

Good morning Senator Lyons and members of the Senate Health and Welfare Committee. And a special good morning and thank you to Senator Ingram, who sponsored the bill that brings us together today. My name is Debra Leonard. I am here today to ask for your support of S.197, a bill that would protect Vermonters from discriminatory practices based on their genetic information.

To introduce myself, I am currently 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 28 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 Genomics Roundtable.

In Vermont, we are transitioning our health care and payment models toward prevention of disease to keep people as healthy as possible. Overall health and wellbeing are determined by many factors. About 60% of overall health determination 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. 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 healthcare. The University of Vermont Health Network is changing this. On November 1<sup>st</sup> of last year, we began offering genomic testing to our patients through a few of our providers, so we can begin integrating genetically determined health risks into the care of our patients. While we often think about genetic diseases as rare conditions, diseases are associated with approximately six thousand of our twenty thousand genes, and the World Health Organization estimates that single gene genetic disorders affect about 1% of the world's population. And this does not include diseases caused by a combination of changes in multiple genes. Knowing genetically-driven disease risks before the onset of symptoms can allow us to monitor for disease onset, to identify the early stages of disease when interventions may be more effective, and to provide appropriate treatments because we will have a diagnosis.

I would like to share a personal story. My husband, Greg Merhar, and I gave each other our genomes for Christmas in 2014 and received our results in 2015. Greg's genome showed genetic changes that cause a rare genetic disease called Familial Mediterranean Fever or FMF. We realize now that Greg had symptoms of FMF since he was a teenager, 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, 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. Genetics also can help physicians consider diagnoses they may not otherwise consider.

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 healthcare. 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. So 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.197, if passed, would more fully protect Vermonters from most any type of discrimination based on their genetic information. As we move forward with broader use of preventive genetic testing, these protections will be important for Vermonters to benefit from this advancement in healthcare.

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