

# Screening for Critical Congenital Heart Disease (CCHD)

*If you have any questions about this information, please talk with your baby's doctor.*

## Frequently Asked Questions

### ♥ What is critical congenital heart disease (CCHD)?

Congenital Heart Disease (CHD) is a problem in the way a baby's heart develops before the baby is born or the way blood flows through the heart. Congenital (kuh n jen-i-tl) means it is something a baby is born with. CHD is one of the most common birth defects in babies. When a mother is pregnant, ultrasound can find some, but not all, types of CHD.

Some forms of CHD are more serious than others and need treatment sooner. This is called **Critical Congenital Heart Disease** or CCHD.

### ♥ How common is CCHD?

In the United States, about 7,200 (or 18 per 10,000) babies born every year have CCHD. (Source: Centers for Disease Control and Prevention)

### ♥ What are the causes of CCHD?

The causes of CCHD among most babies are not known. Some babies have heart defects because of changes in their genes or chromosomes (kroh-muh-sohms).

Another possible cause is a combination of genes and certain risk factors; such as infection, use

of drugs or certain medications during pregnancy.

### ♥ What are the signs and symptoms of CCHD?

- Bluish skin, lips or fingernails
- Delayed growth and development
- Poor feeding
- Does not gain weight
- Fast breathing
- Shortness of breath
- Tiredness

**Screening Saves Lives**

### ♥ Why is pulse oximetry used to screen for CCHD?

Some babies with CCHD can look and act healthy at first. **Pulse oximetry** (ok-sim-i-tree) **screening**, sometimes called “**pulse ox**” **screening**, is a simple and painless way to measure the oxygen level in your baby's blood. This can help identify babies that may have CCHD.



Screening for CCHD is recommended and supported by:

- U. S. Department of Health and Human Services
- American Heart Association
- American College of Cardiology
- American Academy of Pediatrics
- March of Dimes

### ♥ What is a normal pulse ox reading?

In healthy babies, pulse ox readings between 95 and 100 percent are normal. **It is possible that a baby with CCHD can have a normal pulse ox reading.** Call your baby's doctor if your baby has any of the symptoms on the previous page.

### ♥ What happens if the pulse ox screening shows a low oxygen level?

If the pulse ox screening shows a low oxygen level, this does not always mean your baby has CCHD. Sometimes, a newborn baby's lungs and heart are still adjusting after birth, and they may have a low reading.

If the pulse ox screening shows low oxygen level, your baby's doctor will talk with you about this and may order other tests. Your doctor may ask for another pulse ox screening, a chest x-ray and/or an ultrasound of the heart.

If found early, CCHD can often be treated.

### ♥ What is the treatment for CCHD?

CCHD treatment usually requires surgical repair and/or medications

Your baby's doctor will let you know if any type of treatment is necessary.

### ♥ Support Groups and Online Resources:

- American Heart Association  
[www.amhrt.org/](http://www.amhrt.org/)
- Baby's First Test  
<http://www.babysfirsttest.org/>
- Children's Heart Association  
[www.heartchild.info/](http://www.heartchild.info/)
- Children's Heart Foundation  
[www.childrensheartfoundation.org/](http://www.childrensheartfoundation.org/)
- Congenital Heart Information Network -  
[www.tchin.org/](http://www.tchin.org/)
- Kids with Heart -  
[www.kidswithheart.org/](http://www.kidswithheart.org/)

# What Does It Mean When Your Baby Has a Positive Screen For CCHD?

