

"Genetic counseling is a critically important component of the appropriate use and integration of genetic tests and services"

Report of the Secretary's Advisory Committee on Genetics, Health, and Society. 2006



Genetic Counselors

Uniquely qualified and solely dedicated to providing competent genetic counseling services¹

Genetic counselors are health care providers uniquely trained in Master's degree programs to provide quality genetic counseling services. Genetic counselors are certified by the American Board of Genetic Counseling.

In health care settings, genetic counselors are tasked with:

- Eliciting and interpreting medical and family histories.
- Calculating the risk of occurrence or recurrence of a genetic condition.
- Imparting clear, accurate and comprehensive information regarding medical conditions with a genetic component, including risks, symptoms, screening and treatment options as well as testing options to patients and healthcare providers.
- Providing psychosocial support to individuals and families coping with a genetic condition.

Genetic counselors work closely with individuals and families to:

- Determine the appropriateness of pursuing genetic technologies.
- Facilitate informed decision-making.
- Communicate with the family, laboratories and other healthcare providers.
- Promote screening and preventative care to minimize health risks.

Genetic counselors:

- Recognize and respond to ethical and moral dilemmas.
- Identify factors that promote or hinder client autonomy.
- Understand issues surrounding privacy, informed consent, confidentiality, and real or potential discrimination.

Each year, thousands of Michigan residents benefit from the services provided by genetic counselors.

- *1 in every 20 babies is born with a birth defect³*
- *20-30% of all infant deaths is due to genetic disorders⁴*
- *1 in every 9 pediatric hospital admissions is for a child with genetic disorder⁵*
- *1 in every 8 adult hospital admissions is for a genetic cause⁶*
- *50% of mental retardation has a genetic basis⁷*
- *15% of all cancer has an inherited susceptibility⁸*
- *10% of chronic disease (heart, diabetes, arthritis) has a significant genetic component⁹*

Genetic counselors work in various health care settings in Michigan, including universities, industry, public and private health care settings.

Areas of practice include:

- Pediatric Genetics
- Cancer Genetics
- Neurogenetics
- Reproductive Genetics
- Infertility Clinics
- Other specialty Clinics

To find a genetic counselor, go to www.nsgc.org or www.abgc.net.

To view the centers where genetic counselors work, visit www.migeneticsconnection.org.

Genetic counseling is the process of helping people understand and adapt to the medical, psychological, and familial implications of genetic contributions to disease. ²

Genetic Counselor Licensure in Michigan Points to Consider

Genetic Counselor Licensure will provide Michigan citizens:

- Assurance that individuals using the title genetic counselor have attained minimum education and certification standards.
- Assurance that genetic counselors maintain a minimum level of continuing education.
- Increased access and lower costs to consumers for genetic services.^{1,2}
- Reduction in the likelihood of causing harm by receiving inaccurate information about genetic risks from individuals who do not meet these minimum education and certification standards.³
- A mechanism by which claims of incompetent, unethical, unlawful behavior of a genetic counselor can be reported and investigated as well as provide a means to sanction a genetic counselor for proven offenses of these claims and/or for operating outside of their scope of practice.

To accomplish these goals, a genetic counselor licensure bill must require the following:

- A Masters or higher degree from a genetic counseling program accredited by the American Board of Genetic Counseling (ABGC) or equivalent program
- Certification or Active Candidate Status by the American Board of Genetic Counseling/Medical Genetics
- A minimum level of continuing education in order to maintain a license
- Exemption from licensure for other licensed healthcare providers whose scope of practice overlaps that of genetic counselors.
- Adherence to a professional code of ethics (e.g. National Society of Genetic Counselors' Code of Ethics).

¹Report of the Secretary's Advisory Committee on Genetics, Health, and Society: Coverage and Reimbursement of Genetic Tests and Services. 2006, p B-3-15.

²Gibons, A. Employer-based coverage of genetic counseling services. *Benefits Quarterly*. 2004, p.48-58.

³Report of the Secretary's Advisory Committee on Genetics, Health, and Society: Coverage and Reimbursement of Genetic Tests and Services. 2006, p 51-52.



