



Facing Hereditary Cancer EMPOWERED

March 31, 2026

RE: In strong support of HB 7861

Dear Chairman Solomon, First Vice-Chairman O'Brien, Second Vice-Chairwoman Caldwell and Esteemed Members of the House Corporations Committee,

On behalf of FORCE (Facing Our Risk of Cancer Empowered), a leading nonprofit for people at risk for hereditary cancer, providing trusted information, support, and advocacy, and representing Rhode Island constituents, we urge your support of HB 7861.

The majority of our constituents carry an inherited genetic mutation that increases their risk of cancers including breast, ovarian, prostate, pancreatic and colorectal cancer.

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.

For instance, the National Comprehensive Cancer Network (NCCN) and similar medical society guidelines recommend that individuals with MLH1 and similar mutations begin screening colonoscopies every one to two years between the ages of 20 and 25. If polyps are found, they are removed, eliminating the risk that the growths will 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.

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 ideal candidates 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 that it 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 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 reward people for being educated and proactive about their health. Individuals with knowledge of their predisposition to disease are empowered to take measures to mitigate that risk.

The insurers assert 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. Several states have an extension of GINA but most lack any meaningful protections in life, long-term care or disability insurance. Florida, one of the most conservative states in the country, passed a model anti-genetic discrimination law in 2020. Rhode Island should follow suit and prohibit insurers from canceling, limiting, increasing the premiums, or denying coverage based on genetic information.

In summary, we strongly support HB 7861 and urge you to endorse this legislation, ensuring that all Rhode Island residents have equal access to the insurance they need.

Thank you for your consideration,



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