Utah Birth Defect Network (UBDN)

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# CCHD Screening

## Utah Critical Congenital Heart Defect (CCHD) Screening Project

**ADDITIONAL READING**

Read the October 26, 2012 issue of MMWR on CCHD Screening

BD surveillance and CCHD screening

Data on CCHD frequency

IBIS indicators - CHDs

Utah Birth Defect Network

**OUR PARTNERS**

University of Utah

Intermountain Healthcare

March of Dimes

Intermountain Healing Hearts

*For the present and the foreseeable future, babies will continue to be born with CCHD and their best hope for optimal outcomes remains prompt diagnosis and appropriate treatment.*

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Utah Birth Defect Network

## Recommendation for CCHD Screening

In September 2011, the Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children recommended adding critical congenital heart defects (CCHD) to the uniform screening panel for newborns. However, as recognized by the Secretary of HHS in her response letter, adding such screening raises many complex issues, which States need to address convincingly prior to implementation. Utah is one of six sites selected by HRSA to look at the feasibility, benefits, and costs associated with implementing pulse oximetry screening to detect CCHDs.

## Critical Congenital Heart Defects

CCHDs are a subset of congenital heart defects. Congenital heart defects are structural malformations of the heart. The malformations may affect the heart itself (its valves, chambers, or internal walls), or the large arteries and veins that carry blood into the heart or from the heart out to the body. The net result is that normal flow patterns of the blood are changed, and the body does not receive sufficient oxygen through the blood.

In the case of CCHDs, a baby can become *critically* ill soon after birth, and may die or suffer severe damage if not treated quickly and appropriately. Appropriate treatment includes heart surgery and specialized care by physicians trained in pediatric cardiology.

## Pulse Oximetry

Pulse oximetry is a noninvasive test in which a probe is attached to certain areas of the baby's skin to assess the amount of oxygen in the blood (oxygen saturation).

Babies with CCHDs tend to have lower oxygen saturation compared to their unaffected peers, *even if* they may not have obvious external clinical signs such as cyanosis ("blue babies") or heart failure. Compared to echocardiography, pulse oximetry requires relatively inexpensive equipment, can be performed by nursing staff, and provides quantitative results (percent oxygen saturation of blood). For these reasons, pulse oximetry is considered an attractive screening option for critical congenital heart defects.

## Improving Health Outcomes

Ideally, primary prevention would improve outcomes by ensuring that babies are born with healthy hearts. However, the causes of most CCHDs are currently unknown. For the present and the foreseeable future, babies will continue to be born with CCHD and their best hope for optimal outcomes remains prompt diagnosis and appropriate treatment.

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♥ Congenital heart defects (CHDs) account for 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. However, CCHD screening is not currently included on our state newborn screening panel.

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

Watch the PSA about birth defects prevention on YouTube with your tablet or Smartphone

# Utah CCHD Screening Project

The Utah Department of Health, working in collaboration with the University of Utah and Intermountain Medical Center (IMC), plans to conduct 2 six-month pilots to examine what it would take to implement pulse oximetry screening (**time, costs, processes**) and what **benefits** it would have. In addition to these questions that all states face, Utahns need to confront the issue of living at a high **altitude**. Salt Lake City, for example, is at 4,300 feet/1,320 meters above sea level. Altitude can change normal oximetry levels and this issue may require modifying the screening cutoffs.

A project **core team** has been assembled, consisting of experts in the fields of pediatric cardiology, nursing, epidemiology, health economics, and health promotion and education. The team will take on the project tasks throughout the study period and meet monthly. Additionally, an **advisory committee** consisting of partners from the University of Utah, Utah Department of Health, Intermountain Healthcare, the March of Dimes, Utah Hospital Association, Intermountain Healing Hearts (family support association), and community physicians has been established and has begun to meet quarterly.

The project consists of three phases:

Phase I: Planning and development of screening protocol

Phase II: Pulse oximetry screening pilot at University of Utah Hospital and Intermountain Medical Center well-baby nurseries

Phase III: Data analysis and recommendations for statewide implementation of screening

Some tasks now completed or in progress include the following:

- Review of published screening guidelines and protocols, for guidance in developing a standardized screening protocol to be used at pilot sites
- Review and purchase of education and training materials to train those directly involved with performing the screening and to educate parents about the screening
- Survey sent to all birthing facilities in Utah to investigate the availability of pulse oximeters, current screening protocols, capacity for cardiac care for newborns and telemedicine, and ability to transmit screening data

To learn more about newborn CCHD screening efforts in Utah, please contact us by email at UBDN@utah.gov or by phone at 866-818-7096 or 801-584-8239.

# 2013 Birth Defects Awareness Campaign

Birth defects are common, costly, and critical. January is National Birth Defects Prevention Month and 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, 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 to increase 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.

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