

# Heart Smart: CCHD Screening for Parents (6:02)

GENETIC ALLIANCE

**Male Voice:** Pulse oximetry is a simple, painless, inexpensive means to help us detect critical congenital heart disease.

**Female Voice:** Screening for critical congenital heart disease using pulse oximetry can improve outcomes and save lives.

**Second Female Voice:** The goal would be for every hospital and birthing center in the country to screen babies, and that is what the pulse ox test is looking for.

(0:40)

## CRITICAL CONGENITAL HEART DISEASE (CCHD) SCREENING: BECAUSE EVERY BABY DESERVES A HEALTHY START

**Female narrator:** Pulse oximetry, called pulse ox for short, is a simple, painless, and non-invasive test that helps identify babies with heart defects known as congenital heart disease or CHD, the number one birth defect in children. Pulse ox is just one of several tools medical professionals use to help identify newborns with serious heart problems before they ever leave the nursery. Many leading health organizations have endorsed adding screening for critical congenital heart disease to the recommended uniform screening panel.

**Gerard R. Martin, MD, Children's National Medical Center:** This is going to be a game changer for us and now we're just going to have a little bit more safety for those babies when they're born, so that we find them and get them to early treatment, and that will improve the lives of many babies.

**Nancy Nagel, MSN, RN, Holy Cross Hospital:** I tell families that it's an easy, it's a painless, and it's a very quick way to detect for the presence of CCHD in their newborn.

(1:35)

## CCHD SCREENING HELPS TO ENSURE YOUR BABY'S HEALTHY START

**Olivia Easley, MD, parent:** My daughter Veronica died suddenly and unexpectedly from an undiagnosed congenital heart defect that could have been picked up had she received screening when she was born. She appeared perfectly healthy. I had all the prenatal tests, including a 20 week ultrasound. Everything was normal. So we were under the impression that she was a perfectly healthy baby with a perfect heart. She died suddenly. They found that she had this heart defect that could have been fixed surgically, had we known about it. So when I learned about pulse ox screening, that this could have been done, it really made me angry that she had not been screened. I hope that one day all babies are tested before they leave the hospital, so that no baby dies from a treatable condition the way my daughter did.

(2:42)

## HOW DOES CCHD SCREENING WORK?

**Elizabeth Bradshaw, MSN, RN, Children's National Medical Center:** CCHD screening should be done at or as close to 24 hours of age as possible. We screen the right hand and the right foot. They perform a pulse ox measurement on both of those.

**Female Narrator:** The pulse ox screening measures your baby's blood oxygen levels. If the levels are normal, that's all there is to it. If the levels fall below the normal range, the test will be conducted more times to ensure accuracy and an average reading

(3:14)

## WHAT HAPPENS IF MY BABY'S SCREENING IS NOT NORMAL?

**Female Narrator:** If the pulse oxygen levels recorded are lower than normal, your baby will be rescreened because sometimes babies take time to adjust to breathing outside the womb.

**Female RN:** If a screen does not give the results that we are looking for, we do multiple screens. If at the end of those multiple screens, the results are still not what we want, we are in touch with the baby's pediatrician, and they determine what the next course of action is.

**Female Narrator:** The goal is to be sure to catch any concerns for your baby's health before he or she leaves the hospital. Of course no screening can catch all heart defects or other issues. If you notice that your baby has any of the following signs or symptoms of CCHD, be sure to consult your pediatrician immediately.

(Two slides depicting signs and symptoms of CCHD)

(4:18)

## WHY IS CCHD SCREENING SO IMPORTANT?

**Elizabeth Starks, MS, CGC, Genetic Alliance:** We think that it's so important to catch babies that have any treatable condition early. So in addition to the heel stick, in addition to the hearing screening, we think that CCHD screening fits in so nicely because we can save babies' lives, and that's huge.

**Female Narrator:** Approximately 8 of every 1,000 infants born have a form of CHD. While this screening can't detect all forms of CHD, it helps with early identification of some at-risk babies.

**Gerard R. Martin, MD, Children's National Medical Center:** Our goal ultimately is that no baby with critical congenital heart disease will leave a nursery and not be treated for a condition in which we have excellent results.

**Female RN:** We want all newborns that are leaving the hospital to have access to the CCHD test. And we have tried to show that that's possible.

**Female Voice:** We really want parents and providers to know that CCHD screening using pulse oximetry can improve outcomes and potentially save lives.

**Second Female Voice:** This is just another test in the panel that is for the benefit of your baby to give your baby the best chance at living a long healthy life.

**Female Narrator:** To learn more about CCHD screening using the pulse ox test, ask your health team. You can also go to [Baby's First Test](#).