### **Newborn Screening for Critical Congenital Heart Disease**

Along with hospitals across the nation — and following the recommendation of the U.S. Department of Health and Human Services — this facility is part of a project that screens all newborns for heart problems. It is also part of a project to evaluate how the screening performs in Utah, which is at a higher altitude than most states in the country. Although most newborns do not have a heart problem, early detection and treatment can be crucial for helping babies who do.

This fact sheet explains the screening and answers some questions that new parents may have about the screening. The text has been adapted with permission from Children's National Medical Center, which is at the forefront of this effort to improve infant health.

### What is congenital heart disease?

**Congenital heart disease (CHD)** refers to a problem in the structure of the heart or the blood flow through the heart. CHD is the most common birth defect, affecting about 8 out of every 1,000 newborns. Its cause is usually unknown.

If the CHD is serious, called a **critical congenital heart defect (CCHD)**, it needs to be detected and repaired early in a baby's life to help prevent other related health problems. Newborn screening with pulse oximetry can allow for early detection.

### What is pulse oximetry?

**Pulse oximetry** ("pulse ox," for short) is a simple test that measures how much oxygen is in the blood. It requires placing a sticky strip, like a band-aid, on the baby's hand or foot. The strip has a small red light that is the sensor. The sensor is attached to a wire, which is attached to a monitor that shows the pulse ox reading.

A pulse ox test takes just a few minutes when a baby is still, quiet, and warm. The testing may take longer (or may need to be delayed) if a baby is squirming, crying, or cold. For this reason, care providers may ask you to help keep your baby warm, calm, and quiet while the test is being performed. Screening can help detect congenital heart disease, the most common birth defect in newborns. Early detection can mean earlier treatment — and safer babies.



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Pulse ox is a quick, safe, and painless way to check for a common sign of CCHD — low oxygen levels.

Since pulse ox measures the amount of oxygen in the blood, it can identify a baby with low oxygen levels. Low oxygen may signal that a baby's heart or lungs are not working properly.

If screening with pulse ox identifies a baby with low oxygen, the care team will probably order additional testing. One common follow-up test is an ultrasound of the heart, or **echocardiogram** ("echo"). The echo can help the team check for a serious problem in the structure of the heart or the blood flow through the heart.

#### Can the pulse ox test hurt my child?

The pulse ox test is painless. It is noninvasive — meaning it doesn't require pricking the skin or putting anything inside your baby's body. There are no side effects or known risks from pulse ox.

#### When will the pulse ox test be performed?

The pulse ox screening happens after your baby is 24 hours old, but before you take your baby home from the hospital.

#### What is a normal reading?

Established guidelines help providers know the normal range for a pulse ox reading on a healthy newborn's hand or foot. A provider can tell you the standard range expected in your hospital.

Keep in mind that if your newborn's reading is lower than your hospital's standard normal range, it doesn't necessarily mean your baby has a heart or lung problem. A low reading can be normal in newborns whose lungs and heart are still adjusting to life outside the womb. If your baby's care providers are concerned about the screening results, they will order more tests to check for a problem.

## Can a baby with CCHD have a normal pulse ox reading?

Pulse ox screening can check for a common sign of CCHD — low oxygenation — but **it may not detect all heart problems in all babies.** For this reason, it's important that you bring your baby to regular checkups with a primary care doctor. The doctor can provide advice and monitoring over time and as your baby grows.

# When to call your baby's care provider

In the hospital or after you go home, **contact a provider right away** if you notice any of these possible signs and symptoms of CCHD in your new baby:

- Tires easily during feedings (tends to fall asleep very early in the feeding)
- Sweats around the head, especially during feeding
- Is breathing fast when resting or sleeping
- Has pale or bluish skin color
- Sleeps a lot, and when awake isn't playful or curious for very long
- Has a puffy face, puffy feet, or both
- Is often irritable (fussy), difficult to console

# Talking with your baby's care team about this screening

If you have any questions or concerns about the CCHD screening, talk to your providers. You can choose not to have your baby screened for a serious heart condition. To make your decision, it may help to discuss the information in the table below. If you choose to refuse, notify the nursing staff. Finally, if you have questions as you talk with care providers, be sure to ask.

Potential benefits	Risks and potential complications	Alternatives
This screening may provide early identification of a significant heart problem in a newborn. Early identification allows for earlier contact with specialists who can help manage the infant's care in a timely and appropriate way, reducing the potential for complications.	<ul> <li>CCHD screening is done with pulse oximetry. Pulse oximetry itself presents no risks to a newborn. However, it's important to keep in mind the following:</li> <li>Screening will not catch all heart defects in every infant tested. There is a chance that a heart defect missed by the screening will cause symptoms later.</li> <li>This screening will produce some false positive results. This means that some newborns with healthy hearts will not pass the screening and then may undergo additional testing.</li> </ul>	None.







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