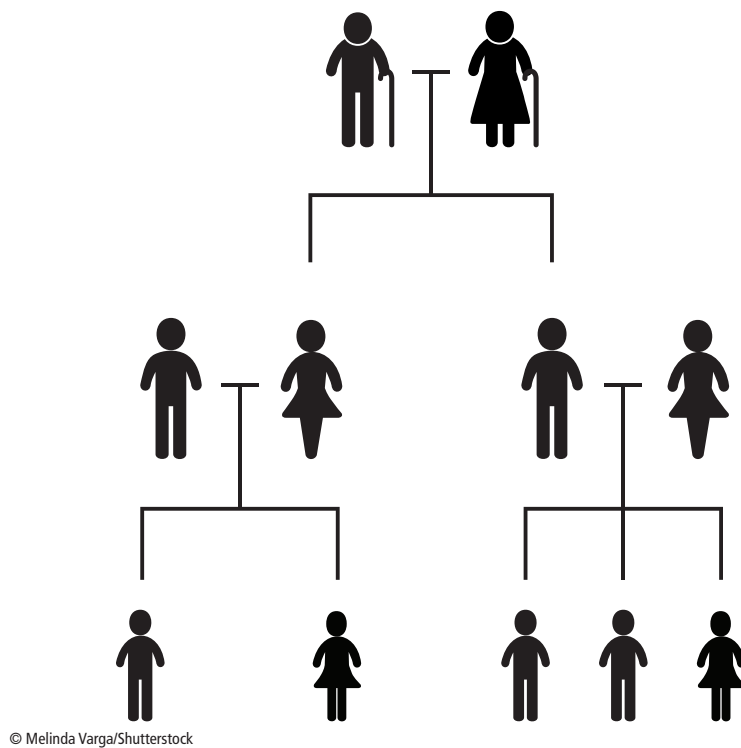




CHAPTER 22

Genetic Counselors*

Key Terms

Accreditation Council for Genetic Counseling (ACGC)
American Board of Genetic Counseling (ABGC)
Carrier testing
Chromosomes

Genetic counselor
Human Genome Project
Mutations
National Society of Genetic Counselors (NSGC)
Newborn screening

Pedigree
Predictive genetic counseling
Prenatal screening
Psychiatric genetic counseling
Reproductive technology

* All information in this chapter, unless otherwise indicated, was obtained from Bureau of Labor Statistics. *Occupational Outlook Handbook 2016–2017 Edition*. Washington, DC: U.S. Department of Labor; 2016.

GENETIC COUNSELORS

Significant Points

- A master's degree from an accredited program in genetic counseling is required to be eligible for licensure and to take the certification exam.
- Genetic counselors interpret laboratory results and communicate findings related to genetic conditions to physicians and patients.
- Genetic counselors assist patients and families in making healthcare decisions based on risks for genetic disorders.
- Employment opportunities for genetic counselors are excellent because of advanced technology in DNA testing.
- Most jobs for genetic counselors are in hospitals and offices of physicians in urban areas and teaching hospitals.

Work Description

Genetic counselors provide information and advice to other healthcare providers and to individuals and families concerned with the risk of inherited conditions. A career as a genetic counselor combines a strong scientific background with counseling skills. Genetic counselors assess individual or family risk for a variety of inherited conditions, such as

genetic disorders and birth defects. They provide information and advice to other healthcare providers and to individuals and families concerned with the risk of inherited conditions.

Genetic counseling is a rapidly growing career with projections for demands for genetic counselors to increase by 29% between 2014 and 2024, making it one of the fastest-growing health professions. The **Human Genome Project** has uncovered the genetic basis for many diseases, which has increased the demand for genetic counselors to assist individuals, families, and physicians in making decisions regarding health care and treatment.

Genetic counselors identify specific genetic disorders or syndromes that are inherited or passed down from parents to their children. For parents who are expecting children, counselors use genetic tests to predict whether a baby is likely to have hereditary disorders, such as Down syndrome or cystic fibrosis, among others (**FIGURE 22.1**).

Genetic counselors can also test whether an adult is likely to develop a chronic disease such as cardiovascular disease or ovarian cancer. Counselors identify the probability of developing certain diseases by studying patients' genes through DNA or chromosomal testing. Counselors often perform the lab tests themselves, although sometimes they have medical laboratory technologists perform the tests, which they then interpret and use for counseling. They share this information with other health professionals, such as physicians, and with patients and their families. Physicians use the results of lab tests to make decisions regarding treatment; for example, chemotherapy drugs to treat breast cancer are selected based



FIGURE 22.1 Genetic counselors discuss prenatal screening for genetic disorders with the parents.

