

CCHD Screening Informed Choice Document

Congenital heart defects occur 8 in 1000 births, with about 25% of those being CCHD¹, defined as defects requiring surgery or catheterization before one year of age. Congenital heart disease is a problem in the structure of the heart or the blood flow through the heart. It is the most common birth defect and the cause is not really known.

Your midwife can screen your baby for congenital heart disease by doing a simple, painless, non-invasive pulse oximetry screening. The screening takes only a few minutes and can let us know if your baby might have a serious heart problem. The screening will be done after your baby is 24 hours old, and is usually done at your first postpartum visit. The pulse oximeter measures how much oxygen is in the baby's blood. The pulse oximeter has a sensor that looks like a Band-Aid with a wire and a small red light. The pulse oximeter sensor is wrapped around your baby's right hand and stays in place until the oxygen saturation level is determined. Then, the sensor is wrapped around one of the baby's feet, and the procedure is repeated. The oxygen saturation level can be helpful in letting us know if your baby's heart and lungs are functioning properly. If your baby's oxygen saturation levels are low, it is possible your baby may have a serious heart problem, and are said to have "failed" their CCHD screening. Babies who fail their screening are referred to a doctor for additional testing, such as an ultrasound of the heart.

Prenatal ultrasound is a very important screening tool, but it does not identify all life threatening heart defects. Research has shown it identifies about 23% of pregnancies or 11% of live births with heart defects². Even though your midwife will do a thorough examination of your baby after the birth, only about 50% of babies with heart disease are identified by physical exam or symptoms^{3, 4, 5}. The pulse oximetry screening provides us with one more tool to help us identify babies who may need advanced care.

The likelihood of a false positive screening is very low (less than 1%)⁶. The pulse oximetry screening will not detect all forms of problems in the baby's heart, but the screening is a valuable and potentially lifesaving tool for your baby. There are no known risks for pulse oximetry.

I have read the information in this informed choice document and have had an opportunity to discuss this information with my midwife. My questions have been answered to my satisfaction.

- I consent to pulse oximetry screening for CCHD for my baby.
- I decline pulse oximetry screening for CCHD for my baby.

Client _____ Date _____

Midwife _____ Date _____

¹ Oster M, Lee K, Honein M, Colarusso T, Shin M, Correa A. Temporal trends in survival for infants with critical congenital heart defects. *Pediatrics*. 2013;131(5):e1502-8.

² British Paediatric Cardiac Association. Current and potential impact of fetal diagnosis on prevalence and spectrum of serious congenital heart disease at term in the UK. *Lancet*. 1999 Oct 9;354(9186):1242-7 ik.

³ Chang RK, Gurvitz M, Rodriguez S. Missed Diagnosis of Critical Congenital Heart Disease. *Arch Pediatr Adolesc Med*. 2008 Oct;162(10):969-74. doi: 10.1001/archpedi.162.10.969.

⁴ Wren C, Richmond S, Donaldson L. Presentation of congenital heart disease in infancy: implications for routine examination. *Arch Dis Child Fetal Neonatal Ed*. 1999;80(1):F49.

⁵ de-Wahl Granelli A, Wennergren M, Sandberg K, et al. Impact of pulse oximetry screening on the detection of duct dependent congenital heart disease: a Swedish prospective screening study in 39,821 newborns. *BMJ*. 2009;338:a3037.

⁶ Manja, Veena et al. "Critical Congenital Heart Disease Screening by Pulse Oximetry in a Neonatal Intensive Care Unit." *Journal of perinatology : official journal of the California Perinatal Association* 35.1 (2015): 67–71. PMC. Web. 25 Feb. 2016.