

# 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 not normal, 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, potential life-threatening heart defects can be identified early in the seemingly healthy newborn baby. It is important 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?

A hearing screening should be completed for all newborns prior to discharge from the hospital. For more information, please visit the Newborn Hearing Screening Program web page at: [chfs.ky.gov](http://chfs.ky.gov) (search: Newborn Hearing Screening).

## Do you need more information?

Talk with your baby's health care provider, or call our office at: 502-564-3756, or go to our website: [chfs.ky.gov](http://chfs.ky.gov) (search: Newborn Screening).

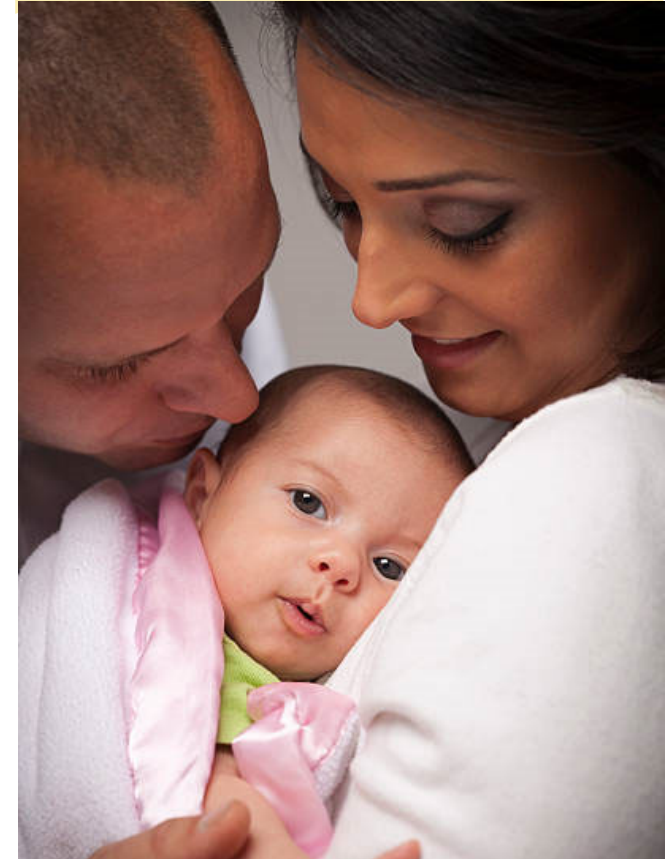
**Kentucky Newborn Screening Program**  
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**Kentucky Public Health**  
Prevent. Promote. Protect.

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# Newborn Screening



# Saving Lives

# One Screen at a Time

The Kentucky Newborn Screening Program





## 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?

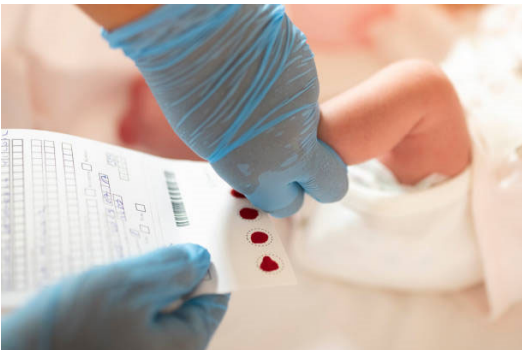
Babies are tested for many rare but serious medical conditions. Babies with these conditions may look healthy at birth. If not detected and treated, these conditions can cause problems such as slow growth, developmental delay, and even death.

## When does my baby get the test?

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

## Who does the test?

Hospital staff or the midwife that delivered your baby will perform the test.



# Get the facts

## 1 How is my baby tested for disorders?

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. Your baby's blood is then tested for multiple disorders which can cause serious health problems, if not treated early.

## 2 How do I get the results?

Your baby's health care provider will have a copy of the test results. You can ask about these results when you take your baby for a check-up.

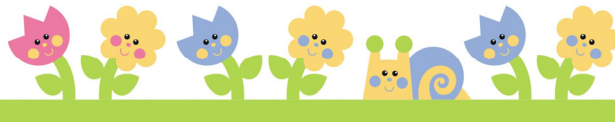


## 3 Is the blood test safe for my baby?

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

## 4 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, and will talk to you about the test results. A positive or unusual result does not always mean that a disorder is present. This is a screening test which finds those babies who may be at risk. If you are contacted, more tests may be needed to find out if your baby has a disorder. If you are asked to have your baby tested again, please do it as soon as possible.



## 5 How are these disorders treated?

Each 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. The early diagnosis and treatment of the disorder will allow your baby the best chance of normal growth and development.

## 6 What if I move?

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

