

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 Inadequate funding, outdated authorizing language, and lack of analysis on how to innovate within our newborn screening programs will only be exacerbated the longer the Senate delays.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  
Traverse Therapeutics  
Ultragenyx