

April 4, 2017

The Honorable Roy Blunt
Chairman
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Patty Murray
Ranking Member
Subcommittee on Labor, Health and Human
Services, Education, and Related Agencies
Committee on Appropriations
United States Senate
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray:

As you begin to craft the fiscal year (FY) 2018 Labor, Health and Human Services, and Education (LHHS) appropriations bill, the undersigned organizations committed to the health of our nation's mothers, infants, children, and families urge you to prioritize funding for programs that provide critical support to state newborn screening programs. We ask that you provide **at least \$29.8 million to the Centers for Disease Control and Prevention's (CDC) Newborn Screening Quality Assurance Program (NSQAP) and at least \$19.9 million to the Health Resources and Services Administration's (HRSA) Heritable Disorders program**. This funding level will ensure states have the access to resources and technical expertise to support ongoing activities and implement new conditions to their state newborn screening panels.

Newborn screening is one of our nation's most successful public health programs. Each year, nearly every one of the approximately 4 million infants born in the United States is screened for certain genetic, metabolic, hormonal and/or functional conditions. If left untreated, these conditions can cause disability, developmental delay, serious illness, and even death. The early detection afforded by newborn screening ensures that infants who test positive for a screened condition receive prompt treatment, saving or improving the lives of more than 12,000 infants each year.

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 new 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 is screened for conditions that have a recognized treatment. Additional funding for NSQAP and the Heritable Disorders program in FY 2018 would help states implement testing for new conditions, including providing supplies and technical expertise to state public health laboratories; supporting systems for follow-up and referral for infants with screen positive test results; and education for parents, health care providers and other stakeholders.

CDC and HRSA activities have significantly improved the quality of newborn screening programs throughout the country. In 2007, prior to the passage of the Newborn Screening Saves Lives Act, only 10 states and the District of Columbia required infants to be screened for all 29 disorders that were recommended at that time. Today, 46 states, the District of Columbia, and Puerto Rico require screening

for at least 29 of the 34 core conditions on the RUSP. With three new conditions added to the RUSP in the past two years and more coming, it is vitally important to maintain robust funding to support state efforts to add the new conditions to their newborn screening panels in a timely manner.

We thank you for your attention to our request and look forward to working with you to ensure that the United States identifies and treats each of the one in 300 infants who has a condition that can be detected through newborn screening. If you have questions, please contact Rebecca Abbott, Deputy Director of Federal Affairs at the March of Dimes, at rabbott@marchofdimes.org or 202.292.2750.

Sincerely,

American Academy of Pediatrics
American Association for Clinical Chemistry
American Congress of Obstetricians and Gynecologists
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Cure SMA
EveryLife Foundation for Rare Diseases
Genetic Alliance
March of Dimes
Muscular Dystrophy Association
National Organization for Rare Disorders
Parent Project Muscular Dystrophy