike.McKay@senate.state.md.us

Cumberland Office
100N Mechanic Street
Cumberland, Maryland 21502
240-362-7040

Williamsport Office
2N Conococheque Street
Williamsport Town Hall
Williamsport, Maryland

January 24, 2025

RE: Fire/EMS Coalition Support for SB476

Dear Chair Beidle, Vice Chairman Hayes, and Members of the Committee,

The Fire/EMS Coalition would like to express their support for Senate Bill 476:
Health Insurance – Genetic Testing and Cancer Imaging – Required Coverage and Prohibited Cost-Sharing. This bill will require certain organizations to provide coverage for genetic testing that will screen for any defects that can lead to cancer. This will come at no cost to the individual.

The Fire/EMS Coalition supports Senate Bill 476 as it will provide full coverage and screenings to those who are on the frontlines.

Sincerely,

Senator Mike McKay
Representing the Appalachia Region of Maryland
Serving Garrett, Allegany, and Washington Counties

<u>Voting Organizations</u>:
Maryland Fire Chief's Association (MFCA)
Maryland State Firefighter's Association (MSFA)
State Fire Marshal (OSFM)
Maryland Fire Rescue Institute (MFRI)
Maryland Institute for Emergency Medical Services System (MIEMMS)
Metro Fire Chief's Association
Professional Firefighters of Maryland

<u>Our Mission Statement</u>

The Maryland Fire/EMS Coalition unites Republicans and Democrats in support of fire/emergency services legislation that benefit all first responders. Becoming a member does not require taking positions on legislation; rather Coalition members are asked to offer support in a way that best benefits fire/emergency services in their respective Legislative Districts.

SB 476 Genetic Testing.pdf
Uploaded by: Pamela Beidle
Position: FAV

Pamela G. Beidle
Legislative District 32
Anne Arundel County

Chair, Finance Committee
Executive Nominations Committee

Joint Committee on Gaming Oversight
Joint Committee on Management of Public Funds
Spending Affordability Committee

Miller Senate Office Building
11 Bladen Street, Suite 3 East
Annapolis, Maryland 21401
410-841-3593 · 301-858-3593
800-492-7122 *Ext.* 3593
Pamela.Beidle@senate.state.md.us

THE SENATE OF MARYLAND
ANNAPOLIS, MARYLAND 21401

February 12, 2025

Senate Bill 476
Health Insurance – Genetic Testing and Cancer Imaging
Required Coverage and Prohibited Cost-Sharing

Good afternoon Vice Chair Hayes and Members of the Finance Committee;

Thank you for the opportunity to present SB476, Health Insurance – Genetic Testing and Cancer Imaging Required Coverage and Prohibited Cost-Sharing. This bill increases access to recommended genetic testing for inherited gene mutations and evidence-based screenings by eliminating burdensome patient cost-sharing requirements.

Genetic testing can provide important information to breast cancer patients, their families and their medical providers. The results from genetic testing is often a catalyst for patients to access targeted prevention and treatment strategies. In the U.S., approximately 5-10 percent of breast cancers are related to a known inherited gene mutation.

Most patients have heard of BRACA 1 and BRACA 2 but they are not the only breast cancer related genes. Now, it's more common to be tested for multiple other moderate to high-risk gene mutations in a practice called panel testing or multi-gene testing.

This is a *Health Equity Issue*, according to a 2020 American Association for Cancer Research Report, 65 percent of young white women with breast cancer were offered genetic testing, whereas only 36 percent of young Black women with breast cancer were offered this same testing. Additional studies show that minority patients were more likely to utilize genetic testing following a cancer diagnoses and less likely following a family history of cancer, resulting in a missed opportunity for mutation detection and cancer prevention for these patients. This is important because we know that black woman have a 40% higher mortality rate for breast cancer than their white counterparts.

By eliminating the cost barrier to genetic testing and evidence-based screenings, individuals will have access to critical information regarding their lifetime cancer risk and ensure they have access to medically recommended early detection and cancer surveillance, therefore I respectfully request a favorable report on SB 476.

