

Good afternoon Senator Cummings and members of the Senate Finance Committee. My thanks to the senators who sponsored S.247, including Senator Hardy from this 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, specifically DNA and RNA, for medical purposes, including for cancer, infectious diseases and inherited 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.

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. 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 a group of 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, genetic diseases are associated with approximately six thousand of our twenty thousand genes, and we are finding that single gene genetic disorders affect about 20% of the Vermont population, and carrying a genetic change that could cause disease in children is present in about 80% of Vermonters. By identifying genetically-driven disease risks before the onset of symptoms we are able 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. So genetic information is not always deterministic of disease severity or outcomes without options for healthcare interventions.

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, and general aches and pains. Over his lifetime, Greg underwent many medical studies and tried many over-the-counter remedies, but nothing worked. To our surprise and joy, we found out that FMF is treatable with Colchicine, a drug also used to treat gout. Greg has been taking Colchicine since 2015 and is largely pain free. 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 and employment discrimination based on their genetic information, but does not protect against other forms of discrimination based on genetic information. 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. These risks are documented in the articles my colleague, Jason Williams, shared with the committee. 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 help understand their disease risks and can take appropriate preventative measures to improve it. 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.