

TESTIMONY OF ANGELA TREPANIER, CGC, Assistant Professor, Director
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National Society of Genetic Counselors

before the
STATE OF MICHIGAN HOUSE OF REPRESENTATIVES
HEALTH POLICY COMMITTEE

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Chairman Corriveau, Vice-Chairwoman Segal, and distinguished Members; I am Angela Trepanier, a Certified Genetic Counselor, from Detroit. I am a faculty member and director of the genetic counseling graduate program at the Wayne State University School of Medicine. I am also a member of the Michigan Association of Genetic Counselors, past president of the National Society of Genetic Counselors (NSGC), and a current board member for both the Genetic Counseling Foundation and the National Coalition of Health Professional Education in Genetics. On behalf of Michigan Genetic Counselors, we want to thank Representative Donigan for introducing HB 5684 and those that have cosponsored it on this committee. I appreciate the opportunity to testify in favor of this important legislation that would provide licensure for certified genetic counselors in Michigan.

Genetic counselors are healthcare providers with significant training and expertise in molecular biology, medical genetics and psychosocial counseling, obtained through a 2 year Masters level program. There are 32 accredited training programs in the United States and Canada including two in Michigan, housed at the University of Michigan and at Wayne State University.

Genetic counselors are part of a health care team providing information and support to individuals and families concerned about risk of genetic disorders. Genetic counselors collect 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. Genetic counselors are employed in a wide range of clinical care, academic, laboratory, research, and biotechnology settings. Within Michigan there are over 60 genetic counselors, most of whom provide direct patient care in a variety of specialties including but not limited to Obstetrics, Oncology, Pediatrics, Neurology, Cardiology, Ophthalmology, and preimplantation genetic diagnosis. There are also several genetic counselors working for the Michigan Department of Community Health on public health genomics programs including newborn screening follow up and chronic disease genomics. In fact, Michigan is a model state in terms of advancing public health genomics initiatives.

HB 5684 is extremely important as the bill would help protect the public from potential harms that may result from this occupation remaining unregulated. Harms caused by untrained individuals attempting to provide genetic counseling include:

- Misinformation regarding genetic risk or lack of risk;
- Misunderstanding of the implications of genetic information such as family history or test results, which can lead to:
 - unnecessary medical treatment and/or surgery
 - lack of prevention or disease monitoring strategies
 - irreversible management decisions
 - Avoidable fear, anxiety and guilt
- Inappropriately undertaking costly genetic testing

Currently, there are 3000-4000 known hereditary diseases and conditions and that number is growing. In 2009, genetic testing was available for about 1900 different diseases, up 15% from 2008, and up an incredible 760% from 1994, the year I graduated from my genetic counseling program (see chart below). Genetic testing is now routinely available for conditions like Huntington disease, cystic fibrosis, various forms of mental retardation and muscular dystrophies, just to name a few. In addition, everyday we learn about genetic contributions to common diseases, like heart disease, mental illness, macular degeneration and dementia. We are also learning how genetic tests can help identify who is going to have an adverse reaction to certain medications, a field called pharmacogenomics. Providers without specific genetics training may use genetics and incorporate testing in their practices but compared to other areas of medicine, very few genetics services have reached consumers. Furthermore, one study showed that 72% of non-genetics physicians rate themselves as having only fair to poor knowledge of genetics. This could translate to a reduction in the quality of care as evidenced by another study which showed that approximately 30% of non-genetics health care providers misinterpreted the results of a genetic test for susceptibility to colon cancer that they ordered on their patients. The consequences of such misinterpretation are potentially devastating since these individuals would have been told that they were no longer at risk for colon cancer and were likely to stop potentially life-saving endoscopic screening. With the science evolving so rapidly, it is unfair to expect these providers to recognize the scope of and deliver such specialized care. Genetic counselors are the effective genetic service care coordinators for patients being treated by non-genetics physicians and can ensure the delivery of high quality, up-to-date genetics services.