SB476_NCCN_FAV
Uploaded by: Sean T. McCarson, MPA
Position: FAV

National Comprehensive Cancer Network®

Crystal S. Denlinger, MD, FACP
Chief Executive Officer
denlinger@nccn.org
3025 Chemical Road, Suite 100
Plymouth Meeting, PA 19462
215.690.0300

February 10, 2025

RE: Support for SB 476 & HB 830– Genetic Testing & Cancer Imaging Required Coverage and Prohibited Cost-Sharing

Dear Honorable Members of the Maryland Senate Finance Committee:

The National Comprehensive Cancer Network® (NCCN®) appreciates the opportunity to comment on companion bills SB 476 & HB 830, an act relating to coverage of genetic testing and cancer imaging. Genetic Testing is of paramount importance as it relates to NCCN's mission of improving and facilitating, quality, effective, equitable, and accessible cancer care and prevention so all people can live better lives. NCCN will focus our supportive comments on the importance of comprehensive genetic (germline) testing for residents of Maryland and the role of NCCN Guidelines® in determining clinically appropriate care.

NCCN Background
As an alliance of 33 leading academic cancer centers in the United States, including Johns Hopkins Kimmel Cancer Center, NCCN® is a developer of authoritative information regarding cancer prevention, screening, diagnosis, treatment, and supportive care that is widely used by clinical professionals and payers alike. The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a comprehensive set of guidelines detailing the sequential management decisions and interventions that currently apply to 97 percent of cancers affecting patients in the United States. NCCN Guidelines® and Library of Compendia products help ensure access to appropriate care and are used by payers representing more than 85% of covered lives in the United States including CMS. NCCN imposes strict policies to shield the guidelines development processes from external influences. The NCCN guidelines development is supported exclusively by the Member Institutions' dues and does not accept any form of industry or other external financial support for the guidelines development process. The NCCN Guidelines® are updated at least annually in an evidence-based process integrated with the expert consensus of multidisciplinary panels of expert oncology health care professionals from NCCN Member Institutions. Most Guidelines panels also include a patient advocate, who has an equal role in the process to Member Institution representatives. The NCCN Guidelines® are transparent, continuously updated, available free of charge online for non-commercial use and are available through a multitude of health information technology (HIT) vendors.

Germline Testing vs. Biomarker Testing
Cancers can develop as a result of pathogenic or likely pathogenic (P/LP) variants in certain genes, such as those involved in the regulation of cell growth and/or DNA repair[1,2]. Family studies have long documented an increased risk for several forms of cancer among first-degree relatives (i.e., parents, siblings, children) and second-degree relatives (i.e., grandparents, aunts or uncles, grandchildren, nieces or nephews) of affected individuals. These individuals may have an increased susceptibility to cancer as the result of one or more P/LP variants present in parental germline cells. Hereditary cancers are often characterized by P/LP variants associated with increased risk for certain cancers and transmission to offspring through the mother and/or father[3,4].

An individual suspected of being at risk for hereditary cancer should be offered genetic counseling[5,6] and testing as appropriate, consistent with recommendations from the U.S. Preventive Services Task Force

(USPSTF) and the NCCN Clinical Practice Guidelines[7]. With respect to hereditary cancers, advances in molecular genetics have identified several genes associated with inherited susceptibility to several types of cancer (i.e., BRCA1/2, PALB2, ATM) and have provided a means of characterizing the specific P/LP variant present in certain individuals and families exhibiting an increased risk for cancer. The field of cancer genetics has implications for all aspects of cancer-related care of individuals with hereditary or familial cancers, including prevention, screening, and treatment[8].

Despite a wide body of literature supporting the need for guideline adherent genetic testing, coverage, and access to appropriate genetic testing is still widely variable leaving many patients unable to access appropriate care. A 2023 study evaluating genetic testing for cancer patients between 2013 and 2019 found that only 6.8% of patients went through germline genetic testing within two years of their cancer diagnosis[9]. This critical care gap must be addressed to ensure all people can access optimal cancer care. SB 476/HB 830 creates coverage for appropriate germline testing as recognized in our evidence-based clinical practice guidelines. As such, NCCN is pleased to support SB 476/HB 830.

To be sure, there are differences in germline testing and biomarker testing. NCCN applauds the work of your legislative body in successful passage of access to clinically appropriate biomarker testing in Chapter 322 of 2023 through cross-filed companion bills SB 0805/HB 1217. Your legislative success in advancing coverage access to patients becomes effective July 1, 2025.

