CCHD  Critical Congenital Heart Defects

A quality initiative to increase awareness and screening of CCHD for all babies born in Kansas.

Did you know?
- Congenital Heart Defects (CHD) are the most common type of birth defect (1% of all births)
- Nearly 7,200 babies are born each year with critical congenital heart defects (CCHDs)
- Babies can appear HEALTHY without any signs something is wrong
- An estimated 300 babies with an unrecognized CCHD are discharged each year from newborn nurseries in the US
- A simple bedside screening can be done using pulse oximetry
- Once identified, babies with CCHD can be seen by cardiologist and can receive treatment that can prevent death or disability

Kansas Public Health Quality Initiative Project

The Kansas Department of Health and Environment (KDHE) has launched a quality initiative and program to increase awareness of Critical Congenital Heart Defects (CCHD) and ensure that all babies in Kansas are being screened for CCHD after birth. The project will also strive towards assurance of prompt care, connection to resources, long-term follow-up, and improvement of overall health outcomes for infants with CCHD.

The CCHD workgroup was convened in November 2013 and is open to individuals or organizations interested in advancing CCHD screening as a quality initiative. Work group members include families of children with a CCHD, The Kansas Hospital Association (KHA), the American Heart Association, the March of Dimes, physicians representing private and hospital-based practices (including KU Medical Center, Wesley, Children’s Mercy, and more), and KDHE Newborn Screening (NBS) Program staff.

Recent data from a February 2014 survey of birthing facilities and midwives, reflects approximately 65% of Kansas infants are currently being screened for CCHD at birth, prior to discharge. This accounts for only about 70% of birthing facilities. Of those who reported screening, 38%

began screening in 2013. Only about 10% of the facilities and midwives who responded to the survey were not currently screening for CCHD.

Through targeted technical assistance and support, the KDHE NBS program will provide education and training to birthing facilities that are not currently screening for CCHD. This will support the goal of 100% of Kansas babies being screened for CCHD.

To date, four sites have been selected and are being approached for the first phase of the pilot project. Additionally, a training program is being developed and KDHE and our partners are excited to have the opportunity to work with the community to implement a screening program that has the potential to save lives and improve outcomes for newborns.

*Survey results are current as of March 18, 2014. Efforts to obtain additional responses is ongoing. Data will be updated periodically throughout the CCHD QI project.

Find out more at www.kdheks.gov/Newborn_Screening

Kansas Newborn Screening Program
1000 SW Jackson Street, Topeka, KS 66612 ~ (785) 296-0109