In my own experience, I have seen evidence of these issues not only in the patients I have served but also with a friend. In her first pregnancy, my friend had a blood test, called a maternal serum AFP test, which showed her AFP was very high. This result meant that there was an increased chance that her baby had an

open neural tube defect, a condition where a part of the baby's spine does not close properly. Her physician did an amniocentesis procedure which looks at a baby's chromosomes and the AFP level. The chromosome part of the test was normal and my friend was told that her baby was okay. She was still concerned at which point she called me. I put her in contact with a genetic counselor in her area, knowing that it was also important to look at what the AFP part of the amniocentesis showed. The genetic counselor reviewed the amniocentesis results and found that the amniotic fluid AFP was very elevated. An ultrasound was performed and revealed that the baby had a lethal birth defect, one in which the entire spine had not closed properly. My friend went from thinking that her baby was going to be fine to learning that her baby would be stillborn or die shortly after birth. The genetic counselor was able to provide support and connect my friend and her husband to resources to help them plan for the birth and subsequent death of their baby. As this story shows, involvement of genetic counselors can aid in alleviating knowledge gaps that can occur in primary care and enhance the provision of genetics services.

Genetic counselors provide services that not only increase quality but also cost-effectiveness. We assure tests are utilized appropriately. Many health care providers often request unnecessary testing or incorrect tests increasing the cost of health care. Non-genetics health care professionals have also been demonstrated to underestimate patients' genetic risks because of ineffective family history evaluation. In addition, fewer than half of them have taken continuing education courses in genetics. For many genetic conditions, 50% of first degree relatives (siblings, parents, children) of a person with a genetic mutation will also carry a mutation and are at risk to manifest the disease or transmit the mutation. Identifying those who carry a mutation offers the opportunity for preventive screening and treatment, thus lowering the chance of disease manifestations. Moreover, identifying those family members who do *not* carry a mutation eliminates the need for expensive clinical follow-up.

We urge you to enact this legislation as it would establish requirements for the licensure of genetic counselors ensuring minimum standards for individuals in terms of academic achievement, clinical experience, and skills necessary to deliver high quality genetic counseling services. It would also establish continuing education requirements. Given the rapid changes in genomic medicine, continuing education is essential to ensure that genetic counselors are providing the most up-to-date, evidence-based services. Currently, in Michigan there is no legal standard for who can represent themselves as genetic counselors. As the field of medical genetics grows, there is and will continue to be a need to provide the citizens of Michigan with accurate information regarding their genetic risks and results of genetic tests. At present, there is no mechanism that assures citizens that the individual who is providing this information is qualified to do so. In a climate where direct-to-consumer genetic testing via internet companies is widely available despite widespread concerns about the medical value of these tests, the citizens of Michigan need to have access to professionals who

