



## Critical Congenital Heart Disease (CCHD)

### Screening newborns for CCHD saves lives

#### What is 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. According to the Centers for Disease Control and Prevention, about 4,800 infants are born each year with CCHD. The Secretary of the U.S. Department of Health and Human Services added screening for CCHD to the Recommended Uniform Screening Panel (RUSP) in September 2011.

#### Why Screen for CCHD?

Infants with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth. 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 unrecognized CCHD are discharged each year from newborn nurseries in the United States.

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.

#### Screening for CCHD is Simple and Non-invasive

CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the infant 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. Tracking can be done through state birth defects surveillance programs.

#### Arizona Newborn Screening for CCHD begins July 1, 2015

March of Dimes supports newborn screening for conditions and disorders like CCHD 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.

#### Key Points

- CCHD is a heart defect that causes severe, life-threatening symptoms and requires medical intervention within the first few hours, days, or months of life.
- Infants with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth.
- It has been estimated that at least 280 infants with unrecognized CCHD are discharged each year from newborn nurseries in the United States.
- CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the infant is discharged from the hospital or birthing center and before the infant shows signs of the condition.

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