January 18, 2024

The Honorable Charles Schumer
Majority Leader
United States Senate
Washington, DC 20510

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Mitch McConnell
Minority Leader
United States Senate
Washington, DC 20510

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

The Honorable Patty Murray
Chairwoman
U.S. Senate Committee on Appropriations
Washington, DC 20510

The Honorable Kay Granger
Chairwoman
U.S. House Committee on Appropriations
Washington, DC 20515

The Honorable Susan Collins
Vice Chair
U.S. Senate Committee on Appropriations
Washington, DC 20510

The Honorable Rosa DeLauro
Ranking Member
U.S. House Committee on Appropriations
Washington, DC 20515

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Schumer, and Minority Leader McConnell:

On behalf of undersigned organizations committed to the health of our nation's mothers, infants, children, and families, we ask that you please prioritize newborn screening programs as you and your colleagues continue with the ongoing negotiations on the FY '24 Labor, Health and Human Services, and Education Appropriations Bill.

Newborn screening is one of our nation's most successful public health programs, serving almost 4 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 and treated within the first few days of life. These successes have been made possible by the annual federal investment in the Centers for Disease Control and Prevention's (CDC) Newborn Screening Quality Assurance Program (NSQAP), the Health Resources and Service Administration's (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).

Both the House and Senate Appropriations Committees proposed strong funding levels for all three programs, and we ask that you maintain full funding for these programs in a final bill.

Additionally, we ask that you prioritize support for the Centers for Disease Control and Prevention (CDC) for timely implementation of newborn screening conditions with a goal of complete Recommended Uniform Screening Panel (RUSP) implementation in all 50 states by 2025.

Federal support and funding are essential to the success of our nation's newborn screening programs. State 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 12,000 infants. This early detection is crucial for improving the likelihood of effective treatment and long-term healthy development for the child.

The 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 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 are facing.

Similarly, HRSA's Heritable Disorders Program provides assistance to states to improve and expand their newborn screening programs and promote parent and provider education. HRSA also supports the work of the Advisory Committee on Heritable Disorders in Newborns and Children, the HHS Secretary's advisory committee that recommends which disorders should be included on the RUSP. HRSA also provides states with assistance to help ensure every infant in every state is screened for conditions on the RUSP.

Lastly, 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.

Again, we ask that you provide strong support for newborn screening programs in the final FY '24 federal budget. Thank you for your continued support of the newborn screening programs that are advancing the nation's newborn screening system and saving lives.

Sincerely,

ALD Alliance
American Academy of Allergy, Asthma & Immunology
American Academy of Pediatrics
American College of Medical Genetics and Genomics

Association for Diagnostics and Laboratory Medicine
Association of Public Health Laboratories
Boomer Esiason Foundation
Cure SMA
Cystic Fibrosis Foundation
EveryLife Foundation for Rare Diseases
Foundation for Angelman Syndrome Therapeutics
The Firefly Fund
HCU Network America
Hunter's Hope Foundation
Immune Deficiency Foundation
Jeffrey Modell Foundation
March of Dimes
Muscular Dystrophy Association
National Organization for Rare Disorders
Parent Project Muscular Dystrophy
Rare Disease Innovations Institute, Inc.