April 21, 2026

The Honorable Shelley Moore Capito
Chair
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education and Related Agencies
170 Russell Senate Office Building
Washington, DC 20510

The Honorable Tammy Baldwin
Ranking Member
Senate Appropriations Subcommittee
on Labor, Health and Human Services,
Education and Related Agencies
141 Hart Senate Office Building
Washington, DC 20510

The Honorable Robert Aderholt
Chairman
House Appropriations Subcommittee on
on Labor, Health and Human Services,
Education and Related Agencies
2358-B Rayburn House Office Building
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
House Appropriations Subcommittee on
on Labor, Health and Human Services,
Education and Related Agencies
2413 Rayburn House Office Building
Washington, DC 20515

Dear Chair Capito, Ranking Member Baldwin, Chairman Aderholt and Ranking Member DeLauro:

As you begin work on this year's budget process, the undersigned 25 organizations write to ask for your continued strong support for the Centers for Disease Control and Prevention (CDC) Newborn Screening Quality Assurance Program (NSQAP), the Health Resources and Service Administration (HRSA) Heritable Disorders Program, and the Hunter Kelly Newborn Screening Research Program at the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) in the FY 2027 Labor, Health and Human Services, and Education Appropriations Bill.

We appreciate the sustained investments made over the last few years, and **we respectfully ask that you provide increased funding in the amount of $29 million for the CDC Newborn Screening Quality Assurance Program (NSQAP) and $29 million for the HRSA Heritable Disorders Program** to continue to invest in newborn screening programs. Additionally, we ask that you include the following committee report language directing the Department of Health and Human Services to ensure the critical work previously done by the Advisory Committee on Heritable Disorders in Newborns and Children continues particularly the addition of new conditions to the Recommended Uniform Screening Panel (RUSP).

> *Newborn screening is one of our nation's most successful public health programs. It serves nearly 4 million infants each year and detects life-threatening diseases in newborn babies before they can cause irreversible damage or death. The termination of the federal Advisory Committee on Heritable Disorders in Newborn and Children (ACHDNC), the nation's chief newborn screening advisory body, has*

eliminated the only federal evidence review process to add new conditions to the Recommended Uniform Screening Panel (RUSP). The Committee requests that the Secretary provide a report to this Committee within 60 days on an implementation plan to continue this important work and preserve the nation's federal newborn screening evidence-based review process. This report shall include a clear, publicly transparent, evidence-based process to add new conditions to the RUSP to ensure there is a trusted federal approach that states can utilize to add new conditions to their newborn screening panels.

Newborn screening is one of our nation's most successful public health programs, serving almost four million infants each year and saving countless lives through the early detection of congenital and inherited disorders that may not present clinical symptoms at birth, but can cause permanent disability or death if not detected or treated within the first few days of life. Federal support and funding are essential to the success of our nation's newborn screening programs. State and U.S. territory programs report a 99.9% or higher participation rate in newborn screening, which routinely includes a blood, pulse oximetry, and hearing test for the infant and leads to the early detection of diseases for more than 14,000 infants. This early detection is crucial for improving the likelihood of effective treatment and long-term healthy development for the child.

Programs at CDC and HRSA have a significant impact on, and make critical contributions to, state and U.S. territory newborn screening programs. The CDC's NSQAP performs quality testing for more than 500 laboratories to ensure the accuracy of newborn screening tests in the United States and around the world. Further, the CDC helps states and U.S. territories implement newborn screening and works with partners to develop new screening tests for specific disorders. These efforts are incredibly resource intensive, particularly due to strained public health budgets many states and U.S. territories are facing. Increasing appropriations for CDC's newborn screening programs would facilitate an expansion of their training programs and quality assurance assistance to states and U.S. territories, both of which are currently substantially limited due to inadequate funding.

HRSA's Heritable Disorders Program assists states and U.S. territories to improve and expand their newborn screening programs and promote parent and provider education. HRSA provides states and U.S. territories with assistance, and funds the National Technical Assistance Center, to help ensure every infant in every state and U.S. territory is screened for conditions on the RUSP. While most states and U.S. territories apply for HRSA's Propel and Co-Propel grant programs, not all states and U.S. territories receive assistance purely due to limited funding available. With the growing number of conditions detectable at birth with effective treatment available, additional funding for HRSA's efforts to review and recommend new disorders for states and territories to screen is more salient than ever.

NIH's Hunter Kelly Newborn Screening Research Program contributes to advancing newborn screening in several key areas including identifying, developing, and testing promising new screening technologies; increasing the specificity of newborn screening;

expanding the number of conditions for which testing is available; and developing experimental treatments and disease management techniques. As such, we ask that you continue to provide robust and predictable increases for the National Institutes of Health (NIH) and its centers.

In conclusion, prolonged delays in adding new screens to state and U.S. territory panels result in preventable deaths and disability. These increased resources will support staffing, equipment, quality testing, and technical assistance to states and U.S. territories as they work to include all RUSP conditions on their panels to avoid preventable deaths and disability. Thank you for your continued support of the newborn screening programs that are advancing the nation's newborn screening system and savings lives.

We look forward to working with you this year to ensure the nation's newborn screening programs are supported. For more information, please contact KJ Hertz at March of Dimes (khertz@marchofdimes.org).

Sincerely,

Association for Diagnostics & Laboratory Medicine
American Academy of Neurology
American Academy of Pediatrics
American College of Medical Genetics and Genomics
American Society of Hematology
Association of Public Health Laboratories
Cystic Fibrosis Foundation
EveryLife Foundation for Rare Diseases
Family Voices National
Firefly Fund
Foundation for Angelman Syndrome Therapeutics
HCU Network America
Immune Deficiency Foundation
Jack Bear Foundation
March of Dimes
MLD Foundation
Muscular Dystrophy Association
National Organization for Rare Disorders
National Society of Genetic Counselors
Nemours Children's Health
Parent Project Muscular Dystrophy
Patient Advocacy Strategies
National PKU Alliance
Rare And Black
Society for Public Health Education