

Testimony of John Richardson, Director of Policy and Government Relations,
National Society of Genetic Counselors
Before the Maryland Senate Education, Health & Environmental Affairs Committee
in support of
SB 34 State Board of Physicians – Genetic Counselors – Licensing.

Dear Chairman Pinsky, Vice Chair Kagan and distinguished Members;

I am John Richardson, Director of Policy and Government Relations for the National Society of Genetic Counselors (NSGC). I am also a resident of Edgewater, MD. On behalf of the NSGC, we want to thank Senator Lam for introducing SB 34, a bill to license genetic counselors, and this committee for their work to usher this important legislation through the Senate last year. SB 34 will help protect the public from unqualified individuals providing genetic counseling while improving access to high quality genetic services in Maryland. I appreciate the opportunity to testify in favor of this important legislation that would provide licensure for certified genetic counselors in Maryland.

Who are genetic counselors?

- Genetic counselors are healthcare providers with significant training and expertise in human and medical genetics, patient education, and psychosocial counseling; obtained through a 2-year accredited Masters level program.
- There are 52 accredited graduate training programs in the United States including two in Maryland, housed at the University of Maryland School of Medicine, and a joint program at Johns Hopkins University/National Human Genome Research Institute.
- Genetic counselors are certified through the American Board of Genetic Counseling. It is one of the fastest growing professions, having grown 100 percent over the previous ten years and an expected growth of 80 percent the next 10 years.
- Genetic counselors are part of a healthcare team providing information and support to individuals and families concerned about risk of genetic disorders. They identify individuals and families at risk of genetic conditions and quantify these risks; explain inheritance and natural history; provide informed consent for genetic testing; identify, review, and select testing options; promote adaptation to genetic risk, and serve as patient advocates.
- Genetic counselors work in a wide range of clinical care, academic, laboratory, research, and biotechnology settings. In Maryland, there are approximately 160 certified genetic counselors, a majority of whom provide direct patient care in a variety of specialties.
- In addition, there are a number of genetic counselors working at the National Institute of Health on public health genomics programs and research including a focus on rare diseases.

Why do we need genetic counseling licensure?

- 1) Currently in Maryland, 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.

SB 34 would establish legal requirements for the licensure of genetic counselors ensuring high quality genetic counseling services. The bill protects Marylanders from the potential harms of receiving inaccurate information about genetic risks that can occur when individuals who do not meet minimum education and certification standards provide this information. Documented harms identified in Maryland include misunderstanding or misinterpreting genetic information (e.g., family history, genetic test results) leading to unnecessary treatment/surgery, lack of

necessary screening and surgery, treatment or preventative measure, lack of informed consent, financial harms, and avoidable fear or anxiety.

Many genetic test results are complex and are difficult to interpret for practitioners who do not have training in genetics. An example of the types of harm that occur would be a woman whose test results indicated a variance of unknown significance. In this instance, a genetic mutation is not known to be pathogenic and heightened surveillance may be warranted. In some instances these results are misinterpreted by non-genetics practitioners and these women have needlessly undergone mastectomies. There are many other possible physical harms that occur when genetic tests results are misapplied.

There are also financial harms. Exciting innovation has led to a very dynamic genetic testing marketplace. The prices of genetic tests vary broadly and test selection can be a challenge for non-genetics practitioners. While a \$10,000 test may be required for some patients, others may benefit from a \$500 test. Genetic counselors have the expertise to ensure the right test is selected for the right person, which can save individuals and health systems, such as Medicaid, money. Studies have shown that healthcare providers without training in genetics often order more expensive genetic testing than is indicated, amounting to unnecessary healthcare expenditures. A number of studies suggest that 30 percent of genetic tests ordered by providers without specialized training are inappropriate.

2) SB 34 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 complexity of genetic testing with an estimated 10 new tests coming to market daily.

3) SB 34 would provide reassurance that the quality of genetic services in the State of Maryland are comparable to that of neighboring states. Nationally, 29 states have enacted licensure laws for genetic counselors including our nearest neighbors: Pennsylvania, Delaware, and Virginia. Without licensure, individuals without appropriate credentials could provide genetic counseling and therefore decrease the quality of services in our state as compared to neighboring states.

4) SB 34 would ensure that the State of Maryland is working to retain and attract highly educated healthcare professionals. As home to two genetic counseling graduate programs at a time when genetic counselors are in high demand, it is important that our State retain as many graduates as possible. Graduates consider the availability of licensure when seeking employment as it allows independent practice and efficient care delivery. Without licensure, the State may also have a hard time attracting new graduates from outside Maryland to practice here or may not get the same caliber of graduates as states with licensure.

In conclusion, the NSGC is hopeful that the committee will work with Senator Lam to enact genetic counselor licensure that will ensure the people of Maryland receive high quality genetic counseling services. I thank the Chairman, Vice Chair, Senator Lam and this committee for your attention to this important issue, and I offer myself as a resource as you move forward.