

KDHE NEWBORN SCREENING (NBS) PROGRAM

Kansas Law and Program

In 1965, KSA 65-180 through 183 was enacted to: mandate screening for phenylketonuria (PKU) with later amendments adding congenital hypothyroidism and galactosemia, at no charge for the testing; provide an education program; maintain a registry of individuals with confirmed diagnosis; and provide necessary treatment product. In 1990, hemoglobinopathy screening was added on a request basis only, but only three years later screening was mandated for all newborns. Although families may refuse testing based on religion, nearly all Kansas families participate in the program.

The KDHE Public Health Laboratory provides the screening kits (both initial and repeat) to hospitals and physicians. The administrative officer or other person in charge of each hospital/institution or the attending physician is responsible for obtaining the test specimen for each newborn. (The baby's heel is pricked and a small sample of blood is collected.) The specimens are mailed to the State Lab. After completing the tests, the Laboratory reports are mailed back to the hospitals and physicians.

Out of range test results are forwarded to KDHE's Bureau for Children, Youth & Families for nursing follow-up to ensure that the family/child receives consultation and diagnostic tests. The nurse contacts the physician by letter or phone depending on the urgency of the test results. Technical assistance and education is available for the primary care provider. A second letter may be sent by the nurse to the physician to check on the outcome of diagnostics and services.

For those with a confirmed diagnosis, KDHE's Children with Special Health Care Needs program may initiate nursing care coordination to connect the family with specialists in Wichita and Kansas City. Metabolic foods and formula are provided for infants and children with confirmed diagnoses for PKU and congenital hypothyroidism. WIC nutritionists may assist with technical assistance and consultations as necessary. Medical specialists provide one-on-one education to families and educational pamphlets have been developed for distribution to new parents, hospitals, other organizations and the public.

Regularly scheduled training/education activities are needed to meet the needs of the community-based personnel (service providers and families) involved in the NBS program.

Currently, the laboratory component of this program is primarily funded by state general funds. The nursing follow-up is covered by Maternal and Child Health Block Grant funds. Treatment costs may be covered by Medicaid, state funds, family, insurance or some combination of these.

Tandem Mass Spectrometry

While Kansas screens for the four most prevalent newborn disorders, there is new technology called tandem mass spectrometry (aka MS/MS) which can screen for over 30 rare genetic disorders using the same blood spot currently collected in Kansas. Since 1999 the American Academy of Pediatrics has recommended that all parents should receive information about the availability of expanded screening so that if they choose to do so they can receive this at their own expense. Under federal directives, KDHE programs started providing family educational materials about availability of newborn screening. Advice to parents about the availability of expanded newborn screening through MS/MS was placed on the KDHE website.

Most states have adopted MS/MS technology. About four including Kansas have not. States have formed advisory committees to provide oversight of expanded screening. There is a comprehensive review of States' responses in the March 2003 GAO audit report entitled, *Newborn Screening: Characteristics of State Programs*. Current screening conditions by state are at: <http://genes-r-us.uthscsa.edu/nbsdisorders.pdf>

In 2004, the American College of Medical Genetics convened a group to develop recommendations relating to State testing. They developed selection criteria (e.g., limit screening tests to those with high probability of survival of the infant and those with treatment availability). The executive summary of their findings and recommendations may be found at <http://mchb.hrsa.gov/screening/summary.htm>.

In March of 2005, KDHE requested technical assistance from the National Newborn Screening and Genetics Resource Center relating to expanded screening. In August of 2005, a team of six national experts in expanded screening visited the State and conducted a review. Their 2006 report is available through KDHE.