ACMG
American College of Medical Genetics and Genomics
*Translating Genes Into Health®*

February 25, 2026

The Honorable Scott Peters
US House of Representatives
2369 Rayburn House Office Building
Washington, DC 20515

The Honorable Gus Bilirakis
US House of Representatives
2306 Rayburn House Office Building
Washington, DC 20515

The Honorable Chrissy Houlahan
US House of Representatives
1727 Longworth House Office Building
Washington, DC 20515

The Honorable Troy Balderson
US House of Representatives
2429 Rayburn House Office Building
Washington, DC 20515

The Honorable Kevin Mullin
US House of Representatives
1404 Longworth House Office Building
Washington, DC 20515

The Honorable Mike Carey
US House of Representatives
1433 Longworth House Office Building
Washington, DC 20515

The Honorable Marc Veasey
US House of Representatives
2186 Rayburn House Office Building
Washington, DC 20515

The Honorable Maria Elvira Salazar
US House of Representatives
2162 Rayburn House Office Building
Washington, DC 20515

**Re: Genomic Answers for Children's Health Act of 2026**

Dear Representatives Peters, Bilirakis, Balderson, Carey, Houlahan, Mullin, Salazar, and Veasey:

The American College of Medical Genetics and Genomics (ACMG)[1] thanks you for your commitment to improving children's access to genetic sequencing technologies. We support the goals of the Genomic Answers for Children's Health Act and the need to improve access to exome and genome sequencing (ES/GS) by reducing barriers that prolong the diagnostic odyssey for children with suspected genetic conditions.

[1] Founded in 1991, the American College of Medical Genetics and Genomics (ACMG) is a prominent authority in the field of medical genetics and genomics and the only nationally recognized medical professional organization solely dedicated to improving health through the practice of medical genetics and genomics. The only medical specialty society in the US that represents the full spectrum of medical genetics disciplines in a single organization, the ACMG provides education, resources and a voice for more than 2,500 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.


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ES/GS have become essential diagnostic tools with significant benefit to patients when used in accordance with professional recommendations and guidelines. Evidence supports the use of clinical ES/GS to diagnose infants and children suspected of having a genetic or inherited disease.[2,3] Early and accurate diagnosis improves clinical management, informs treatment decisions, avoids unnecessary procedures, and can significantly reduce long-term healthcare costs. Professional guidelines also recommend its use as a first-tier test for children with congenital anomalies, global developmental delay, intellectual disability, and other suspected genetic or rare disorders.[4,5] For some conditions, ES/GS can help identify the etiology of a diagnosis and lead to appropriately tailored care.[6,7,8]

Under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, Medicaid programs must already cover diagnostic services necessary to correct or ameliorate defects and conditions discovered by the screening services.[9] This includes ES/GS when medically necessary and in accordance with professional recommendations and guidelines. Despite the evidence and professional guidelines supporting the use of this diagnostic service, we continue to hear reports from patients and healthcare professionals of coverage denials for pediatric Medicaid beneficiaries. If Medicaid programs are outright denying coverage, they are not complying with the current law. However, under EPSDT, Medicaid programs are permitted to recommend cost-effective alternatives. In some instances this may be appropriate, but in many cases programs may arbitrarily recommend inappropriate alternatives that extend the costly

[2] The NICUSeq Study Group. Effect of Whole-Genome Sequencing on the Clinical Management of Acutely Ill Infants With Suspected Genetic Disease: A Randomized Clinical Trial. JAMA Pediatr. 2021;175(12):1218–1226. doi:10.1001/jamapediatrics.2021.3496

[3] Kingsmore, S.F., et al. Rapid genomic sequencing for genetic disease diagnosis and therapy in intensive care units: a review. npj Genom. Med. 9, 17 (2024). https://doi.org/10.1038/s41525-024-00404-0

[4] Manickam, K., et al. Exome and genome sequencing for pediatric patients with congenital anomalies or intellectual disability: an evidence-based clinical guideline of the American College of Medical Genetics and Genomics (ACMG). Genet Med (2021) Nov;23(11):2029-2037. https://www.gimjournal.org/article/S1098-3600(21)05168-6/fulltext

[5] Rodan, L.H., et al. Genetic Evaluation of the Child With Intellectual Disability or Global Developmental Delay: Clinical Report. Pediatrics (2025) 156 (1): e2025072219. https://doi.org/10.1542/peds.2025-072219

