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ACMG Takes Action to Address National Gap in Newborn Screening Leadership

BETHESDA, MD – July 2, 2025 | In response to the continued need for evidence-based reviews of newborn screening (NBS) conditions following the recent dissolution of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), the American College of Medical Genetics and Genomics (ACMG) is moving forward with organizing a new advisory framework to uphold the integrity and scientific rigor of nationally coordinated NBS recommendations.

To initiate this process, the ACMG will convene a virtual stakeholder roundtable this summer to gather input on the structure, function, and membership of a new expert advisory group. For the upcoming stakeholder roundtable, the ACMG plans to include representation from organizations involved with the former ACHDNC as well as other key stakeholders recommended by members of the ACMG's RUSP Continuation Task Force.

"In the absence of the ACHDNC, the ACMG is stepping forward to preserve and protect the collaborative infrastructure that has been vital to the success of newborn screening in the United States," said Mira B. Irons, MD, FACMG, FAAP, President of ACMG. "This effort will be guided by transparency, scientific rigor, and engagement with the diverse stakeholders that have long supported and advanced NBS."

The ACMG remains committed to advocating for the reinstatement of a federally authorized advisory body and the reauthorization of the Newborn Screening Saves Lives Act. In the meantime, ACMG will lead the development of an interim structure to maintain momentum in the evidence review of and recommendations for conditions for NBS inclusion.

Further updates on the roundtable outcomes and next steps will be shared soon.

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About the American College of Medical Genetics and Genomics (ACMG) and ACMG Foundation

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. *Genetics in Medicine* and the new *Genetics in Medicine Open*, a gold open access journal, are the official ACMG journals. ACMG's website, www.acmg.net, offers resources including policy statements, practice guidelines, and educational programs. The ACMG Foundation for Genetic and Genomic Medicine works to advance ACMG educational and public health programs through charitable gifts from corporations, foundations and individuals.

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