February 26, 2025
RE: SB 757 – The Genetic Testing Protection Act
Position: SUPPORT

Thank you for the opportunity to comment on Senate Bill 757. My name is Lisa Schlager, and I am the Vice President of Public Policy for FORCE, a national nonprofit that advocates for people facing hereditary cancers. Comments on behalf of our broader community have been submitted by my colleague, Lisa Peabody.

Today, I am writing to share my personal perspective as an individual affected by the issue under consideration—genetic discrimination. In 1999, I was recently married and looking forward to starting a family. A relative shared that she had been diagnosed with a genetic mutation that increases the risk of cancer. I was encouraged to pursue genetic testing. I chose to do this through a research study because information on these mutations was still evolving, and I wanted to contribute to the science.

Ultimately, I learned that I carry a BRCA1 genetic mutation. Children have a 50% chance of inheriting a mutation from a parent with the mutation. Passed down from my father, this mutation causes a high risk of breast and ovarian cancer, as well as increased risk of pancreatic and prostate cancers. Upon receiving my results from the genetic counselor, I was warned not to let my healthcare providers put information about the mutation in my medical chart because it was still legal for a health insurer to drop your policy if you were deemed to be too risky or expensive. I was also told that I could be denied life or other types of insurance.

The advice to refrain from noting the mutation in my medical chart simply wasn’t feasible. Medical guidelines for those with certain mutations recommend more intensive, more frequent cancer screenings starting at younger ages than the general population. Women with BRCA mutations are supposed to start breast screening at age 25. Information about my mutation was necessary to justify insurance coverage of mammograms and breast MRIs, alternating every six months. Later, information about the mutation served as justification for my risk-reducing salpingo-oophorectomy—guideline-recommended removal of ovaries and fallopian tubes after I had children—and a prophylactic mastectomy after precancerous cells were found in my breast.

I was fortunate because genetic mutations weren’t on the insurers’ radar yet. I was able to get a term life insurance policy and had no issues with my health insurance (perhaps because I was on a group health plan through my husband’s employer). In time, the Genetic Information Nondiscrimination Act (GINA) passed, and the Affordable Care Act followed shortly thereafter. These laws alleviated concerns about health insurance coverage, but discrimination in life, long-term care, and disability insurance is still legal at the federal level.

I am evidence that “knowledge is power.” Information about my genetic predisposition to cancer has enabled me to be proactive with my health. My risk of breast and ovarian cancer is now lower than that of the general population. Currently, I undergo annual pancreatic cancer screenings to catch the disease at the earliest stages should it occur. With information about a genetic mutation, cancer and other diseases can be prevented or detected earlier when they are easier to treat.

However, a lot has changed since I first learned about my mutation. Life, long-term care and disability insurers are using information about an individual's genetic mutation (or a mutation in their family) to deny policies or increase rates to an exorbitant level. My brother is the primary breadwinner in his family. He refuses to undergo genetic testing for fear that he will be denied additional insurance should he need it. Not knowing if you have a mutation doesn't mean you aren't at risk. But like many Americans, he is fearful that this information will be used against him.

Since young women with mutations should start breast cancer screening at age 25, many have genetic testing around this age. My 24-year-old daughter will be getting tested for the mutation this spring. "Get insurance before you test" is the advice given. Let's be honest: most people in their early to mid-20s are just starting their careers, few are married, and even fewer have children. They are not yet in a position to invest in life, long-term care, or disability insurance.

A representative from New York Life testified at the recent House hearing on the companion bill for SB 757. He stated that they don't make underwriting decisions based solely on an individual's genetic mutation. This is not what we hear from people around the country. The following are just a few of the many accounts we've received:

> Thank you for your recent request for life insurance… We have completed your underwriting review. After careful consideration, we regret that we are not able to approve your request for coverage.
>
> Our action was based on:
>
> - Your medical history of positive BRCA mutation

> I recently applied for life insurance, and after a completely healthy assessment, the cost for coverage that our rep quoted me QUADRUPLED, simply because of my BRCA1 genetic predisposition.

> I was denied life insurance when my husband tried switching. I'm stuck with his employer's plan that we had before my genetic testing. They lowered my payout and upped premiums when they got word, without notifying us.

The use of genetics and genomics in medicine and health is rapidly growing. It facilitates personalized screening, prevention, and treatments. Maryland medical institutions such as Johns Hopkins are leading the way in using genetic information to improve health. **Awareness and evidence-based interventions empower people to be proactive with their health, to reduce their risk.** Why are we penalizing them?

The insurance industry claims that it needs information about genetic mutations for effective risk calculation in underwriting. Insurers didn't have access to this information in the past; they did just fine by basing their decisions on personal and family health history. A genetic mutation is not a guarantee that the individual will get the disease. Likewise, a person without knowledge of a mutation is still at risk.

In the case of long-term care or disability insurance, if an individual gets sick and can no longer work, who ends up supporting them? Who pays for their care if they lack insurance? Ultimately, these people turn to Medicaid and other state or federal programs for assistance. Wouldn't it be preferable for the insurance industry to address this need?

In 2020, Florida passed a law banning the use of genetic information. The law stipulates that insurers cannot deny coverage, limit, or cancel insurance coverage, or set different premiums based on genetic information or DNA. Since passage of that law, Florida's insurance marketplace has remained just as robust as ever, with rates increasing only 2% (far less than the rate of inflation).

Maryland has a chance to be a leader, to close a glaring gap in federal law. Please protect my children, my family members and my fellow Marylanders from genetic discrimination. Prohibit insurers from considering genetic information in their coverage decisions; personal and family health history should suffice. I urge you to endorse SB 757, ensuring that all Maryland residents have access to the insurance they need.

Thank you for your time and consideration,

Lisa Schlager

Lisa Schlager
Chevy Chase, MD
lisas@facingourrisk.org