[6] Stafford, C. F., and Sanchez-Lara, P. A. (2022). Impact of Genetic and Genomic Testing on the Clinical Management of Patients with Autism Spectrum Disorder. Genes, 13(4), 585. https://doi.org/10.3390/genes13040585

[7] Liu, C., et al. Clinical utility of exome sequencing in hearing loss: a retrospective cohort study. Front Genet (2025) 16(2025): 20251643537. https://doi.org/10.3389/fgene.2025.1643537

[8] Koh H.Y., et al. Utility of Exome Sequencing for Diagnosis in Unexplained Pediatric-Onset Epilepsy. JAMA Netw Open (2023) 6(7): e2324380. https://doi.org/10.1001/jamanetworkopen.2023.24380

[9] 42 USC 1396d(r)(5)


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diagnostic odyssey, prolong patient suffering, and increase long-term harms and costly medical needs that come with a delayed diagnosis and treatment.

At the same time, the ACMG appreciates that the Genomic Answers for Children's Health Act recognizes ES/GS as a first-tier diagnostic tool and explicitly includes analysis, interpretation, and reporting within the definition of sequencing services, with one part of the legislation aiming to clarify this coverage. However, it is imperative that state Medicaid programs recognize that this coverage **already exists in statute**. As such, this clarification in coverage could also be achieved by the Centers for Medicare and Medicaid Services (CMS) through an updated Federal Guidance or Letter to State Health Officials since authorizing statute is already in place. By directing CMS to clarify coverage, it reiterates to state Medicaid programs that this is a covered testing service under the EPSDT benefit, without opening up the EPSDT statute. We encourage pursuing all approaches available to achieve the desired outcome of improved coverage of ES/GS for deserving children as efficiently as possible.

Further, it would be beneficial to have Medicaid programs provide data on rates of denials and their associated justification, including situations in which an alternate test was recommended. In some cases, it is likely that ES/GS are not the most appropriate test. However, we continue to hear reports of denials for ES/GS when it is consistent with clinical recommendations as a first-tier test. Additionally, GAO reports published in 2023[10] and 2024[11] identified concerns with Medicaid managed care organizations (MCOs) use of prior authorizations and made recommendations to CMS to improve the issue and clarify state responsibilities. These included requiring states to collect data on MCO prior authorization decisions. While the GAO's recommendations have yet to be implemented, the GAO indicates that an update from CMS is expected on March 24, 2026. The requirement for HHS reporting on state payment rates, utilization, and health outcomes is also an important step toward transparency and accountability. We encourage the development of meaningful outcome measures, including diagnostic yield, changes in clinical management, time to diagnosis, and impact on downstream healthcare utilization that support test utilization. Transparent reporting will help ensure that reimbursement reflects the full scope of sequencing and interpretation services and supports long-term sustainability across Medicaid programs.

[10] Dept of Health and Human Services, Government Accountability Office. High Rates of Prior Authorization Denials by Some Plans and Limited State Oversight Raise Concerns About Access to Care in Medicaid Managed Care. July 2023. OEI-09-19-00350

[11] Dept of Health and Human Services, Government Accountability Office. Managed Care Plans' Prior Authorization Decisions for Children Need Additional Oversight. April 2024. GAO-24-106532

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The EPSDT is a critical benefit giving our nation's most vulnerable children a chance of a healthy life. The ACMG shares your commitment to ensuring that children with suspected genetic conditions receive timely, evidence-based care. We also support the bill's direction to convene stakeholders and conduct outreach and education regarding EPSDT coverage. Awareness gaps among healthcare professionals, families, and managed care organizations remain a significant barrier to access. ACMG stands ready to participate in stakeholder discussions and contribute clinical expertise to identify best practices that minimize inappropriate denials, reduce administrative burden, and promote consistent implementation across states.

We look forward to working with you, CMS, and other stakeholders to support effective implementation of the EPSDT benefit and to ensure that Medicaid beneficiaries have meaningful access to appropriate genomic services. We also look forward to exploring ways to improve coverage for those children and adults who don't currently have coverage or access to ES/GS. For questions or additional information, please contact Michelle McClure, PhD, ACMG Director of Public Policy at mmcclure@acmg.net.

Sincerely,

Mira Irons MD

Mira B. Irons, MD, FACMG
President
American College of Medical Genetics and Genomics


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