

You're a *what?*

Genetic counselor

By the time many parents see Brenda Finucane, all they want is an explanation for their child's puzzling problems. It's Brenda's job to give parents that explanation and help them move forward.

Brenda is a genetic counselor in Elwyn, Pennsylvania. Her job is to inform clients about genetic disorders and help them to understand and manage the disorder. Many families have struggled with a child's problem for a long time, and Brenda helps give a name to some of their concerns. "For a lot of families," she says, "it can really be a big relief to finally have an answer."

One of Brenda's areas of expertise is in a disorder called fragile X syndrome. This condition can result in physical, intellectual, emotional, or behavioral problems—and is a common cause of some disorders, such as autism.

Like nearly all genetic counselors, Brenda begins work on each case by meeting with clients and gathering medical and other information. She uses this information to construct a "pedigree," a specialized family tree. The pedigree is a health history of an individual's biological family and includes detailed information ranging from family members' inherited conditions, such as blindness and deafness, to their ages and causes of death.

A pedigree assists genetic counselors in mapping genetic patterns within the family. For example, Brenda might encounter a child whose genetic testing for autism has confirmed fragile X syndrome as the cause, and the mother has been identified as a carrier. The pedigree shows that a maternal aunt has a child with special needs, another maternal

aunt is being treated for infertility, and the maternal grandfather is suffering from Parkinson's disease. All of these can be attributed to the fragile X gene.

Brenda's role in such cases is multifaceted. First, she must translate the complex scientific concepts involved into language that the client can understand. Second, she must share the news with the client—sometimes the most difficult part of her job. "Often, families are hoping something will go away," she says, "and I have to tell them that it won't."

Finally, Brenda helps the client understand how to deal with the condition. As Brenda says, "We help families adapt to the information they get from us." For example, a parent might feel guilty about being the carrier of a genetic condition. Brenda helps the parent adapt emotionally, assuring him or her that guilt is a common reaction and explaining that our genetic makeup is not something we can control.

In explaining a child's genetic condition, Brenda also makes parents aware of how the condition may progress, including its medical, educational, and psychological ramifications. She then directs clients to other resources, such as support organizations and healthcare or educational specialists, for more assistance.

Genetic conditions have implications for the extended family, but the information often is too complex for the client to explain. A genetic counselor might write a letter summarizing the condition to help clients share this information with other family members.

When it first emerged about 50 years ago, genetic counseling focused primarily on prenatal testing to detect genetic conditions.

John Mullins

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But counseling services have evolved to keep pace with a greater knowledge of genetics and wider application of genetic diagnostic testing.

Today, there are several types of genetic counselors, and their expertise covers thousands of genetic conditions and spans the entire human life cycle. Genetic counselors work in a variety of specializations, such as cancer counseling, prenatal counseling, or pediatrics—Brenda’s specialty. And some counselors develop specific areas of expertise, as Brenda has with fragile X.

The U.S. Bureau of Labor Statistics does not have data on employment or wages for genetic counselors. According to the American Board of Genetic Counseling, however, there are roughly 2,400 certified genetic counselors in the United States. And they earn a median annual salary of about \$63,000, according to data from the National Society of Genetic Counselors.

Genetic counselors must have a master’s degree in genetic counseling from a program accredited by American Board of Genetic Counseling. There are currently 30 of these master’s programs nationwide, and admission

to them usually requires completion of significant undergraduate coursework in biological science. The programs combine scientific aspects of genetics with counseling study and take about 2 years to finish. In addition, most employers require certification, and some states require licensure.

Most genetic counselors work in medical offices and hospitals. Brenda, however, works for a nonprofit organization that helps people who have developmental disabilities. She travels around the country to provide consultations in schools, developing behavioral and educational plans for students with fragile X and other genetic syndromes. She also handles most of her own administrative tasks, such as scheduling and billing.

All genetic counselors need science knowledge and interpersonal skills. That blend was what first appealed to Brenda, and that appeal has lasted more than 25 years. “I love the science, but I didn’t want to work in a lab,” she says. “Genetic counseling allows me to combine my lifelong interest in science with the opportunity to interact with families affected by genetic disease.”

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Photo courtesy of Genetic Services at Elwyn

Brenda Finucane, left, often consults with other genetic counselors.