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## **ACMG Response to the NASEM Report on Newborn Screening and Recent Federal Government Actions**

**BETHESDA, MD – May 12, 2025** | On May 1, 2025, the National Academies of Sciences, Engineering, and Medicine (NASEM) released its report, *Newborn Screening in the United States: A Vision for Sustaining and Advancing Excellence*, in response to a Congressional request.

The American College of Medical Genetics and Genomics (ACMG) commends NASEM for its thoughtful and timely recommendations. Newborn screening (NBS) is among the most effective public health initiatives in US history. Its continued success depends on maintaining a coordinated, well-supported infrastructure that ensures timely evaluation and adoption of new technologies and treatments.

The NASEM report outlines nine recommendations to sustain and improve NBS nationwide:

1. Establish national leadership and set priorities
2. Incorporate multistakeholder and rightsholder input into NBS priorities
3. Optimize decision-making on conditions for NBS
4. Support NBS program excellence through a performance system
5. Amplify shared NBS resources
6. Expand NBS education and awareness among the public and healthcare professionals
7. Specify standards for retention, sharing, and use of dried newborn bloodspots and derived data
8. Expand and coordinate research to inform NBS policy and practice
9. Promote responsible application of technologies to NBS

These recommendations underscore the need for a nationally coordinated system grounded in scientific evidence, supported by federal and state agencies, and inclusive of the voices of clinicians, researchers, patients and public health experts. Central to that system is the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which has played a crucial role in developing recommendations and resources utilized by state NBS programs, including recommendations for conditions appropriate for NBS based on thorough evidence reviews.

Unfortunately, the NASEM report coincides with troubling federal actions that threaten the integrity of the national NBS system. On April 3, 2025, the US Department of Health and Human Services (HHS) terminated the ACHDNC. The Administration has also proposed eliminating the Health Resources and Services Administration (HRSA) as a standalone agency and cutting funding for essential maternal and child health programs, including HRSA's NBS activities. These actions come at a time when new technologies hold the promise to transform newborn screening, making the need for national coordination more urgent than ever.

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The ACMG has a robust history in shaping the NBS landscape, from leading the expert panel that informed the creation of the Recommended Uniform Screening Panel (RUSP), to actively participating in the ACHDNC and advocating for evidence-based expansion of screened conditions. In the wake of ACHDNC's termination, the ACMG has convened a RUSP Continuation Task Force to evaluate how we can support the ongoing review of NBS conditions and preserve the collaborative framework that has been essential to past progress.

While our long-term goal is the reinstatement of the ACHDNC, or the creation of a similar federally mandated advisory body, the ACMG is committed to ensuring that newborn screening does not lose momentum. We are exploring interim solutions to uphold the integrity of evidence reviews and engage the organizations and experts who have long supported this work.

The ACMG intends to work closely with our advocacy partners to use the NASEM report as a catalyst to call on Congress to reauthorize the Newborn Screening Saves Lives Act, which expired in 2019. With appropriate updates, this legislation can secure the future of NBS and shield it from ongoing policy disruptions.

We remain steadfast in our commitment to newborn screening and will continue to provide leadership through expert guidance, stakeholder convening and advocacy for the infrastructure and funding needed to protect and advance this life-saving program.

### **About the American College of Medical Genetics and Genomics**

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 2,600 clinical and laboratory geneticists, genetic counselors and other healthcare professionals. ACMG's mission is 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. *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](http://www.acmg.net), offers resources including policy statements, practice guidelines, and educational programs.

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