

Testimony on Senate Bill 364
Senate Public Health and Welfare Committee
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Chairman Suellentrop and members of the Committee, my name is Heather Smith and I am the System of Supports Section Director for the Kansas Department of Health and Environment (KDHE), which includes the Kansas Newborn Screening and Birth Defect Programs. Thank you for the opportunity to appear before you today to discuss the SB 364. SB 364 amends the existing program statutes (K.S.A. 65-180 through 65-183), naming the Kansas newborn screening act, updating outdated terminology, and increasing funding capitations placed under the medical assistance fee fund (per K.S.A. 40-5326) to support the appropriate resources necessary to conduct a quality, effective, and efficient newborn screening program.

The implementation of an advanced universal newborn screening program provides newborns in Kansas with genetic or metabolic conditions, hearing loss, and critical heart defects the best chance at healthy development and positive outcomes. Currently, the Kansas Newborn Screening Program screens for a total of 32 conditions; however, the current U.S. Department of Health and Human Services Recommended Uniform Screening Panel (RUSP) includes 35 conditions.

The remaining three conditions that Kansas is not currently screening for include Mucopolysaccharidosis type I (MPS-I), Pompe Disease, and X-linked adrenoleukodystrophy (X-ALD). These three conditions were recommended by the Kansas Newborn Screening Advisory Committee in May 2018 for addition to the Kansas screening panel. Implementing screening for these conditions would put Kansas as only the sixth state in the nation to screen for all conditions on the core panel.

As the State Agency with the statutory obligation to provide this essential public health program, KDHE's goal is to provide a quality program "to protect the health and welfare of newborns for treatable disorders." The most recent expansion to the Kansas panel included screening for Spinal Muscular Atrophy (SMA), effective February 1, 2020. Other recent additions to the Kansas panel include severe combined immunodeficiency disease (SCID) in November 2017 and critical congenital heart defects (CCHD) in February 2018. Two of these three conditions (SCID and SMA) were only made possible due to financial assistance and support through non-renewable federal grants.

In 2012, K.S.A. 65-180 was amended establishing the newborn screening fund which is funded through the medical assistance fee fund (K.S.A. 40-3213 and K.S.A. 40-3236). In 2017, the statute was further amended to limit the resources available under this fund to \$2.5M. Program expenditures have nearly exhausted the limitations under this budget the past two years. With the expansion of three conditions over the past three years and the recommendation for an additional three conditions in the coming years, the program will be underfunded and unable to meet growing needs.

The number of conditions Kansas screens for has increased from 29 to 32 over the past few years. While the birth

rate has declined in recent years, many of the costs associated with the screening program are fixed costs and would not necessarily be reduced if we are simply screening fewer infants, such as staffing and instrumentation costs. In addition, the Newborn Screening Program experienced staff turnover in the years preceding the funding capitation, which was based on prior year expenditures and not reflective of the funding needs when the program is fully staffed.

Standard cost inflation principles consider that nearly any program expenditure (e.g. testing supplies, rental of equipment, staff salary, costs associated with maintenance and hosting of data systems, and other basic program operation costs) will also increase with time. Lastly, a recent programmatic assessment completed in 2019 indicates the Kansas screening program could improve services to families through formal partnerships and consultation with medical specialists or genetic providers, data system enhancements, and a courier service to assure more timely transport and receipt of specimens to the state laboratory, such as transport of specimens over the weekend. None of these activities will be feasible or sustainable at the current funding level.

It is important to recognize that under K.S.A. 65-180, subsection (e), the agency is required to provide support to families of phenylketonuria (PKU) and maple syrup urine disease (MSUD) to support necessary treatment products and medically necessary food treatment products, such as medical protein food source (often referred to as "formula") to treat these conditions. It should be noted that the Newborn Screening Program and financial assistance for these products are not funded together. Any capitation increase through the medical assistance fee fund should not result in a decrease to the PKU formula state general fund line item, as it would be detrimental to many children and families across the state who need this specific formula to support brain development and prevent, delay, or reduce medical complications.

As stated previously, SB 364 requests that the funding capitation be raised to allow for programmatic growth, future expansion, and the flexibility to meet the needs of the families served through the screening program. Thank you for this opportunity to appear before you. I will now stand for questions.