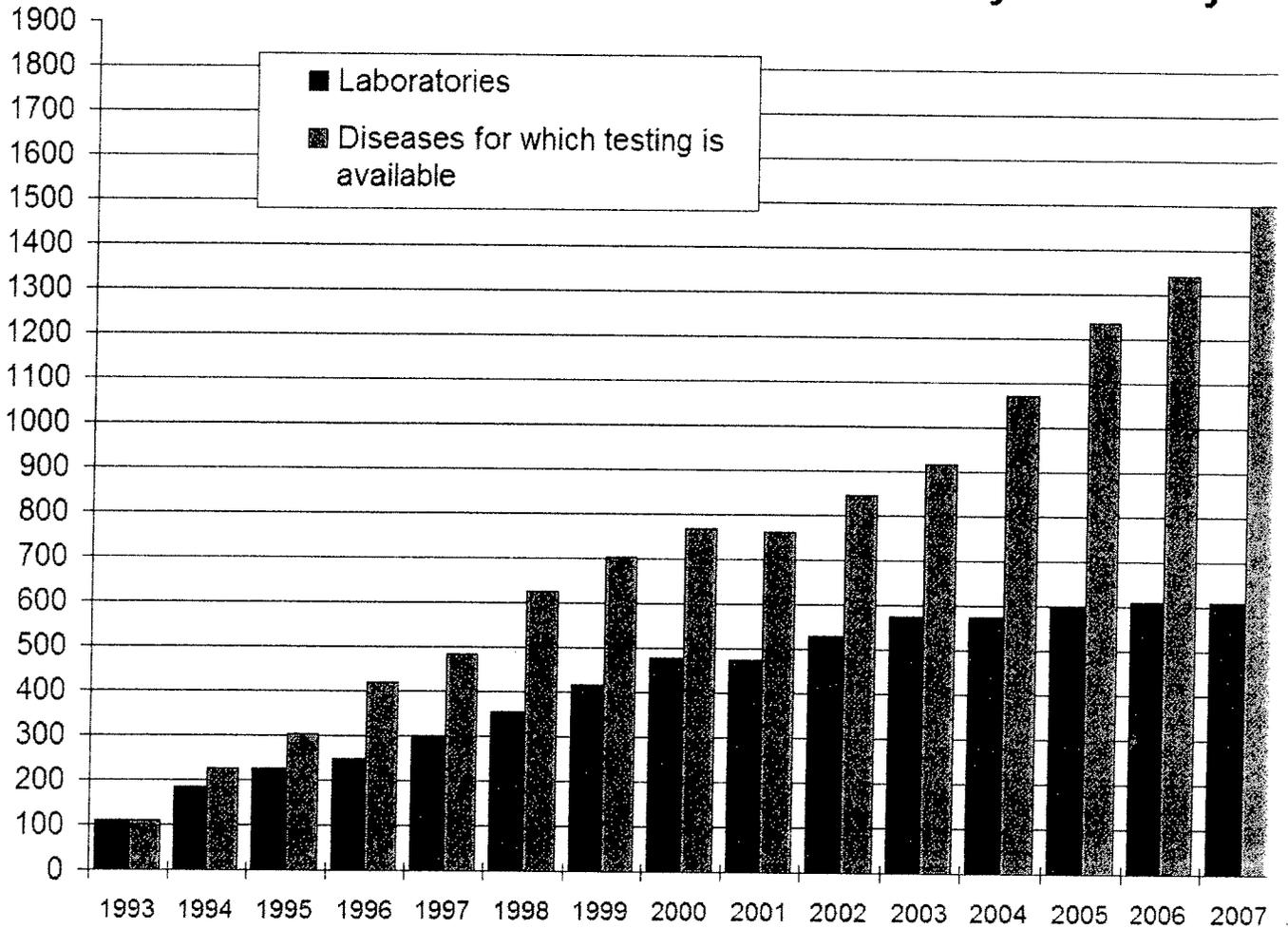
have been deemed qualified by the state to help them understand their potential genetic risks.

Additionally, there is no way for employers to assure they are hiring individuals who have the appropriate training and education to provide genetic counseling services or that would prohibit unskilled individuals from using the title of genetic counselor.

This is also important to Michigan as the field of genetic counseling is growing rapidly; membership to the NSGC has grown by over 50% in the past 6 years and the number of genetic counseling training programs in the U.S. has increased significantly. As I previously stated, there are currently 2 training programs in Michigan and we graduate approximately 12 students per year. Currently, about 45% of my graduates seek employment in Michigan and make up almost a quarter of the current workforce. Because other states are increasingly offering the ability to become licensed, students may not apply to our programs and those who do may seek employment outside of Michigan in states with licensure. We may also have a hard time attracting new graduates from outside the state to practice here or may not get the same caliber of graduates as states with licensure get. These circumstances place our state at a disadvantage compared to others and it could result in a loss of revenue and tax base. In addition, it could decrease patient access to the specialized health care services that genetic counselors provide and could decrease the quality of care provided in the state.

In conclusion, significant scientific advances in genomics are predicted to revolutionize the practice of medicine and are already beginning to do so. To ensure that these scientific breakthroughs are translated to the practice of medicine, public policy must encourage the integration of genomics and genetic counseling into the health care system. The Michigan Association of Genetic Counselors is hopeful that the committee will work with Representative Donigan to enact genetic counseling licensure that will ensure the people of Michigan receive quality genetic counselor services. We believe the people of Michigan will be well served. 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.

GENETests: Growth of Laboratory Directory



Data source: GeneTests database (2009) / v