

## VT House Commerce and Economic Development Committee 4-20-2022

Thanks to Chairman Marcotte and the rest of the Commerce and Economic Development Committee for the opportunity to provide testimony in opposition to Senate Bill 247.

To introduce myself, my name is Dr. Deborah VanDommelen. I am the Chief Medical Director at Northwestern Mutual and have been asked to speak on behalf of the American Council of Life Insurers (ACLI).

In addition to my clinical training in Family Medicine, I have a public health degree from Harvard University and an Honors degree in Genetics from the University of Wisconsin-Madison. As a medical director at an insurance company, I maintain my Board certification in Family Medicine and have also been Board certified in Insurance Medicine (an additional 4 years of training to gain expertise in mortality, morbidity, and life expectancy).

My comments today are meant to explain how S. 247 is more likely to do harm to Vermonters than result in the benefits espoused by the University of Vermont. That position is based on five tenets:

- Insurers need access to what the applicant knows to properly price the product and maintain affordability.
- Genetic information is similar to other sensitive medical information on which we already base underwriting decisions.
- There are options for obtaining insurance coverage without genetic testing affecting availability.
- The decision to forgo genetic testing or share the results with an insurer should be left up to the patient or consumer.
- In fact, the very decision to purchase life, disability, and long term care coverage is a voluntary choice rather than a mandate.

### We Need to Know What They Know

As a family physician, my commitment to caring for families throughout the life cycle translated well to my current goal of protecting them financially when the **unexpected** happens. One purpose of underwriting is to properly address the existing or known risks for premature death, so that the premiums will be sufficient to pay the claims that **cannot** be predicted. We only get one chance to get that right for a policy that can be in place for 40-50 years. Unlike health or car insurance, we cannot raise rates if there are unexpectedly higher claims. Therefore, interfering with the ability to properly place risks and price for them can lead to the inability to pay claims decades down the road. Part of my job is to protect the current policyowners to make sure we can fulfill the promises we have already made.

UVM has outlined a vision to be a regional center for excellence in genetics that will draw people from multiple states for testing. That plan creates a huge potential for insurance tourism and puts the smaller population in Vermont at risk given the populous states that surround it. Knowing that this law would force insurers to put both residents and non-residents

at higher risk into the low risks pools means that pricing will likely have to go up. That situation would undermine our goals to make coverage affordable and accessible to the largest number of people possible. Those who are the most financially vulnerable and in need of coverage would be the first to be priced out of the market.

In fact, even the American College of Medical Genetics and Genomics recognizes these risks. They recently noted that while legislative efforts like this one may be rooted in good intentions, preventing the symmetric flow of relevant health information “***may adversely alter insurance underwriting in a way that has unanticipated consequences for both the industry and the individuals who are, or wish to be, insured.***”

Ultimately, we need to know what the applicant knows.

#### Genetic Exceptionalism

Another problem that S. 247 creates is genetic exceptionalism, where these test results are treated differently than other medical information. As insurers, we are trusted with very sensitive information, and we take that responsibility seriously. By setting genetic information apart from the rest of the medical record, inequities are produced within risk groupings. For example, there are inherited risks for blood clots. The tests previously used to look for these clotting disorders were not as accurate as the current genetic testing. With this new bill, insurers would no longer be able to consider an inherited blood clotting risk because the previously allowable testing technique has transitioned to a genetic test. This condition is just one example of where genetic tests are becoming part of the clinical standard of care.

Dr. Leonard has indicated that she expects to see genetic information on every medical record soon. In fact, she commented in a [2016 Burlington Free Press interview](#) that “**taking a patient's genetic information is no different than taking her blood pressure, temperature, heart rate, height and weight.**”

We agree with that characterization in that genetic information should be treated the same way as those other measurements, since they are relevant to predicting longevity.

Insurance relies on a spectrum of predictive information to assess risk at the population level. The insurance infrastructure would fall apart if we could only act on individually determinative information. That scenario would be the equivalent of requiring us to wait until the person has a stroke rather than being able to assess the risk based on high blood pressure or abnormal cholesterol levels.

With the strong protections already in place, there is no need for these additional restrictions.

