

July 6, 2017

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 Cole and Ranking Member DeLauro:

The undersigned organizations committed to the health of our nation's mothers, infants, children, and families write to **oppose proposed budget cuts included in President Trump's fiscal year (FY) 2018 budget that would stymie ongoing efforts to improve state newborn screening programs. Specifically, we ask that you reject the elimination of the Health Resources and Services Administration's (HRSA) Heritable Disorders program.** Elimination of the Heritable Disorders program would roll back the progress made over the last decade to improve the performance of state newborn screening programs and would limit states' ability to quickly add new conditions to their newborn screening panels. If enacted, the cuts would result in adverse health outcomes for many of our nation's infants.

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.

While each state operates its own newborn screening program, the Heritable Disorders program addresses nationwide challenges experienced by all states. Through grants made available by the program, states have supported the implementation of screening for new conditions and have improved how quickly infants with a positive screen receive results and are connected with follow-up services. Heritable Disorder grants facilitate national and regional collaborations to provide technical assistance, disseminate best practices, and share data. The program also administers the Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), which provides the Secretary of Health and Human Services with evidence-based recommendations on which conditions should be added to the Recommended Uniform Screening Panel (RUSP). **Our organizations strongly oppose the elimination of the Heritable Disorders program and reject the justification that states may continue to support these activities with their Maternal and Child Health Block Grant awards.** Congress has signaled its intent that HRSA support nationwide newborn screening initiatives through passage and reauthorization of the Newborn Screening Saves Lives Act (P.L. 110-204 and P.L. 113-240). Performing these activities at the federal level is efficient and reduces what would otherwise be duplicative efforts and expenditures by states.

The President's FY 2018 budget also calls for a slight reduction below the FY 2017 enacted level for CDC's Environmental Health Laboratory. The Lab's Newborn Screening Quality Assurance Program (NSQAP) is tasked with performing 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. **Our organizations urge you to reject any cuts to NSQAP that would restrict the program's ability to provide its one-of-a-kind service to state newborn screening programs.**

CDC and HRSA activities have significantly improved the quality of newborn screening programs throughout the country. In 2007, prior to the passage of legislation authorizing federal newborn screening activities, 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. The current uniformity across states is due in large part to efforts funded by the Heritable Disorders program and NSQAP. With three new conditions added to the RUSP in the past two years and more under consideration, 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. **Our organizations ask that you provide the highest possible funding for the Heritable Disorders program and NSQAP during the FY 2018 appropriations cycle.**

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,

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 Medical Genetics and Genomics
American Congress of Obstetricians and Gynecologists
American Public Health Association
American Society of Hematology
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Association of Women's Health, Obstetric & Neonatal Nurses
Colorado School Medicaid Consortium (The Consortium)
Cure SMA
Cystic Fibrosis Foundation
EveryLife Foundation for Rare Diseases
First Focus Campaign for Children
Genetic Alliance
Immune Deficiency Foundation
Lakeshore Foundation
Little Miss Hannah Foundation
March of Dimes
MLD Foundation
Muscular Dystrophy Association
National Association of County & City Health Officials

National Organization for Rare Disorders (NORD)
Nemours Children's Health System
NGLY1.org
Parent Project Muscular Dystrophy
SCID, Angels for Life Foundation
Teratology Society

CC: Members of the United States House Labor, Health and Human Services, Education, and Related
Agencies Appropriations Subcommittee