

Testimony of

Linda Steinmark, MS, CGC

in support of

SB 857- AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS

February 20, 2015

Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan and members of the Public Health Committee: My name is Linda Steinmark and I am a certified genetic counselor. I work at The Hospital of Central Connecticut and the Hartford Healthcare Cancer Institute.

I am writing to testify regarding **SB 857 An Act Concerning Licensure for Genetic Counselors**. I would like to express my gratitude to the Public Health Committee for raising this important bill.

I support this bill and the proposed substitute language.

Genetic counseling is an integral part of patient care throughout the lifespan. The role of genetics is unlike any other part of medicine, as the impact of genetic test results not only affects the patient but their family members – their children and siblings, relatives whether they are close or estranged.

Genetic counselors are uniquely trained to assist patients in comprehending the benefits and limitations of genetic testing, and provide psychosocial support as they process these familial implications. I have witnessed an aunt unexpectedly diagnosed with late stage ovarian cancer struggle with how to tell her beloved niece she may also be at risk. I have counseled the niece about the benefits and consequences of genetic testing for hereditary breast and ovarian cancer, and helped her find a way to discuss this risk with her own children when she learned she in fact did carry that same genetic mutation.

This story is not unique, and it plays out every day in our state's cancer centers, OB/GYN practices, pediatric and adult clinics. As genetic counselors, we find ourselves in the role of educator about genetic principles and features of hereditary syndromes at times of heightened stress in our patients' lives. A couple may be seeking an answer as to why they have experienced multiple miscarriages, certainly an emotional time in their lives. Knowing the genetic basis can help them understand the recurrence risk for a future pregnancy and can assist in family planning. A family struggling to raise an infant with birth defects and/or developmental delays would want to know how this might affect their future children. A person with a recent cancer diagnosis, worried about their own health and an often complex regimen of treatments or surgeries, will also try to understand what this means for their loved one and his or her future cancer risk. Bottom line - these are not simple blood tests.

Genetic counselors provide the information and support necessary for individuals to make a truly informed decision whether genetic testing is right for them at that time. We also take a detailed family history and identify the most appropriate test and the most informative person in the family. We facilitate family communication and follow-up care to appropriate providers.

As our understanding of the genetic basis of disease grows, so will the need for qualified genetic counselors. Physicians and nurse practitioners who refer to genetics need to know that they are sending their patients to a qualified genetic counselor. Licensure of genetic counselors will provide that assurance.

Involving genetic counselors in the genetic testing process improves patient safety and lowers healthcare costs. Studies have shown that non-genetics healthcare providers may not elicit or comprehend the importance of family history and subsequently order the wrong test. Not only is this a waste of healthcare dollars, but negative test results would provide a patient and their relatives with a false sense of security regarding their health risks. For a full understanding of the range of harms that may occur, please refer to the NSGC testimony.

Licensure of genetic counselors will improve patient access. Reports from states where licenses are issued have shown that high quality genetic counseling is increasing in communities. Hospitals are better able to credential genetic counselors, paving the way for hiring more genetic counselors to meet the growing demand.

Thank you for providing this opportunity to express my support for licensure for genetic counselors in Connecticut.

Sincerely,

Linda Steinmark. MS, CGC