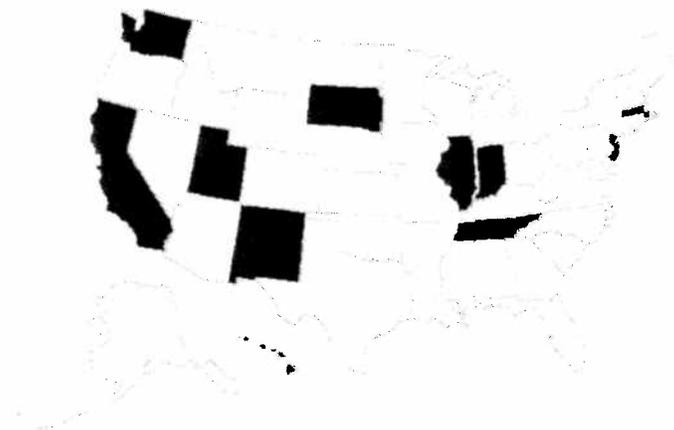
**The leading advocate for quality genetic counseling
services in the State of Michigan.**

Michigan: At the Forefront in Genetic Legislation

Michigan's government has stood proudly at the forefront in passing legislation regarding matters related to genetics that affect our state's citizens. These laws and policies have aided in the protection of genetic information and defined the appropriate uses of rapidly advancing genetic technology. Various examples of such laws and policies can be reviewed at <http://www.migeneticsconnection.org/policy.shtml>.

Currently, Michigan is only one of two states with informed consent laws for genetic testing (Act 29 of 2000). The 1999 report from the Governor's Task Force on Genetic Privacy paved the way to passage of this law and others that were quite revolutionary at the time. These laws and policies address the burgeoning genetic issues that confront families including those related to newborn screening, employment discrimination due to genetic information, health insurance protection in light of genetic test results, and informed consent for genetic testing.

Now is the time to add further protections by licensing genetic counselors, the health professionals specifically trained to address the complex issues associated with genetic disease.

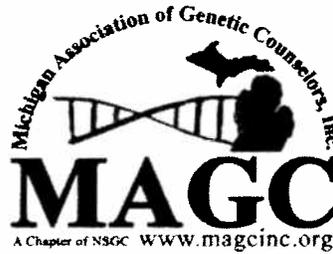


**States with
legislation for
licensing genetic
counselors**

Currently, 11 states have passed legislation that licenses genetic counselors. In fact, some of Michigan's nearest neighbors in the Great Lakes Region, Illinois and Indiana, have enacted laws for genetic counseling licensure and Ohio and Wisconsin are actively pursuing it. This movement has set a standard for our region. It is critical that Michigan remain at the forefront in genetic legislation, protecting the quality of care our citizens receive.



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Supporters of Licensure for Michigan Genetic Counselors

The following individuals and organizations have provided the Michigan Association of Genetic Counselors (MAGC) with letters documenting their support for licensure of Michigan Genetic Counselors. Copies of the letters are available on request.

Organization and Institutions

Children's Hospital of Michigan Division of Metabolic and Genetic Disorders
Children's Hospital of Michigan Division of Pediatric Neurology
Henry Ford Hospital Department of Medical Genetics
March of Dimes Michigan Chapter
Michigan Health and Hospitals Association
Michigan Section of the American College of Obstetricians and Gynecologists
Michigan State Medical Society
National Society of Genetic Counselors
University of Michigan Medical School
VCFS International Support and Educational Foundation
Wayne State University Genetic Counseling Program
Wayne State University Department of Obstetrics and Gynecology
Wayne State University School of Medicine
William Beaumont Hospital

Individuals

| | |
|------------------------|---|
| David Aughton, MD | Chief, Division of Genetics, Beaumont Hospital |
| Mahbubal Huq, MD, PhD | Professor Division of Pediatric Neurology/Children's Hospital of Michigan/Detroit Medical Center |
| Russel Jelsema, M.D. | West Michigan Obstetrics & Gynecology |
| Theodore Jones, MD | Interim Chair Department of Obstetrics and Gynecology Director Maternal Fetal Medicine, Wayne State University/Hutzel Women's Hospital |
| Jennifer Lewandowski | President VCFS International Support and Educational Foundation |
| Timothy Madion, MD | Grand Traverse Women's Clinic |
| Michael Simon, MD, MPH | Director, Cancer Genetic Counseling Service Karmanos Cancer Center/Detroit Medical Center |
| David Stockton, MD | Chief, Division of Metabolic and Genetic Disorders Children's Hospital Of Michigan/Detroit Medical Center |
| Helga Toriello, PhD | Director Clinical Genetics, Spectrum Health |
| Barry Wolf, MD, PhD | Chair, Medical Genetics, Henry Ford Hospital |
| Julie Zenger Hain, PhD | Director Clinical Cytogenetics, Oakwood Hospital |