

Sample of Informed Decision Making Conversation between a midwife and parents regarding
CCHD screening
March 2016

Midwife: Today I'd like to talk about the newborn congenital heart defect screening. It's a test we do for babies when they are between 24 and 48 hours old.

Parent 1: What's congenital mean?

Midwife: Good question! Congenital means "born with," so a congenital defect is a birth defect.

Parent 1: Oh, ok.

Midwife: Heart defects are the most common birth defect. There are many kinds of congenital heart defects. There could be defects in the structure of the heart such as a hole in the heart, defects in the way the blood flows, or the rhythm of the heartbeat could be irregular.

Some congenital heart defects are not life-threatening and some are. Life-threatening defects are called critical congenital heart defects. Babies with critical heart defects need medical intervention either very soon after birth or before they are one. That's why we are now offering a screen to detect these serious heart defects.

In 2014, the Virginia General Assembly passed legislation requiring all hospitals to do a critical congenital heart defect screen on every baby born in their hospital. Home birth and birth center midwives are not mandated to do the test. But the Virginia Department of Health encourages midwives to perform the screen. I offer it because I think it's important.

This is how we do the test. We use this little machine called a pulse oximeter, or "pulse ox." It measures the amount of oxygen in blood. We put this little probe on the baby's right hand and either foot. The probe shines a light through the blood vessels and measures the heart beat and the amount of oxygen in the blood. Have you ever been to the ER or to the doctor and had them put an "ET" light on your finger?

Parents: Yes, we've had that before.

Midwife: Well this probe does the same thing. Low levels of oxygen in the blood can be associated with some congenital heart defects. In order to pass the test, the baby's oxygen levels must be at least 95% in either the right hand or either foot and the difference between the two numbers must be 3% or less. For example, if the pulse ox measurement is 97% on the right hand and a 94% on the foot, the baby passes.

Parent 2: We had the 20 week ultrasound. If our baby had a congenital heart defect, wouldn't it have shown up on that ultrasound?

Midwife: Not necessarily. Prenatal ultrasound detects approximately half of all congenital heart defects.

In the womb, the baby is getting blood and oxygen from the placenta via the cord. The heart doesn't need to pump blood to the lungs to pick up oxygen to carry around the body. When babies are born, their circulation changes. They stop getting oxygen from the cord, and their lungs expand and the heart starts pumping blood to the lungs to pick up oxygen. If there is a

problem in the function of the heart, it may not cause a problem until the transition from intrauterine to extrauterine life is complete, which happens at about 48 hours of life. That's why we do the screening at the first postpartum home visit between 24 and 48 hours.

Parent 2: Does the pulse ox screening catch all heart defects?

Midwife: No. Pulse ox screening only detects babies who have more serious forms of congenital heart disease which is identified by the fact that oxygen levels are lower than normal. 2-4% of babies with critical congenital heart disease are missed by pulse ox. And some babies who have heart defects appear normal at birth and normal for months. So it's important to know the signs of critical congenital heart disease in infants. They are:

- Blue skin, especially in the lips and fingernails.
- Rapid or troubled breathing
- Swelling or puffiness in the face, hands, feet, legs, or areas around the eyes
- Shortness of breath or tires easily during feedings
- Sweating around the head, especially during feeding
- Poor weight gain

Parent 2: How common are these heart defects?

Midwife: According to the CDC, 1% of babies born in the USA have a congenital heart defect. That's 40,000 babies a year. And 25% of them have a critical heart defect.

Here's a handout from the Virginia Newborn Screening Department on critical congenital heart defect screening for you to read over. Do you have any other questions?

Parent : Does the probe hurt the baby?

Midwife: It doesn't hurt. We don't have to poke the baby or draw any blood for the test.

Parent 1: Do you recommend it?

Midwife: Yes. Because it's simple and easy. The benefit to screening is that it's very likely to catch a heart defect and if the baby has one, he can get early treatment. The only risk of the test is that there are false positives and false negatives. Meaning, the baby could fail the screen and be normal or could pass the screen and have a heart defect. There's no alternative to the pulse ox screening. You can read about it and talk about it and you have until the 24 hour postpartum visit to decide whether or not to do it.

Parents: Ok. Thanks.