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on the cancer's genetic profile obtained via genetic testing. When a genetic disorder is diagnosed the genetic counselor helps the individual and families understand the genetic disease and ways that the disease can be treated. Families can ask questions and express concerns about their health and options for treatment. As with other counseling, the genetic counselor will continue counseling until understanding and acceptance is achieved by individuals and/or families.

Genetic counselors are often consulted by a physician when a genetic disorder has been identified through prenatal or newborn screening or carrier testing. Individuals and families may also seek genetic counseling after an individual or family member has received a medical diagnosis that is genetically transmitted. Couples may seek genetic counseling in order to make a decision about having children. Examples of when couples may seek counseling are if there is a history of a miscarriage or stillbirth, the birth of a child with a genetic disorder or birth defect, or a family history of a genetic disease.¹ Genetic counselors usually schedule an hour for each session and will schedule a follow-up session to discuss the results of genetic tests. Additional follow-up sessions will be scheduled by the counselor to evaluate understanding and how well the individual and family are managing the genetic condition.

During an initial counseling session the counselor will ask questions to obtain a more complete family and medical history to complete a **pedigree** or specialized family tree that includes the health conditions and causes, and the age of death of the biological family members. The family tree aids the genetic counselor in mapping genetic patterns. For example, genetic testing of a child with autism may confirm the cause as fragile X syndrome and identify that the mother is the carrier. Additional information about family members through completion of the pedigree confirms other conditions in the family that can be attributed to the fragile X gene—a maternal aunt has a child with special needs, another maternal aunt was treated for infertility, and the maternal grandfather died of Parkinson's disease.³

The counselor may recommend that specific tests be done in potential parents to determine if either is a carrier for a genetic disease. Tests that are done are cytogenic tests, which evaluate for abnormalities in **chromosomes**, and biochemical testing to evaluate for **mutations** in critical proteins—enzymes, hormones, and other regulatory proteins and molecular testing for small mutations of DNA.³ The counselor will conduct follow-up sessions with the family after testing to provide not only information but emotional support to reduce anxiety and to assist the family in adjusting to the test results. The genetic counselor can also assist the family in making decisions about communicating genetic testing results with extended family members that may be impacted by a diagnosis—for example, early-onset Alzheimer's disease, which has a genetic basis.³

Prenatal screening is recommended for all pregnant women over 35 years of age because of a higher risk for the chromosomal abnormality responsible for Down syndrome.



FIGURE 22.2 Genetic screening in newborns identifies genetic disorders and allows for early intervention.

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All state public health departments conduct **newborn screening** to identify inherited disorders such as phenylketonuria (PKU) that requires a diet restricted in the amino acid phenylalanine in the infant soon after birth to prevent mental retardation (**FIGURE 22.2**).

Carrier testing may be done for partners who are considering having a family to determine if either partner carries the risks for genetic diseases known to be present in their family. For example, sickle cell anemia is transmitted to offspring if both parents are carriers for the disease. **Predictive genetic counseling** may be done when adult family members have been diagnosed with dementia, cardiovascular disease, or cancer at an early age. Adult women who have a strong family history of breast cancer may seek further information to evaluate for the presence of BRCA mutations that dramatically increase the risk for breast cancer.³ **Psychiatric genetic counseling** is a newer area of genetic counseling that may be requested by individuals with a history of autism or a serious mental illness such as schizophrenia or bipolar disease in their family.¹ This information can be used when parents have concerns about the behavior of one of their children to assist the physician or behavioral counselor determine if there is a genetic basis for the behavior and to seek appropriate treatment.

Work Environment

Genetic counselors held about 2,400 jobs in 2014. Genetic counselors work in university medical centers, private and public hospitals, physicians' offices, and diagnostic laboratories. In 2014, 39% worked in hospitals and 20% worked in offices of physicians. They work with families, patients, and other medical professionals.

Work Schedules

Most genetic counselors work full time and have a standard work schedule. Counselors may also work evenings or Saturdays to meet the needs of working families.

Employment Opportunities

In the 1960s, when the career of genetic counseling developed, counselors spent the majority of time in prenatal counseling.² Demand for genetic counselors has increased over the past decade in response to more knowledge about diseases that are genetically transmitted because of the Human Genome Project. There is greater public awareness of the genetic basis of disease as well as improved technology for genetic testing for many diseases. In addition, there is greater demand for **reproductive technology** for couples who have been unsuccessful in having a biological child.³

Education and Legal Requirements

Genetic counselors typically need at least a master's degree in genetic counseling or genetics, and some earn a PhD. Certification is required by most employers.

