

March 7, 2012

Testimony
Public Health Committee

**Support for Raised Bill Number 56
An Act Concerning Pulse Oximetry Screening for Newborn Infants**

Submitted By: Erin E. Jones, Director of Public Affairs

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth, and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of Critical Congenital Heart Disease (CCHD) to Connecticut's newborn screening panel and supports SB 56, which would allow for screening of newborns for CCHD via pulse oximetry.**

Why Screen for Critical Congenital Heart Disease (CCHD):

Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life.

- Babies with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth
- In the United States, about 4,800 babies are born each year with CCHD according to the CDC
- In the United States, an estimated 280 infants are discharged from nurseries with undetected CCHD

How to Screen for Critical Congenital Heart Disease (CCHD):

CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry is a bedside test that determines the percent oxygen saturation in a baby's blood through a sensor that is usually attached to the baby's finger or foot. If low levels of oxygen saturation in the blood are detected, then further testing can be performed to diagnose any abnormalities in the heart structure or blood flow through the heart.

Several states, New Jersey, Indiana, and Maryland, have adopted legislation to include CCHD screening in their Newborn Screening Programs. March of Dimes urges Connecticut to do the same. All types of CCHD have medical and surgical interventions that can improve outcomes. Early detection via newborn screening will allow affected infants to receive such life-saving interventions promptly.

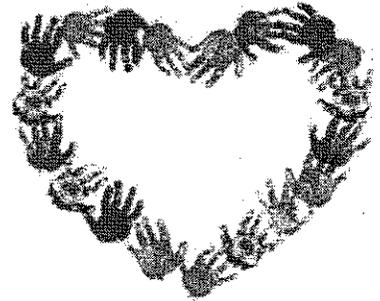
Please feel free to contact me for more information, questions or concerns,
Erin E. Jones, State Director of Public Affairs, 860.815.9352 or ejones2@marchofdimes.com

Pulse Oximetry Screening for Critical Congenital Heart 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.
- Pulse oximetry newborn screening 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.
- Certain hospitals routinely screen all newborns using pulse oximetry screening. However, pulse oximetry screening is not currently included in most state newborn screening panels.

Understanding Critical Congenital Heart Defects

- **Congenital heart defects (CHDs) account for 24% of infant deaths due to birth defects.**
- **In the United States, about 4,800 (or 11.6 per 10,000) babies born every year have one of seven *critical congenital heart defects* (CCHDs, which also are known collectively in some instances as *critical congenital heart disease*).**
- **These seven CCHDs are:**
 - » **Hypoplastic left heart syndrome**
 - » **Pulmonary atresia (with intact septum)**
 - » **Tetralogy of Fallot**
 - » **Total anomalous pulmonary venous return**
 - » **Transposition of the great arteries**
 - » **Tricuspid atresia**
 - » **Truncus arteriosus**

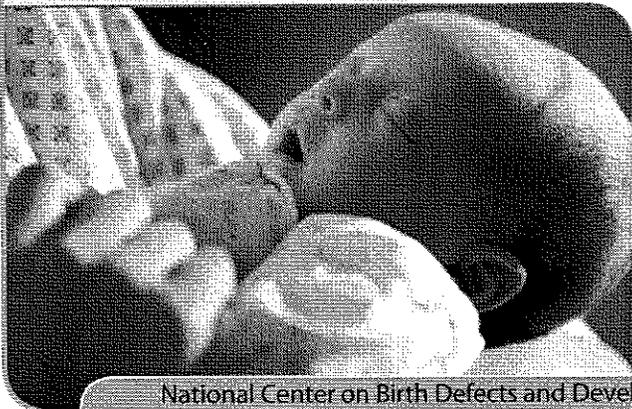


Babies with one of these CCHDs are at significant risk for death or disability if their CCHD is not diagnosed and treated soon after birth. These seven CCHDs among some babies potentially can be detected using *pulse oximetry screening*, which is a test to determine the amount of oxygen in the blood and pulse rate. Other heart defects can be just as severe as these seven CCHDs and also require treatment soon after birth. However, pulse oximetry screening may not detect these heart defects as consistently as the seven disorders listed as CCHDs.

The Importance of Screening for Critical Congenital Heart Defects

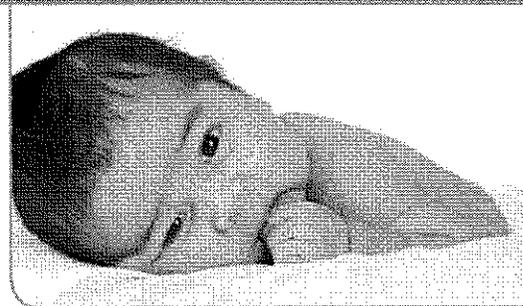
Some babies born with a heart defect can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious complications within the first few days or weeks of life and often require emergency care.

