



# OLR RESEARCH REPORT

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## GENETIC COUNSELORS

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You asked about genetic counselors, including what they do, where they work, and other states' licensing requirements.

### SUMMARY

Genetic counselors are health care professionals with specialized training in human genetics who provide information about genetics and genetic diseases. People seek genetic counseling services for a variety of reasons, such as learning more about their own or their family's genetic conditions or when testing during pregnancy shows an increased risk of certain conditions.

Genetic counselors work in a variety of settings, such as universities, hospitals, and laboratories. To be certified as a genetic counselor by the American Board of Genetic Counseling (ABGC), an individual must have a master's degree in genetic counseling from an accredited program and pass an examination, among other requirements.

Thirteen states license genetic counselors; Connecticut does not. Most of these licensing statutes were passed recently, many within the last five years. To be licensed, states generally require applicants to have a master's degree in genetics or a related field and pass an examination, among other requirements. States with licensing statutes generally exempt certain categories of people (e.g., licensed physicians, students) from various requirements and provide civil or criminal penalties for

violating the licensing laws. Some states address other issues including requiring health care provider referrals for genetic counselors to provide their services; establishing advisory committees to oversee the profession; and specifying when a counselor can disclose confidential information.

## **GENETIC COUNSELING**

### ***Definition and Scope of Practice***

The National Society of Genetic Counselors (NSGC), a membership organization of over 2,500 genetic counselors, defines the profession this way:

Genetic counselors are health 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, public health and social work.

Genetic counselors work as members of a health care team, providing information and support to families who have members with birth defects or genetic disorders and to families who may be at risk for a variety of inherited conditions. They identify families at risk, investigate the problem present in the family, interpret information about the disorder, analyze inheritance patterns and risks of recurrence and review available options with the family.

Genetic counselors also provide supportive counseling to families, serve as patient advocates and refer individuals and families to community or state support services. They serve as educators and resource people for other health care professionals and for the general public. Some counselors also work in administrative capacities. Many engage in research activities related to the field of medical genetics and genetic counseling

<http://www.nsgc.org/About/FAQsaboutGeneticCounselorsandtheNSGC/tabid/143/Default.aspx>).

NSGC's statement of genetic counselors' scope of practice includes the following examples: (1) providing expertise in clinical genetics, (2) counseling and communicating with patients on matters of clinical genetics, and (3) providing services according to professional ethics and values. The full scope of practice statement is attached to this report; it is also available here:

[http://www.abgc.net/docs/GC\\_Scope\\_of\\_practice\\_final.pdf](http://www.abgc.net/docs/GC_Scope_of_practice_final.pdf).

Some states that license genetic counselors define the term in their licensing statutes (more information on licensing appears below). For example, Delaware defines the practice of genetic counseling as including any or all of the following:

1. obtaining and interpreting individual, family, and medical development histories;
2. determining the mode of inheritance and risk of transmission of genetic conditions;
3. discussing the inheritance, features, natural history, and means of diagnosis;
4. identifying, coordinating, and explaining genetic laboratory tests and other diagnostic studies; but the genetic counselor must refer a client to a licensed physician if, in the course of providing service to a client, a counselor finds an indication of disease or condition that requires medical assessment;
5. assessing psychosocial factors and recognizing social, educational, and cultural issues;
6. evaluating the client's or family's responses to the condition or risk of recurrence and providing client-centered counseling and anticipatory guidance;
7. communicating genetic information to clients in an understandable manner;
8. facilitating informed decision making about testing and management alternatives;
9. identifying and effectively using community resources that provide medical, educational, financial, and psychosocial support and advocacy; and

10. providing accurate written documentation of medical, genetic, and counseling information for families and health care professionals (24 Del. Code Ann. § 1799H).

### ***Reasons People Seek Genetic Counseling Services***

Genetic counseling services are typically sought by people or families who have certain genetic disorders or are seeking more information about genetic disorders, often in connection with pregnancy. For example, the March of Dimes website suggests that genetic counseling may be valuable for anyone with unanswered questions about the origins of diseases or family traits, including the following:

1. people with inherited disorders or birth defects, or who are concerned they might have them;
2. women who are pregnant or planning to be after age 35;
3. couples who already have a child with intellectual disability, an inherited disorder, or a birth defect;
4. couples whose infant has a genetic disease diagnosed by routine newborn screening;
5. women who have had babies who died in infancy or three or more miscarriages;
6. people concerned that their jobs, lifestyles, or medical history may pose a risk to the outcome of a pregnancy (common causes of concern include exposure to radiation, medications, illegal drugs, chemicals, or infections);
7. couples who would like testing or more information about genetic conditions that occur frequently in their ethnic group;
8. couples who are first cousins or other close blood relatives; or
9. pregnant women whose ultrasound examinations or blood testing indicate that their pregnancy may be at increased risk for certain complications or birth defects (March of Dimes, Genetic Counseling, available at [http://www.marchofdimes.com/pregnancy/trying\\_geneticcounseling.html](http://www.marchofdimes.com/pregnancy/trying_geneticcounseling.html)).

