

February 17, 2022

The Honorable Ann Meyer and Jeff Edler

1007 E Grand Ave

Des Moines, IA 50319

RE: Support of Newborn Screening Bills HSB 690 and SSB 3122

Dear Representative Meyer and Senator,

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 HSB 690 and SSB 3122.

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.

HSB 690 and SSB 3122 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,

EveryLife Foundation for Rare Diseases

March of Dimes

Gene Giraffe Project

MTS Sickle Cell Foundation, Inc.

Iowa Krabbe Network

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.W.E. Foundation