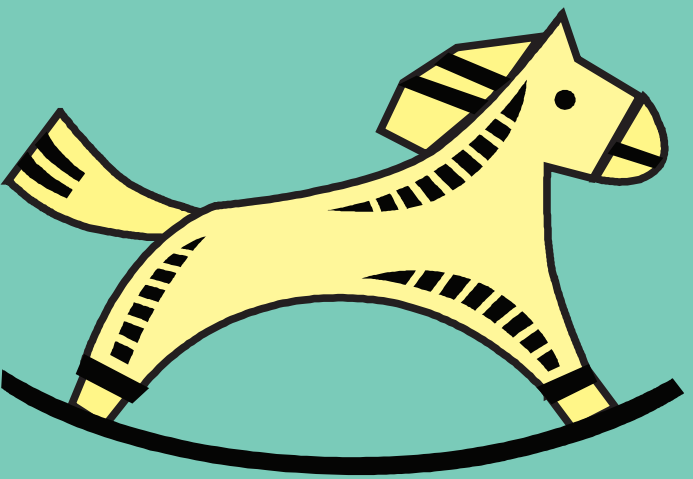
What if the CCHD screening results are normal?

Most babies who pass the CCHD screening will not have a CCHD. It is important to know that screening cannot identify every child with a heart problem. Parents should watch for the following warning signs:

- Bluish color to the lips or skin
- Grunting
- Fast breathing
- Poor feeding
- Poor weight gain
- Sweating around the forehead – especially during feeding.

If you see any of these signs, contact your baby's health care provider right away!



Facts/additional information

- Approximately 2 out of every 1,000 babies are born with a CCHD.
- CCHD screening can save a baby's life if a serious heart defect is diagnosed before the baby goes home.

For additional information, contact the Missouri Department of Health and Senior Services at 800-877-6246 or visit health.mo.gov/cchd

Missouri Department of Health and Senior Services
Bureau of Genetics and Healthy Childhood
P.O. Box 570
Jefferson City, MO 65102-0570
800-877-6246

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NEWBORN SCREENING for CRITICAL CONGENITAL HEART DISEASE

Missouri Department of Health and Senior Services

Critical Congenital Heart Disease

What is newborn screening?

Newborn screening refers to screenings performed on newborns shortly after birth to protect them from the dangerous effects of disorders that otherwise may not be detected for several days, months, or even years. Missouri law requires all babies born in the state to be screened for over 70 different disorders. Most of these disorders are screened by collecting a small amount of blood from the newborn's heel and sending the sample to the Missouri State Public Health Laboratory for testing. However, there are also two screenings included in Missouri's newborn screening panel that are non-invasive and can be completed at the bedside. These include newborn hearing screening and critical congenital heart disease screening.

What is CCHD?

Critical congenital heart disease (CCHD) occurs when a baby's heart or major blood vessels do not form correctly, causing a defect. There are many different types of heart defects that range from mild to severe. Babies with "critical" heart defects need urgent treatment, which may include medicine or surgery. If left untreated, these defects can lead to death or can cause serious developmental delays.

Why is CCHD screening important?

While prenatal ultrasounds may detect some cases of CCHD, not all CCHDs can be detected before birth. Without screening shortly after birth, babies with CCHD are sometimes sent home without care because they appear healthy. At home, these babies can develop serious health problems and often require emergency care. If CCHD is detected early, however, infants can be treated and lead healthier lives.

How is CCHD screening performed?

CCHD screening is a simple test that can be done at the bedside to determine the amount of oxygen in the baby's blood. Low oxygen levels can be a sign of CCHD. The test is done using a machine called a pulse oximeter. The pulse oximeter uses an infrared light sensor that is gently wrapped around the baby's right hand and one foot. Light passes through the skin and tissue and is read by the sensor to estimate the blood oxygen level. The test is painless and takes just a few minutes.

When is CCHD screening performed?

CCHD screening should be performed 24 to 48 hours after birth or before discharge from the hospital. If your baby is born at home or in a birthing center, discuss how to have your baby screened for CCHD with your midwife or your baby's doctor.

Screening should be done while your baby is warm, calm and awake. If your baby is crying, moving, fussing, or cold, the screening will take longer and may need to be repeated.

What if the CCHD screening results are abnormal?

A healthy baby may have a low oxygen reading. Babies with low oxygen levels may have a CCHD. Other conditions like breathing problems or infections may also cause a low blood oxygen level. If your baby has a low oxygen reading, the health care provider will check your baby carefully. An ultrasound of the heart (also called an echocardiogram or "echo") may be done to look for a CCHD. The echocardiogram may be done in a hospital or a doctor's office. It will need to be read by a children's heart doctor (pediatric cardiologist). If the echocardiogram shows a problem, the medical team will discuss the next steps with you.