

The ACMG Establishes Newborn Screening Coalition to Continue National Leadership in Advancing Evidence-Based Newborn Screening

BETHESDA, MD – October 10, 2025 | The American College of Medical Genetics and Genomics (ACMG) announced today that its Board of Directors has approved the establishment of a Newborn Screening Coalition, reaffirming ACMG's commitment to safeguarding and advancing the nation's newborn screening system. The action, approved on September 29, 2025, ensures continuity in the evidence-based evaluation of genetic and congenital disorders in the absence of a federal advisory committee.

Following the April 2025 dissolution of the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), previously administered by the Health Resources and Services Administration (HRSA), ACMG President Mira B. Irons, MD, FACMG convened a Taskforce of ACMG members to develop a process for maintaining national oversight and evaluation of potential additions to the Recommended Uniform Screening Panel (RUSP). The Taskforce, chaired by Cynthia Powell, MD, FACMG, convened a roundtable with more than 120 attendees to gather feedback from the broader newborn screening community. This feedback supported the Taskforce's recommendation to the ACMG Board of Directors to establish the Newborn Screening Coalition.

"ACMG has been deeply engaged in advancing newborn screening since its inception," said Dr. Irons. "This coalition will uphold the standards of evidence-based review and transparency that families, clinicians, and policymakers have come to expect, ensuring there is no interruption in progress toward improving early detection and treatment for newborns."

The ACMG Newborn Screening Coalition will:

- Advise the public and newborn screening programs about potential conditions for inclusion on the RUSP.
- Develop and conduct evidence-based reviews of nominated conditions, open to public comment prior to Coalition vote.
- Publish and disseminate recommendations, including rationale for both affirmative and negative votes.
- Foster collaboration across medical, laboratory, and public health communities to ensure equity and readiness in state newborn screening programs.

The Coalition’s membership will include 15 voting members representing medical, laboratory, public health, and patient advocacy professionals. The ACMG will be contacting select organizations in the near future regarding nominating a professional from their organization.

The ACMG will administrate the Coalition to ensure continuity of the evidence-based review and decision-making processes in the absence of a federal advisory body. A business plan for long-term sustainability is under development by ACMG leadership in collaboration with the ACMG Foundation for Genetic and Genomic Medicine, with launch of the Coalition in Q1 2026.

“Families and clinicians depend on timely and scientifically rigorous recommendations to guide newborn screening programs,” said Dr. Powell. “This Coalition will provide a transparent, collaborative, and credible pathway for continuing that work.”

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 *Genetics in Medicine Open*, a gold open access journal, are the official ACMG journals. ACMG’s website, 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 philanthropic gifts from corporations, foundations and individuals.

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