

Dear Health and Human Services Committee.

Nebraska Cures has been a leading advocate for health science research for over 20 years. We support policies rooted in science and strive to advance the quality of life and economy for Nebraskans. In alliance with our mission, we strive to educate policymakers on sound health science and address state initiatives regarding health science policy.

I am writing to express our opposition to LB 1060, which seeks to remove the requirement for newborn screenings in Nebraska. We believe that these required newborn screenings are an essential component of public health and contribute to the well-being of our youngest citizens.

Newborn screening programs have proven to be invaluable in identifying and addressing potential health issues in infants at an early stage. Of the nearly four million babies born each year in the United States, nearly 13,000 receive a diagnosis from their newborn screening<sup>1</sup>. The timely detection of certain medical conditions allows for prompt intervention, significantly improving outcomes and reducing the overall burden on both families and the healthcare system. These programs are a cost-effective means of safeguarding the health of our community and preventing the long-term economic and social costs associated with untreated medical conditions.

Eliminating the newborn screening requirement could have serious consequences for the health and development of our children. Early detection of conditions such as metabolic disorders, hearing impairments, and congenital diseases is crucial for initiating appropriate medical interventions that can prevent long-term complications and disabilities. For example, phenylketonuria, PKU (a disorder tested for), is manageable if detected early and treatment (dietary changes and supplements) is began as soon as possible<sup>2</sup>. If treatment is delayed, infants can develop symptoms including behavioral problems, seizures, and severe developmental and intellectual disabilities. Other diseases in the screening panel are similarly treatable to preserve the highest quality of life through development and prevent unnecessary complications, but only if earliest detection is assured.

We believe that LB 1060 should not advance out of committee. Thank you for your consideration.

Sincerely,

**David Crouse** 

David a. Crouse

Nebraska Cures Board President

https://www.mayoclinic.org/diseases-conditions/phenylketonuria/symptoms-causes/syc-20376302

<sup>&</sup>lt;sup>1</sup> CDC National Center for Health Statistics (2023) https://www.cdc.gov/nchs/fastats/births.htm

<sup>&</sup>lt;sup>2</sup> Phenylketonuria (PKU) Mayo Clinic