



TESTIMONY IN SUPPORT OF SB 155

March 3, 2022

Chair Hilderbrand and Members of the Senate Committee on Public Health and Welfare:

The Kansas Chapter, American Academy of Pediatrics (KAAP) represents over 90% of the practicing pediatricians in the state. The KAAP has the fundamental goal that all children and adolescents in Kansas have the opportunity to grow safe and strong. It is with this goal in mind that we want to share our support of SB 155 which provides resources necessary to sustain the mandated public health program focused on preventing disability or morbidity that can result from treatable conditions if not identified at birth.

Most babies are healthy when they are born. However, even a few healthy appearing babies may have a rare, serious health problem. In addition to newborn hearing and critical heart defect screening, the newborn screening process includes a blood test to identify specific illnesses and conditions that may be genetic, metabolic, or endocrine (hormone) in nature. The goal is that these “hidden” disorders can be detected before the baby develops symptoms. With early identification, we can start treatment promptly, refer babies to the appropriate subspecialists, and prevent or reduce serious complications including irreversible brain damage and death.

The role of the state of Kansas is to design, coordinate, and manage an effective newborn screening program (NBS). Through collaboration between public health, hospitals, physicians, and parents, newborn screening has been available to all newborns in Kansas since 1965. While NBS programs vary by state, there are national recommendations to guide and support states in the development of their programs. The Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) works to set these national guidelines along with the U.S. Secretary of Health and Human Services. Together they have established the [Recommended Uniform Screening Panel \(RUSP\)](#), which is a list of conditions that all newborn screening programs should include, currently 36 core conditions that every baby should be screened for. However, Kansas currently screens for 34 of these core conditions. Even since this was discussed last session, a 36th condition for Mucopolysaccharidosis-II was added this year.

With recent advances in medicine, genetics, and technology, we are able to provide better care for our most vulnerable Kansans by expanding newborn screening. Increasing the funding cap is essential to support the resources necessary to conduct a quality, effective, efficient, and progressive newborn screening program to keep up with the standard of care in newborn screening. It is true that an ounce of prevention is worth a pound of cure, and in this case, maybe even more. As pediatricians who care for infants and children with the illnesses detected by newborn screening, we ask you to vote in favor of SB 155, including funding and increase capitation, to allow Kansas to adapt to new screening recommendations and facilitate quality



programmatically growth in a timely manner Investing in the health of Kansas children has an excellent return on investment.

Thank you for the opportunity to share how expanding the newborn screening program can benefit Kansas children and families. Please let us know if we can provide further information, education, or resources.

Respectfully submitted,

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Legislative Coordinator
Kansas Chapter, American Academy of Pediatrics

References:

1. <https://www.babysfirsttest.org/newborn-screening/states/kansas>

Baby's First Test is the nation's resource center for newborn screening information. This provides current educational and family resources about newborn screening at the local, state, and national levels.

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

Health Resources and Services Administration Federal Advisory Committees. Advisory Committee on Heritable Disorders in Newborns and Children. Updated February 2020.

3. <https://pediatrics.aappublications.org/content/121/1/192>

Newborn Screening Expands: Recommendations for Pediatricians and Medical Homes—Implications for the System. Newborn Screening Authoring Committee. *Pediatrics* Jan 2008, 121 (1) 192-217; **DOI:** 10.1542/peds.2007-3021. Reaffirmed 2017.