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Kansas Action for Children
Written testimony in support of HB 2250
House Committee on Social Services Budget

Chairperson Carpenter and Members of the Committee:

Kansas Action for Children (KAC) is a nonprofit, nonpartisan organization. Our vision is to make Kansas the best state to raise -- and be -- a child, and our organization shapes health, education, and economic policies that improve the lives of Kansas children and families.

Today, we share our support of HB 2250, which increases the Newborn Screening Program's capitation limit from \$2.5 million to \$5 million, as well as updating outdated terminology in statute. This would make permanent a proviso included in the FY21 budget¹, providing necessary resources to continue a mandated public health program and allow for future growth as new conditions are identified.

The Newborn Screening Program (NSP)² currently screens more than 38,000 Kansas newborns each year for 34 different genetic or metabolic conditions, hearing loss, and critical heart defects. These conditions are undetectable at birth without screening. Early diagnosis and treatment gives these newborns the best chance at healthy development. Undetected and untreated, many of these conditions can lead to lifelong medical treatments and high costs, as well as serious complications, including brain damage and death.

As new conditions are identified, the list of recommended screenings continues to grow. The US Department of Health and Human Services Recommended Uniform Screening Panel³ (RUSP) currently recommends screening for 35 conditions; at least three more will

¹ See p. 208 of enrolled SB 66 (2020),

http://kslegislature.org/li_2020/b2019_20/asures/documents/sb66_enrolled.pdf

² https://www.kdheks.gov/newborn_screening/

³ <https://www.hrsa.gov/advisory-committees/heritable-disorders/rusp/index.html>

be added in the future.

Over the last four years, Kansas has added five conditions to the NSP, but with the capitation in place, resources have been almost exhausted. Soon, the program will be underfunded and unable to meet growing needs. The increased cap will allow additional funds to be allocated, as needed, from the medical assistance fee fund. The NSP is mandated by law to not assess fees to providers or families, keeping the program universal for all Kansas newborns and their families.

Increasing the NSP's capitation amount allows the program to add necessary resources to screen for additional recommended conditions, while maintaining an effective and efficient program. Making this change doesn't necessarily mean that the NSP's budget will be increased to \$5 million. Instead, it gives the program flexibility to respond in the future.

Thank you for the opportunity to share our support of HB 2250, and please do not hesitate to contact me at heather@kac.org if you have any questions.