## **INFORMATION ABOUT THE PROFESSION**

The following information about the genetic counseling profession is drawn from NSGC's *2010 Professional Status Survey: Executive Summary*. Forty-nine percent of NSGC's 2,316 full members responded to the survey.

Approximately one-third of survey respondents reported working in a university medical center; another third work in a public or private hospital or medical facility; 9% work in a commercial diagnostic laboratory; 5% work in a physician's private practice; and 20% work in other settings such as government agencies, insurance companies, and pharmaceutical companies. Two-thirds of respondents reported working in traditional areas of genetic counseling, including cancer, pediatric, and prenatal.

Seventy-seven percent of respondents reported having a master's degree in genetic counseling and 21% reported having a master's in genetics (human or medical). Six percent reported having another master's degree, 2% reported having a Ph.D, and 6% reported having another advanced degree.

Eighty-three percent of respondents reported providing direct patient care; 17% reported providing non-clinical roles. Other roles included laboratory support; management, research or study coordinators; project management; clinical coordination; and case management, among others.

The full executive summary is available here:

<http://www.nsgc.org/Portals/0/Publications/PSS%202010%20Executive%20Summary%20FINAL.pdf>.

## **EDUCATION AND TRAINING**

The ABGC certifies genetic counselors and accredits graduate programs in genetic counseling. To become certified, someone must have a master's degree in genetic counseling from an ABGC-accredited program and pass an examination, among other requirements. According to ABGC, applicants to accredited master's degree programs in genetic counseling often have bachelor's degrees in medical sciences, psychology, or health care, but could also have undergraduate degrees in other fields. More information about the certification process is available at ABGC's website: <http://www.abgc.net/Certification/certification.asp>.

ABGC’s website lists 58 certified genetic counselors in Connecticut (<http://www.abgc.net/ABGC/AmericanBoardofGeneticCounselors.asp>; click “Find a Certified Genetic Counselor,” then search by state; last searched January 4, 2012).

There are 31 ABGC-accredited graduate programs in the United States; none are in Connecticut. A full list of the programs is available here: [http://www.abgc.net/Training\\_Program\\_Accreditation/US\\_Accredited\\_Programs.asp](http://www.abgc.net/Training_Program_Accreditation/US_Accredited_Programs.asp).

## STATE LICENSING

We found licensing laws for genetic counselors in 13 states. Table 1 lists these states and the statutory citations for each state’s genetic counselor licensing laws.

Table 1: State Genetic Counselor Licensing – Statutory Citations

State	Citation
California	Cal. Health & Safety Code §§ 124981 – 124982
Delaware	Del. Code Ann. tit. 24, § 1799G <i>et seq.</i>
Hawaii	Haw. Rev. Stat. § 451K-1 <i>et seq.</i>
Illinois	225 Ill. Comp. Stat. 135/1 <i>et seq.</i>
Indiana	Ind. Code § 25-17.3-1-1 <i>et seq.</i>
Massachusetts	Mass. Gen. Laws ch. 112, § 252 <i>et seq.</i>
New Jersey	N.J. Stat. Ann. § 45:9-37.111 <i>et seq.</i>
New Mexico	N.M. Stat. § 61-6A-1 <i>et seq.</i>
Oklahoma	Okla. Stat. tit. 63, § 1-561 <i>et seq.</i>
South Dakota	S.D. Codified Laws § 36-36-1 <i>et seq.</i>
Tennessee	Tenn. Code Ann. § 63-6-801 <i>et seq.</i>
Utah	Utah Code Ann. § 58-75-101 <i>et seq.</i>
Washington	Wash. Rev. Code § 18.290.010 <i>et seq.</i>

Generally, states that license genetic counselors require applicants to have at least a master’s degree in genetics or a related field, pass an examination, and pay licensing fees. These states also generally require continuing education for license renewal, and issue provisional or temporary licenses under certain conditions.

Some states require the applicant to be certified by ABGC or the American Board of Medical Genetics (ABMG) (ABMG certification requires an M.D. or D.O. degree, or Ph.D for certain specialties). These states include Delaware, Illinois, New Mexico, and Tennessee.

Below are examples of other features of these states' licensing statutes.

### ***Exemptions from Licensure***

Most states that license genetic counselors specify certain categories of people who are exempt from licensing requirements. These categories typically include physicians or specified other health care providers and students meeting certain criteria. For example, Indiana provides that licensed physicians or nurses are exempt, provided they do not use the title of "genetic counselor" or a similar title. Indiana also exempts (1) students or interns from accredited schools who are participating in a supervised training program or (2) people from another state who are ABMG- or ABGC-certified and acting as consultants in Indiana (Ind. Code § 25-17.3-4-4).

