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FOR IMMEDIATE RELEASE
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The Newborn Screening Collaborative Seeks Input on Conditions for Potential Review

BETHESDA, MD – March 9, 2026 | Established in 2025, the Newborn Screening Collaborative (NBSC) is a volunteer group of patient advocacy, public health, and healthcare professionals dedicated to using transparent, evidence based reviews of specific conditions to guide the public and US newborn screening programs about conditions for which every baby should be screened. The NBSC is preparing for its first official meeting this summer and is seeking stakeholder input on conditions that might be appropriate for future review. To support this effort, the NBSC is now accepting pre-submissions for possible nominations for review within the next year.

Organizations and individuals can request a pre-submission form by emailing nbsc@acmg.net. Pre-submissions will be accepted through April 30, 2026. Requested information includes the name of the condition(s), a brief rationale for review, and a high-level summary of available supporting data. Please note that only preliminary information is needed at this stage; the formal nomination process will open in the coming months. Additional information about the NBSC—including the Collaborative's charter, current roster, and upcoming meeting details—will be posted at acmg.net/nbsc.aspx as it becomes available. Questions may be directed to nbsc@acmg.net.

To receive future communications about the NBSC, such as updates and meetings, please opt-in here.

About the Newborn Screening Collaborative

Established in 2025, the Newborn Screening Collaborative (NBSC) is a volunteer group of patient advocacy, public health, and healthcare professionals from a broad range of medical specialties whose mission is to promote evidence-based activities to advance newborn screening. The NBSC aims to use transparent, evidence-based reviews of specific conditions or categories of conditions to advise the public and newborn screening programs in the US about potential conditions for which every baby should be screened. By facilitating the development of systems to allow data collection, extraction, and/or analysis from different sources, including newborn screening, natural history studies, translational research, pilot studies, and interventional clinical trials, and by utilizing input from other professional organizations and stakeholders, the NBSC will support long term outcomes follow-up and recommendations for improving newborn screening systems. The NBSC is overseen by the American College of Medical Genetics and Genomics (ACMG) and supported by the ACMG Foundation for Genetic and Genomic Medicine (ACMGF).

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