

Scope of Practice Request
Genetic Counselors

August 15, 2012

Background

Genetic counselors are master's-trained health care professionals who combine their knowledge of basic science, medical genetics, epidemiological principles, and counseling theory with their skills in genetic risk assessment, education, interpersonal communication and counseling to provide services to clients and their families for a diverse set of genetic or genomic indications.

Genetic counselors help people "...understand and adapt to the medical, psychological and familial implications of genetic contributions to disease." The process of genetic counseling "... integrates the following: interpretation of family and medical histories to assess the chance of disease occurrence or reoccurrence; education about inheritance, testing, management, prevention, resources and research; counseling to promote informed choices and adaptation to the risk or condition." ¹

Genetic counselors help the individual and the family to:

- (1) comprehend the medical facts including diagnosis, probable course of the disorder, and the available management,
- (2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives,
- (3) understand the alternatives for dealing with the risk of recurrence,
- (4) choose a course of action which seems to them appropriate in view of their risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and
- (5) to make the best possible adjustment to the disorder in an affected family member and/or the risk of recurrence of that disorder ²

Genetic counselors practice in clinical and nonclinical settings. Clinical settings include: university-based medical centers, private hospitals, and rarely, private practice. Nonclinical settings include: pharmaceutical, commercial / diagnostic laboratories, educational institutions, non-profit organizations, and public health.

A complete description of Scope can also be found at the following website

http://www.nsgc.org/client_files/SOP_final_0607.pdf and is attached as an addendum.

1. a plain language description of the request

The goal of this request is to accept the scope of practice definition for genetic counselors and move, through the appropriate process, to license genetic counselors in Connecticut.

2. public health and safety benefits that the requestor believes will be achieved should the request be implemented and, if applicable, a description of any harm to public health and safety should the request not be implemented

Genetic counselors have specialized knowledge for ordering the right test at the right time for the right reasons. Patients rely on the advice of genetic counselors in making significant medical decisions. These decisions include whether or not to have major prophylactic surgeries, whether to have genetic testing prenatally, the types of prevention screening that one might undertake to prevent fatal diseases, and discussions of genetic test results with other at-risk family members. Genetic counselors provide unbiased counseling and referrals to help patients cope with the difficult pragmatic, ethical and social implications related to genetic testing.

In summary, professional licensure can ensure that patients and consumers are protected from unqualified providers. Consumers and patients can feel confident that they are receiving quality genetic counseling services from reliable professionals.

According to the Secretary's Advisory Committee on Genetics, Health, and Society on Genetics Education and Training of Health Professionals:²

- Advances in genetics and genomics will aid in the understanding of disease processes and will assist in the use of therapeutic and preventative approaches that will significantly improve health outcomes.
- Education and training in genetics and genomics is lacking for most primary care and non-genetics specialists, and this may lead to erroneous or delayed diagnoses, incorrect disease management, deficient family planning counseling, and unnecessary costs for patients and payers.

3. the impact that the request will have on public access to health care

Formal professional recognition of genetic counselors via licensure will allow the public to gain access to the valuable services of genetic counselors. It is not expected that licensure will reduce access.

Licensure is expected to increase awareness of the professional services of licensed genetic counselors and has the potential to increase access to genetic services by helping hospitals and other medical professionals recognize who is qualified to deliver these professional services.

4. a brief summary of state or federal laws that governing the profession

There are no Connecticut or federal laws that govern genetic counseling profession, with respect to scope of practice or professional status.

5. the state's current regulatory oversight of the health care profession making the request

There is no current regulatory oversight of genetic counselors by the State of Connecticut.

6. all current education, training and examination requirements and any relevant certification requirements applicable to the health care profession making the request

The current education requirement is to complete a Master's level program accredited by the American Board of Genetic Counseling (www.abgc.net).

In addition, genetic counselors may sit for a national board certification exam which is administered by the American Board of Genetic Counseling (ABGC). The ABGC also oversees maintenance of certification.

7. a summary of known scope of practice changes either requested or enacted concerning the healthcare profession in the five-year period preceding the date of the request

None.

8. the extent to which the request directly impacts existing relationships within the health care delivery system

Genetic counselors currently practice in a wide variety of settings and interact with a wide range of providers. Defining scope of practice, and licensure, will only enhance our collaborative relationship. Providers will be able to trust that their patients will receive accurate, up-to-date information from qualified professionals.

9. the anticipated economic impact of the request on the health care delivery system.

There are approximately 49 genetic counselors practicing in the State of Connecticut. Other genetic counselors who provide service through commercial laboratories that are out of state may apply for licensure in Connecticut.

Collection of licensing fees is anticipated to offset any costs of administering a licensing program for genetic counselors in the State of Connecticut. Also, the state would not have to create or administer a certification exam, or maintenance of certification program, specifically for genetic counselors.

10. regional and national trends concerning licensure of the health care profession making the request and a summary of relevant scope of practice provisions enacted in other states

Regional trends are towards licensure of genetic counselors:

California -Cal. Health & Safety Code §§ 124981 – 124982

Delaware -Del. Code Ann. tit. 24, § 1799G et seq.

Hawaii -Haw. Rev. Stat. § 451K-1 et seq.

Illinois - 225 Ill. Comp. Stat. 135/1 et seq.

