



NEWBORN SCREENING IN KANSAS

BACKGROUND

- Screening of newborn infants for metabolic disorders dates back to the 1960s, when the heel stick test for phenylketonuria (PKU) was developed.
- Every state and U.S. territory now screens newborns for certain disorders of metabolism.
- These conditions may not be visible at birth but, unless detected and treated early, can cause physical problems, mental retardation, and even death.
- Many of these problems can be avoided through careful monitoring and special diets, nutritional supplements, and other therapies.
- If not detected early, the lifetime costs for medications, hospitalizations, and special education can exceed **\$1 million** for just one affected child.¹
- Recent advances in technology now enable screening for many different conditions using the same sample of blood.

MARCH OF DIMES POLICY

The mission of the March of Dimes is to improve the health of babies by preventing birth defects and infant mortality. We accomplish this through programs of research, education, community services, and advocacy. The March of Dimes urges screening all newborns for specific conditions when three criteria are met: 1) there is a documented benefit to the child; 2) there is a reliable test; and 3) where early detection is possible from the newborn blood spot (or other specific means, as in newborn hearing screening). Currently, 29 conditions meet these three criteria, as identified by the American College of Medical Genetics.

CURRENT NEWBORN SCREENING PRACTICES IN KANSAS

- Kansas currently screens every newborn for 7 of these conditions.²
- Only Arkansas and West Virginia offer as few screens as Kansas.³
- KSA 65-180 prohibits the establishment of a newborn screening fee.

RECOMMENDATION

The March of Dimes supports expansion of the state's capacity to screen for and provide follow-up services for additional metabolic conditions recommended by the American College of Medical Genetics. In addition, we support increased education for parents and health professionals regarding comprehensive newborn screening.

For more information on March of Dimes legislative priorities and issues, contact:

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¹ Source: Centers for Disease Control and Injury Prevention

² Hemoglobinopathies are counted as three separate screens

³ Source: National Newborn Screening and Genetics Resource Center, August 1, 2006