

Testimony on HB 2250
Social Services Budget Committee
Drew Duncan, Screening & Surveillance Unit Director
KDHE Bureau of Family Health
February 18, 2021

Chairman Carpenter and members of the Committee, my name is Drew Duncan and I am the Screening and Surveillance Unit Director for the Kansas Department of Health and Environment (KDHE), which includes the Newborn Screening and Birth Defect Programs. Thank you for the opportunity to appear before you today to discuss HB 2250. HB 2250 amends the existing program statutes (K.S.A. 65-180, 65-181 and 65-183), naming the Kansas newborn screening act, updating outdated terminology, and increasing funding capitations placed on the program's sole funding source, the medical assistance fee fund pursuant to K.S.A. 40-3236.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 screen varies across the United States and is noted as high as \$203 per specimen. In 2019, the program screened nearly 37,000 infants.

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 includes 35 conditions on the core panel and many more on the secondary panel. Kansas currently screens for 34 of the core panel conditions. Kansas added five conditions over the past four years, two of which were only made possible due to financial assistance and support through non-renewable federal grants. Implementing the 35th condition will make Kansas one of only nine states to screen for all conditions on the RUSP.

The implementation of an advanced universal newborn screening program provides newborns with genetic or metabolic conditions, hearing loss, and critical heart defects the best chance at healthy development. With the expansion of five conditions over the past four years and the recommendation for Kansas to remain up-to-date with the uniform screening panel, the program is underfunded and unable to meet growing needs. Identified needs include long-term follow-up activities, consultation with medical providers, data system enhancements, additional laboratory testing equipment, increased cost of testing supplies, and a courier service to assure more timely transport and receipt of specimens to the state laboratory.

It's important to note that HB 2250 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.