Indiana - Ind. Code § 25-17.3-1-1 et seq.

Massachusetts -Mass. Gen. Laws ch. 112, § 252 et seq.

New Jersey - N.J. Stat. Ann. § 45:9-37.111 et seq.

New Mexico - N.M. Stat. § 61-6A-1 et seq.

Oklahoma -Okla. Stat. tit. 63, § 1-561 et seq.

South Dakota - S.D. Codified Laws § 36-36-1 et seq.

Tennessee -Tenn. Code Ann. § 63-6-801 et seq.

Utah - Utah Code Ann. § 58-75-101 et seq.

Washington - Wash. Rev. Code § 18.290.010 et seq.

Last updated: April 26, 2012

Other states including Hawaii, Nebraska and Pennsylvania have licensure laws and are currently in rulemaking. Bills have been introduced in the following states: New York, Florida, Michigan, Minnesota, Rhode Island, Wisconsin and Texas.

Other states are preparing to introduce bills, including Idaho, Colorado, Kansas, Maryland, Missouri, New Hampshire, Ohio, Oregon and Virginia.

In June of 2012, our CT ad hoc committee conducted a brief electronic survey of the 49 genetic counselors identified as residing and/or practicing in Connecticut. The survey inquired about attitudes towards the possibility of licensure for genetic counselors. There were 31 responses, or a 63% response rate. 96.43% (27) of surveyed genetic counselors supported state licensure. One respondent was against licensure (3.6%). Three respondents did not answer (and not included in the percentile).

11. identification of any health care professions that can reasonably be anticipated to be directly impacted by the request, the nature of the impact and efforts made by the requestor to discuss the request with such health care professions

Genetic counselors in Connecticut receive referrals from a variety of providers, including adult and pediatric primary care, surgery, oncology, endocrinology, gynecology, obstetrics, other medical specialists, in a variety of locations. This request in no way is intended to limit access to genetic counseling or testing. We have received letters of support, which were forwarded to the Public Health Committee when there was a bill entertained by the Public Health Committee. These letters came from patients, as well as from other health care providers and included support from physicians and nurses throughout the state.

12. a description of how the request relates to the health care profession's ability to practice to the full extent of the profession's education and training

Full recognition of genetic counseling as a profession increases our status to providers and the public. Defining genetic counselors protects consumers against commercial and for-profit companies who put their own interests ahead of the public consumer. Professional licensure can ensure that patients and consumers are protected from unqualified providers and can feel confident that they are receiving quality genetic counseling services from reliable professionals.

Addendum (as attachments):

1. NSGC Scope of Practice
National Society of Genetic Counselors, Inc. (2007) Genetic Counselors' Scope of Practice. Accessed August 15, 2012 at http://www.cap.org/apps/docs/statline/pdf/nsgc_genetic_counselor_scope_of_practice.pdf
2. State of Connecticut OLR Research Report on Genetic Counselors. 2012-R-0004. James Orlando, Associate Analyst. January 2012.

References:

1. Resta R., Bowles Biesecker B., Bennett R.L. et. al. A New Definition of Genetic Counseling: National Society of Genetic Counselors' Task Force Report. *The Journal of Genetic Counseling* 2006; 15(2):77-83.
2. American Society of Human Genetics (ASHG) Ad Hoc Committee on Genetic Counseling, 1975
3. Genetics Education and Training: Report of the Secretary's Advisory Committee on Genetics, Health, and Society (February 2011).
http://oba.od.nih.gov/oba/SACGHS/reports/SACGHS_education_report_2011.pdf
4. National Society of Genetic Counselors, Inc. (2007) Genetic Counselors' Scope of Practice. Accessed August 15, 2012 at
http://www.cap.org/apps/docs/statline/pdf/nsgc_genetic_counselor_scope_of_practice.pdf

Location:

LICENSING; MEDICAL PERSONNEL; MEDICAL RESEARCH;

Scope:

Other States laws/regulations;



January 10, 2012

2012-R-0004

GENETIC COUNSELORS

By: James Orlando, Associate Analyst

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.

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).

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.

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

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Executive Office
401 N. Michigan Avenue
Suite 2200
Chicago, IL 60611 USA
Phone: 312.321.6834
FAX: 312.673.6972
E-mail: nsgc@nsgc.org
Web: www.nsgc.org

Washington, DC Office
2025 M Street, NW
Washington, DC 20036 USA



Genetic Counselor Scope of Practice:

- (a) obtain and evaluate individual, family, and medical histories to determine genetic risk for genetic/medical conditions and diseases in a patient, his/her offspring, and other family members;
- (b) discuss the features, natural history, means of diagnosis, genetic and environmental factors, and management of risk for genetic/medical conditions and diseases;
- (c) identify and coordinate genetic laboratory tests and other diagnostic studies as appropriate for the genetic assessment;
- (d) integrate genetic laboratory test results and other diagnostic studies with personal and family medical history to assess and communicate risk factors for genetic/medical conditions and diseases;
- (e) explain the clinical implications of genetic laboratory tests and other diagnostic studies and their results;
- (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) identify and utilize community resources that provide medical, educational, financial, and psychosocial support and advocacy; and
- (h) provide written documentation of medical, genetic, and counseling information for families and health care professionals.