Education and Training

A master's degree program in genetic counseling is required to be eligible for licensure and to take the certification exam. A bachelor's degree in one of the biological or social sciences is recommended for applicants. Often those with a degree in biology, genetics, psychology, or public health or those already employed in nursing or social work may choose to become a genetic counselor. Coursework in genetic counseling includes clinical genetics, population genetics, cytogenetics, and molecular genetics, as well as psychosocial theory, ethics, and counseling techniques. Classes emphasize genetics, public health, and counseling techniques. Advanced courses focus on clinical observations, review of previous genetic research, and health communication strategies.

Master's degree programs in genetic counseling require clinical training in a medical genetics center approved by the **Accreditation Council for Genetic Counseling (ACGC)**. The website in the *Additional Information* section at the end of this chapter lists accredited programs in the United States and Canada.⁴ An application requires a written personal statement and personal interview. The **National Society of Genetic Counselors (NSGC)** website provides tips to prepare the application packet.⁵

Licensure and Certification

There are currently 15 states that require a license in genetic counseling, and other states have pending legislation for licensure. Certification is typically needed to get a license.

Certification and Other Qualifications

The **American Board of Genetic Counseling (ABGC)** provides certification for genetic counselors. To become certified, a student must first complete a master's degree program

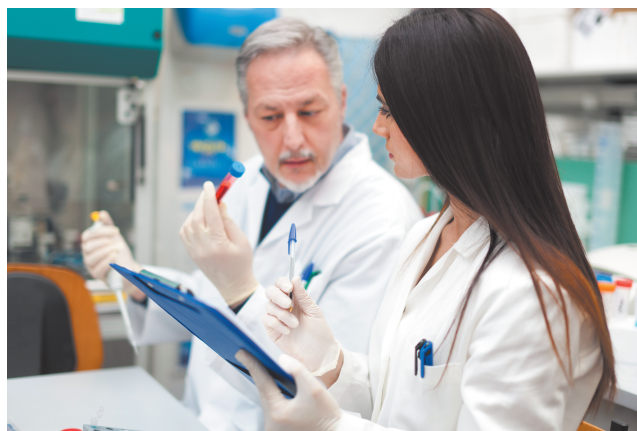


FIGURE 22.3 Genetic counselors discuss lab results with physicians.

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that has been accredited by the Accreditation Council for Genetic Counseling. There are currently 34 certified programs in the United States and Canada. Students then must pass a comprehensive exam and continue to accrue continuing education units throughout their careers.

Genetic counselors need a strong science background and the ability to explain complex information in a way that can be understood by someone without a science background. Critical-thinking skills are necessary in interpreting lab results and medical information accurately (**FIGURE 22.3**).

Compassion and sensitivity are important in determining what information will be useful and how to deliver news to individuals and families that is potentially upsetting. Genetic information is rapidly expanding, which requires that genetic counselors participate in professional organizations or conferences to keep abreast of developments in genetics and genomics to provide the most up-to-date services to patients.

Advancement

Genetic counselors that work in industry generally earn higher salaries. Since the profession is small, the opportunities for advancement are limited. Supervisory positions or training others to become genetic counselors may increase responsibilities and salaries.

Employment Trends

According to a 2014 survey from the National Society of Genetic Counselors, approximately three-fourths of genetic counselors work in traditional areas of genetic counseling: prenatal, cancer, and pediatrics. The survey noted that the number of specialized fields for genetic counselors has increased. More genetic counselors are specializing in fields such as cardiovascular health, genomic medicine, neuropsychiatric genetics, and assisted reproductive technologies. Other job opportunities are in research and product development and marketing in the pharmaceutical industry.

TABLE 22.1 Projections Data for Genetic Counselors, 2014–2024

Occupational Title	Employment, 2014	Projected Employment, 2024	Change, 2014–2024	
			Number	Percentage
Genetic counselor	2,400	3,100	700	29%

Public awareness of the genetic basis for disease and scientific advances in reproductive technologies have increased the demand for genetic counselors. Work opportunities for genetic counselors are expanding to include not only clinical practice but public policy, public health, administration, research, teaching, and private practice.⁶

Ongoing technological innovations, including lab tests and developments in genomics, are giving counselors the opportunities to conduct more types of analyses. Cancer genomics, for example, can determine a patient's risk for specific types of cancer. The number and types of tests that genetic counselors can administer and interpret has increased over the past few years.

