

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. As of January, 2014, more than 86% of U.S. states have requirements for hospitals to screen newborns for critical CHDs. In states that do not require screening, many hospitals screen babies for critical CHDs as the standard of care.
- 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 measures 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 may help prevent death or disability early in life.

Newborn screening for critical congenital heart defects (critical CHDs) may 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, critical CHDs 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 for critical CHDs using pulse oximetry is a tool that works with prenatal diagnosis and physical exams after birth to improve detection of critical CHDs. 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 in the United States, an additional 875 newborns with a critical CHD could be identified at birth hospitals by screening, before they show signs of having a critical CHD.

If doctors can confirm that a baby has a critical CHD, the baby will receive needed care in a timely manner. Researchers have found newborn screening for critical CHDs to be cost effective, meaning that the health benefits of screening outweigh its costs.

Pulse oximetry screening detects low blood oxygen levels. Examples of other conditions that may lead to low blood oxygen levels are infection and pneumonia. A baby with these conditions may also be identified through pulse oximetry screening and receive needed care in a timely manner.

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**

CDC's Activities for Critical CHDs

In 2011, screening for critical CHDs was added to the Recommended Uniform Screening Panel for newborns. Since then, CDC has been studying 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:

- Examining how different states have implemented screening for critical CHDs in their hospitals, how many babies with critical CHDs have been identified, and problems that might impact the success of critical CHD screening
- Studying whether critical CHD screening is a 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 with a critical CHD is diagnosed 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 well the current pulse oximetry screening methods work



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 screening data from hospitals and birth defects tracking data to adjust and refine the guidelines for screening for critical CHDs
- Evaluating methods to help make a diagnosis (e.g., telemedicine) for newborn nurseries with limited resources
- Analyzing the impact of screening on long-term outcomes among children with critical CHDs
- Studying screening methods 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 implementing critical CHD screening including assisting with establishing screening procedures, data collection, and reporting

These activities will 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/ncbddd/heartdefects/cchd-facts.html>.

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