



The University of Vermont
LARNER COLLEGE OF MEDICINE

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The Honorable Michael Marcotte
Chair, House Committee on Commerce & Economic Development
Vermont General Assembly
Vermont State House
115 State Street
Montpelier, VT 05633-5301

April 23, 2022

Dear Chair Marcotte:

Thank you for your continued consideration of Senate Bill 247 (S.247). I am writing to provide comment on some of the information presented to the Committee on Friday by life insurance industry representatives.

I still contend that the impact of not allowing genetic testing information to be used in underwriting without a corresponding medical diagnosis in the medical record will have minimal financial impact on life insurance companies. The presentation by Jill Rickard indicates that medical care influences underwriting (slide 9) and I agree, and medical care in the medical record can be used for underwriting. Predictive genetic testing, without a corresponding diagnosis, is NOT deterministic and does not reflect medical care. I am concerned that predictive genetic test results would be misused by life insurance companies, since almost no genetic diseases cause premature death. Only 1.5-2% of adult onset genetic diseases cause premature death, and most of these disease risks would be known to the life insurance companies through the “family history” (see below) in the medical record. In addition, predictive genetic tests that identify disease risks may lengthen the life span of someone who otherwise might have died earlier without this knowledge. Therefore, the financial losses anticipated by Ms. Rickard (slides 12-18) are not accurate because the increase in mortality is not realistic. The genetic diseases identified by predictive genetic testing are occurring today anyway, we just do not diagnose the diseases until later in the course of the disease when preventive or early treatment strategies are not an option. **The goal of predictive genetic testing is to lengthen people’s lives who otherwise may have died prematurely.** This is why we are asking you to support the broadest use of genetic testing in Vermont and reduce patients’ fear of discrimination in insurance underwriting, so predictive genetic testing can be broadly used in healthcare.

The fear of genetic discrimination in these insurance policies is real and clearly demonstrated across multiple studies as well as in our experience at the University of Vermont Health Network. Contrary to industry claims, patients’ fears will not be reduced by providing more nuanced information during genetic counseling, since the insurers testified that underwriting practices among companies are highly variable, making the guidance they suggest providing during counseling not possible. We urge you to support this bill, or the reasonable compromise that has been floated. With the bill or the proposed compromise amendment limiting the prohibition on using genetic information in underwriting to life insurance policies of \$2M or less, we could protect patients while monitoring how the industry responds to the more sweeping law in Florida. Please put patients before the profit margin of life insurance companies.

Thank you also for considering more inclusive language than “family history” to use the S.247. The word “family” reflects a social construct that may not reflect the genetic relatedness of individuals. In medicine, we are really seeking to know the diseases that have occurred in people genetically related to the individual, so we could monitor for those diseases. A term such as “genetic relatives disease history” may better reflect the medical purpose of what we now call “family history” in the medical record.

Thank you again for the opportunity to provide my thoughts to you as you consider S.247.

Sincerely,

A handwritten signature in black ink, appearing to read "Debra G.B. Leonard". The signature is written in a cursive, flowing style.

Debra G.B. Leonard, M.D., Ph.D.