

Representative Joseph J Solomon, Jr  
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Representatives Solomon, O'Brien, Caldwell, and Esteemed Members of the House Corporations Committee,

The Rhode Island Genetic Counselors want to thank Representatives McEntee, Ruggiero, Kazarian, Caldwell, and Craven for introducing *AN ACT RELATING TO BUSINESSES AND PROFESSIONS – GENETIC COUNSELORS LICENSING ACT {LC003344}*.

As practicing genetic counselors working in Rhode Island and serving Rhode Island patients and families, we are **for** House Bill No. 6643. Issuing Genetic Counseling licensure would establish requirements and implement minimum standards for individuals regarding academic achievement, clinical experience, and skills necessary to deliver high quality genetic counseling services. Currently, our state has no legal standard for those who can identify themselves as genetic counselors; therefore anyone can label themselves a genetic counselor even if they have absolutely no training, putting the quality of care Rhode Island patients are receiving at risk.

Genetic counselors are healthcare providers with extensive training and expertise in human and medical genetics, patient education, and psychosocial counseling—obtained through a two-year Master's-level program. Students enter the field from a variety of disciplines including biology, genetics, psychology, and public health. There are 52 accredited graduate programs in the United States.

Genetic counselors play a critical role within a healthcare team and provide information and support to individuals and families affected by, and concerned about, risk of genetic disorders. Genetic counselors:

- Collect and interpret family and medical histories
- Identify individuals and families who are at risk for genetic conditions
- Explain inheritance and natural history to patients and family members
- Quantify chance of occurrence and recurrence
- Review available genetic testing options
- Provide informed consent for genetic testing
- Order genetic testing and deliver results to patients
- Discuss management, prevention, and research opportunities
- Serve as patient advocates and refer individuals and families to community or state support services as appropriate

Genetic counselors are employed in a wide range of clinical care, academic, laboratory, research, and biotechnology settings. There are approximately 15 genetic counselors in Rhode Island, a majority of whom provide direct patient care in a variety of specialties such as Oncology, Pediatrics, Neurology, Cardiology, and Obstetrics. Genetic counselors also work for genetic testing laboratories and health plans.

### **Why do we need genetic counseling licensure?**

The GENETIC COUNSELORS LICENSING ACT {LC003344} would help protect the public from potential harms that may result if this occupation remains unregulated. Documented harms that untrained individuals cause attempting to provide genetic counseling include:

- Incorrect diagnosis based on misinterpretation of genetic test results
- Misinformation regarding genetic risk
- Lack of informed consent or proper education prior to presymptomatic or predispositional testing
- Inappropriately ordering costly genetic testing
- Misunderstanding of the implications of genetic information such as family history or genetic test results, which can lead to:
  - Unnecessary medical treatment and/or surgery
  - Lack of prevention or disease monitoring strategies
  - Irreversible management decisions
  - Fear, anxiety, and guilt that could otherwise be avoided or reduced

The availability of genetic and genomic testing services is rapidly growing. The National Institutes of Health Genetic Testing Registry lists genetic tests for more than 5,800 different diseases. As the number of tests increases, so too does the complexity of testing. Experiences with whole exome and genome sequencing as well as next-generation sequencing panels show a myriad of issues that have to be considered when attempting to analyze an individual's entire genome.

For example, what is the appropriate action when risk for an adult-onset condition is incidentally identified in a child who undergoes full exome sequencing to identify the cause of birth defects? Or, what is the appropriate action when a clinically available single-nucleotide polymorphism-based microarray test, which is routinely ordered for individuals with intellectual disability or birth defects, shows that a child is the product of an incestuous relationship? Genetic counselors are uniquely trained to manage these situations

The Secretary's Advisory Committee on Genetics, Health and Society's 2011 Executive Summary on Genetics Education and Training attests to the growing role genomics has in healthcare and the challenge that many non-genetics providers have in developing or maintaining the expertise necessary to navigate genomics medicine:

*"The growing integration of genetics and genomic findings into mainstream medicine and the emergence of direct-to-consumer genetic testing amplify the need for understanding risk assessment, multi-gene and genomic diagnostics, genetic-based treatment, and effective strategies in communicating genetic test results to patients and consumers. However, health care professionals, the public health workforce, patients and consumers are challenged to keep pace with this dynamic and rapidly evolving field."*

Genetic counselors are ideally suited to work with physicians and other healthcare providers to deliver high quality, up-to-date genomics services and to ensure that patients using these services are adequately informed. With training in genetics and counseling, genetic counselors are key to appropriately integrating genomics into healthcare and avoiding the significant harm that can occur when genetic risk is not identified or when a patient is not properly counseled before or after a genetic testing is performed.

