

# Critical Congenital Heart Disease

## What is Critical Congenital Heart Disease Screening?

Critical congenital heart diseases (CCHD) are the most common of all birth defects. They can affect 1 in every 100 babies born in the United States each year and account for nearly 30% of infant deaths due to birth defects. About half of these are found after birth when a normal infant has life-threatening problems and requires emergency care.

## What can be done to find CCHD before babies have trouble?

Kentucky is now doing a simple test before the baby is sent home from the hospital after birth. This is called Pulse Oximetry Testing.

## What is Pulse Oximetry Testing?

Pulse Oximetry Testing is performed by putting a sensor on the baby's foot and hand to read the oxygen percentage in the baby's blood. This is not painful to the baby and only takes minutes to perform.

## What happens if the Pulse Oximetry testing is not normal?

If this test is abnormal, the hospital staff will call your baby's health care provider to discuss the results. Additional tests and seeing a specialist may be needed.

## What are the advantages to Newborn Screening for CCHD?

By doing this simple test, potentially life-threatening heart defects can be identified early in the seemingly healthy newborn baby. It is essential to find these defects and treat them early with special care.

## Disorders identified by Newborn Screening Labs

- Congenital Hypothyroidism (CH)
- Phenylketonuria (PKU)
- Cystic Fibrosis (CF)
- Galactosemia
- Biotinidase Deficiency
- Congenital Adrenal Hyperplasia (CAH)
- Hemoglobinopathies
- Amino Acid Disorders
- Organic Acid Disorders
- Fatty Acid Disorders
- Critical Congenital Heart Defects
- Severe Combined Immunodeficiency (SCID)
- Peroxisomal Lysosomal Storage Disorders
- Krabbe
- Spinal Muscular Atrophy (SMA)

## Are there other screenings my baby need?

A hearing screening should be completed for all newborns prior to discharge from the hospital.

# Newborn Screening



## Saving Lives

One Screen at a Time

## Kentucky Newborn Screening Program

### Kentucky Newborn Screening Program

275 East Main St., Frankfort, KY 40621

Phone: 502-564-2154



Visit our website for more information



**Kentucky Public Health**

Prevent. Promote. Protect.

# Get the Facts

## What is Newborn Screening?

Kentucky law requires that all newborns have screening tests (lab work, pulse oximetry for critical congenital heart disease, and hearing) to identify hidden disorders that can cause serious problems for your baby if not treated soon after birth.

### Why does my baby need testing?

Babies are tested for many severe but rare medical conditions. Babies with these conditions may look healthy at birth. If not detected and treated, these conditions can cause problems such as slow growth, developmental delay, and even death.

### When does my baby get tested?

The best time to have the newborn screening tests done is 24-48 hours (1-2 days) after birth.

### Who performs the tests?

Hospital staff or the midwife who delivered your baby will perform the newborn screening tests.

### How is my baby tested?

A few drops of blood from your baby's heel are put on a special test paper, which is allowed to dry and then sent to the Kentucky State Lab. At the lab your baby's blood is tested for multiple disorders, which can cause serious health problems if not treated early.

### How do I get my baby's test results?

Your baby's health care provider will have a copy of your baby's newborn screening test results. You can discuss these results with your baby's health care provider at your baby's next check-up.

### Is the blood test safe for my baby?

Yes, the blood test is safe. The risk of infection is low.

### What happens if my baby's test results are positive or unusual?

Your baby's health care provider will be contacted if there are any positive or unusual test results. A positive or unusual result does not always mean a disorder is present. This screening test is designed to find babies who may be at risk for serious health problems. If you are contacted regarding positive or unusual test results, more tests may be needed. If you are asked to have your baby tested again, it is vital to do so as soon as possible.

### How are these health disorders treated?

Each health disorder is different. Some disorders are treated with special diets, and other disorders are treated with medications. If treated early, your baby may grow up to lead a normal, healthy life. In a few cases, the disorders may not be completely treatable. Early diagnosis and treatment of any of these health disorders will allow your baby the best chance of average growth and development.

### What if I move after my baby is tested??

Let your health care provider know if you have a new address or phone number. This information is vital if your baby needs further follow-up.

