

Screening for Critical Congenital Heart Disease (CCHD) with Pulse Oximetry: Frequently Asked Questions

Screening for CCHD by checking pulse oximetry (also known as pulse ox) is recommended and supported by: the U.S. Department of Health and Human Services, the American Heart Association, the American College of Cardiology, the American Academy of Pediatrics, and the March of Dimes.

What is Critical Congenital Heart Disease (CCHD)?

Congenital Heart Disease (CHD) is when a baby's heart develops in a different way before birth. Congenital means something a baby is born with. CHD is the most common type of birth defect. Some forms of CHD are more serious than others and need treatment sooner. These more serious forms are called **Critical Congenital Heart Disease** or **CCHD**.

How common is CCHD?

In the U.S., about 7,200 (or 2 per 1,000) babies born each year have CCHD. (source: Centers for Disease Control and Prevention)

What are the causes of CCHD?

We do not know what causes CCHD in most babies.

What is pulse oximetry (also known as pulse ox)?

Pulse oximetry is a simple way of measuring how much oxygen the blood is carrying. It involves attaching a small sticky probe to the hand and foot for about 1 minute. It is painless. It has no side effects.

What is a normal pulse oximetry reading?

In healthy babies, normal pulse oximetry readings are between 95-100%, with less than a 4% difference between the right hand and either foot. *A baby with CCHD can have a normal pulse oximetry reading*. Passing the pulse oximetry screening does not rule out CCHD.

What does it mean if my baby does not pass the pulse oximetry screening?

If the pulse oximetry screening shows a low oxygen level, this does not definitively mean your baby has CCHD. Sometimes a newborn's lungs and heart are still adjusting after birth. This can also lead to a low pulse oximetry reading.

What happens next if my baby does not pass the pulse oximetry screening?

Your baby's doctor or nurse will speak with you and order other tests. These tests might include another pulse oximetry reading, a chest x-ray, and/or an ultrasound (echocardiogram or "ECHO") of the heart.

Who will perform the follow-up measures?

Your baby's nurse or a nursing assistant will complete a follow-up pulse oximetry. A radiology technician will perform a chest x-ray. A Cardiologist or an echocardiography technician will perform an "ECHO". Your baby may need to be transferred to another hospital to get these tests.

When will we get the results?

You will have results of any tests soon after they are done, usually before your baby leaves the hospital. Your doctor will discuss with you the timing of the tests and when to expect results.

What is the treatment for CCHD?

CCHD usually requires surgical repair. Your baby may not need surgery during this hospital stay. A pediatric cardiologist (heart doctor) will explain what happens next.

Support Groups and Online Resources:

American Heart Association www.amhrt.org

Baby's First Test www.babysfirsttest.org
Children's Heart Association www.heartchild.info

Children's Heart Foundation <u>www.childrensheartfoundation.org</u>

Congenital Heart Information Network <u>www.tchin.org</u>

Kids with Heart <u>www.kidswithheart.org</u>

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