

## S.247 Testimony

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Good morning Chair Lippert and members of the House Health Care Committee. My name is Debra Leonard. I am here today to ask for your support of S.247, a bill that would protect Vermonters from discriminatory practices based on their genetic information.

To introduce myself, I am the Chair and Professor of the Department of Pathology and Laboratory Medicine at the University of Vermont Health Network and the Robert Larner College of Medicine at the University of Vermont. In addition to my medical training, I have a doctorate in molecular biology, which is the study of genetic material used to control cell and body functions. My medical specialty is called Molecular Pathology or Genomic Medicine, which focuses on testing of genetic material from patients for medical purposes, including for cancer, infectious diseases and inherited diseases, also called genetic diseases. I have practiced for almost 30 years, and seen major advances during the course of my career, including testing advancements that allow us to know the genetic sequence of an individual's genome, for medical purposes, for research, or even for an individual's curiosity about their genomic information. I have served on a national genomics committee advisory to the Secretary of Health & Human Services, and a National Academies of Medicine Genomics Roundtable, which have guided national policies in genetics and medicine.

In Vermont, we are transitioning our health care and payment models to a focus on early detection and even prevention of disease to keep people as healthy as possible. Overall health and wellbeing are determined by many factors. About 60% of overall health is based on social determinants, such as education level, income, which can determine access to housing, food and medical care, and personal behaviors such as exercise, smoking, and diet. Under S.247, information about all of these health determinants would still be available for life insurance companies to use for their underwriting, along with personal and family medical history. Medical care only contributes about 10% to overall health and wellbeing. The other 30% is determined by an individual's genetics, yet we do not routinely use this information in health care. The University of Vermont Health Network is changing this. On November 1<sup>st</sup> of 2019, we began offering genomic testing to our patients through our primary care providers, working to integrate genetically-determined health risks into the care of our patients. While we often think about genetic diseases as rare conditions, today genetic diseases are associated with approximately six thousand of our twenty thousand genes, and we continue to learn more about genes that cause or increase the risk of specific diseases. In this medical program at the University of Vermont Health Network, we are identifying disease risks caused by single gene changes in about 20% of the Vermont population, and identifying a genetic change that could cause disease in the patient's children in about 80% of Vermonters.

Genetic information is rarely deterministic of disease or disease severity. Genetic changes more often predict an increased chance that someone will get a disease, but that person may never get the disease before dying of other causes. And most often, knowing of the increased disease risk before the onset of symptoms allows physicians to monitor for disease onset, to identify the early stages of disease when interventions may be more effective, to provide appropriate treatments because we have a diagnosis, and, in some cases, mitigate the onset of symptoms or disease through lifestyle changes or medical intervention. Because genetic information is not deterministic of disease onset, an individual's genetic information should not be used for underwriting for life insurance policies without the onset of the

actual disease, referred to as *disease manifestation* in the Federal GINA law. GINA provides protections up until the point when an individual's disease has manifested, or become medically evident.

I would like to share a personal story. My husband, Greg Merhar, and I gave each other our genome sequences for Christmas in 2014 and received our results in 2015. My results were rather boring, but Greg's results were life changing. Greg's genome showed genetic changes that cause a genetic disease called Familial Mediterranean Fever, or FMF. We realize now that Greg had symptoms of FMF since he was a child, but the symptoms are not very specific, although severe, and include extreme abdominal pain, slow healing from injuries, rashes, and general aches and pains. Over his lifetime, Greg had many medical studies to try to get a diagnosis, and tried many over-the-counter remedies for his symptoms, but nothing worked. To our surprise and joy, we found that FMF is treatable with Colchicine, a drug also used to treat gout. Greg has been taking Colchicine since 2015 and his pain is now manageable. He says he met me so he could get a diagnosis and feel better. His primary care physician has patients with FMF, but didn't really think about FMF as a cause for Greg's symptoms because Greg does not look Mediterranean – he has blond hair and blue eyes. Genetic identification of disease risks can help physicians consider diagnoses they may not otherwise consider. And genetic results can be life changing for people.

Unlike Greg and me who were just curious and bold about learning our genomic information, many people fear the misuse of their genetic information, so may not agree to have genetic testing to inform their health and health care. The Federal Genetic Information Nondiscrimination Act (GINA) of 2008 only protects Americans from health insurance discrimination and employment discrimination based on their genetic information, but does not protect against other forms of genetic discrimination. Vermonters may see the risks of genetic discrimination as greater than the potential health benefits, and not agree to have genetic testing to inform their healthcare. S.247, if passed, would more fully protect Vermonters from discrimination based on their genetic information, including life insurance and long term care insurance, and help ensure Vermonters feel safe having genetic testing to inform their health care. As we are already moving forward with broader use of preventive genetic testing here in Vermont, these protections will be important for Vermonters to benefit from this advancement in health care.

Thank you for your attention. I would be happy to answer questions.