

April 14, 2021

The Honorable Allison Russo
436 State Capitol
Columbus, OH

RE: HB 110 – Budget Newborn Screening Language

Dear Representative Russo,

As patient advocacy organizations representing the rare disease community in Ohio and across the United States, we write today to thank you for your leadership on newborn screening and express our support for newborn screening language in HB 110. Every year, millions of babies born in the U.S. are screened for a variety of devastating and often fatal diseases and conditions that might otherwise go undetected. These simple screens 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 reduce the need for costly and risky medical procedures later in life.

The proposed language provides a thoughtful approach to expanding newborn screening in Ohio that ensures that all Recommended Uniform Screening Panel (RUSP) conditions are added to the screening panel in a reasonable amount of time with the appropriate funding. The RUSP is periodically updated using a thorough, science and evidence-based deliberative review process involving a national committee of experts in newborn screening. By allowing Ohio to implement work done by these medical experts at the federal level, we can remove the obstacles to needed testing and minimize the irreversible disease progression and loss of life that comes from untreated diseases.

Ohio is a leader in the field of newborn screening, screening for 33 of 35 conditions currently on the RUSP. However, one of the conditions not currently on the Ohio newborn conditions, ALD, was recommended for addition more than five years ago. This legislation would empower Ohio's expert newborn screening advisory council to promptly review any new condition added to the Recommended Uniform Screening Panel (RUSP) and, if recommended by this council, add that condition to the Ohio's newborn screening panel. It also implements a timeline for when the screening must begin, and ensures that the process will allow future funding of screening for all RUSP conditions. This language will eliminate any unnecessary delay in screening for diseases, ensuring babies born in Ohio 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 become law.

Sincerely,

EveryLife Foundation for Rare Diseases