

**Testimony on SB 155
Public Health and Welfare Committee
Drew Duncan, Screening & Surveillance Section Director
KDHE Bureau of Family Health
March 3, 2022**

Chairman Hilderbrand and members of the Committee, thank you for the opportunity to provide testimony in support of SB 155. My name is Drew Duncan and I am the Screening & Surveillance Section Director, which oversees the Kansas Newborn Screening programs. SB 155 would rename K.S.A. 65-180 et. seq, the newborn screening act, update outdated terminology, and increase funding capitations placed on the program's sole funding source, the medical assistance fee fund pursuant, to K.S.A. 40-3236.

For the purpose of today's testimony, I would like to focus on 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 statute 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 to be as high as \$203 per specimen. In 2021, Kansas newborn screening programs screened more than 34,500 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 were not reflective of an expanded or fully staffed program. In FY 2021, the \$5 million budget proviso supported \$3.4 million in program expenditures. Kansas aims to screen for all treatable conditions listed on the U.S. Department of Health and Human Services Recommended Uniform Screening Panel (RUSP). The RUSP includes 35 core conditions, and many more conditions on the secondary panel. Kansas currently screens for 34 of the 35 recommended core conditions, with planning to add the 35th condition underway. Over the last five years, Kansas has added five conditions; two of which were made possible due to financial assistance and support through non-renewable federal grants.

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 five years and recommendation for Kansas to remain up-to-date with the uniform screening panel, the program will be 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 is important to note that SB 155 does not allocate \$5M to the program annually, rather, the proposed change to the statute increases the capitation 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.