

# Screening for Critical Congenital Heart Defects



- About 1 in every 4 babies born with a heart defect has a critical congenital heart defect (critical CHD, also known as critical congenital heart disease).
- Babies with a critical CHD are at increased risk for death or disability if their condition is not diagnosed soon after birth. More than 75% of U.S. states have statewide requirements for hospitals to screen newborns for critical CHDs. In states that do not have required screening, many hospitals within these states screen babies for critical CHDs.
- Newborn screening for critical CHDs involves a simple, painless, bedside test called pulse oximetry in which sensors are placed on the baby's skin. This test estimates the amount of oxygen in a baby's blood. Low levels of oxygen in the blood can be a sign of a critical CHD.
- Newborn screening using pulse oximetry can identify some infants with a critical CHD before they show signs of the condition. Timely care and treatment can help prevent death or disability early in life.

**Newborn screening for critical CHDs can help identify newborns with these conditions and allow for timely care and treatment. CDC is working with partners to assess the impact and outcomes of newborn screening for critical CHDs.**

## Understanding Critical CHDs

In the United States, about 7,200 (or about 1 out of 550) babies born every year have a critical CHD. Babies with a critical CHD usually need surgery or other procedures in the first year of life. **Some babies born with a critical CHD appear healthy at first and may be sent home with their families before their heart defect is detected.** These babies are at risk for having serious complications within the first few days or weeks of life and often require emergency care.

Typically, these types of heart defects lead to low levels of oxygen in a newborn and may be identified using pulse oximetry screening at least 24 hours after birth. Once identified, babies with a critical CHD can be seen by heart doctors (cardiologists) and can receive specialized care and treatment that could prevent death or disability early in life.

## The Importance of Screening for Critical CHDs

Newborn screening through pulse oximetry can improve detection of critical CHDs in newborn babies who may not show signs of having a critical CHD. Pulse oximetry screening does not replace a complete history and physical examination, which sometimes can detect a critical CHD before oxygen levels in the blood become low. CDC estimates that, each year, an additional 1,200 newborns with a critical CHD could be identified at birth hospitals by screening, before they even show signs of having a critical CHD.

It is estimated that for every 200 children with a critical CHD, at least one death due to an undiagnosed critical CHD could potentially be avoided if all hospitals screened newborn babies for critical CHDs. If doctors can confirm that a baby has a critical CHD, the baby will receive the care he or she needs in a timely manner. Researchers have found newborn screening for critical CHDs to be a cost effective tool, meaning that the health benefits of screening outweigh the costs of screening.

Critical CHDs are listed below. Those **bolded** are critical CHDs that pulse oximetry screening is most likely to detect:

- Coarctation of the aorta
- Double-outlet right ventricle
- **d-Transposition of the great arteries**
- Ebstein anomaly
- **Hypoplastic left heart syndrome**
- Interrupted aortic arch
- **Pulmonary atresia (with intact septum)**
- Single ventricle
- **Total anomalous pulmonary venous connection**
- **Tetralogy of Fallot**
- **Tricuspid atresia**
- **Truncus arteriosus**

National Center on Birth Defects and Developmental Disabilities  
Division of Birth Defects and Developmental Disabilities



## CDC's Activities for Critical CHDs

In 2011, screening for critical CHDs was added to the Recommended Uniform Screening Panel for newborn screening. Since then, CDC has been researching how well newborn screening for critical CHDs works, the concerns of state and local governments involved in carrying out screening, the costs of screening for critical CHDs, and the health outcomes of babies who get screened. CDC's tracking and research activities for critical CHD screening include:

- Looking at how different states have started screening for critical CHDs in their hospitals, how many babies with critical CHDs have been found, and problems that might impact the success of critical CHD screening
- Studying if critical CHD screening is good value for the money, or cost-effective, as more states begin to screen babies for critical CHDs
- Learning what factors might impact whether a baby is diagnosed with a critical CHD before being sent home
- Exploring how birth defects tracking programs and newborn screening programs can work together to facilitate critical CHD screening in states
- Investigating how to leverage an electronic health record framework to improve reporting



## Moving Forward

Although researchers are learning more about critical CHD screening efforts, much work remains. Moving forward, CDC is dedicated to learning more about tracking, implementation, and research, including:

- Using data from screening in practice to adjust and refine the set of guidelines for screening for critical CHDs
- Evaluating methods to help make a diagnosis (e.g., telemedicine) for newborn nurseries with limited resources
- Linking critical CHD screening and birth defects tracking data to evaluate current screening methods
- Analyzing the impact of screening on long-term outcomes among children with critical CHDs
- Researching screening among certain populations (e.g., those living at higher altitudes)
- Tracking screening implementation across the United States
- Developing critical CHD screening procedures for Neonatal Intensive Care Units
- Continuing to work with states that are starting critical CHD screening, including work on establishing screening procedures, data collection, and reporting

These activities can provide important information for our continued efforts to study the impact of critical CHD newborn screening across the United States.

For more information visit <http://www.cdc.gov/features/congenitalheartdefects/index.html>.

### National Center on Birth Defects and Developmental Disabilities

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