

Response to Question for the Record

Prepared by Gordon F. Tomaselli, M.D.
American Heart Association, Volunteer Leader
Marilyn and Stanley M. Katz Dean, Emeritus
Professor of Medicine, Albert Einstein College of Medicine;
Adjunct Professor of Medicine
Johns Hopkins University School of Medicine

Submitted to the House Committee on Energy and Commerce
Subcommittee on Health

April 24, 2024

For: The Honorable Neal Dunn, M.D.

Question: Genetic counselors play an essential role when there are genetic aspects to disease and conditions. They ensure patients and family members who would benefit from genetic testing gain access to appropriate testing and ensure physicians and their patients understand test results well. Genetic counselors also help navigate follow-up care and identify clinical trials that may be of benefit. Today, Medicare does not reimburse genetic counselor services. Should this policy change?

Answer: The completion of the human genome project ushered in a new era of personalized health care and disease prevention and precision medicine. There is an important role for genetic counselors in patient care.^{1,2} The National Society of Genetic Counselors defines genetic counseling as the process of helping people understand and adapt to medical, psychological, and familial implications of genetic contributions to disease. This process integrates the following:

- Assessing and explaining how inherited diseases and conditions may affect patients and their families;
- Assessing and explaining how family and medical histories may impact the chance of disease occurrence or recurrence;
- Communicating to patients what genetic tests may or may not be right for them, and what those tests may or may not tell; and
- Communicating to patients and their families how to make the most informed choices about their healthcare conditions.³

Genetic counseling is important in identifying risk, the selection of appropriate tests, facilitating medical follow-up and providing support. In addition, genetic testing may also include cascade screening, which is the identification of an individual with the condition and/or a pathogenic variant associated with the condition and then extending genetic testing and genetic counseling to his/her biologic relatives. At risk relatives can then be targeted for medical treatment that might avert disease onset. Lastly, emerging care models emphasize an integrated sequence of

workflow that includes risk analysis, selection of appropriate genetic tests, and interpretation of results with inclusion of a genetic counselor at each step in the delivery of care.⁴

The American Heart Association believes genetic counselors to be vital members of the cardiovascular care team and supports policies that ensure access for all patients with cardiovascular (and other heritable) disease and their families who need comprehensive genetic counseling services. To ensure that all cardiovascular patients and their families have access to the vital services of genetic counselors:

- Medicare, Medicaid, and private insurers should provide coverage for genetic counseling services provided by board certified genetic counselors.
- Medicare, Medicaid, and private insurers should include genetic counselling as a billable service for the use of telehealth.

For more information, please see the American Heart Association's policy statement on genetic counseling: <https://www.heart.org/-/media/Files/About-Us/Policy-Research/Policy-Positions/Clinical-Care/Genetic-Counselors-Improving-Access.pdf>

References:

1. Collins FS, Green ED, Guttmacher AE, Guyer MS and Institute USNHGR. A vision for the future of genomics research. *Nature*. 2003;422:835-47.
2. Feero WG, Guttmacher AE and Collins FS. The genome gets personal--almost. *JAMA*. 2008;299:1351-2.
3. National Society of Genetic Counselors. About Genetic Counselors. Frequently Asked Questions. 2020;2020.
4. Ormondroyd E, Mackley MP, Blair E, Craft J, Knight JC, Taylor J, Taylor JC, Wilkie AO and Watkins H. Insights from early experience of a Rare Disease Genomic Medicine Multidisciplinary Team: a qualitative study. *Eur J Hum Genet*. 2017;25:680-686.