

May 5, 2017

The Honorable Lauren Book
202 Senate Office Building
404 South Monroe Street
Tallahassee, FL 32399-1100

The Honorable Heather Fitzenhagen
412 House Office Building
402 South Monroe Street
Tallahassee, FL 32399-1300

RE: SB 1124/HB 963 – Newborn Screening

Dear Senator Book and Representative Fitzenhagen,

As patient organizations representing patients in Florida and across the United States, we write today to thank you for your leadership on newborn screening and express our support for SB 1124 and HB 963. Every year, millions of babies born in the U.S. are screened for a variety of diseases and conditions that might otherwise go undetected. These simple screens help provide lifesaving early warnings of conditions, allowing for the earliest diagnosis and access to potentially life-saving treatments for babies. In many cases, early detection can avert costly and risky medical procedures later in life.

Florida had been a leader in newborn screening, but its current approach to reviewing and approving screening for additional diseases has created a lag behind current medical recommendations. SB 1124 and HB 963 provide a thoughtful approach to expanding newborn screening in Florida. This legislation would empower Florida's Genetics and Newborn Screening Advisory Council to ensure the state implements their newborn screening recommendations within one year. It would also require the Advisory Council to consider new diseases added to the federal Recommended Uniform Screening Panel (RUSP) within one year, ensuring babies born in Florida have the same opportunity for diagnosis and treatments as babies born across state lines.

The RUSP list is periodically updated through a thorough, science and evidence based deliberative review process involving a national committee of experts in newborn screening. By allowing Florida to take advantage of the work done by these medical experts at the federal level and empowering the Genetics and Newborn Screening Advisory Council, we can remove the obstacles to needed testing and minimize the suffering that comes from untreated diseases.

SB 1124 and HB 963 would ensure that Florida babies born with debilitating diseases are diagnosed and treated at the earliest age possible and without life-threatening delays. This

approach is critical for improving health outcomes for children and providing the brightest future for all babies born in Florida.

For these reasons, we are proud to support SB 1124 and HB 963. We are grateful for your leadership on this issue and look forward to working with you and your offices to ensure these bills become law.

Sincerely,

EveryLife Foundation for Rare Diseases

Advancement of Research for Myopathies
Aidan Jack Seeger Foundation
ALD Connect, Inc.
Alpha-1 Foundation
American Academy of Neurology
American Behcet's Disease Association
Amyloidosis Foundation
Arrhythmia Alliance
Arrowhead Pharmaceuticals
Association for Creatine Deficiencies
Association of Gastrointestinal Motility Disorders, Inc.
Bridge The Gap - SYNGAP Education a
CALIFORNIA coalition for PKU and allied disorders
Canadian Association of Pompe
CARES Foundation, Inc.
Children's PKU Network
Consortium of MS Centers
Cure CMD, International Patient Advocacy Non Profit Organization
Cure Sanfilippo Foundation
CureBatten
CureFA
EDSers United
GCAF GIST Cancer Awareness Foundation
Gene Giraffe Project
Genetic Alliance Australia
Global Genes
Hannah's Hope Fund
Human Growth Foundation
Hydrocephalus Association
Hypertrophic cardiomyopathy association
Immune Deficiency Foundation
International FOP Association

International Society for Mannosidosis and Related Diseases
International Waldenstrom's Macroglobulinemia Foundation
Jain Foundation, Inc
Jeffrey Modell Foundation
Jonah's Just Begun
Kennedy's Disease Association
LAL Solace
Little Miss Hannah Foundation
Lung Transplant Foundation
Lupus and Allied Diseases Association
Lymphangiomatosis & Gorham's Disease Alliance
Lysosomal Disease Network
MLD Foundation
MPS6CESS Foundation
National Leiomyosarcoma Foundation
National Lymphedema Network
National MPS Society
National PKU Alliance
New England Connection for PKU and Allied Disorders
New England Regional Genetics Group
NTM Info & Research
NTSAD
Olivia's Heart Project
Organic Acidemia Association
Organization for rare diseases india
Oxalosis & Hyperoxaluria Foundation
Parent Project Muscular Dystrophy
Pediatric Hydrocephalus Foundation
Phoenix Fox Foundation
PTEN World
Pulmonary Fibrosis Advocates
Rare and undiagnosed network
Rare Disease United Foundation
RARE Science
RareConnect.org
Reflex Sympathetic Dystrophy Syndrome Association
SCID, Angels for Life Foundation
Stickler Involved People
Sudden Arrhythmia Death Syndromes (SADS) Foundation
Taylor's Tale
The Charlotte and Gwenyth Gray Foundation to Cure Batten Disease
The Immune Deficiency Foundation
The Kortney Rose Foundation

The Myelin Project
The OsteoPETrosis Society
The TLC Foundation for Body-Focused Repetitive Behaviors
The XLH Network, Inc.
Tuberous Sclerosis Alliance
United Leukodystrophy Foundation
United Pompe Foundation
VHL Alliance
Wilson Disease Association
Zeqing for a Cure