

Testimony of Kathy Valverde
House Professional Licensure Committee
July 23, 2008

Good morning.

I have the privilege and honor to speak on behalf of the genetic counseling licensure committee and to represent the diverse group of genetic counselors in the Commonwealth of Pennsylvania. Let me begin by describing the genetic counselors roles and then discuss why licensure is so important.

What Do Genetic Counselors Do?

Genetic Counselors are health care professionals who have specialized graduate degrees and training in medical genetics and counseling. They are part of a health care team providing medical information and support to families who have genetic conditions or who are at risk to develop genetic disorders. Genetic counselors research the genetic condition present in a family; interpret information about the disorder; analyze inheritance patterns; provide recurrence risk information and review available options with both the family and their health care providers.

Why is Licensure so Important?

Guarantee of *Minimal Qualifications* of Practitioners

- The general public is not aware of the minimal standards for genetic counselors. State regulation of this profession will ensure that a genetic counselor is adequately trained and competent to provide genetic counseling.
- At the present time, anyone can call themselves a genetic counselor. Title protection limits individuals from calling themselves genetic counselors unless they meet the standards and qualifications established by licensure.

Guarantee of *Quality* Genetic Counseling Services

- Genetic Counselors in Pennsylvania are not required to take the national American Board of Genetic Counseling certification examination. Individuals who have demonstrated their competency by qualifying and passing an examination are less likely to commit errors that result in harm to a consumer of such service. Mistakes in practice may be inevitable, but regulating providers through competency guidelines will reduce their frequency and help to avoid the emotional and economic costs associated with errors in practice.

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Accessibility of Genetic Services to the Public

- Genetic counselors have an extensive knowledge base in medical genetics and their expertise is often invaluable to other members of the health care team. Patients who receive inaccurate or NO genetic counseling may have unnecessary genetic tests; inappropriate testing or may not be provided access to testing.
- Licensure would be the first step towards making genetic counseling more accessible to the general public. This is especially important in the more rural areas of Pennsylvania. Pittsburgh and Philadelphia have a wealth of genetic counseling services but those residents living in the central part of the state have difficulty accessing these services.

Legal Recourse

- Patients do not have legal recourse if they are harmed by a genetic counselor practicing in Pennsylvania. Without state regulation, incompetent genetic counselors cannot be punished by the state nor restricted from practicing. Consumers cannot call a state agency to record a complaint against a genetic counselor.

Why is Licensure of Genetic Counselors so important now?

Genetic Counseling is a relatively new profession established 40 years ago. The early genetic counselors did not have the technological resources that are so readily available today. These genetic counselors saw patients to discuss single gene, rare disorders where testing typically provided a yes or no answer. Advances in technology now allow testing for common complex disorders. These test results provide information about the level of risk, and can be difficult to interpret. Many of these tests are now available directly to consumers. Some direct to consumers testing companies provide appropriate genetic counseling services while others do not. State licensure of genetic counseling would provide consumers with access to highly trained individuals to help with interpretation and counseling of these test results.

In summary, licensure will ensure the responsible practice of genetic counselors in Pennsylvania, protecting the consumer from harm and providing a mechanism for recourse when consumers are harmed. Just as physicians and nurses have both board certification and state licensure, so should genetic counselors.

Thank you