



TESTIMONY

To: Senate Ways and Means Committee
Senator Carolyn McGinn, Chair

From: Diane Daldrup, State Director Program Services & Public Affairs
March of Dimes Greater Kansas Chapter

Date: February 29, 2012

Re: SB 436 – Creating the Kansas Newborn Screening Fund

Kansas Newborn Screening Overview

Newborn screening (NBS) is a public health program that provides early identification and follow-up for treatment of infants affected by certain genetic, metabolic, hormonal and/or functional conditions. These conditions have no immediate visible effects on an infant, but unless they are detected and treated early, they can cause intellectual and physical disabilities, and even death.

Newborn screening saves lives. By identifying treatable conditions at birth, affected children can begin treatment immediately, consequently avoiding developmental delays and disabilities, mental retardation, or even death. Currently, the Kansas NBS program includes screening for 29 of the 31 core conditions recommended by the U.S. Secretary of Health and Human Services. The program includes laboratory testing, repeat screens, short-term follow-up, treatment formula, consultation services including diagnostic tests, and database maintenance.

In Kansas, \$2.2 million is spent each year for the NBS program. This amount covers program costs for over 42,000 newborns plus an additional 2,100 (approximately 5%) necessary repeat screens. The Kansas NBS program is currently funded through the Children's Initiatives Fund (approximately \$2.1 million) with supplemental funding from the Title V Block Grant, Medicaid, and general funds.

NBS Financial Sustainability

The Kansas NBS program needs a dedicated revenue source in order to ensure the sustainability of the program and to ensure that newborns and their families do not lose access to this important service. SB 436 would establish such a dedicated revenue stream, utilizing an existing funding source, that has the potential to sustain the newborn screening program for multiple years and will effectively provide this essential service without charge to Kansas families.

The mission of the March of Dimes is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. The March of Dimes supports the passage of SB 436 to establish a dedicated revenue source to support newborn screening. It is a positive approach to addressing the long-term funding needs of this important program and a positive step towards continuing to improve the lives of Kansas children.

Governor Brownback and Secretary Moser should be commended for developing this proactive solution that addresses a critical need in our state. I strongly urge the committee to approve the passage of SB 436 to help ensure the state's financial backing of this important program. The March of Dimes appreciates working with the legislature, Governor Brownback, KDHE, and other interested parties to develop a long-term funding plan for this important public health program.