

April 25, 2018

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
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United States House of Representatives
Washington, DC 20515

Dear Chairman Cole and Ranking Member DeLauro:

The undersigned organizations committed to the health of our nation's mothers, infants, children, and families thank you for your strong support of federal newborn screening programs in the Consolidated Appropriations Act, 2018 (PL 115-141). The additional funding provided to the Centers for Disease Control and Prevention's (CDC) Newborn Screening Quality Assurance Program (NSQAP) and the Health Resources and Services Administration's (HRSA) Heritable Disorders program will ensure states have the resources and technical expertise to support ongoing activities and implement new conditions to their state newborn screening panels. As you begin to craft the fiscal year (FY) 2019 Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations bill, we urge you to again prioritize funding for programs at CDC and HRSA that provide critical support to state newborn screening programs.

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 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 tests and works with partners to develop new 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, 41 states and Puerto Rico require screening for at least 31 of the 34 core conditions on the RUSP.

Unfortunately, current federal funding for newborn screening programs at CDC and HRSA falls short of the level needed to help state newborn screening programs operate optimally. With three new conditions added to the RUSP in the past two years and more expected in the near future, it is vitally important to maintain robust funding to support state efforts to add the new conditions to their newborn screening panels. Further, rapid changes in screening technologies and the addition of more complex disorders to the RUSP escalate the need for additional federal support. To confront these challenges, the federal government must increase its investment in newborn screening programs.

- **NSQAP:** State laboratories need enhanced financial and technical assistance to support the development and evaluation of testing methods for new conditions, to expand the use of CDC's quality assurance materials, and to update critical infrastructure. NSQAP would need **\$15 million** to meet this need, in addition to sustained support for ongoing program activities. If budget constraints prohibit Congress from allocating the \$15 million required, **we urge the Committee to make an initial investment by appropriating at least an additional \$6 million for NSQAP in FY 2019, for a total of \$20.65 million.**
- ***Heritable Disorders:*** The federal government should expand its efforts to support the addition of new conditions to state newborn screening panels. Beginning in FY 2015, Congress provided an additional \$2 million annually to support the wider implementation, education and awareness of newborn screening for a single disorder, SCID. 46 states now universally screen infants for severe combined immunodeficiency (SCID). We urge Congress to provide HRSA with an additional **\$6 million** to build on that successful program by supporting states with implementation, education and awareness of newborn for new conditions recently added to the RUSP, including Pompe disease, Mucopolysaccharidosis I (MPS I), and X-linked adrenoleukodystrophy (X-ALD). **This would bring the total amount allocated to the Heritable Disorders program in FY 2019 to \$21.9 million.**

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 born every year 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,
1,000 Days
Academy of Nutrition and Dietetics
American Academy of Allergy, Asthma & Immunology
American Academy of Pediatrics
American Association for Clinical Chemistry
American Association on Health and Disability
American College of Obstetricians and Gynecologists
American Public Health Association
Association of Maternal & Child Health Programs
Association of Women's Health, Obstetric and Neonatal Nurses
Colorado School Medicaid Consortium
Cure SMA
Cystic Fibrosis Foundation
First Focus

Genetic Alliance
Lakeshore Foundation
Louisiana Public Health Institute
March of Dimes
MLD Foundation
Muscular Dystrophy Association
National Association of County and City Health Officials
National Organization for Rare Disorders (NORD)
Parent Project Muscular Dystrophy (PPMD)
Pathways for Rare and Orphan Studies
SCID, Angels for Life Foundation
Teratology Society

cc: Member of the House Labor, Health and Human Services, Education, and Related Agencies Appropriations Subcommittee