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# Genetic Counselors and the Fight for Medicare Recognition



# By Elizabeth Fieg



Genetic counselors are the key to increasing patient access to valuable genetic healthcare services; passing the H.R. 3235 bill is the key to increasing patient access to genetic counselors.

Genetic testing is more accessible than ever, thanks to an increase in public awareness and the continuously decreasing costs of genetic sequencing. Genetic information is being used to diagnose rare disorders, develop targeted and novel therapies, facilitate reproductive planning, guide treatment decisions, and inform people of their risk to develop certain medical problems. The decision of whether or not to pursue genetic testing can be complex and difficult, and many people benefit from meeting with a genetic counselor to understand the benefits and limitations of their options.

#### Genetic Counselors and the Fight for Medicare Recognition

Genetic counselors are important health care providers who are uniquely qualified to communicate and interpret genetic information. The majority of genetic counselors see patients in a clinical setting, often working closely with other healthcare providers in specialty areas like medical genetics, cardiology, obstetrics and gynecology, oncology, and endocrinology. In the United States, genetic counselors receive training through a master's degree program and are certified by the American Board of Genetic Counseling. They might also be licensed, depending on the state in which they practice; currently 26 states have licensure laws to recognize and regulate the genetic counseling profession.

Despite all of this, genetic counselors are not currently recognized by Medicare, the largest health insurer in the United States. This is a significant barrier, essentially preventing genetic counselors from seeing Medicare patients without a physician.

Sidelining genetic counselors from serving this patient population, even though they are the best-qualified providers for those very services, makes no sense. To address this, a bipartisan bill currently under consideration in Congress — H.R. 3235, the "Access to Genetic Counselor Services Act" — would authorize and recognize appropriately credentialed genetic counselors as reimbursable providers under Medicare. The bill has broad support from the medical and scientific community, academic institutions and hospitals (including Partners Healthcare and Brigham & Women's Hospital), research and biotech companies, and patient advocacy groups.

The lone opposition to H.R. 3235 comes from the American College of Medical Genetics and Genomics (ACMG), a professional organization composed of primarily medical geneticists, laboratory geneticists, as well as genetic counselors and other genetics professionals. Though the ACMG has stated that they are supportive of genetic counselors and believe that genetic counselors should be reimbursed for their services, ACMG leadership has taken issue with the individual state licensure laws that allow genetic counselors to order genetic testing for their patients and are using the bill as a platform to express this concern.

ACMG has long defined the activity of ordering genetic testing as something that falls under the practice of medicine which should only be done by a physician or under a physician's supervision. This suggestion that genetic counselors are not qualified to order genetic testing is, at best, a stretch. Genetic counselors are extensively trained in ordering genetic tests, and many genetic counselors are involved in the education of medical genetics fellows and other trainees, serving as experts to help guide others in

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selecting and ordering the appropriate genetic test. How is it that genetic counselors are qualified to train others, but not to order tests themselves?

The disappointing and short-sighted actions of ACMG leadership likely do not reflect the majority consensus of the organization's membership, as signified by ACMG declining to poll its membership on H.R. 3235. In fact, many members of this organization have expressed overwhelming support for genetic counselors and have signed a letter to reflect this. ACMG leadership has ignored geneticists who continue to voice disagreement with its actions. It is unfortunate that a professional organization composed of roughly one-third genetic counselors would directly work against the best interests of its own membership, and it is unacceptable that patients are the ones who will be hurt most by this policy position.

Numerous studies have demonstrated the significant healthcare savings and better patient outcomes associated with having a genetic counselor involved in the genetic testing process. The same cannot be said about genetic testing ordered by clinicians with little to no genetics training, and who often have no desire to take on the arduous task of providing pre-test counseling, identifying the most appropriate test for the clinical indication, coordinating sample collection, navigating the process of prior authorization and insurance coverage, evaluating complex and potentially unclear test results, and then communicating these results to the patient in a clear and supportive way.

The current pandemic makes this issue especially timely. Telemedicine resources are being utilized to comply with social distancing recommendations and meet the needs of patients across the country, with Medicare and other insurers offering unprecedented emergency expansion of telehealth services. But until genetic counselors are recognized as practitioners by Medicare, the emergency coverage of telemedicine will not include genetic counseling services provided by genetic counselors. Medicare beneficiaries represent a population that is particularly vulnerable to COVID-19 and should be provided necessary clinical care, including genetic counseling, through virtual telemedicine technology. Passing H.R. 3235 through a COVID-19 federal package would ensure that the needs of Medicare patients are met during this pandemic, and beyond.

We are currently facing an undisputed and severe medical genetics workforce shortage. Medical geneticists are unable to meet the needs of patients on their own because there are not enough of them. Genetic counselors are a clear solution to this problem. The

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size of the genetic counseling workforce has doubled over the last 10 years, there are roughly three times more genetic counselors than there are medical geneticists, and the typical wait time for an appointment with a genetic counselor decreases greatly if a medical geneticist does not need to be present. Increased autonomy for genetic counselors does not mean decreased value of physicians; we should be able to work together *and* independently to better serve patients. Recognizing genetic counselors as autonomous healthcare providers through H.R. 3235 will increase patient access to timely and appropriate genetic counseling services.

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