



Increasing Access to Genetic Counselors

Between 2016 and 2019, Medicare payments for genetic testing quadrupled. Yet, Medicare currently doesn't pay for genetic counseling services provided by genetic counselors.

Pending legislation hopes to correct that discrepancy. H.R. 3876, the “Access to Genetic Counselor Services Act,” was introduced in the House of Representatives in June 2023, and the Senate heard S. 2323, a bill with the same name, in July 2023. Both bills are awaiting consideration by lawmakers this session.

Genetic counselors play a vital role

Genetic counselors are trained to identify and order genetic tests for patients, analyze genetic

testing results, and counsel patients and families about test results. They also keep up with changes in the field.

As the use of genetic testing grows without Medicare coverage for genetic counselors, physicians are often forced to handle genetic counseling, which is inefficient and can contribute to physician burnout, greater physician liability, and increased costs. If Medicare covers access to genetic counselors (as many private insurers do), this workload will shift to genetic counselors.

The number of genetic counselors is growing, too. About 6,500 are practicing in the United States today; by 2030, more than 10,000 are expected, according to John Richardson, Director of Policy and Government Relations for the National Society of Genetic Counselors (NSGC).

Barriers to access

Currently, Medicare patients shoulder out-of-pocket costs for genetic counseling, which discourages patients from seeking this valuable service.

According to Colleen A. Campbell, PhD, MS, CGC, President of NSGC and Director of Genetic Counseling Operations at the University of Iowa Hospitals and Clinics, the lack of Medicare reimbursement also affects hospital hiring.

“Currently, genetic counselors must see patients face to face along with a physician’s visit, and this creates an extra step for patients,” Dr. Campbell says.

Due to costs, genetic counselors are typically hired by academic medical centers, which limits geographic access to patients. In Iowa, for example, “all the genetic counselors for neuromuscular conditions are in the eastern part of the state in one hospital at the University of Iowa Hospitals and Clinics,” Dr. Campbell says. “As a result, it’s not uncommon for a community hospital to ask how they can hire a genetic counselor. They understand the service is valuable for their patients and their providers, and the hospital wants to do the right thing, but they’re limited by the lack of reimbursement.”

Medicare does not reimburse for telehealth visits with genetic counselors, which is especially challenging for patients in rural areas.

How does this affect people with neuromuscular diseases?

Patients who work with genetic counselors are more likely to adhere to medical management recommendations because counselors can spend the time to fully explain complex genetic findings so patients can make informed decisions. Studies show greater patient satisfaction

when they work with genetic counselors. “Patients also report decreased fear, anxiety, depression, and psychological distress after meeting with a genetic counselor,” Dr. Campbell says.

She notes that neurology is a rapidly growing specialty among genetic counselors. “I think that’s a reflection of the new genetic tests and improved knowledge,” she says.

That knowledge translates into recruiting for and educating patients about relevant clinical trials. “Genetic tests can help determine who will benefit and who won’t, and that’s an important aspect in terms of costs,” she says. “Ultimately, genetic counselors empower patients and their families and providers to use genetics to make informed decisions about their health, and they provide emotional support to the families.”

How can providers help?

More than 400 organizations are supporting this bill, and more are welcome to help it move closer to becoming a law.

“Hospitals are going to be one of the larger employers in any congressional district, and having these hospitals weigh in will be very helpful,” says John.

“The physician’s voice is also important,” he says. “Empowering those voices will help us get over the finish line.”

Resources:

- Join MDA’s campaign to support the Access to Genetic Counselor Services Act [here](#).
- Find resources and templates for contacting your members of Congress from NSGC [here](#).
- Learn more about the Access to Genetic Counselor Services Act from the NSGC [here](#).