HB 0830 - 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 HB 0830. 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 HB 0830 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

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