



January 30, 2019

Members, Senate Human Resources Committee
1007 East Grand Avenue
Des Moines, Iowa 50319

Re: Senate File 60

Dear Members of the Senate Human Resources Committee,

On behalf of the nearly 1-in-10 Iowa residents with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) writes in support of making Iowa's newborn screening panel as consistent with the federal Recommended Uniform Screening Panel (RUSP) as possible.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

All of the disorders for which there are screens on the RUSP are considered rare, meaning that they affect fewer than 200,000 individuals in the United States. Further, they are all conditions that if left untreated during the early stages of their progression can cause severe physical and developmental impairment or even death. Fortunately, improved treatment standards for each of these disorders are available. Combined with the effectiveness and reliability of newborn screening, these treatments make it possible for states to prevent grave harm from befalling infants born with any of the conditions included on the RUSP.

Adopting screening for new RUSP recommendations as soon as possible is critical, however, it is much more involved than simply expanding a panel of tests. Newborn screening is a complex system that requires constant upkeep, resources, and coordination between various stakeholders. Before a state can include additional conditions on its panel, NORD believes it must be fully capable of carrying out implementation. Rushed implementation can often lead to harmful scenarios, such as a high rate of false positives or an abundance of scared and confused parents who are unsure of where to turn. Whether it is a matter of developing educational materials, ensuring proper follow-up, improving lab infrastructure, or identifying disease specialists in the state, every state owes its citizens a well-functioning and comprehensive newborn screening program.

Consequently, while NORD is strongly supportive of Iowa adopting the conditions on the RUSP, we hope the Committee will be mindful of the current capacity of the state's newborn screening program and ensure that any necessary changes are made before beginning screening.



Thank you for your consideration of this letter and your ongoing support of the rare disease community in Iowa through the advancement of newborn screening. Please feel free to reach out to us directly to discuss this further using the contact information below. We would be more than happy to meet with you to discuss the ways in which we can support Iowa's newborn screening program.

Sincerely,

Tim Boyd, M.P.H.
Director of State Policy
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