

Good morning and thank you for allowing me to testify in support of S.197 by phone. I believe that this bill could help to destigmatize genetic testing, improve care for patients with inherited cancer risks and potentially save health care dollars. My name is Marie Wood and I am a medical oncologist and clinical researcher and have been at the University of Vermont for over 20 years. My clinical work focuses on breast cancer and genetics and my research focuses on both genetics and prevention. I am a professor of medicine and am the Associate Director of Cancer Control and Public Health Science at the University of Vermont Cancer Center and also the Director of the Familial Cancer Program at UVMCC. Nationally I serve as the co-chair of Prevention for the Alliance for Clinical Trials (a cooperative group developing clinical trials for patients with and at risk for cancer). I also serve on the NCI prevention steering committee and NCI Central IRB that reviews prevention studies for protection of patients' rights.

I have been working in the area of cancer genetics since my fellowship at the University of Colorado (in the early 1990's). I have established two clinical and research programs in cancer genetics (one at the University of Colorado, which is still in existence, and one at the University of Vermont when I arrived in 1997). I have been working with people with inherited risk for cancer since the discovery of BRCA 1 in 1994 and was involved in the first clinical genetic testing for this gene. I have seen and been involved in considering the impact of cancer genetic testing (not only medical, but also ethical, legal and social impact) for the great majority of my medical career.

In the early days of genetic testing, we kept separate "shadow" charts for patients undergoing genetics testing. We did this to protect patients from misuse of their information. While we did not understand all of the possible ramifications, we did worry about employment and health insurance. With the introduction of GINA legislation in 2008, more widespread use of genetic testing for cancer risk and the need for providers caring for these patients to have access to this information, we were obliged to put testing information into patient's medical record. That is now our standard practice and provides critical guidance for cancer prevention and sometimes cancer treatment. This is an example of how we provide the best medical care if we remove all barriers to genetic testing.

There has been an explosion in our understanding of cancer genetics with discovery of many new cancer related genes. Genetic testing offers a way to identify risk and take action (for example starting high risk screening, such as screening breast MRI or more frequent colonoscopy, or having preventative surgeries, such as colectomy or bilateral mastectomies). This is most important for unaffected individuals as they may be able to avoid a cancer diagnosis with these actions. Currently, the uptake of testing among family members when a gene mutation is identified in a patient is <30%. This may be due to concerns regarding potential for discrimination. Our group completed and published a national study showing that fear of discrimination was a significant barrier to genetic testing for untested relatives. It is therefore imperative that we do as much as possible to destigmatize genetic testing.

Genetic testing for cancer risk has the potential to save health care dollars as well. This becomes evident when you consider today's high cost of treating cancer and compare that with the cost of cancer screening. For example, colonoscopy (which can identify and remove early pre-cancerous polyps) can prevent colon cancer in people with inherited risk for colon cancer. Colonoscopy is far less costly than treatment of colon cancer. Additionally, preventative surgeries to remove breasts and/or ovaries can reduce the risk for breast and/or ovarian cancer by >90% and is far less costly than treatment for either of those cancers. Moreover, this does not even consider the quality of life associated with avoiding a cancer diagnosis and treatment.

In closing I want to thank you for your consideration of this important legislation which I believe stands to destigmatize genetic testing, improve patient care and save health care dollars. I am happy to answer any questions.