

January 14, 2022

The Honorable Patty Murray
Chair
Subcommittee on Labor, Health and Human
Services, and Education
Senate Committee on Appropriations
Washington, DC 20510

The Honorable Rosa DeLauro
Chair
Subcommittee on Labor, Health and Human
Services, and Education
House Committee on Appropriations
Washington, DC 20515

The Honorable Roy Blunt
Ranking Member
Subcommittee on Labor, Health and Human
Services, and Education
Senate Committee on Appropriations
Washington, DC 20510

The Honorable Tom Cole
Ranking Member
Subcommittee on Labor, Health and Human
Services, and Education
House Committee on Appropriations
Washington, DC 20515

Dear Chairs Murray and DeLauro and Ranking Members Blunt and Cole:

The undersigned organizations committed to the health of our nation's mothers, infants, children, and families thank you for your ongoing support of federal newborn screening programs.

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 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).

The coalition is very grateful to both Subcommittees for your generous spending proposals for FY 2022, and we urge you to continue working together to maintain your commitment to newborn screening programs at the CDC, HRSA, and NICHD as you negotiate an omnibus spending bill. **We strongly urge you to include at least \$23 million for the CDC NSQAP and \$25.883 million for HRSA programs, as reflected in the House-passed Labor, Health and Human Services, Education Appropriations spending bill, in a FY 22 omnibus package.** We also ask that you continue to provide robust support for NICHD.

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.

Programs at CDC and HRSA have a significant impact on and make critical contributions to state 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 implement newborn screening and works with partners to develop new screening tests for specific disorders.

HRSA's Heritable Disorders Program provides assistance to states to improve and expand their newborn screening programs and to promote parent and provider education. HRSA also supports the work of the Advisory Committee on Heritable Disorders in Newborns and Children, which provides states with a Recommended Uniform Screening Panel (RUSP) to help ensure every infant in every state is screened for conditions that have a recognized treatment.

The 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. This work promotes the continued improvement of the newborn screening process, increasing the resources available to doctors for treating diseases that, when left undiagnosed, may cause irreversible neurological, intellectual, and physical damage.

Thank you for your past support of the newborn screening programs that are advancing the nation's newborn screening system and saving lives. We urge you to continue this support with funding increases for both CDC and HRSA programs as proposed in the FY 22 House-passed bill. Thank you for your consideration of our request.

Sincerely,

American Academy of Allergy, Asthma & Immunology
American Academy of Pediatrics
American Association for Clinical Chemistry
American College of Obstetricians and Gynecologists
Association of Maternal & Child Health Programs
American College of Medical Genetics and Genomics
Association of Public Health Laboratories
Cystic Fibrosis Foundation
CureDuchenne
Cure SMA
EveryLife Foundation for Rare Diseases
Expecting Health
HCU Network America
Immune Deficiency Foundation
March of Dimes
Muscular Dystrophy Association
National Organizations for Rare Disorders
Newborn Foundation
Newborn Screening Translational Research Network
Rare Disease Innovations Institute
Save Babies Through Screening Foundation
The XLH Network