

Testimony of Ginger Nichols, Certified Genetic Counselor
To the
PUBLIC HEALTH COMMITTEE
Regarding SB no. 857
AN ACT CONCERNING LICENSURE FOR GENETIC COUNSELORS
Friday, February 20, 2015

Senator Gerratana, Representative Ritter, Senator Markley, Representative Srinivasan, distinguished members of the Public Health committee: Thank you for the opportunity to submit testimony regarding **Senate Bill 857: An Act Concerning Licensure for Genetic Counselors**.

I support licensure of genetic counselors.

My name is Ginger Nichols. I live in Sandy Hook, CT. I am a Board Certified Genetic Counselor, and I have been working as a genetic counselor at UConn Health for over 14 years.

First, I would like to start by offering my sincere thanks for raising Bill 857; which I would support with amendments. A bill such as this could represent a major step toward ensuring that CT residents are aware of the level of education, training and professional standards of genetic counselors. Licensure of genetic counselors is important for public protection, to help ensure that patients know when they are being counseled by a genetic counselor and when they are not. It is also important to help other health care professionals know who is qualified to consult with or refer their patients to. There is a nationwide movement for genetic counselor licensure with 19 states currently issuing licenses or in rulemaking with six other states introducing bills. In addition, six more states are preparing to introduce bills.

Who are Genetic Counselors?

As you may know, genetic counselors are healthcare practitioners with significant training and expertise in genetics and counseling, obtained through a rigorous two year Master's degree program accredited by the Accreditation Council of Genetic Counseling (ACGC). Following the completion of an accredited program, candidates are eligible for certification by sitting for a national board certification examination, which is administered every year by the American Board of Genetic Counseling (ABGC).

While many other health care professionals have some genetic education, it is typically included in their broader studies as a single class or single course. Only master's level genetic counselors focus on coursework dedicated to genetics and counseling throughout their two years of training. After graduation, genetic counselors keep up-to-date, through their training and continuing education, with advances in genetic technology, refinements in genetic testing and the implications of testing for the individual and their family members.

Genetic medicine is expanding rapidly and has an influence on many medical issues throughout the lifespan (including common disease like cancer and heart disease). In Connecticut and around the country, genetic counselors work in a wide range of clinical, academic, laboratory, research, public health, and biotechnology settings. Many of the genetic counselors who live and work in Connecticut provide direct patient care in a variety of specialties such as Cardiology, Infertility, Musculoskeletal, Neurology, Obstetrics, Oncology, Ophthalmology, Pediatrics and Teratology. The state recently invited Jackson Laboratories to build a genomics research center in Farmington and there are genetic counselors in CT who work for clinical and research laboratories.

Working as part of a health care team, genetic counselors provide information and support to individuals and families concerned about risk of genetic disorders. Genetic counselors explain, in easy-to-understand terms, difficult and constantly evolving genetic information to patients

While providing this service, some of the roles a genetic counselor may offer include:

- collect and interpret family and medical histories,
- identify individuals and families at risk of genetic conditions,
- explain inheritance and natural history,
- quantify chance of occurrence and recurrence,
- review available testing options and coordinate testing and/or diagnostic studies,
- provide informed consent for genetic testing,
- discuss management, prevention and recommended risk reducing measures,
- provide written documentation of medical, genetic, and counseling information for families and health care professionals,
- discuss available research opportunities,
- serve as patient advocates and refer individuals and families to support services as appropriate,
- and/or refer to appropriate healthcare professionals for follow-up specialized care.

All of this is provided in a context of supportive care and sensitivity that is tailored to each patient's / family's particular needs. Specialized and current knowledge is critical for providing accurate genetic counseling and thus ensuring that patients benefit from genetic information.

Genetic counselors role and scope of practice is defined by the National Society of Genetic Counselors.

The availability of genetic and genomic testing services is rapidly growing. The National Institutes of Health and Genetic Testing Registry currently lists 25,514 genetic tests for 4,200 disorders and 2,800 genes. Scientific advances in the field of Genetics will continue to provide new and more complex testing options. Genetic counselors trained in a masters degree certified program are ideally suited to work with health care providers to ensure the delivery of high quality, up to date genetic services; and to make sure that that patients have all the information needed to make an informed decision about what is right for them.

The Importance of Licensure

- ***Health and Safety of the Public***

It is my hope that licensure can protect patients / consumers from unqualified providers and unregulated practices. The State can prevent harm by ensuring that providers who represent themselves as genetic counselors have the appropriate training and continuing education. Several published case series have documented cases of adverse events (including many in Connecticut) that have arisen when genetic counseling and/or testing occurred without the involvement of a certified genetic counselor. Documented harms caused by individuals calling themselves genetic counselors without the accredited training have included:

- Incomplete risk assessments
- Misinformation regarding genetic risk or lack of risk
- Misunderstanding of implication of genetic information from family history or test results leading to:
 - Unnecessary medical treatment and / or surgery
 - Wrong tests ordered, leading to costly genetic testing
 - Lack of prevention strategies or disease monitoring
 - Avoidable fear, guilt, or anxiety
- Lack of informed consent prior to testing, particularly for presymptomatic or predispositional testing

- ***Access to Healthcare***

- The demand for genetic counseling and testing is increasing.
- Licensure of genetic counselors will assist those healthcare providers making referrals by identifying qualified and appropriately trained professionals.
- Licensure will remove constraints on billing for genetic counseling, thereby allowing medical centers to hire more genetic counselors and improve patient access.

Economic Impact

There are approximately 60 -70 genetic counselors practicing in the state of Connecticut.

- Incorporating genetic counselors into the testing process has been shown to lead to cost-efficient risk identification and more appropriate genetic testing.
- Savings in healthcare spending for patients with cancer, neurological disorders, cardiac disorders, and other genetic diseases has been documented.
- The Master's level education requirements, certification exam, and maintenance of certification program for genetic counselors exist on a national basis and are the basis for all of the currently pending and enacted licensure legislation in the country.
 - Therefore, there should be little cost to the state as:
 - This bill will not require the state to develop a new training program.
 - This bill will not require the state to develop a certification examination.
 - This bill will not require the state to administer a re-certification process.

In closing, thank you for your consideration of licensure for genetic counselors. I would like to propose some amendments to the current language of this bill and would be willing to speak with you further about these details.

Selected References:

- Benseid TA, Veach PM and Niendorf KB (2014). What's the harm? Genetic counselor perceptions of adverse effects of genetics service provision by non-genetics professionals. *Journal of Genetic Counseling*. 23(1):48-63.
- Brierley KL, Campfield D, Ducaine W, et al (2010). Errors in Delivery of Cancer Genetics Services: Implications for Practice. *Connecticut Medicine*. 74(7): 413-423.
- Brierley K, Blouch E, Cogswell W, et al (2012). Adverse events in cancer genetic testing: medical, ethical, legal, and financial implications. *The Cancer Journal*. 18(4):303-309.
- CT OLR Research Report 1/10/12, 2012-R-0004: <http://www.cga.ct.gov/2012/rpt/pdf/2012-R-0004.pdf>
- National Society of Genetic Counselors document on scope of practice: http://www.nsgc.org/client_files/SOP_final_0607.pdf
- UnitedHealth, Center for Health Reform & Modernization: Personalized Medicine: Trends and prospects for the new science of genetic testing and molecular diagnostics. Working Paper 7, March 2012.
- NCBI Genetic Testing Registry : <http://www.ncbi.nlm.nih.gov/gtr/>