Robert S. Wildin M.D. for April 20, 2022.

Good afternoon, Chair Marcotte and members of the House Commerce and Economic Development Committee. I am grateful for the opportunity to explain today why I ask you to support S.247, a family-oriented bill that will balance the healthy individual's genetic testing decisions with access to life, long-term care and disability insurance.

I am a Medical Geneticist. I specialize in the diagnosis, management, and counseling of individuals and families affected by genetic disease. My clinic is at the Children's Specialty Center of the UVM Medical Center in Burlington. My geneticist and genetic counselor colleagues and I help patients of all ages who already have a clinical diagnosis or have signs or symptoms that might or might not signal a genetic disease.

Pertinent to this bill, which only addresses those without diagnosed disease, we also help *healthy* people who are already at increased risk because they have a blood relative diagnosed with a genetic disease. And we serve people who wish to learn through genomic screening if they have any actionable health risks that are not predicted by their family's history. This includes healthy adopted individuals who don't know anything about their biological family's health.

Among all these groups are many who want to expand their family but worry about passing something on, or who want to take ownership of their own healthcare journey. For those who do not even know if they have their family's disease gene, this can create a terrible dilemma. Why?

We offer genetic testing, but it comes with a catch for those who don't have any symptoms: in seeking the knowable risks, they can lose access to resources and services many of us take for granted, like life insurance. When they consent to testing, we physicians are required by Vermont law to inform them of this *non-medical risk*. It is difficult to watch as people try to make the best decision for themselves and their families under this odd paradox.

What do I mean when I say "actionable" genetic test results? There are some genetic disorders, like Cystic Fibrosis, where precision treatments based on DNA differences have revolutionized therapy, decreased morbidity including hospitalizations, and tripled lifespan. For others like Marfan Syndrome, while no "magic bullet" drug exists, medical and surgical therapies decrease morbidity and hold catastrophic outcomes at bay for decades, *when detected early*. Cancer is more treatable when it is detected at early stages. Early detection and treatment also costs less and leads to less impact on one's family and livelihood.

But many genetic disorders destroy silently, undetected in routine care. Inherited susceptibility leads to advanced cancer at young ages when it's not on anyone's radar. Susceptibility to heart rhythm disorders can end teenagers' lives suddenly, something that if known in advance, is preventable. Screening for genetic susceptibility, either in those with disease in their family or with DNA screening tests, allows for early medical management. Even for conditions without prevention options, education for self-efficacy helps at risk people recognize warning signs and, when they occur, seek care immediately.

Balancing policy is never easy, but having some concept of what happens now, and the impact of this bill may help. Currently, Vermont's healthcare providers are required by state law to obtain *written informed consent* that includes the risk of discrimination in obtaining life and disability insurance. This requirement exists regardless of the presence or absence of diagnostic signs or symptoms. Patients may postpone or decline to do testing so their health record will not reflect a future health risk, in the event they might choose to purchase insurance. What this bill will do is allow individuals to make decisions relevant for their health care without it coercing their decision and timing for buying an insurance product.

The risk of adverse selection in insurance underwriting has been cited as a consequence of this bill, and the example of Huntington's Disease, or HD, a rare but devastating progressive brain disorder, has been used as an example of how someone might get genetic testing predicting early death and buy a giant life insurance policy.

So how big an issue is this? About 5 per 100,000 individuals, or 0.005% of the population with European ancestry, inherit a gene for HD. That number is even lower among non-Europeans. Some of these will die of something else before succumbing to HD. The annual incidence of *manifest* HD is about 0.38 per 100,000 (95% confidence interval [CI]: 0.16, 0.94), or 0.0038% diagnosable per year.

Notably, virtually all people with the HD-causing genetic difference inherit it from a parent. They know of a family history of manifested HD well before they themselves are diagnosable. Because the incidence is so low, and *because the legislation before you allows underwriters to use family health history* information in their underwriting, the impact of any predicted adverse selection for HD would seem rather limited.

A more common example: DNA differences in the BRCA1 and BRCA2 genes increase the lifetime risk for breast cancer in women *and* men, ovarian and fallopian cancer in women, and prostate cancer in men. The age of onset is also reduced, meaning routine population screening occurs too late for many. Breast cancer is the

most likely disease to appear in women, occurring in 50% to 70% of women with BRCA1 or 2 in their lifetimes. That means that up to 50% of women with a genetic predisposition may *never* be diagnosed with breast cancer.

What can you do if you know you have a BRCA1 or 2 gene difference? One can choose to do routine cancer screening tests earlier and more frequently, to detect and treat cancers when they are small and less aggressive. For some organs, one can also opt to have the tissues at highest cancer risk removed before cancer develops or spreads.

These measures are usually undertaken because one wants to live longer, and living longer is, as I understand it, is "good" for issuers of life insurance.

So, what about BRCA1 and 2, by the numbers? The lifetime risk for breast cancer *in the general population* is 12%, a number that may still surprise many. The incidence of testing positive for BRCA1 or 2 in population screening is about 1 in 450 (0.2%). So, if BRCA1/2 gene testing status were to be fully hidden from life insurance underwriters, as proposed in this bill, only 1/1000 (0.2% x 50% lifetime risk) of insured would get breast cancer *as a result of their genetic difference*, while 1 in 8 would get breast cancer a*s a result of being part of the general population*. If you also consider that many genetically at-risk individuals will also take measures to prevent mortality from breast cancer, a dramatic impact on insurance payouts is again doubtful.

In consideration of equity, it may be worth noting that some ancestry groups are at higher risk than others. BRCA1 or 2 gene differences are more prevalent in people with Ashkenazi Jewish ancestry and among the Inuit from Ammassalik, Greenland (1:40, and 1:10-1:100, respectively). People from the Lake Maracaibo region of Venezuela have a much high prevalence of HD (1:143).

We don't know everything about how to use information hidden in one's DNA to improve health and well-being. But we know enough to make a difference, we manage uncertainty, and we learn something every day. People deserve a choice to have that information and share it with their health care providers without fear that it will disadvantage them in their desire to protect themselves and their family.

Fear of negative consequences, real or imagined, may influence willingness to take even simple measures to reduce the risk of death or disability. Scientific studies have found that people often choose <u>not to get</u> genetic testing because legal protections against non-health uses of the information are incomplete, and that avoidance behavior has meaningful implications for individual and public health.

I am here to support S.247 because I believe that allowing Vermonters to use their own private genetic information to live longer *outweighs the* alleged adverse impacts on the insurance industry due to rather narrow limitations on underwriting life, disability, and long-term care insurance.

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