Pulse oximetry newborn screening can identify some infants with a CCHD before they show signs of a CCHD. Once identified, babies with a CCHD can be seen by cardiologists and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.



When and How Babies Are Screened

Pulse oximetry is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a *pulse oximeter*, with sensors placed on the baby's skin. The test is painless and takes only a few minutes. Screening is done when a baby is 24 to 48 hours of age, or as late as possible if the baby is to be discharged from the hospital before he or she is 24 hours of age.



Pulse oximetry screening does not replace a complete history and physical examination, which sometimes can detect a CCHD before the development of low levels of oxygen in the blood. Pulse oximetry screening, therefore, should be used along with the physical examination.

Pulse Oximetry Screening Results

If the results are "negative" (in-range result), it means that the baby's test results did not show signs of a CCHD. This type of screening test does not detect all CCHDs, so it is possible to still have a CCHD or other congenital heart defect with a negative screening result. If the results are "positive" (out-of-range result), it means that the baby's test results showed low levels of oxygen in the blood, which can be a sign of a CCHD. This does not *always* mean that the baby has a CCHD. It just means that more testing is needed.

The baby's doctor might recommend that the infant get screened again or have more specific tests, like an *echocardiogram* (an ultrasound picture of the heart), to diagnose a CCHD. Babies who are found to have a CCHD also might be evaluated by a clinical geneticist. This could help identify genetic syndromes associated with CCHDs and inform families about future risks.



Centers for Disease Control and Prevention Activities

The Centers for Disease Control and Prevention (CDC) is part of the U.S. Department of Health and Human Services (HHS) Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC). SACHDNC was authorized by Congress to provide guidance to the HHS Secretary about which conditions should be included in newborn and childhood screening programs, as well as how systems should be developed to ensure that all newborns and children are screened and, when necessary, receive appropriate follow-up care. In September 2010, SACHDNC recommended that the HHS Secretary add pulse oximetry screening for CCHDs (i.e., the heart defects listed previously) to the Recommended Uniform Screening Panel. Some states currently are developing their own policies on pulse oximetry screening for CCHDs. As this screening is implemented, CDC will play an important role in the surveillance and tracking of babies with a CCHD found through pulse oximetry screening.

For more information on pulse oximetry screening for CCHDs, please visit
<http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html>

National Center on Birth Defects and Developmental Disabilities

For more information please contact the Centers for Disease Control and Prevention

1600 Clifton Road NE, Atlanta, GA 30333

Telephone: 1-800-CDC-INFO (232-4636)/TTY: 1-888-232-63548

Email: cdcinfo@cdc.gov Web: www.cdc.gov

Newborn Screening Fact Sheet

Prepared by the March of Dimes Connecticut Chapter

BACKGROUND

Newborn screening (NBS) is a public health program which provides early identification and follow-up for treatment of infants affected by certain genetic, metabolic, hormonal and/or functional conditions.

The Newborn Screening Program in CT screens all newborns for a wide spectrum of congenital and inherited diseases. Each year the CT Department of Public Health screens more than 40,000 newborns and save the lives of or greatly improves the outcomes for approximately 25 to 40 children "confirmed positive" with a disorder each year. These early medical interventions prevent severe disabilities and death.¹ As required under Connecticut State Law (19a-55), the state currently screens for 50 disorders including 30 of the 31 conditions recommended by the U.S. Secretary of Health and Human Services.

WHY SCREEN FOR CRITICAL CONGENITAL HEART DISEASE (CCHD)

Congenital heart disease (CHD) is a problem with the heart's structure and/or function which is present at birth. Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life. Some infants born with CCHD can appear healthy at first and can be sent home with their families before their heart defect is detected. It has been estimated that at least 280 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States.² CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital or birthing center. Pulse oximetry measures the percent oxygen saturation of hemoglobin in the arterial blood through a sensor that is attached to the baby's finger or foot. If low levels are detected and confirmed on repeat testing, then further testing can be performed to diagnose any abnormalities in heart structure or blood flow through the heart.

MARCH OF DIMES POLICY

The March of Dimes is the leader in advocacy for comprehensive newborn screening for all infants in the United States. Our mission is to improve the health of women of childbearing age, infants, and children by preventing birth defects, premature birth and infant mortality. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. **As such, the March of Dimes supports the addition of CCHD to CT's newborn screening panel.**

For more information contact:

Erin E. Jones, State Director of Program Services
Connecticut Chapter, March of Dimes
500 Winding Brook Drive., Glastonbury, CT 06033
860-815-9352
ejones2@marchofdimes.com

¹ Connecticut Department of Public Health, Newborn Screening Program

² Knapp, AA, Metterville, DR, Kemper, AR, Prosser, L, Perrin, JM. Evidence review: Critical congenital cyanotic heart disease, Final Draft, September 3, 2010. Prepared for the Maternal and Child Health Bureau, Health Resources and Services Administration.