EXECUTIVE SUMMARY

This summary reviews the information the federal advisory committee used when deciding whether to recommend adding Critical Congenital Heart Disease (CCHD) to the Recommended Uniform Screening Panel (RUSP) in 2010.

About the condition

CCHD is a group of the most serious heart disorders present at birth. About 200 out of every 100,000 babies have CCHD. Children with CCHD are born with a wide range of problems with the heart's structure. These problems prevent the heart from pumping blood normally to the lungs and rest of the body. Because blood carries oxygen, parts of the body may not get enough oxygen. There are many types of CCHD, and all can cause serious health problems. These problems can worsen quickly and cause death in early childhood. Babies with CCHD need treatment early in life.

Treatment for CCHD

Babies with CCHD need treatment early in life. Many babies need surgery right away. Other babies need medicines or other procedures to help with blood flow or heart problems. The type of treatment a baby needs depends on the baby's heart problem and symptoms.

Detecting CCHD in newborns

CCHD may be found before birth with a prenatal ultrasound. After birth, newborn CCHD screening usually happens when a baby is between 24 and 48 hours old. Newborn CCHD screening uses a device called a pulse oximeter to measure oxygen in the baby's blood. Newborns with low blood oxygen are at higher risk for CCHD. They need more tests to diagnose the condition.

Public health impact

Detailed data on how newborn CCHD screening would affect public health were not available at the time of the report. However, newborn screening for CCHD saves lives by allowing diagnosis early in life. Babies who get a diagnosis before leaving the hospital may avoid both life-threatening symptoms and treatment delays that can cause death.

Committee decision

The Committee voted in 2010 to recommend adding CCHD to the RUSP. As of 2011, the RUSP recommends that state newborn screening programs include CCHD.