KANSAS CHAPTER
AMERICAN ACADEMY OF PEDIATRICS

TESTIMONY IN FAVOR OF SB 364

February 24, 2020

Chairman Gene Suellentrop and Members of the Senate Public Health and Welfare Committee,

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 364 which amends the existing newborn screening statutes, increases funding, and supports an advanced universal newborn screening program in Kansas.

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 35 core conditions that every baby should be screened for. However, Kansas currently only screens for 32 of these core conditions.

With recent advances in medicine, genetics, and technology, we are able to provide better care for our most vulnerable Kansans by expanding newborn screening. Increased funding, updated terminology, and additional testing is needed 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 364. Investing in the health of Kansas children has an excellent return on investment.

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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.

Recommended Uniform Screening Panel
Core Conditions
(As of July 2018)

Core Condition	Metabolic Disorder			Endocrine Disorder	Hemoglobin Disorder	Other Disorder
	Organic acid condition	Fatty acid oxidation disorder	Amino acid disorder			
Propionic Acidemia	X					
Methylmalonic Acidemia (methylmalonyl-CoA mutase)	X					
Methylmalonic Acidemia (Cobalamin disorders)	X					
Isovaleric Acidemia	X					
3-Methylcrotonyl-CoA Carboxylase Deficiency	X					
3-Hydroxy-3-Methyglutaric Aciduria	X					
Holocarboxylase Synthase Deficiency	X					
ß-Ketothiolase Deficiency	X					
Glutaric Acidemia Type I	X					
Carnitine Uptake Defect/Carnitine Transport Defect		X				
Medium-chain Acyl-CoA Dehydrogenase Deficiency		X				
Very Long-chain Acyl-CoA Dehydrogenase Deficiency		X				
Long-chain L-3 Hydroxyacyl-CoA Dehydrogenase Deficiency		X				
Trifunctional Protein Deficiency		X				
Argininosuccinic Aciduria			X			
Citrullinemia, Type I			X			
Maple Syrup Urine Disease			X			
Homocystinuria			X			
Classic Phenylketonuria			X			
Tyrosinemia, Type I			X			
Primary Congenital Hypothyroidism				X		
Congenital adrenal hyperplasia				X		
S,S Disease (Sickle Cell Anemia)					X	
S, βeta-Thalassemia					X	
S,C Disease					X	
Biotinidase Deficiency						X
Critical Congenital Heart Disease						X
Cystic Fibrosis						X
Classic Galactosemia						X
Glycogen Storage Disease Type II (Pompe)						X
Hearing Loss						X
Severe Combined Immunodeficiencies						X
Mucopolysaccharidosis Type 1						X
X-linked Adrenoleukodystrophy						X
Spinal Muscular Atrophy due to homozygous deletion of exon 7 in SMN1						X

Recommended Uniform Screening Panel[1]
SECONDARY[2] CONDITIONS [3]
(As of July 2018)

Secondary Condition	Metabolic Disorder			Hemoglobin Disorder	Other Disorder
	Organic acid condition	Fatty acid oxidation disorders	Amino acid disorders		
Methylmalonic acidemia with homocystinuria	X				
Malonic acidemia	X				
Isobutyrylglycinuria	X				
2-Methylbutyrylglycinuria	X				
3-Methylglutaconic aciduria	X				
2-Methyl-3-hydroxybutyric aciduria	X				
Short-chain acyl-CoA dehydrogenase deficiency		X			
Medium/short-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency		X			
Glutaric acidemia type II		X			
Medium-chain ketoacyl-CoA thiolase deficiency		X			
2,4 Dienoyl-CoA reductase deficiency		X			
Carnitine palmitoyltransferase type I deficiency		X			
Carnitine palmitoyltransferase type II deficiency		X			
Carnitine acylcarnitine translocase deficiency		X			
Argininemia			X		
Citrullinemia, type II			X		
Hypermethioninemia			X		
Benign hyperphenylalaninemia			X		
Biopterin defect in cofactor biosynthesis			X		
Biopterin defect in cofactor regeneration			X		
Tyrosinemia, type II			X		
Tyrosinemia, type III			X		
Various other hemoglobinopathies				X	
Galactoepimerase deficiency					X
Galactokinase deficiency					X
T-cell related lymphocyte deficiencies					X

1. Selection of conditions based upon “Newborn Screening: Towards a Uniform Screening Panel and System.” *Genetic Med*. 2006; 8(5) Suppl: S12-S252” as authored by the American College of Medical Genetics (ACMG) and commissioned by the Health Resources and Services Administration (HRSA).
2. Disorders that can be detected in the differential diagnosis of a core disorder.
   Nomenclature for Conditions based upon “Naming and Counting Disorders (Conditions) Included in Newborn Screening Panels.” *Pediatrics*. 2006; 117 (5) Suppl: S308-S314.