August 20, 2018

The Honorable Rodney Frelinghuysen
Chairman
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Nita Lowey
Ranking Member
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Tom Cole
Chairman
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Committee on Appropriations
United States House of Representatives
Washington, DC 20515

Dear Chairman Frelinghuysen, Ranking Member Lowey, Chairman Cole, and Ranking Member DeLauro**:**

As you move forward with the FY2019 Labor, Health and Human Services, Education, and Related Agencies (LHHS) Appropriations bill, the undersigned organizations committed to the health of our nation's mothers, infants, children, and families urge you to preserve funding for programs that provide critical support to state newborn screening programs. While current federal funding is insufficient to adequately address the challenges facing state newborn screening programs, a sustained investment will prevent cuts to essential activities. Therefore**, we ask that you provide at least $19 million to the Centers for Disease Control and Prevention's (CDC) Environmental Health Laboratory to support its newborn screening activities and at least $16.8 million to the Health Resources and Services Administration's (HRSA) Heritable Disorders program**. While this level of funding will not allow the programs to operate optimally, funding at this level is essential for the programs to perform their basic functions.

Newborn screening is one of our nation's most successful public health programs. Each year, nearly every one of the more than 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 Environmental Health Laboratory 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.
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 31 of the 34 core conditions on the RUSP. With four new conditions added to the RUSP in the past two years -- and spinal muscular atrophy just added in July -- 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 understand the difficulties presented by the constrained budget environment, and we deeply appreciate your efforts to date to increase support for these vital public health programs in FY2019. The modest federal investment in state newborn screening programs yields outstanding dividends in health outcomes and infants' and families' quality of life.

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 Cindy Pellegrini, Senior Vice President for Public Policy and Government Affairs at the March of Dimes, at cpellegrini@marchofdimes.org or 202.659.1800.

Sincerely,

American Academy of Pediatrics
American College of Medical Genetics and Genomics
American College of Obstetricians and Gynecologists
American Association of Clinical Chemistry
Association of Maternal and Child Health Programs
Association of Public Health Laboratories
Cures SMA
Cystic Fibrosis Foundation
Genetic Alliance
March of Dimes
Muscular Dystrophy Association
National Organization for Rare Disorders