September 12, 2022

The Honorable Patty Murray
Chair
Committee on Health, Education, Labor and Pensions
United States Senate
Washington, DC 20510

The Honorable Richard Burr
Ranking Member
Committee on Health, Education, Labor and Pensions
United States Senate
Washington, DC 20510

Dear Chairwoman Murray and Ranking Member Burr:

As you return from the August state work period, the undersigned organizations committed to the health of our nation's mothers, infants, children, and families urge you to take action on S. 350, the "Newborn Screening Saves Lives Reauthorization Act of 2021," which is sponsored by Senators Maggie Hassan (D-NH) and Roger Wicker (R-MS). The House version of the bill (H.R. 482) passed with overwhelming bipartisan support last summer. Given the very limited availability on the Senate calendar, now is the time for the Senate to act on this bill and advance it to the floor.

It is imperative that the Senate acts quickly to pass this legislation. Each year thousands of babies are born with a genetic, metabolic, hormonal, or functional condition that is not clinically apparent at birth. A simple set of tests performed at birth can detect these life-threatening illnesses, allowing crucial time for early treatment to prevent more serious long-term health problems. Unfortunately, critical gaps and challenges still remain. Discrepancies in the number of tests given from state to state cause children to tragically die or become permanently disabled from otherwise treatable disorders.

This bill would address these challenges and help pave the way forward for improved, life-saving screening practices. This legislation would:

- Update the authorizing language for the Federal newborn screening programs, allowing them to keep up with the latest technology and approaches;
- Increase the authorized funding levels to bring them more in line with the needs of the programs; and
- Commission a study on the next generation of newborn screening.

This legislation overwhelmingly passed the House in June 2021 but has not been considered in the Senate. The Senate's delay continues to jeopardize the health and well-being of thousands of newborns across the country born with serious and life-threatening conditions. Inadequate funding, outdated authorizing language, and lack of analysis on how to innovate within our newborn screening programs will only be exacerbated the longer the Senate delays. We cannot afford to wait until the next Congress.

We greatly appreciate your consideration of our request. This bipartisan bill is a cost-effective strategy that saves lives, prevents disability, and improves the quality of life for thousands of infants and families each year. We look forward to working with you to ensure that our nation's critical newborn screening programs are reauthorized without any further delay.

Sincerely,

Non-Profit Advocacy and Association Partners

ALD Alliance
American Academy of Allergy, Asthma & Immunology
American Academy of Pediatrics
American Association for Clinical Chemistry
American College of Medical Genetics and Genomics
American College of Obstetricians and Gynecologists
Association of Maternal & Child Health Programs
Association of Public Health Laboratories
Boomer Esiason Foundation
BDSRA Foundation
CureDuchenne
Cure Sanfilippo Foundation
Cure SMA
Cystic Fibrosis Foundation
EveryLife Foundation for Rare Diseases
E.WE Foundation
Firefly Fund
Friedreich's Ataxia Research Alliance
Galactosemia Foundation
Gene Giraffe Project
Genetic Alliance
Histiocytosis Association
Hunter's Hope Foundation
HCU Network America
Immune Deficiency Foundation
Jeffrey Modell Foundation
Leukodystrophy Newborn Screening Action Network
March of Dimes
MarylandRARE
Mississippi Metabolics Foundation
Muscular Dystrophy Association
Myositis Association
National Ataxia Foundation
National Foundation for Ectodermal Dysplasia
National Fragile X Foundation
National Health Council
National Institute for Children's Health Quality
National MPS Society
National Organization for Rare Disorders
National Partnership for Women & Families
Network of Tyrosinemia Advocates
Newborn Foundation
Newborn Screening Translational Research Network
Organic Acidemia Association
Parent Project Muscular Dystrophy

Prader-Willi Syndrome Association USA
Project GUARDIAN
Rare Access Action Project
Rare Disease Innovations Institute, Inc.
RARE-X
Rare New England
Ryan Foundation for Rare Disease Research
SCID Angels for Life Foundation
Stronger Than Sarcoidosis and Sarcoidosis of Long Island
STXBP1 Foundation
SYNGAP1 Foundation

Newborn Screening Industry Partners

Alexion Pharmaceuticals, Inc.
Amicus Therapeutics
BioMarin Pharmaceutical Inc
Enzyvant
Invitae Corporation
Novartis
Orchard Therapeutics
PerkinElmer
PTC Therapeutics, Inc
Rare Disease Company Coalition
REGENXBIO Inc.
Sarepta Therapeutics, Inc.
StrideBio
Takeda
Tenaya Therapeutics
Travere Therapeutics
Ultragenyx