Minnesota Senate Commerce and Consumer Protection Committee

Testimony in Support of SF1302 for 3/5 Commerce and Consumer Protection Committee Hearing

My name is Charles Nettell, and I live in Eden Prairie, Minnesota. I am a volunteer Patient Advocate Leader with FORCE and I strongly support SF 1302. FORCE (Facing Our Risk of Cancer Empowered) is a leading nonprofit for people at risk for hereditary cancer, providing trusted information, support and advocacy. Most of FORCE"s constituents carry an inherited genetic mutation, like a BRCA mutation or Lynch Syndrome, that significantly increases their risk of cancers, including breast, colorectal, endometrial, ovarian, prostate, pancreatic and gastric cancers.

Patients at risk of hereditary cancers often struggle to cover the costs of guideline recommended genetic testing and "supplemental" cancer screenings. Many health insurers deny coverage or charge large copays and deductibles for these services. This is an access barrier for the members of our community who may be at high risk of hereditary cancer and need multigene panel genetic testing with more intensive, more frequent cancer screenings at younger ages. Several years ago, I underwent genetic testing and learned I carry a BRCA2 genetic mutation. With a BRCA2 mutation I am at higher risk for prostate, pancreatic, male breast cancer and melanoma. The National Comprehensive Cancer Network recommends more frequent and, in some cases, enhanced screenings for these cancers. It also recommends screenings start at an earlier age. Passage of SF1302 means I will be able to get the recommended screenings I need to detect the cancers for which I am at high risk while the cancers are still treatable.

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 10-15% of cancers, including breast, ovarian, endometrial, prostate, pancreatic, and colorectal. While the BRCA1 and BRCA2 mutations may be the most well-known, there are dozens of other hereditary genetic mutations that increase cancer risk. Multigene panel genetic testing is the current standard of care.

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, known to increase cancer risk.

With next-generation sequencing (NGS), the cost of looking for a mutation in one gene is the same as that of looking at dozens of genes. There is no rational reason to limit coverage with no cost-sharing to just the BRCA genes. The BRCA genes are included in these multigene panels, but insurers bill the patient because the panel looks at additional genes as well.

Cancer screening guidelines for the high-risk, hereditary cancer community are different than those for the average-risk community. In comparison to the general population, considered “average risk” of cancer, individuals at increased risk may need other screening and/or risk-reducing interventions: o Breast cancer screenings - more intensive, more frequent screenings that may include

- Breast MRIs, ultrasounds and/or 3D mammograms, in addition to regular mammograms and clinical breast exams as early as age 25; far younger and more intensive than mammograms recommended at 40 years of age for average-risk individuals. Colorectal cancer screenings – colonoscopies every 1-2 years starting as early as age 20-25, versus other screening options such as a FIT test, or colonoscopies every 10 years starting at age 45 for the general population.
- Prostate cancer screening – annual prostate-specific antigen (PSA) tests and digital rectal exams (DRE) beginning at age 40 versus optional screening for the average risk person.
- Pancreatic cancer screening – annual pancreatic cancer screening as early as age 30-35, with alternating MRI/magnetic resonance cholangiopancreatography (MRCP) and/or endoscopic ultrasound (EUS). Note that pancreatic screening is only recommended for individuals with a family history of this cancer or an inherited genetic mutation that increases risk.

Coverage of multigene panel genetic testing and “supplemental” high-risk cancer screenings may be denied by private/commercial health insurance plans. Alternatively, insurers may “cover” the service, but the patient is left with large out-of-pocket expenses because most or all the cost of the procedure is applied to an individual’s deductible, sometimes $3000 or more. Individuals may forgo guideline-recommended screening

because of the cost, even though they are at high risk of being diagnosed with breast cancer.

Individuals with knowledge of their predisposition to hereditary cancer have the greatest potential to prevent or detect cancer early when it is easier and less expensive to treat. This ultimately saves lives and money. There are several other states that have already passed similar laws, and Minnesota should do the same. I ask the committee to vote in favor of SF 1302.

Thank you for your consideration,
Charles Nettell
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