However, whereby biomarker testing typically analyzes a sample of tumor tissue or other bodily fluids to guide treatment decisions based on specific mutations in an existing cancer, germline testing leads patients to important shared clinical decision-making conversations with their providers on customizing screening and prevention care plans and may have implications for cancer treatment recommendations in certain cancers. There are some cancers where germline mutations can impact cancer treatment recommendations, such as BRCA mutations in prostate, breast, ovarian, and pancreatic. Eliminating coverage barriers for both tests benefits both patients and providers when biomarker testing is appropriate in identifying potential inherited mutations within a tumor; however, germline testing leads to increased awareness not only within the patient community, but for the family members who may also share these mutations and can lead to personalized shared clinical decision-making on appropriate lifetime screening and prevention plans.

Access to both forms of precision medicine reduce cost barriers to patients and payers, can help prevent disease diagnosis and/or progression, reduces more costly and toxic treatment options, and can also reduce onerous administrative prior authorization burdens on already overly worked providers.

NCCN Biomarkers Compendium®

The NCCN Guidelines® include biomarkers used for the purposes of diagnosis, screening, monitoring, surveillance, prediction, therapeutic decision-making and prognostication. The NCCN Biomarkers Compendium® contains biomarker information derived directly from the NCCN Guidelines to support decision-making around the use of biomarker testing in patients with cancer and is intended to be a resource for payers, providers, and health care entities navigating the rapidly changing evidence base for medically necessary biomarker testing in oncology. Information is provided in a searchable database that is updated continuously in conjunction with the NCCN Guidelines® to remain evergreen. In addition to providing information regarding clinical indication(s) for specific biomarker testing, the NCCN Biomarkers Compendium provides essential details for testing methodologies recommended within the NCCN Guidelines.

NCCN Supports Clinically Appropriate Germline Genetic Testing
NCCN recommends covering genetic testing as delineated in evidence-based nationally recognized clinical practice guidelines such as ours. NCCN would like to note that the most recent versions of our Guidelines are always available on our website. As NCCN Guidelines® are continuously updated to stay current with the evidence, NCCN encourages your committee to refer to the current recommendations and Guideline versions on the NCCN website as a health policy tool to ensure those decisions are up to date with the standard of care.

NCCN appreciates the opportunity to comment on and support SB 476/ HB 830. We are proud to support this legislation in harmony with our coalition partners. As a nationally recognized clinical guidelines organization, NCCN is happy to serve as a resource during the legislative process. We look forward to working together to ensure access to high-quality cancer care.

Respectfully,

Crystal Denlinger, MD, FACP
Chief Executive Officer
National Comprehensive Cancer Network
denlinger@nccn.org 267.622.6654

References

1. Fearon ER, Vogelstein B. A genetic model for colorectal tumorigenesis. Cell 1990;61:759-767. Available at: http://www.ncbi.nlm.nih.gov/pubmed/2188735.

2 Vogelstein B, Kinzler KW. The multistep nature of cancer. Trends Genet 1993;9:138-141. Available at: http://www.ncbi.nlm.nih.gov/pubmed/8516849.

3 . Lynch HT, Watson P, Conway TA, Lynch JF. Clinical/genetic features in hereditary breast cancer. Breast Cancer Res Treat 1990;15:63-71. Available at: http://www.ncbi.nlm.nih.gov/pubmed/2322650.

4 Pharoah PD, Day NE, Duffy S, et al. Family history and the risk of breast cancer: a systematic review and meta-analysis. Int J Cancer 1997;71:800-809. Available at: http://www.ncbi.nlm.nih.gov/pubmed/9180149

5 Lancaster JM, Powell CB, Chen LM, Richardson DL. Society of Gynecologic Oncology statement on risk assessment for inherited gynecologic cancer predispositions. Gynecol Oncol 2015;136:3-7. Available at: http://www.ncbi.nlm.nih.gov/pubmed/25238946.

6. Shiovitz S, Korde LA. Genetics of breast cancer: a topic in evolution. Ann Oncol 2015;26:1291-1299. Available at: https://www.ncbi.nlm.nih.gov/pubmed/25605744.

