



House Committee on Health and Human Services

March 5th, 2025

Proponent of HB2399

Chairman Carpenter and Member of the Committee,

On behalf of the Kansas Council on Developmental Disabilities (KCDD), we appreciate the opportunity to submit testimony supporting HB2399, which establishes an advanced universal newborn screening program, expands screening for treatable genetic conditions, and ensures access to necessary treatment services. KCDD works to support Kansans of all ages with developmental disabilities, ensuring they have the opportunity to make choices about their participation in society and their quality of life. Our mission is to empower individuals with intellectual and developed disabilities (I/DD) and their families to lead systems change, build capacity, and advocate for inclusive, integrated, and accessible communities where everyone belongs and thrives.

Newborn screening is a critical public health measure that can lead to early diagnosis and intervention, significantly improving health outcomes and preventing long-term disabilities and rare conditions. In Kansas, newborn screenings are free and help so many individuals and families identify and treat conditions. We currently have testing for around 34 conditions while families in Missouri might have access to 64 conditions. The Secretary of the U.S. Department of Health and Human Services has a federal Recommended Uniform Screening Panel ([RUSP](#)) that gives recommendations to states on which screenings they should add to their panel. In order to add the recommended screenings, we need to increase funding.

For individuals with developmental disabilities and rare conditions, early identification is often the difference between a lifetime of barriers and the opportunity to thrive. Without screening, conditions like congenital hypothyroidism, phenylketonuria (PKU), or other metabolic disorders may go undetected until symptoms appear—often after the window for early treatment has closed. The result can be significant intellectual and physical disabilities that impact every aspect of a person's life. But with early detection, children can receive essential medical care, dietary management, and therapies that prevent these devastating outcomes, allowing them to grow, learn, and participate fully in their communities.

KCDD strongly supports the provisions in HB 2399 that:

1. **Expand newborn screening** to include additional treatable conditions as determined by medical best practices.
2. **Ensure access to necessary treatment services** for diagnosed infants, including reimbursement for medically necessary food and treatment products.
3. **Provide financial assistance** to families in need, reducing the burden of costly medical interventions and ensuring equitable access to care. Kansas is one of only three states offering newborn screening services at no cost to families and we want to ensure that our state newborn screening program can continue that support through treatment.
4. **Establish a structured follow-up program** to monitor treatment and provide ongoing support to individuals and families navigating these diagnoses.

This legislation aligns with our mission to promote policies that enhance health equity and improve outcomes for Kansans with intellectual and developmental disabilities. By investing in early detection and intervention, the state can prevent unnecessary health challenges, reduce long-term healthcare costs, and give every child the best possible start in life.

We urge the Committee to advance HB 2399 and thank you for your leadership in supporting the health and well-being of Kansas families. We welcome any opportunity to further discuss the impact of this bill and appreciate your consideration.

Thank you,

Allyson McCain
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Kansas Council on Developmental Disabilities (KCDD)