Critical Congenital Heart Disease

What is Critical Congenital Heart Disease Screening?

Critical congenital heart diseases (CCHD) are the most common of all birth defects. These can affect 1 in every 100 babies born in the US each year. About half of those born with CCHD are found after birth, when a seemingly healthy baby 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 measures the oxygen level of the baby's blood. 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, hospital staff will call the baby's attending pediatrician 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 a seemingly healthy newborn baby. It is important to find these defects immediately so that treatment can begin early.

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
- Severe Combined Immunodeficiency (SCID)
- Various Lysosomal Disorders (Pompe, MPS 1)
- Krabbe

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 Early Hearing Detection web page at:

http://chfs.ky.gov/ccshcn/CCSHCNunhs.htm

Do you need more information?

Talk with your child's provider, call our office or go to our website:

Kentucky Newborn Screening Program
275 East Main St., Frankfort, KY 40621
502-564-3756
http://chfs.ky.gov/dph/mch/ecd/newbornscreening.htm

Kentucky UNBRIDLED SPIRIT

Kentucky Public Health
Prevent. Promote. Protect.

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 developmental delay, slow growth, and even death.

When does my baby get the test?

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

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's lab work 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. 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 doctor 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 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 doctor know if you have a new address or phone number. This information is important if your baby needs further follow-up.