

**Proponent Testimony on HB 2399
Health & Human Services Committee
Drew Duncan, Screening & Surveillance Section Director
Kansas Department of Health and Environment Bureau of Family Health
March 5, 2025**

Chairman Carpenter and members of the Committee:

My name is Drew Duncan, and I am a Section Director for the Kansas Department of Health and Environment (KDHE). I oversee Screening & Surveillance which includes the Kansas Newborn Screening programs. Thank you for the opportunity to appear before you today to discuss HB 2399. HB 2399 amends the existing program statutes (K.S.A. 65-180, 65-181 and 65-183), establishes an advanced universal screening program, updates outdated terminology, and increases funding capitations placed on the program's sole funding source, the medical assistance fee fund pursuant to K.S.A. 40-3236.

The proposed change I would like to focus on today is increasing funding capitations to ensure resources are available to conduct a quality, effective, and efficient newborn screening program. Kansas Newborn Screening (NBS) is a mandated public health program established in 1965 to protect the health and welfare of newborns with treatable disorders. Kansas law requires newborn screening be provided at no cost to providers or families. Kansas is one of only three states that provides this essential public health service free of charge. The cost of a newborn screening varies across the United States and is noted as high as \$203 per newborn. In 2023, the program conducted more than 35,000 screenings.

In 2012, K.S.A. 65-180 was amended establishing the newborn screening fund. In 2017, the statute was further amended to cap funding at \$2.5M. The funding capitation was based on prior year expenditures that did not reflect an expanded or fully staffed program. Kansas aims to screen for all treatable conditions listed on the U.S. Department of Health and Human Services Recommended Uniform Screening Panel (RUSP). This now includes 38 conditions on the core panel, with many more conditions expected to be added in the future. Kansas currently screens for 36 of the core panel conditions, with planning underway to screen for the remaining two (Krabbe and GAMT). Since 2020, Kansas has added five conditions to the newborn screening panel, made possible with non-renewable federal grants and the budget proviso that increased the NBS capitation to \$5M.

The implementation of an advanced universal newborn screening program provides newborns with genetic or metabolic conditions, hearing loss, and critical congenital heart defects the best chance at healthy development. With the expansion of five conditions over the past five years and the recommendation for Kansas to remain up to date with the uniform screening panel, the program will be underfunded under the current statutory capitation. Underfunding could result in a reduction of activities that were made possible under the budget proviso and limit the ability of newborn screening program to grow as new conditions are added to the RUSP.

It's important to note that HB 2399 does not allocate \$5M to the program annually, rather, the proposed change to the law increases the cap placed on the funds to support growth, sustainability, and the flexibility to meet the needs of families.

Thank you for this opportunity to appear before you. I will now stand for questions.