

June 24, 2019

The Honorable Lucille Roybal-Allard
United States House of Representatives
2083 Rayburn House Office Building
Washington, DC 20515

The Honorable Michael Simpson
United States House of Representatives
2084 Rayburn House Office Building
Washington, DC 20515

The Honorable Katherine Clark
United States House of Representatives
2448 Rayburn House Office Building
Washington, DC 20515

The Honorable Jaime Herrera Beutler
United States House of Representatives
2352 Rayburn House Office Building
Washington, DC 20515

Dear Reps. Roybal-Allard, Simpson, Clark and Herrera Beutler,

On behalf of the undersigned organizations committed to the success of our nation's newborn screening system, we thank you for your leadership in introducing the *Newborn Screening Saves Lives Reauthorization Act of 2019* and offer our endorsement of this important legislation.

For almost 60 years, newborn screening has been saving and improving the lives of children across the United States through early identification of diseases that cause permanent disability or death if not treated early. It is one of the most successful public health programs of our time, positively impacting hundreds of thousands of children and their families. The Federal Government plays a crucial role in supporting state newborn screening programs: investing in research to advance newborn screening science; providing states with funds and technical assistance to improve their newborn screening programs; facilitating the sharing of best practices among states; educating providers, patients, and the public about newborn screening; and maintaining a recommended list of conditions that states should include on their newborn screening panels. These activities were authorized in the original *Newborn Screening Saves Lives Act of 2008* (P.L. 110-204) and reauthorized in 2014. Since passage of the 2008 bill, states have made a number of improvements to their programs with assistance from federal programs, including increasing the number of conditions on newborn screening panels to align with federal recommendations and decreasing the time it takes for the providers and families of infants with conditions identified through newborn screening to be notified and for babies to receive follow-up care.

The *Newborn Screening Saves Lives Reauthorization Act of 2019* will ensure essential federal newborn screening programs at the Centers for Disease Control and Prevention, the National Institutes of Health, and the Health Resources and Services Administration continue for the next five years. It makes targeted improvements, including increasing funding for those activities, ensuring federal agencies have the flexibility to address emerging technologies and new conditions, and improving surveillance activities. The bill also commissions the National Academy of Medicine to issue a report on the modernization of newborn screening and make appropriate recommendations.

Our organizations thank you for introducing legislation to support and advance our nation's newborn screening system. We stand ready to help you in your efforts to quickly pass the *Newborn Screening Saves Lives Reauthorization Act of 2019*. For additional information, please contact Rebecca Abbott, Deputy Director of Federal Affairs for Public Health at March of Dimes (202.292.2750 or rabbott@marchofdimes.org).

Sincerely,

1,000 Days

Aidan Jack Seeger Foundation

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 Public Health Association

American Society of Hematology

Asian & Pacific Islander American Health Forum

Association of Maternal & Child Health Programs

Association of Public Health Laboratories

Association of University Centers on Disabilities

Caring America

Children's National Health System

Cystic Fibrosis Foundation

EveryLife Foundation for Rare Diseases

First Focus Campaign for Children

Hydrocephalus Association

Immune Deficiency Foundation

Lakeshore Foundation

March of Dimes

Mississippi Urban League

MLD Foundation

Muscular Dystrophy Association

National Association of County Health Officials

National Birth Defects Prevention Network

National Organization for Rare Disorders

Newborn Foundation

Parent Project Muscular Dystrophy (PPMD)

Pathways for Rare and Orphan Studies

Prevent Blindness