### Ways to Access Coverage

Please know that the insurance industry is aware of the concerns raised by genetic healthcare providers. For that reason, we have done proactive outreach with the National Society of Genetic Counselors to educate them on how to help their patients access life insurance coverage. With proper informed consent, the perceived fear of genetic discrimination does not need to affect a patient's choice to undergo genetic testing.

The simplest option is to purchase coverage **before** getting a genetic test. Nothing prevents individuals from: 1) applying and getting underwritten for our products, and 2) getting a genetic test afterwards. In this case, **no** genetic test would be part of the underwriting process – a process that we only conduct once.

Unfortunately, even those who already have coverage can mistakenly assume their policy can be cancelled if they get tested. This is an informed consent issue, and we can do better.

For those who have already undergone testing, guaranteed issue is an option for life insurance. Keep in mind that 65% of working adults already have group life insurance through their employer which does not require underwriting.

### Freedom of Choice

My personal interest in genetics dates back to the 1980s when the Human Genome Project was being designed and promised their discoveries would cure all cancer within 10 years. Sadly, that goal has not been reached more than 30 years later.

There are many individual and personal reasons for not wanting genetic testing, including the fact that there are many more conditions for which there is nothing that can be done compared to those for which healthcare intervention offers tangible benefits.

People should have the freedom to wait until the benefits are more obvious and should have the autonomy to decide when and with whom to share those results.

For those who agree to testing, the bill would prevent them from sharing genetic test results that could allow them to get the best insurance offer. For example, if there is a strong family history of inherited early onset dementia, the insurer would not be allowed to use a negative test that proves the applicant did not inherit it, given there is no associated diagnosis.

### Disability and Long Term Care Insurance

I would also like to take a moment to address other products like Disability Insurance and Long Term Care. There are many similarities between individual life, disability, and long-term care insurance. Purchasing is **a voluntary and personal decision** as part of financial planning. Underwriting occurs once and lasts for the duration of the policy which is typically decades. Again, testing that is done later cannot be used to change premiums or take away coverage.

Group **disability coverage** is provided by the majority of employers without any underwriting. Individual disability coverage is voluntary and meant to supplement what employers offer.

Long term care, on the other hand, is offered by only a small portion of employers. So, access is dependent on each state supporting the health of the individual long term care market.

There are those who have told us to “price for it.” That approach is much more problematic for long term care given the pricing challenges that already exist. Further increases put the viability of the entire product at risk. By expanding coverage to a few, existing policyowners could be priced out of the market. LTC is unique. While rates cannot be increased on an individual bases, it may be necessary to do so for the entire pool to address unfavorable claims experience. Price increases necessitated by adverse selection are detrimental to meeting insurance coverage needs as it limits – and potentially cuts off – consumer choice.

Let me offer an example: dementia is the most common reason for extended long term care claims. There are multiple known inherited risk factors for premature cognitive decline. Given the small population of VT and even smaller number of long-term care policyholders, insurance tourism could force insurers to shut down the long-term care market to protect those existing policyholders.

Be aware that the negative effects of adverse selection will show up sooner in disability insurance and long-term care, since the inability to work or perform personal care will occur many years before premature death would affect a life product.

### Summary

We generally applaud the efforts of institutions like UVM to improve health outcomes. However, it is not clear to me if UVM has identified a true versus perceived problem that is affecting a significant number of Vermonters. It is speculation that insurers are the reason that patients at UVM would decline testing. It is also speculation that passing this law would make a difference in the decision of those patients. The Dutch study cited by Dr. Leonard actually acknowledges the limited benefit of this very type of legislation. More certain are the negative pricing effects this bill could have on a larger percentage of Vermonters already experiencing the challenges of inflation on their household budget.

ACLI has addressed similar concerns from clinicians and researchers in Louisiana, for example. For that reason, we suggest [that state’s model](#) – which was developed by the **insurance commissioner** – be considered as an alternative.

*It prevents insurers from basing coverage on applicant or family member participation in research unless the results are in the medical records and predict future mortality or morbidity.*

As an alternative, the compromise suggested by the FDR has merit. ACLI is also open to helping with the consenting process that seems to be at the heart of UVM's worries. If the university would be open to our outreach, a compromise is possible without putting consumers and the insurance market at risk.