

Testimony of John Richardson, Director of Policy and Government Relations  
National Society of Genetic Counselors  
Before the Rhode Island House Corporations Committee  
in support of, with amendments,  
House Bill 5147 Genetic Counselor Licensure

Dear Chairman Solomon, Vice Chairwoman O'Brien, and distinguished Members;

The National Society of Genetic Counselors (NSGC) would like to thank Representatives McEntee, Ruggiero, Kazarian, Caldwell, and Craven for introducing H. 5147, a bill to license genetic counselors. I also want to thank Tracey Kehoe, advocate and Ovarian Cancer survivor, for all of her efforts to support this important legislation.

NSGC supports H. 5147, with amendments, as it would help protect the public from unqualified individuals that could provide genetic counseling. The bill will also improve access to high quality genetic services in Rhode Island. Our proposed amendments are listed at the end of my testimony.

Why does Rhode Island need genetic counseling licensure?

- Currently in Rhode Island, there is no legal standard for who can represent themselves as genetic counselors. In addition, there is no definition for what services they are authorized to provide.
- H. 5147 would establish legal requirements for the licensure of genetic counselors ensuring the delivery of high quality genetic counseling services. The bill protects Rhode Islanders from receiving inaccurate information about genetic risks from individuals who do not meet minimum education and certification standards. The lack of genetics education and training can lead to the misunderstanding of genetic information (e.g., family history, genetic test results) and the inappropriate utilization of genetic services. This means an individual may not have had the right test ordered or they unnecessarily underwent treatment or surgery. Conversely a patient may not have undergone necessary surveillance and/or surgery. There are also significant financial harms that occur to individuals and health systems as testing costs range from \$200 to \$50,000. Choosing the right test for the right person is often complex.
- H. 5147 would ensure that individuals using the title of genetic counselor have met minimum education, continuing education, and certification standards. This is particularly important given the growing innovation and complexity of genetic testing with an estimated 10 new tests coming to market daily.
- H. 5147 would provide assurance that the quality of genetic services in Rhode Island are comparable to that of neighboring states. Nationally, 29 states have enacted licensure laws for genetic counselors including your nearest neighbors: Connecticut and Massachusetts. Without licensure, individuals without appropriate credentials could provide genetic counseling and therefore decrease the quality of services in your state as compared to neighboring states.
- H. 5147 would ensure that the State of Rhode Island is working to attract highly educated healthcare professionals. Genetic counselors are in high demand and it is important that Rhode Island compete for these highly qualified individuals. Graduates consider the availability of licensure when seeking employment as it allows independent practice and efficient care delivery. Without licensure, the State is at a disadvantage.

Our understanding is H. 5147 was modeled after the Massachusetts genetic counselor licensure law. Massachusetts was one of the first states to enact genetic counselor licensure fifteen years ago, and

some of the provisions are now outdated. In fact there is an effort to amend the Massachusetts law to ensure it aligns with more recent states that have enacted licensure for genetic counselors. NSGC's proposed amendments will ensure the Rhode Island law reflects best practice today and ensures high quality genetic services for tomorrow. NSGC respectfully requests the following amendments:

- 1) Genetic counselor training programs are now accredited by the Accreditation Council for Genetic Counseling. This organization split from the American Board of Genetic Counseling several years ago.

In Section 5-90-3 Definitions, we recommend Inserting,

*“ACGC means the Accreditation Council for Genetic Counseling (ACGC), accreditation board for genetic counselor training programs or its successor agency”*

- 2) The scope of practice has also been modified to better reflect genetic counselor training and their practice. The following scope of practice is being used today and should H. 5147 should include it:

Section 5-90-3, Page 2 Strike lines 7-29 and Insert:

*“a) obtain and evaluate individual, family, and medical histories to determine genetic risk for genetic/medical conditions and diseases in a patient, his/her offspring, and other family members;*

*b) discuss the features, natural history, means of diagnosis, genetic and environmental factors, and management of risk for genetic/medical conditions and diseases;*

*c) identify, order, and coordinate genetic laboratory tests as appropriate for the genetic assessment;*

*d) integrate genetic laboratory test results and other diagnostic studies with personal and family medical history to assess and communicate risk factors for genetic/medical conditions and diseases;*

*e) explain the clinical implications of genetic laboratory tests and other diagnostic studies and their results;*

*f) evaluate the client's or family's responses to the condition or risk of recurrence and provide client-centered counseling and anticipatory guidance;*

*g) identify and utilize community resources that provide medical, educational, financial, and psychosocial support and advocacy; and*

*h) provide written documentation of medical, genetic, and counseling information for families and health care professionals.*

*i) when necessary, refer patients to a physician for diagnosis and treatment”*

- 3) To align with Amendment #1, in section 5-90-6, Strike lines 22-28 and Insert,  
*“by the ACGC or its successor; and provided, further, that the genetic counselor remains certified in accordance with the ABGC or ABMG, or their successors;*  
*(ii) Earned a master's degree from a genetic counseling training program that is accredited by the ACGC or an equivalent as determined by the ACGC, or a doctoral degree from a medical genetics training program that is accredited by the ABMG or an equivalent as determined by the ABMG;”*
- 4) Absent licensure, there wasn't a requirement for board certification to practice genetic counseling. There is at least one genetic counselor in the state who did not certify, but who graduated from a genetics training program and has been practicing in good standing for 25

years. Most states allow a time limited window for these individuals to apply for licensure if they have a history of providing high quality services to patients. The amendment would require these individuals to apply for licensure within the first six months it is available. We believe this will apply to one or two individuals.

Page 4 Line 34, Strike, "*An*" and Insert: "*Within six months after licensure applications being available, an*"

5) To align with Amendment #1,

Page 6, Line 3 Insert "*ACGC*", before "*approved*"

In conclusion, we look forward to working with the bill sponsors and this committee to enact genetic counselor licensure that will ensure Rhode Islanders receive high quality genetic counseling services. I thank the Chairman, Vice Chair and the committee for your attention to this important issue, and I offer myself as a resource as you move forward.