For Critical Congenital Heart Disease (CCHD)

What is Newborn Screening?

Newborn screening is a way to find babies who have serious medical conditions that need urgent treatment. Most babies are born with no serious health problems. But for those who **do** have a serious health problem, newborn screening can be life-saving.

What is CCHD?

Critical congenital heart disease (CCHD) occurs when a baby's heart or major blood vessels do not form properly. There are many types of heart defects. They range from mild to severe. A "critical" heart defect is one that needs urgent treatment in order to have the best outcome for the baby. Treatment can include medical and surgical procedures.

Why screen for CCHD?

Most babies are born with healthy hearts, and have enough oxygen in their blood. A few are born with CCHD. Although babies are checked very carefully by a doctor after they are born, some babies with CCHD may not have symptoms until later. Screening can help find babies with CCHD before they go home from the hospital.

How is screening for CCHD done?

Pulse oximetry is used to screen babies for CCHD. Pulse oximetry is fast, easy and does not hurt. A small sensor is placed on a baby's right hand and one foot to measure the oxygen level in the blood. Your baby's doctor or nurse will discuss low pulse oximetry readings with you. Screening for CCHD is done for well newborns at about 24 hours of age or before discharge. Screening is done while a baby is warm and quiet. If a baby is crying, moving, fussing or cold, then screening will take longer. It may need to be repeated.

What happens if pulse oximetry reading is low?

Healthy babies may have a low oxygen reading. Babies with low oxygen levels in their blood *may* have CCHD. Other conditions like breathing problems or infections may also cause a low blood oxygen level. The doctor will check the baby carefully. An ultrasound of the heart (also called "echocardiogram" and "heart echo") may be done to look for CCHD. The heart echo may need to be done in a different hospital or doctor's office. It is read by a children's heart doctor (pediatric cardiologist). If the heart echo shows problems, then a baby's medical team will discuss next steps with parents.

What do parents need to know?

Most babies who pass the pulse oximetry screen will not have a CCHD. It is important for parents to know that newborn screening cannot identify every child with a critical heart problem. Warning signs that all parents should watch for are: bluish color to the lips or skin, grunting, fast breathing, poor feeding, and poor weight gain. If you notice any of these signs in your baby, please contact your baby's health care provider right away.



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