

## **Action Needed to Ensure Medicare Beneficiary Access to Life Saving Genetic Services in COVID-19 Pandemic**

**Issue:** Genetic services are the entry point for prevention, diagnosis, and treatment of many life-threatening diseases and conditions that affect Medicare beneficiaries, including cancer, cardiovascular disease and neurological disorders. Medicare covers and reimburses physicians and nurse practitioners for genetic counseling as a “reasonable and customary” service when genetic testing is indicated, but does not reimburse genetic counselors who are uniquely trained to provide the service.

Genetic counselors are experts in genetics and psychosocial counseling who offer essential services to Medicare patients by conducting risk assessments to identify underlying causes of disease, and where appropriate, evaluate genetic testing options based on individual characteristics. Genetic counselors provide appropriate genetic services to patients and work collaboratively as part of the medical team to help ensure physicians are informed and empowered to utilize the results of genetic testing. A significant body of evidence demonstrates that the expertise genetic counselors provide to patient care promotes identification of appropriate testing, patient engagement, and shared decision-making. During the COVID-19 pandemic, Medicare beneficiaries have faced significant disruptions in their ability to receive medically-necessary services from genetic counselors.

### **Solution**

Over 250 organizations representing physicians, patients, hospitals, and laboratories call on Congress to enact the "Access to Genetic Counselor Services Act" to recognize genetic counselors as providers under Medicare. Congress should modernize Medicare and put the program on equal footing with commercial health insurance by enacting a policy that increases access to genetic counselors and allows them to be reimbursed for services delivered to Medicare beneficiaries at 85% of physician payment levels. Enacting such a policy would enhance the ability of beneficiaries to see genetic counselors while ensuring other practitioners retain the right to provide these services if the activities are within their scope of practice. Medicare beneficiaries deserve the same access to genetic counselors as their younger family members.

At a minimum, Congress should allow genetic counselors to provide telemedicine services to Medicare beneficiaries.

### **Medicare Requirements for Genetic Counselor Services Essentially Prohibit Use of Telehealth**

During the COVID-19 pandemic, many genetic counselors have shifted from clinics to work remotely, offering their services via telehealth to protect patients and providers. Rigorous evaluations of genetic counseling provided via telehealth have demonstrated that it is equally effective to services provided in person. For example, a 2016 study by researchers from the University of Pennsylvania and others found that genetic counselor services furnished via remote real-time videoconferencing is “feasible, identifies genetic carriers in community practices, and is associated with high patient satisfaction and favorable cognitive and affective outcomes.”

The migration to telehealth is seamless for patients with commercial health insurance as genetic counselors are licensed as independent practitioners and telehealth is within their scope of practice. Unfortunately, for Medicare beneficiaries, genetic counselors cannot bill Medicare directly. Instead, they must offer their services using arcane “incident to” rules – requiring them to deliver services only in a clinic with direct physician supervision. Under direct supervision, a physician must be “physically present in the same office suite and be immediately available to render assistance if that becomes necessary.” Because direct supervision cannot be achieved using telehealth, genetic counselors are essentially prohibited from using telehealth to serve Medicare patients. As a result, many Medicare beneficiaries may not be receiving appropriate genetic counseling services.

### **Medicare Beneficiaries May Face Worse Outcomes Without Access to Genetic Counselors**

Medicare beneficiaries who have conditions with a genetic component – including life-threatening rare diseases and cancer – are being forced to forego genetic counseling services, with potentially deadly consequences. Genetic counseling and testing is particularly important for certain conditions, such as breast, ovarian, and pancreatic cancer, that are more prevalent in the Medicare population. *The National Comprehensive Cancer*

*Network Guidelines for Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic* indicate that all individuals with pancreatic cancer, all women with ovarian cancer, and all men with metastatic or intraductal prostate cancer should be offered genetic counseling and germline testing.

The following examples demonstrate situations that have occurred during the pandemic, where genetic counseling and testing is necessary for Medicare patients to identify appropriate treatments and save lives:

- A Medicare beneficiary learns that a family member has a genetic condition that causes long QT syndrome – a heart rhythm condition that can cause sudden death. The beneficiary, along with other family members, would benefit from genetic counseling and testing services to determine whether they also carry the gene variant. If they do, their physicians could prescribe a beta blocker, which is known to prevent cardiac events in this patient population. Family members with commercial health insurance can receive services from the genetic counselor via telehealth; however, Medicare will not cover or reimburse telehealth services offered by the genetic counselor, making it difficult for the beneficiary to receive medically appropriate genetic counseling.
- A Medicare beneficiary with stage II breast cancer and a family history of breast, ovarian, and prostate cancer, is currently being treated with chemotherapy at an outreach clinic. Genetic testing is warranted to determine if she also has a BRCA mutation that would make her a candidate for a bilateral mastectomy. The beneficiary lives over an hour away from the genetic counselor, and is fearful of going to the hospital and becoming infected with COVID-19, particularly given her cancer diagnosis. Although it would be best for the patient to receive genetic counseling using telehealth, Medicare will not cover genetic counselor services in that format.
- A Medicare patient whose sister has recently tested positive for a *BRCA1* mutation is waiting for COVID-19 restrictions to be lifted before seeing a genetic counselor to evaluate her risk of breast cancer. The delay in genetic counseling and testing could put the patient's health at risk by delaying potentially life-saving treatment.
- Due to the financial struggles hospitals are enduring because of the suspension of “elective” medical and surgical services, genetic counselors are being furloughed – which eliminates access for Medicare beneficiaries and those with commercial health insurance.

### **Even Absent COVID-19, Medicare Beneficiaries Lack Full Access to Genetic Counselor Services**

In a normal, non-pandemic world, the lack of statutory recognition for genetic counselors restricts their ability to serve Medicare patients. For example:

- The lack of Medicare recognition creates a two-tiered system. Patients with commercial health insurance can receive genetic counseling provided by the genetic counselor alone; however, patients with Medicare do not have the same access to genetic counselor services due to supervision requirements.
- Genetic counselor services to Medicare beneficiaries are only available on the days of the week when genetic counselors can be supervised by a physician/nurse practitioner. If the supervisor is out of town or otherwise unavailable, the patient with Medicare coverage cannot be seen. A national survey has demonstrated that wait times to see a genetic counselor increase significantly under such supervision models.
- Stanford University Medical Center has eight cancer genetic counselors that see patients on any day of the week. The Center's breast/ovarian specialist physician only sees patients one day per week.
- Over 50% of all genetic counselors serve patients with or at risk for cancer. Although cancer is far more prevalent in the Medicare population, this population has the most restricted access.

### **Medicare Telehealth Waivers Do Not Extend to Genetic Counselor Services in Medicare**

The National Society of Genetic Counselors requested a Section 1135 waiver from all Centers for Medicare & Medicaid Services regional offices to allow genetic counselors to deliver telehealth throughout the emergency. We understand, however, that because the Medicare statute does not include genetic counselors, no waiver is available.