

To Whom It May Concern:

My name is Kierra West. I live in Nanjemoy, MD and I'm a volunteer 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](http://www.facingourrisk.org) to learn more. Through FORCE, I work with state and federal legislators to advocate for public policies that support the hereditary cancer community.

I'm asking for your support of HB 1007. This bill prohibits life, long-term care and disability insurers from using an individual's genetic information to determine policy eligibility or premiums.

Genetic testing provides crucial information about cancer risk for individuals with a family history of certain cancers. Obtaining information about their genetic mutation status is vital for individuals who want to manage their risk of cancer. This is a family issue. These genetic mutations are hereditary, so they have implications for an individual's blood relatives and their risk of cancer. Individuals should not be treated differently, discriminated against or be forced to delay genetic testing for fear that life, long-term care and/or disability insurers will deny coverage or increase rates if they have taken the initiative to undergo genetic testing.

If a genetic mutation is identified that individual may begin more intensive cancer screenings, earlier and more often than the average risk person. Depending on the mutation, national medical guidelines recommend that certain cancer screenings start at a younger age and at more frequent intervals than the average risk individual, to diagnose cancer at an earlier stage, when it is more easily treated and cured. Risk-reducing (also known as "prophylactic") surgery may also be an option. Those who undergo risk-reducing hysterectomy or mastectomy, for instance, practically eliminate the risk of ovarian, endometrial or breast cancer.

If a mutation associated with hereditary cancer is identified, this does not mean the individual has or will be diagnosed with cancer. Genetic testing can only tell you if you have a specific gene mutation that increases your risk for certain cancers. A positive test result does not mean you will get cancer and a negative result does not mean that you have no risk of cancer.

Increasingly, physicians are recommending genetic counseling and testing for individuals who may be at higher risk of cancer. The study of high-risk individuals is critical to the development of cancer therapies and preventive treatments for cancer.

Knowing if you have a genetic mutation can guide which treatment will be the most effective. The more people seek genetic testing, the more companies are incentivized to invest in hereditary cancer research for prevention and treatments.

People diagnosed with cancer and other diseases often face significant out-of-pocket costs for their healthcare. 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 under Medicaid and other state assistance programs.

Currently 13 states have an extension of GINA, adding protections for life, long-term care, or disability Insurance. The model anti-genetic discrimination law is in Florida, which has a comprehensive law that prohibits insurance companies from canceling, limiting or denying coverage and from setting different premium rates based on genetic information. This year, at least 4 other states have introduced similar legislation.

Please support HB 1007 and help prohibit life, long-term care and disability insurers from using an individual's genetic information to determine policy eligibility or premiums.

Thank you for taking the time to read my testimony.

Sincerely,

Kierra West  
Patient Advocate Leader  
Nanjemoy, MD