Genetic counselors' expertise enables them to provide services that are cost-effective by ordering the right test for the right person. Many healthcare providers, who are not trained in genetics, request unnecessary or incorrect tests, which significantly increases healthcare costs.

For example, an individual with a family history of breast cancer may benefit from a test that costs \$4,000. However if certain family members have previously undergone testing, then the most appropriate test may only cost \$200 or even be free of charge if acted upon within the required time frame. Genetic counselors have the expertise and take the time to know what test is more appropriate. Data shows that non-genetics healthcare professionals often underestimate patients' genetic risks by failing to collect and analyze a comprehensive family health history.

For many genetic conditions, 50 percent of first-degree relatives (siblings, parents, children) of an individual with a genetic mutation will also carry that mutation and are at risk to manifest the disease or transmit the mutation. Identifying those who carry a mutation facilitates preventive screening and treatment, thus lowering the chance of disease manifestations and lowering healthcare costs.

Identifying family members who do *not* carry a mutation eliminates the need for expensive clinical follow-up.

Clinicians and patients need to know that the genetic counselors that they work with are adequately trained and up-to-date on genomic information. We urge you to enact this legislation, which would establish requirements for genetic counselor licensure and implement minimum standards for individuals regarding academic achievement, clinical experience, and skills necessary to deliver high quality genetic counseling services. In addition, licensure would ensure that genetic counselors obtain continual education credits to maintain their licenses in Rhode Island. Currently, Rhode Island has no legal standard for those who can identify themselves as genetic counselors; therefore, anyone can label themselves a genetic counselor even if they have absolutely no training.

As the field of medical genetics grows, so too does the need to provide the citizens of Rhode Island with accurate information regarding their genetic conditions, genetic risks, and results of genetic tests. No mechanism currently exists to ensure that the individual providing genetic counseling to citizens of Rhode Island is qualified to do so. In a climate where direct-to-consumer genetic testing is available and the complexity of genomic tests is increasing, the citizens of Rhode Island need to have access to professionals who have been deemed qualified by the state.

Additionally, licensure would help employers know that they are hiring individuals who have the appropriate training and credentials to provide genetic counseling services—and would prohibit unskilled individuals from using the title of genetic counselor.

Genetic counselor licensure is also important to Rhode Island because it will help maintain a high quality genetic counseling workforce. To date, 31 states have passed licensure legislation including Connecticut, Massachusetts, and New Hampshire. Without state licensure, qualified genetic counselors may seek employment outside of Rhode Island to work in states with licensure where they can work at the full potential of their competency.

The demand for genetics counselors is increasing and new graduates are in high demand. Without licensure, we may not be able to attract these graduates or we may not receive the same caliber of graduates as states with licensure. As more states obtain licensure, individuals who are not appropriately trained may flock to states without licensure to practice. These circumstances would place

our state at a disadvantage compared to states with licensure and significantly hinder access to quality genetic counseling services.

Many hospitals include licensure as a requirement for credentialing, so a non-licensed practitioner cannot be credentialed. This can create a significant barrier to access for those practitioners' services. Many hospitals won't hire non-licensed practitioners or they require them to work under the supervision of a physician, which limits the number of patients these practitioners can see because their schedules are tied to physicians' schedules.

This does not make sense for genetic counselors because they often have a higher level of genetics training than most physicians—with the exception of medical geneticists. Licensure for genetic counselors will improve access to their services and ensure more patients receive high quality genetic counseling and also reap potential cost savings. Medicaid, for instance, could certainly save more money if more of our Medicaid beneficiaries saw genetic counselors prior to testing.

We thank the Chairman and this committee for your attention to this important issue, and we offer ourselves as a resource as you move forward.

Sincerely,

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