### ***Civil or Criminal Penalties for Violations***

Several states with genetic counselor licensing statutes provide civil or criminal penalties for people who violate the licensing laws or engage in specified prohibited acts, in addition to license suspension or revocation when appropriate. Examples of such penalties follow.

***Delaware.*** In Delaware, it is a class G felony (punishable by up to two years' imprisonment, a fine of \$500 to \$1,500, or both) to engage in the practice of genetic counseling or attempt to do so in violation of the licensing law. The licensing requirement does not apply to certain people, such as physicians or other healthcare professionals who are engaging in the practice for which they are licensed (Del. Code Ann. tit. 24, §§ 1799O, 1799Q).

***Hawaii.*** In Hawaii, anyone who commits either of the following acts is subject to a fine of up to \$1,000, with each day's violation deemed a separate offense:

1. using a designation in connection with the person's name implying that the person is a licensed genetic counselor when he or she is not; or

2. representing that he or she is a licensed genetic counselor while his or her license is forfeited, inactive, terminated, suspended, or revoked (Haw. Rev. Stat. § 451K-15).

**Indiana.** Under Indiana law, anyone who violates any provision of the genetic counseling law commits a class A misdemeanor (punishable by up to a year in prison, up to a \$5,000 fine, or both) (Ind. Code § 25-17.3-5-3).

### ***Referral by Other Health Care Provider***

Illinois and South Dakota prohibit genetic counselors from providing counseling services without obtaining a referral from a doctor or certain other health care providers. For example, in South Dakota, a genetic counselor needs a documented referral from a physician, certified nurse midwife, licensed certified nurse practitioner, licensed clinical nurse specialist, or licensed physician assistant before providing genetic counseling to individuals, couples, groups, or families. The physician or other provider must maintain supervision of the patient. The genetic counselor must submit reports to the provider on any services the counselor provides to the patient and cannot provide genetic testing unless the provider orders it. Genetic counselors may provide general seminars on genetic counseling to a group or organization without a referral if the seminar does not include specific counseling to an individual, couple, or family (S.D. Codified Laws §§ 36-36-7, -8).

### ***Advisory Committees or Other Bodies to Oversee Licensing***

Some state laws establish advisory committees or similar panels to oversee genetic counselor licensing. These states include Delaware, Massachusetts, New Jersey, Oklahoma, South Dakota, and Utah. For example, New Jersey has a five-member Genetic Counseling Advisory Committee, under the State Board of Medical Examiners. The committee consists of one public member, one physician, and three genetic counselors (N.J. Stat. Ann. § 45:9-37.114). The committee's powers and duties include:

1. establishing criteria and standards for education and experience required for licensure;
2. reviewing licensing applicants' qualifications;
3. ensuring proper conduct and standards of practice;
4. issuing and renewing licenses;

5. establishing standards for continuing education;
6. maintaining a record of each licensee;
7. setting fees for examinations, licenses, applications for licensure, renewals, duplications of lost licenses, and other services the committee performs;
8. suspending, revoking, or declining to renew licenses; and
9. promulgating rules and regulations to carry out matters the board delegates to the committee concerning any provisions of the genetic counseling law (N.J. Stat. Ann. § 45:9-37.115).

### ***Confidentiality of Communications***

Two states' licensing statutes (Illinois and New Jersey) specify the circumstances in which a genetic counselor may or may not disclose confidential information received in the course of their work. For example, in New Jersey, a licensed genetic counselor is not required to disclose any confidential information that the genetic counselor acquires from a client or patient while performing genetic counseling services, unless (1) other federal or state law requires disclosure; (2) the genetic counselor is a party to a civil, criminal, or disciplinary action arising from his or her genetic counseling services, in which case a waiver of the privilege is limited to that action; or (3) the patient or client is a criminal defendant and the use of the privilege would violate the defendant's right to present testimony and witnesses on that person's behalf.

A genetic counselor who discloses confidential information in violation of this provision is liable for damages sustained by the patient or client about whom the information relates, as well as attorney's fees and costs. The genetic counselor may also be subject to a penalty of up to (1) \$10,000 for each violation or (2) \$50,000 for a knowing violation or if the board finds that violations have occurred with enough frequency as to constitute a general business practice (N.J. Stat. Ann. § 45:9-37.120).

## **LINKS FOR ADDITIONAL INFORMATION**

American Board of Genetic Counseling:

<http://www.abgc.net/ABGC/AmericanBoardofGeneticCounselors.asp>

National Society of Genetic Counselors:

<http://www.nsgc.org/>

U.S. Department of Energy, Office of Science, Office of Biological and Environmental Research, Human Genome Project Information, Genetic Counseling:

[http://www.ornl.gov/sci/techresources/Human\\_Genome/medicine/genecounseling.shtml](http://www.ornl.gov/sci/techresources/Human_Genome/medicine/genecounseling.shtml)

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