



CCHD Screening

Utah Critical Congenital Heart Defect (CCHD) Screening Project

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Governor Signs Bill Mandating Newborn Screening for Critical Congenital Heart Defects

During the 2013 Utah Legislative General Session, House Bill 276 – Newborn Screening for Critical Congenital Heart Defects - was introduced (Rep. Paul Ray, Chief Sponsor, and Sen. Ralph Okerlund, Senate Sponsor). This bill will add pulse oximetry screening to the Utah Health Code Statute's 226-10-6 Newborn Screening Act (e.g., hearing and blood spot screening).



On February 12, 2013, the Senate Health and Human Services Committee voted and approved this amendment to the Newborn Screening Act. The bill was signed by Utah Governor Gary R. Herbert on March 26, 2013. Statewide screening will be mandated beginning October 1, 2014.

Prior to statewide implementation, the bill states that the Utah Department of Health "shall conduct a pilot program for testing newborns for critical congenital heart defects using pulse oximetry. The pilot program shall include the development of: a) appropriate oxygen saturation levels that would indicate a need for further medical follow-up; and b) the best methods for implementing the pulse oximetry screening in newborn care units."

Pulse Oximetry Screening at High Altitudes



Implementing statewide CCHD screening raises several complex issues. These include training, standardized screening protocols, evaluation of benefits, reporting, and assurance. In Utah, an additional challenge needs to be confronted, namely, evaluating screening cutoffs for babies born at altitude (most of Utah's births are born at or above 4,000 feet of altitude). A specific unknown in Utah is whether the current oxygen saturation cutoff points for sea level in the nationally recommended protocol are appropriate at the altitudes at which babies are born in our state.

Elevated altitude decreases the average values of pulse oximetry, such that cutoff points that are effective at low altitude may cause unaffected babies at higher altitude to fail the screening. Implementing such a protocol without first evaluating it could result in implementing an inaccurate screening tool for CCHD in Utah. Other factors that need to be addressed prior to statewide implementation in Utah include training, guidelines for follow-up testing and confirmatory diagnosis (including echocardiography), and reporting mechanisms from hospitals to the public health system for evaluation and assurance.

Survey Results of Birthing Facilities in Utah

In November 2012, the Utah Department of Health disseminated a survey to all well baby nurseries and stand-alone birthing facilities in Utah. The purpose of the survey was to better understand which facilities currently provide some form of screening for CCHDs (and if so, how), and for all facilities, their current status regarding the availability of pulse oximeters, capacity for



♥ Congenital heart defects (CHDs) account for approximately 25% of all birth defects monitored in Utah and nearly 30% of infant deaths due to birth defects.

♥ Babies with a critical congenital heart defect (CCHD) are at significant risk for death or disability if their condition is not diagnosed soon after birth.

♥ Newborn screening using pulse oximetry can identify some infants with a CCHD before they show signs of the condition.

♥ Once identified, babies with a CCHD can be seen by cardiologists and can receive special care and treatment that can prevent death or disability early in life.

♥ Some hospitals routinely screen all newborns for CCHDs. Mandatory CCHD screening in Utah will begin in October, 2014.

Source: CDC-Screening for Critical Congenital Heart Defect factsheet.

Scan the code below to watch the Public Service Announcement (PSA) about CCHD screening on YouTube with your tablet or Smartphone or click on the following link: bit.ly/10Qg861



cardiac evaluation/consultation for newborns, transfer patterns for children with suspected CCHDs, telemedicine capacity, and management of screening data. The survey was open for three months to allow for adequate response time.

Ninety-four percent of the birthing facilities responded to the survey, including all birthing hospitals and all but three stand-alone birthing facilities. Preliminary results from the survey show that over 90% of the birthing facilities in Utah have access to pulse oximeters. Thirty-three percent of the birthing facilities (n=16) indicated that they currently perform some type of pulse oximetry screening for all newborns with another 29% (n=14) indicating that they have plans to implement screening.

Of the 16 birthing facilities that answered that they currently perform some type of screening, only six reported that they follow a protocol. Currently, none of the facilities that perform screening report any of their data to the Utah Department of Health. Regarding the availability of pediatric cardiologists, 35 facilities reported that pediatric cardiologists are available by phone only, with five available via telemedicine, another five available to come into the facility if needed, and only one available on-site. Seventeen facilities reported the ability to perform newborn echocardiograms. For those facilities requiring a transfer to another facility to obtain an echocardiogram, the distance to the next closest hospital varied from 1 mile to 162 miles away.

These survey results, integrated with further information, will help in making future decisions regarding the implementation of statewide pulse oximetry screening. Thank you to those who completed the survey and provided this valuable information!

CCHD Screening Pilot to begin in May 2013

The University of Utah and Intermountain Medical Center (IMC) well baby nurseries will participate in development and implementation of the CCHD screening pilots. Intermountain Healthcare is the largest healthcare provider in Utah and its facilities deliver over half of all babies in Utah; IMC is its largest nursery. Both institutions have agreed to participate and have representatives in the core workgroup team. These individuals have been instrumental in the success of the project. They have been involved with communicating with their IT departments to integrate the data elements into the EMR system that are required for this project. They are also involved in organizing training sessions for providers and staff as well as reviewing and editing parent educational materials. Site trainings occurred during the month of March at both sites. There will be two pilot periods of screening; the first period anticipated to begin in May, 2013 will last six months, with a brief three-month evaluation period to assess the protocol, training, and education materials. The second 6-month screening period will begin around February, 2014 with evaluation and final analysis to follow.

2013 Birth Defects Awareness Campaign

Birth defects are common, costly, and critical. January was National Birth Defects Prevention Month, however, the entire year will be devoted to raising awareness about birth defects in the U.S. and around the world. The National Birth Defects Prevention Network (NBDPN) and its Parent Advisory Group have developed a public service announcement (PSA) and educational materials which are available in both English and Spanish. Educating the general public, health care providers, policy makers, and public officials about birth defects is an important first step in increasing awareness of the prevalence of birth defects in the U.S.: 1 in 33 babies is born with a birth defect and 25% of these babies have a congenital heart defect. The causes of most birth defects are unknown and more research is needed. The PSAs and educational materials are available, free of charge, on the NBDPN website (www.nbdpn.org). Please help us educate others about birth defects and the need for preconception care to reduce a woman's risk of having a baby with a birth defect.

[Utah Birth Defect Network](http://www.utahbirthdefectnetwork.org)



Birth defects affect us all.
What effect will YOU have on birth defects?