

**TESTIMONY OF ANGELA TREPANIER, CGC,
PRESIDENT OF THE NATIONAL SOCIETY OF GENETIC COUNSELORS
SUBMITTED FOR THE RECORD
PENNSYLVANIA HOUSE PROFESSIONAL LICENSURE COMMITTEE
JULY 23, 2008**

Majority Chairman Sturla, Minority Chairman Adolph, distinguished Members; I am Angela Trepanier, a Certified Genetic Counselor and President of the National Society of Genetic Counselors (NSGC). I appreciate the opportunity to submit testimony for the record in favor of licensure for certified genetic counselors in Pennsylvania.

Genetic counselors are healthcare professionals with specialized graduate degrees and experience in the areas of medical genetics and counseling. Most enter the field from a variety of disciplines, including biology, genetics, nursing, psychology, and public health.

Genetic counselors work with other members of the health care team providing information and support to individuals and families concerned with genetic disorders or birth defects and to people who may be at risk for a variety of inherited conditions. Genetic counselors procure and interpret family and medical histories, identify individuals and families at risk, explain inheritance and natural history, quantify chance for occurrence and recurrence, review available testing options, and discuss management, prevention, and research opportunities. They also serve as patient advocates and refer individuals and families to community or state support services as appropriate.

NSGC is the leading voice, authority and advocate for the genetic counseling profession. Membership represents more than 2,400 masters-level health professionals, most of whom provide direct patient care (totaling over one million visits per year). Members are employed in a wide range of clinical care, academic, research and biotechnology settings, and are located in every state of the U.S. and internationally. NSGC is committed to ensuring that the public has access to quality genetic counseling and genetic testing.

NSGC has developed guiding principles for state licensure efforts. These principles are intended to provide national guidance to policy makers and genetic counselors involved in creating state regulation of genetic counselors.

NSGC's goal in developing this language is to ensure uniformity among the nation's genetic counselors so that laws regulating the practice of genetic counseling are widely applied. Consistency will ensure the highest degree of public protection for consumers who utilize genetic counseling services.

The guiding principles address the critical elements of a state licensing bill including qualifications for licensure, scope of practice, title protection, temporary licenses, continuing education requirements, exemptions, as well as administration.

NSGC supports state licensure acts that encompass these principles and we hope your work on HB 2137 and HB 2138 will reflect the following principles:

Qualifications for Licensure

The following qualifications should be met:

- A) The examination requirements for certification as a genetic counselor by the American Board of Genetic Counseling or the American Board of Medical Genetics; or a medical geneticist by the American Board of Medical Genetics.
- B) Temporary license granted to those individuals with ABGC Active Candidate Status (or ABMG board-eligible). Temporary licensees should practice under general supervision of a licensed genetic counselor or a physician.
- C) Optional grandfather clause (This is an option to be written when there are individuals in the state who graduated before ABGC accreditation and certification were available, were not certified by ABMG, and no longer qualify for ACS with ABGC).

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Scope of Practice

For licensure purposes, NSGC believes the following defines the practice of genetic counseling:

- A) Obtain and interpret individual, family, medical, developmental, and reproductive histories;
- B) Determine the mode of inheritance and risk of transmission of genetic conditions and birth defects;
- C) Discuss the inheritance, features, natural history, means of diagnosis, and management of these conditions;
- D) Identify, coordinate, interpret, and explain genetic laboratory tests and other diagnostic studies;
- E) Assess psychosocial factors, recognizing social, educational, and cultural issues;
- 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) Communicate information to their clients in an understandable manner;
- H) Facilitate informed decision making about testing, management, and alternatives;
- I) Identify and effectively utilize community resources that provide medical, educational, financial, and psychosocial support and advocacy; and
- J) Provide accurate written documentation of medical, genetic, and counseling information for families and health care professionals.

Title Protection

It is important that the public be able to easily discern qualified providers of genetic counseling services. Only licensed individuals should use in connection with his/her name or place of business, the title "genetic counselor," "licensed genetic counselor," "gene counselor," "genetic consultant," "genetic associate" or any words, letters, abbreviations or insignia indicating or implying a person holds a genetic counseling license.

Certain Exemptions

We acknowledge that other health care providers other than genetic counselors have within their scope the ability to provide genetic counseling services. As such, we recommend including a provision that exempts other licensed healthcare providers with overlapping Scopes of Practice from genetic counselor licensure so that they are able to continue to deliver these important services.

Continuing Education Requirements

As genetics is evolving quickly, it is necessary that each licensee should present satisfactory evidence when seeking license renewal that in the period since the license was issued or last renewed the applicant has completed a minimum of 25 hours annually of NSGC or ABMG continuing education units and/or other means as approved by ABGC for re-certification by ABGC or ABMG, prorated for the length of the license.

Administration of Licenses

NSGC believes a Genetic Counselors Licensure Board, made up of licensed genetic counselors, is the ideal regulatory body to issue licenses and provide a mechanism for complaints and disciplinary action. A separate board would be most effective as they would be experts in the field being regulated. NSGC does understand the fiscal constraints some states face. If creating a new Genetic Counselors Licensure Board is not feasible, then NSGC believes the state department of health or the medical board serve as alternatives with either entity strictly following the legislative intent of the licensure law. Enacting legislation should also direct either entity to consult and adopt policies consistent with NSGC and ABGC when addressing genetic counseling policies.

Conclusion

NSGC is hopeful that the committee will work with Representative Killion to enact genetic counseling licensure that will ensure the people of Pennsylvania receive quality genetic counselor services. We believe that if legislation adopts the aforementioned principles, the people of Pennsylvania will be well served. NSGC thanks the Chairman and his committee for your attention to this important issue, and we offer NSGC as a resource as you move forward.