

March 8, 2022

The Honorable Ann Meyer and Jeff Edler

1007 E Grand Ave

Des Moines, IA 50319

RE: Support of Newborn Screening Bills HF 2539 and SF 2345

Dear Representative Meyer and Senator Edler,

As patient advocacy organizations representing individuals diagnosed with rare diseases and family caregivers in Iowa and across the United States, we write today to thank you for your leadership on newborn screening and express our support for HF 2539 and SF 2345.

Every year, millions of babies born in the US are screened for a variety of devastating and often fatal diseases and conditions that might otherwise go undetected. These simple screens help provide lifesaving early identification, allowing for the earliest possible diagnosis and immediate access to potentially life-saving treatments for babies. In many cases, early detection can avert costly and risky medical procedures later in life.

HF 2539 and SF 2345 provide a thoughtful approach to newborn screening in Iowa that ensures that all conditions on the federal Recommended Uniform Screening Panel (RUSP) are added to the screening panel in a reasonable amount of time. The RUSP is periodically updated using a thorough, evidence-based deliberative review process involving a national committee of experts in newborn screening. This legislation allows Iowa to efficiently add new conditions by taking advantage of the work done by these medical experts to remove obstacles to needed testing and minimizing the irreversible disease progression and loss of life that comes from untreated diseases.

Iowa is a leader in the field of newborn screening, screening for 32 of 35 conditions currently on the RUSP. However, Iowa does not currently screen for MPS-1, ALD, and Pompe Disease. MPS-1 and ALD were recommended for addition more than six years ago and Pompe Disease was recommended more than eight years ago. This legislation would empower the Iowa Department of Public Health (IDPH) to ensure that the state implements new screening recommendations within two and a half years and gives the State Hygienic Laboratory the power to raise the newborn screening fee so that it is sufficient to cover the cost of screening and follow-up care. It also would require the existing Congenital and Infectious Disease Advisory Committee (CIDAC) to consider new diseases added to the federal Recommended Uniform Screening Panel (RUSP) within one year, ensuring babies born in Iowa have the same opportunity for diagnosis and treatments as babies born across state lines.

For these reasons, we are proud to support the newborn screening language. We are grateful for your leadership on this issue and look forward to working with you and your office to ensure this language becomes law.

Sincerely,

The EveryLife Foundation for Rare Diseases

Iowa Krabbe Network

THE FAMILY LEADER

March of Dimes

Gene Giraffe Project

Iowa DD Council

MTS Sickle Cell Foundation, Inc.
Leukodystrophy Newborn Screening Action Network
International Foundation for CDKL5 Research
Rare and Undiagnosed Network (RUN)
BDSRA
The Akari Foundation
HCU Network America
Cure Sanfilippo Foundation
Project GUARDIAN
ALD Connect, Inc.
Parent Project Muscular Dystrophy
Association for Creatine Deficiencies
Hunter's Hope Foundation
Cure MLD
Cure CMD
Organic Acidemia Association
Project Alive
Amour Science Foundation
AMDA
The Jansen's Foundation
Adrenal Insufficiency Fund
Partners for Krabbe Research
T.E.A.M. 4 Travis
Alpha-1 Foundation
The Global Foundation for Peroxisomal Disorders
Batten Disease Support and Research Association
MLD Foundation
MarylandRARE
United Leukodystrophy Foundation
STXBP1 Foundation
Cure SMA
The E.WE Foundation
Pompe Alliance
National Ataxia Foundation
Avery's Hope
NTSAD
Stronger than Sarcoidosis
ALD Alliance
Danny's Dose Alliance
Cystic Fibrosis Research Institute (CFRI)
Sickle Cell Association of Kentuckiana
NTM Info & Research
Histiocytosis Association
Syngap1 Foundation
USA- Prader-Willi Syndrome Association (PWSA)
National MPS Society
VHL Alliance
USTMA
Born a Hero, Research Foundation
Supporters of Families with Sickle Cell Disease
Hunter Syndrome Foundation
KrabbeConnect
The Legacy of Angels Foundation
CFC International
National Gaucher Foundation, Inc.
Friedreich's Ataxia Research Alliance (FARA)
United Pompe Foundation
Undiagnosed Diseases Network Foundation (UDNF)