7. Moyer VA. Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer in women: U.S. Preventive Services Task Force recommendation statement. Ann Intern Med 2014;160:271-281. Available at: https://www.ncbi.nlm.nih.gov/pubmed/24366376.

8. Weitzel JN, Blazer KR, MacDonald DJ, et al. Genetics, genomics, and cancer risk assessment: state of the art and future directions in the era of personalized medicine. CA Cancer J Clin 2011;61:327-359. Available at: http://www.ncbi.nlm.nih.gov/pubmed/21858794.

9. Kurian AW, Abrahamse P, Furgal A, et al. Germline Genetic Testing After Cancer Diagnosis. JAMA. 2023;330(1):43–51. doi:10.1001/jama.2023.9526.

FORCE Testimony SB 0476 Stefani Read - Google Docs

Uploaded by: Stefani Read

Position: FAV

SB 0476 - FAV
Written Testimony

To whom it may concern:

My name is Stefani Read currently residing in Westminster, Maryland and I volunteer as both a Peer Navigator and Patient Advocate Leader with FORCE.

FORCE (Facing Our Risk of Cancer Empowered) is a national nonprofit organization dedicated to empowering the millions of individuals and families facing hereditary cancers. Its community includes people with BRCA, ATM, PALB2, CHEK2, PTEN, or other inherited gene mutations and those diagnosed with Lynch syndrome. We accomplish this through education, support, advocacy and research efforts. Visit FORCE's website at www.facingourrisk.org for more information about our mission and hereditary cancers.

I am writing to you today to ask you to support SB 0476. Research shows that inherited genetic mutations play a major role in approximately 10-15% of cancers, including breast, ovarian, prostate, pancreatic, and colorectal cancers. While the BRCA1 and BRCA2 mutations may be the most well-known, there are dozens of other hereditary genetic mutations that increase cancer risk.

Cancer screening guidelines for the high-risk, hereditary cancer community are different from those for the average-risk community. Individuals at higher risk for cancer need increased tests, scans, and other preventative measures. For example, a woman with a BRCA1 mutation needs to screen for breast cancer with more intensive, frequent procedures including MRIs with contrast, ultrasounds, mammograms, biopsies, and clinical breast exams. They are told to begin these screenings as early as age 25; far younger and more intensive than the mammograms recommended at age 40 for average-risk individuals. It is important to note that those examples are just a fraction of the annual medical care they are prescribed to complete to remain cancer free. Patients with mutations are also encouraged to have preventative mastectomies and hysterectomies, which are life changing and difficult surgical procedures that come with their own set of costs and commitments.

I am extremely familiar with the burden this can put on a patient as I am BRCA1+ myself. I learned of my genetic mutation after losing family members to cancer and watching others fight their battles up to this very day. Since diagnosis, it has been an ongoing struggle to manage and afford my preventative care. I have had a hysterectomy and regularly monitor for cancers such as breast, skin, pancreatic, and colon cancers. I have a team of nine doctors and complete over 22 separate scans or tests in a year. Each doctor's visit or test comes with an associated cost, both in time and money. My estimated annual out of pocket costs for BRCA care are in the thousands of dollars even with my health insurance. Just within the past month, I have also had to spend extra time providing additional documentation and asking for more support from my medical team when my insurance company deemed my breast MRI as "potentially unnecessary" even though I am BRCA1+ (and this is not the first time this has happened).

There seems to be a very big disconnect in the insurance industry with how the costs of genetic cancer testing and preventative care is (or more likely, *is not*) covered. I consider myself quite

fortunate in that I am able to afford the copays, deductibles, time off from work, and other costs associated with these tests, but it has not escaped my notice how detrimental these are to others who need this care. Folks with these mutations are already carrying the weight of cancer, whether directly or preventatively. We should not have to make a choice about our care due to costs and we should not have to go bankrupt to stay alive.

With your help passing SB 0476 we can help all Marylanders like me live longer, healthier, and hopefully cancer-free lives. I thank you for your support and I am always available to discuss this further.

Thank you for your time,

Stefani Read

Patient Advocate Leader, FORCE

797 Mountain View Drive

Westminster, MD 21157