



# Genetic Counselors: Improving Access to Their Services for Patients With Cardiovascular Disease and Their Families

## A Policy Statement by the American Heart Association

### Introduction

The completion of the human genome project ushered in a new era of personalized health care and disease prevention and an increased the role of genetic counselors in patient care.<sup>1,2</sup> 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: (1) interpretation of family and medical histories to assess the chance of disease occurrence or recurrence; (2) education about inheritance, testing, management, prevention, resources, and research; and (3) counseling to promote informed choices and adaptation to the risk or condition.<sup>3</sup> 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 at-risk 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.<sup>4</sup>

### Position statement

***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 disease and their families who need comprehensive genetic counseling services.***

### The Role of Genetic Counselors in Cardiovascular Disease Care

An array of cardiovascular diseases (CVD) are heritable. These include monogenic diseases such as genetic cardiomyopathies and genetic arrhythmias that are usually caused by highly penetrant genetic variants that are rare in the population. Heritable CVDs also include more common diseases such as hypertension and coronary artery disease, which are characterized by more complex genetic models with multiple genes and thus have not lent themselves to single gene testing. However, recent research has shown the potential for genetic testing in such areas (see footnote for definition of genetic testing).<sup>5-7</sup> It has also shown that genetic testing can lead to more accurate genetic risk scores, thereby better predicting a patient's likelihood of developing cardiovascular disease.<sup>8</sup>

Cardiovascular genetic data are now being integrated into healthcare protocols and clinicians are increasingly being asked to order cardiovascular genetic testing. Due to the soaring demand and procurement, the financial implications of cardiovascular genetic testing on clinicians and patients alike must be considered. Genetic testing has been shown to be a valuable tool for identifying many of those at risk for an inherited cardiovascular disease and directing them to the right clinician for treatment. Its potential impact is also highly variable and influenced by the patient's genetic makeup, as well as personal and family medical histories and social and physical environments. So inherited cardiovascular diseases can be treated adequately, how clinicians take these variables under consideration along with a patient's test results must be understood in order to make sound clinical decisions. It is also critical that clinicians have the skills to navigate the dynamic nature of this information to ensure informed decision-making

regarding cardiovascular genetic test-selection. Making sense of cardiovascular genetic risk, selecting the most appropriate test, and interpreting test results for a patient and the patient's family, are skills that requires a deep understanding of medical genetics and appreciation of the limitations and benefits of the range of relevant cardiovascular genetic tests available. However, most physicians are not sufficiently trained to determine the appropriate genetic test and interpret genetic information.

### **Genetic Counselors: Scientifically Proven Impact**

The dynamic nature of genetic testing necessitates the integral role of genetic counselors in patient evaluation and care. Genetic counselors are trained to expertly handle and interpret complex genetic information. They must pass a national certification exam and re-certify every 5 years. More specifically, their competencies include understanding personalized genomic medicine and the ability to communicate genomic information to clients.<sup>9-11</sup> Research has shown that using genetic counselors in a multi-disciplinary care team can ensure that patients receive the appropriate test for their condition improve patient outcomes.<sup>12-14</sup>

The benefits of incorporating genetic counseling into clinical decision-making are particularly impactful for many inherited CVDs.<sup>15, 16</sup> Genetic counselors help CVD patients and their care teams understand their genetic profile and how it influences the care of the patient and, in some cases, their family.<sup>17-20</sup> The complexity of current cardiovascular genetic evaluation and testing has led to guidelines recommending evaluation in centers with specialized expertise whenever possible to facilitate access to multidisciplinary teams that include genetic counselors.<sup>17, 21</sup> However, many patients who stand to benefit from their services are not being referred to genetic counselors.<sup>22, 23</sup> In many cases, genetic counselors are not reimbursed by public and many private payers for their services. Many healthcare systems also lack the clinical infrastructure to support genetic counselors. This leads to the lack of inclusion and support for genetic counselors in health systems and more barriers to quality care. A healthcare system that supports genetic counselors leads to increased access to patient care and timely access to genetic counseling. It also facilitates a patient-centered process by enabling patients to make fully informed decisions about their healthcare.<sup>24</sup>

### **Genetic Counselors: Removing Barriers to Their Services**

As stated above, many care models have integrated genetic counselors into the healthcare team, thereby increasing access to their services for patients and their family members. However, barriers to their services still exist. Currently, CMS does not recognize certified genetic counselors as healthcare providers. Therefore, certified genetic counselors cannot be reimbursed under Medicare for providing services. Legislation was introduced in both 2018 and 2019 that would have required genetic counselors be reimbursed for counseling Medicare beneficiaries in the same way these services are covered when provided by a physician, but neither was enacted.<sup>25, 26</sup> In order to ensure that all cardiovascular patients and their families have access to the vital services of genetic counselors, the following policy principles should be considered:

#### **Policy Principles**

*Policy Principle #1: Medicare, Medicaid, and private insurers should provide coverage for genetic counseling services provided by board certified genetic counselors.*

*Policy Principle #2: Medicare, Medicaid, and private insurers should include genetic counselling as a billable service for the use of telehealth.*

*Policy Principle #3: Regardless of specific personal, geographical, or clinical circumstances, access to genetic counseling services should be made available to all patients with cardiovascular disease and their families.*

*Policy Principle #4: Within worksite health promotion programs, genetic counselling services should be voluntary, available to all employees, and in compliance with federal and state regulations.*

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