



**Testimony on Senate Bill 436
House Appropriations Committee**

Secretary Robert Moser, M.D.
Kansas Department of Health and Environment

March 21, 2012

Mr. Chairman and members of the Committee, thank you for the opportunity to speak to you today about newborn screening. This program began in 1965 when testing for phenylketonuria (PKU) began. Since then the program has been expanded and currently screens for 29 metabolic and health disorders. The goal of newborn screening is to identify and treat infants affected by serious disorders to prevent disability and deaths. In FY 2011, 40,697 infants received an initial screening and 2,798 infants had an abnormal screen which required further testing.

This program has two components. First, the Kansas Health and Environment Laboratory receives infant bloodspots, screens them for metabolic conditions and reports lab screenings. Second, the KDHE Bureau of Family Health follows up with families and physicians to report the screening results and assist with genetic and consultant visits. The abnormal results are tracked to diagnosis. In addition, the program provides education and training to outside partners such as nurses and laboratory personnel at collection facilities.

Newborn screening is currently funded by the Children's Initiative Fund. However, CIF is expected to shrink in coming years, thus developing an alternate funding source is necessary. After meeting with stakeholders, we believe SB 436 will provide the best solution to ensure stable funding for this important program. This bill will create a dedicated newborn screening fund that receives revenues from the health maintenance organization privilege fee. The fund will be subject to legislative appropriation and will ensure newborn screening's sustainability in the future.

The Kansas Department of Health and Environment strongly supports SB 436 and asks that you favorably adopt this measure. I will be happy to stand for questions.