

November 10, 2022

Steve Schuh Deputy Secretary, Health Care Financing & Medicaid Director Maryland Department of Health

Warren Waters, Jr. Chief of Staff, Health Care Financing Maryland Department of Health

Re: Maryland Department of Health Medicaid policy for genetic carrier screening

Dear Mr. Schuh and Mr. Waters,

I write to you on behalf of the American College of Medical Genetics and Genomics, the only nationally recognized medical society dedicated to improving health through the clinical practice of medical genetics and genomics and the only medical specialty society in the U.S. that represents the full spectrum of medical genetics disciplines in a single organization. ACMG strives to improve health through the clinical and laboratory practice of medical genetics as well as through advocacy, education, and clinical research, and to guide the safe and effective integration of genetics and genomics into all of medicine and healthcare, resulting in improved personal and public health. In line with our mission, we are aware that the Maryland Department of Health is currently reviewing its Medicaid policies for genetic carrier screening and provide the following information for consideration.

Carrier screening is used to identify individuals or couples that are at risk to have a child with an autosomal recessive or X-linked genetic disorder, and those screened may use the results in their reproductive decision-making or to improve outcomes for their children. It also helps guide genetic counseling and choice in prenatal diagnosis, treatment decisions related to surveillance of an at-risk pregnancy, intervention and fetal treatment, and helps prepare parents and the healthcare team for an infant with unique needs. For certain conditions, carrier screening can also identify patients whose status as a carrier puts them at individual risk of health compromise, allowing for early medical evaluation and testing in a patient that otherwise would have been unaware.

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Carrier screening has been a routine component of obstetrical care since the early 2000s. In a recently published practice resource¹, ACMG outlined four tiers of carrier screening. Specifically, ACMG recommends that Tier 3 carrier screening, which includes screening for over 100 serious inherited conditions, be offered to all pregnant patients and those planning a pregnancy. As such, prior authorizations, documentation of medical necessity, and results from diagnostic tests are not needed prior to Tier 3 carrier screening. Additional screening is recommended to be considered for pregnancies that stem from a known or possible consanguineous relationship or when otherwise warranted by a family or personal medical history. The ACMG recommendations ensure equitable care for a diverse U.S. population.

Lack of clearly defined and up-to-date written policies can result in challenges for healthcare professionals to obtain coverage and create barriers in access to standard testing for Maryland Medicaid beneficiaries. Without coverage, patients may have to pay out of pocket or forgo testing altogether. As the Maryland Department of Health evaluates its current coverage policies, we urge you to consider ACMG's carrier screening recommendations and develop clear coverage policies that reflect current professional recommendations and ensure equitable access for Maryland Medicaid beneficiaries.

For questions or additional information, please contact Michelle McClure, PhD, ACMG Director of Public Policy at mmcclure@acmg.net.

Sincerely,

Marc Williams, MD, FACMG

President

American College of Medical Genetics and Genomics

¹ Gregg AR, Aarabi M, Klugman S, Leach NT, Bashford MT, Goldwaser T, Chen E, Sparks TN, Reddi HV, Rajkovic A, Dungan JS; ACMG Professional Practice and Guidelines Committee. Screening for autosomal recessive and X-linked conditions during pregnancy and preconception: a practice resource of the American College of Medical Genetics and Genomics (ACMG). Genet Med. 2021 Oct;23(10):1793-1806. doi: 10.1038/s41436-021-01203-z. Epub 2021 Jul 20. Erratum in: Genet Med. 2021 Aug 27;: PMID: 34285390; PMCID: PMC8488021.