

YOUR NEWBORN SCREENING GUIDE TO *Critical Congenital Heart Disease*

What is CCHD?

Critical congenital heart disease (CCHD) is one of the conditions found through newborn screening. CCHD refers to a group of heart defects that can be serious and life-threatening. These problems range from mild to severe. CCHD is often treatable, if caught early.

What is newborn screening?

While most babies are born healthy, some infants are born with serious but treatable medical conditions. Newborn screening is a public health program that helps identify these conditions so that babies receive treatment early to prevent harm, even death. Newborn screening usually happens 24 hours after your baby is born and can lead to treatment within the first few days of life.

Why is newborn screening important?

Some babies look and act healthy at first, but may not show serious symptoms until later. Conditions, such as CCHD, can be present in any family, even those without a family history.

How are babies screened for CCHD?

Healthcare professionals check for CCHD by using **pulse oximetry** (or “pulse ox”). Pulse oximetry is a painless, non-invasive test that measures the amount of oxygen in your baby’s blood.

What if my baby’s pulse ox reading is low?

This means that the oxygen levels in your baby’s blood are low, which can have many causes. An out-of-range screening result *does not* necessarily mean that your baby has CCHD. However, since some babies do have the condition, it is very important to talk about next steps with the health professionals at the facility or birth center where your baby was born.

Because the harmful effects of CCHD can develop shortly after birth, follow-up testing should be completed as soon as possible to determine whether or not your baby has a heart problem.

About **2 in 1,000** babies born in the United States is affected with **Critical Congenital Heart Disease.***

Early Signs of CCHD:

- Loss of healthy skin color
- Bluish tint to the lips, skin, or fingernails
- Fast or troubled breathing
- Swelling or puffiness of the face, hands, or feet
- Poor weight gain

If you notice any of these signs, or if you have questions or concerns about your baby's heart, **contact your baby's healthcare professional right away.**

For Support and Resources:

Mended Hearts
www.mendedhearts.org

Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/heartdefects

Little Hearts
www.littlehearts.org

For References* and More Information:

BabysFirstTest.org
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