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Heather Braum, Senior Policy Advisor
Kansas Action for Children
Verbal Proponent Testimony on HB 2399
House Committee on Health and Human Services

Chairman Carpenter and members of the Committee:

Thank you for the opportunity to provide proponent testimony in support of HB 2399, which **would permanently increase the budget cap for the Newborn Screening Program**, among other technical changes. This bill would continue providing necessary resources for a mandated public health program and allow for future growth as new conditions are identified.

Considered “the most time-sensitive function of state government” by a 2021 NCSL podcast,¹ the Newborn Screening Program currently screens every Kansas newborn for a multitude of genetic or metabolic conditions, hearing loss, and critical heart defects.² These conditions are undetectable at birth without screening. **Early diagnosis and treatment give these newborns the best chance at healthy development and outcomes.** If left undetected and untreated, many of these conditions can lead to lifelong medical treatments and high costs, as well as serious complications like brain damage and death. As new conditions are identified, the list of recommended screenings that states add to their programs continue to grow.³

For several years, the Newborn Screening Program has run up against and exceeded a \$2.5 million statutory budget cap due to additional available tests the program has needed to add, as well as added laboratory-related costs and an increased need for family outreach and support. Since 2020, the cap has been temporarily raised to \$5 million each year through annual budget provisos. HB 2399 removes the need, for now, for additional budget provisos.

However, while HB 2399 does permanently codify the annual budget proviso language of increasing the budget cap to \$5 million, **we strongly urge this Committee to consider removing the program’s budget cap in statute entirely**, allowing the program to allocate additional

¹ National Conference of State Legislatures. (December 5, 2021). “The Critical Role of Newborn Screening, Episode 147.” *Our American States* podcast. https://ncsl-podcasts.simplecast.com/episodes/the-critical-role-of-newborn-screening-oas-episode-147-PKw_oXSx

² KDHE. (n.d.) *Blood Spot Screening*. <https://www.kdhe.ks.gov/2052/Blood-Spot-Screening>

³ HRSA. (2024). *Recommended Universal Screening Panel*. <https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp>

funds, as needed, from the medical assistance fee fund, without needing to periodically update this cap as medical research continues to identify new conditions and resulting screening tests are developed, outreach and support opportunities for families are pursued, and laboratory costs increase.

Making this change doesn't mean that the program's budget will run into the tens of millions of dollars. Instead, it gives this critically important program for all Kansas newborns the flexibility to respond into the future – including increased family outreach and support – without needing to return to the Legislature to request additional cap increases.

Kansas must continue to support the Newborn Screening Program as it continues to provide families medical answers when it's most critical, whether that's through negative test results, additional follow-up testing when anomalies are found, or assisting a family with a positive result as they begin navigating the health care system for complex, potentially lifelong care and treatments for their newborn.

We urge the Committee to pass out HB 2399, **supporting continued investment in a small but critically important program that serves all Kansas newborns each year**. If I can be of further assistance, please contact me at heather@kac.org.

About Kansas Action for Children

Kansas Action for Children is a nonprofit advocacy organization working to make Kansas a place where every child has the opportunity to grow up healthy and thrive. We work across the political spectrum to improve the lives of Kansas children through bipartisan advocacy, partnership, and information-sharing on key issues, including early learning and education, health, and economic security for families.