

## Critical Congenital Heart Disease (CCHD) Screening Information Sheet for Parents

### What is Newborn Pulse Oximetry Screening?

Newborn screening is a way to find babies who have serious medical conditions that need urgent treatment. Newborn Pulse Oximetry Screening is a test which will be done before your baby goes home to test his/her oxygen level in the blood. Most babies are born with enough oxygen in their blood and have healthy, normal hearts. A few are born with heart problems which may make their oxygen levels lower. Screening can help detect babies with Critical Congenital Heart Disease before they go home from hospital.

### What is Critical Congenital Heart Disease?

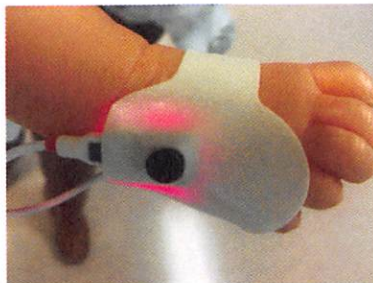
There are many types of heart disease which range from mild to severe. Critical congenital heart diseases (CCHDs) are heart problems that are often associated with lower oxygen levels in the newborn period and can cause life-threatening problems. A "critical" heart defect is one that needs more urgent treatment in order to have the best outcome for the baby.

### Why screen for CCHD?

While most babies are born with a normal heart, a few are born with CCHD. Some babies may not have symptoms until later. Your baby will be checked very carefully after birth, but a physical examination may not always detect heart problems. Screening for CCHD with Pulse Oximetry, along with ultrasounds during pregnancy and examining a newborn can help diagnose babies earlier and improve their outcome.

### How is CCHD screening done?

Pulse oximetry is a fast, safe, non-invasive test that will check your baby's oxygen level in their hand and foot. A sensor is placed on the baby's right hand and one foot to measure the oxygen level in the blood. The screening will be done after the baby is 24 hours old. If you are going home earlier, it will be done before discharge. If a baby is crying or cold, the screening may take a little longer and sometimes, it may need to be repeated to ensure an accurate reading.



### What happens if the screening test is abnormal or my baby's oxygen level is low?

Babies with low oxygen levels in their blood may have CCHD. There are also other conditions like breathing problems or infections that may also cause a low blood oxygen level and in some babies, they have normal hearts but their heart and lungs are adjusting after birth. If the screening test shows a lower oxygen level, the doctor or most responsible primary health care provider will check the baby carefully to look for any other signs that might help them understand why the oxygen level is lower. Depending on the concern, they may do more testing and consult a specialist to help. If there is a concern of a heart problem, the Pediatric Cardiologist will be consulted and an ultrasound of the heart (echocardiogram) may need to be done to look for CCHD. The medical team will discuss the next steps with you.

## What if my baby has CCHD?

Treatment for CCHD varies, but can include medications, medical procedures or surgery depending on the problem. Your medical team will discuss the details of the problem and treatment with you.

Most babies who have a normal Pulse Oximetry Screen will not have CCHD. However, **newborn screening may not identify every child with a critical heart problem**. Signs of CCHD may be pale or bluish colour to the lips or skin, fast breathing, grunting sounds, excessive sleeping, poor feeding, or poor weight gain. If you notice any of these symptoms, please contact your baby's health care provider right away.

## Resources:

<http://www.babysfirsttest.org/newborn-screening/conditions/critical-congenital-heart-disease-cchd>

<https://www.cdc.gov/Features/CongenitalHeartDefects/>