



February 10, 2022

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Representative Ann Meyer
Chair, Committee on Human Resources
1007 E Grand Ave
Des Moines, IA 50319

RE: HSB 690: A bill for an act relating to the newborn screening

Dear Chairperson Meyer,

As a patient advocacy organization representing individuals diagnosed with rare diseases and family caregivers in Iowa and across the United States, we at the EveryLife Foundation for Rare Diseases thank you for your leadership on newborn screening and ask for your support of HSB 690.

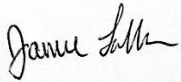
Every year, millions of babies born in the US are screened for a variety of devastating and often fatal diseases and conditions that might otherwise go undetected. These simple screens help provide lifesaving early identification, allowing for the earliest possible diagnosis and immediate access to potentially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

HSB 690 provides 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. It would also require IDPH to give the General Assembly annual reports on conditions added to Iowa's newborn screening panel, conditions under consideration for addition, and an explanation for any delays in addition and/or implementation of conditions to Iowa's newborn screening panel.

For these reasons, we ask for your support of HSB 690. 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,



Jamie Sullivan
Director of Public Policy
EveryLife Foundation for Rare Diseases



Dylan Simon
Associate Director of Public Policy
EveryLife Foundation for Rare Diseases

CC: Annie Kennedy, Chief of Policy, Advocacy, and Patient Engagement
Claire Ellis, Newborn Screening & Diagnostics Policy Fellow