Most growth over the next 10 years for genetic counselors is expected to be in hospitals, and most jobs will be in teaching and research hospitals and in urban areas.

Employment Change

Employment of genetic counselors is projected to grow 29% from 2014 to 2024, much faster than the average for all occupations. However, because it is a small occupation, the fast growth will result in only about 700 new jobs over the 10-year period (TABLE 22.1).

Job Prospects

Genetic counselors can generally expect favorable job prospects. Ongoing innovations in genetic testing are likely to create demand for certified genetic counselors. Most opportunities will be in teaching and research hospitals or in physician's offices in large metropolitan areas.

Earnings

The median annual wage for genetic counselors was \$67,500 in May 2014. The mean annual wages for genetic counselors in the top industries in which these counselors worked as of May 2014 were are shown in TABLE 22.2.

Related Occupations

Occupations that require similar training and have similar job responsibilities are epidemiologists, health educators, medical scientists, physicians, mental health counselors, and marriage and family therapists.

ADDITIONAL INFORMATION

For more information about a career in genetic counseling:

- American Dental Education Association. Explore Health Careers.org. Internet: <http://explorehealthcareers.org/>

For information about accreditation and schools offering education in genetic counseling in the U.S. and Canada visit:

- Accreditation Council for Genetic Counseling (ACGC), P.O. Box 15632, Lenexa, KS 66285. Internet: <http://gceducation.org/Pages/Accredited-Programs.asp>

For information about genetic counselors, how to become a genetic counselor, and states that require licensure visit:

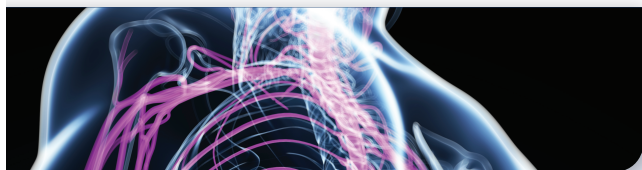
- National Society of Genetic Counselors (NSGC), 330 N. Wabash Avenue, Suite 2000, Chicago, IL 60611. Internet: <http://www.nsgc.org/>

For information on becoming certified as a genetic counselor in the U.S. and Canada contact:

- American Board of Genetic Counseling (ABGC), P.O. Box 14216, Lenexa, KS 66285. Internet: <http://www.abgc.net/ABGC/AmericanBoardofGeneticCounselors.asp>

TABLE 22.2 Mean Salaries for Genetic Counselors, May 2014⁷

Medical and diagnostic laboratories	\$89,060
Management of companies and enterprises	\$82,570
Specialty hospitals	\$70,820
Offices of physicians	\$69,120
General medical and surgical hospitals	\$67,900
Colleges, universities, and professional schools	\$60,390



LEARNING PORTFOLIO

Issues for Discussion

1. Discuss the advantages and disadvantages of communicating with extended family when a family member has been diagnosed with early-onset Alzheimer's disease, which has a genetic basis.
2. Discuss the pros and cons for parents deciding to bring a pregnancy to term, terminating the pregnancy, or putting up the child for adoption when prenatal testing determines that the fetus tests positive for Down syndrome.
3. Go to the National Society for Genetic Counselors website (<http://nsgc.org/p/cm/ld/fid=44>) and review the steps for applying for a master's degree program in genetic counseling. List the steps beginning with choosing an undergraduate degree program through applying for a graduate program.
4. Discuss the similarities and differences in the educational requirements and job responsibilities between a medical social worker and genetic counselor.

Enrichment Activities

1. Go to the National Society for Genetic Counselors' website (<http://nsgc.org/p/cm/ld/fid=52>) to the section *Collecting and Understanding Your Family History*. Prepare a pedigree (family tree) with diseases, age of onset, and age and cause of death of family members as far back as your great grandparents. What diseases are likely to be genetically transmitted based on your pedigree?
2. Go to the website *Baby's First Test* to find out the requirements for the state where you live for testing newborns for genetic conditions. Internet: www.babysfirsttest.org/newborn-screening/states/
3. Review a 25-minute video counseling simulation of a genetic counselor with a patient referred because both

he and his daughter tested positive for a heart abnormality causing a high risk for a sudden heart attack. The video is from the National Society of Genetic Counselors. Internet: <http://videos.nsgc.org/Master%20Genetic%20Counselor%20Series/Bennett%20STUDENT%20Session.mov>

4. Go to the National Human Genome Research Institute to learn more about genetic counseling and testing for genetic diseases. Internet: <http://www.genome.gov/19016905>

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