

Newborn Foundation Screening (10:01)

NEWBORN FOUNDATION

1% OF ALL NEWBORNS HAVE SOME TYPE OF CONGENITAL HEART DEFECT

Annamarie Saarinen, Newborn Foundation & 1in100 Founder, CCHD Parent Advocate: At two days old, we heard an innocent murmur. The innocent murmur turned out to be critical congenital heart disease. Our baby was in heart failure at two days old and we didn't know it. We are now able to use a very simple, cost-effective, completely pain-free tool to evaluate babies for hidden heart defects. It's by far the most prevalent birth defect. We've long needed an extra screening tool for this disease, and now we have one. We have something that can catch this number of heart problems in the newborn nursery. It's a beautiful, beautiful tool.

(0:45)

NEWBORN SCREENING FOR CRITICAL CONGENITAL HEART DISEASE

Dr. Jamie Lohr, MD, University of Minnesota, Amplatz Children's Hospital: There are some severe forms of congenital heart disease that can be difficult to diagnose in the first few days of life, and using a screening technique like pulse oximetry, which is painless, comfortable for the infant, rapid and inexpensive, can help us detect those forms of congenital heart disease before they become symptomatic. I think it's something that we can do very easily for our children to improve their health and make the newborn period safer for all babies.

(1:17)

FEWER THAN 50% OF HEART PROBLEMS ARE DETECTED DURING PREGNANCY

Amy Gaviglio, Genetic Counselor, Minnesota Department of Health, Newborn Screening Program: You can't tell a child has this by looking at them, and oftentimes they actually look perfectly healthy at birth. They look beautiful. They have great Apgar scores. They're crying. They may be discharged to home at a normal schedule. And then things go wrong.

Dr. Emily Borman-Shoap, MD, Medical Director for Newborn Care, University of Minnesota, Amplatz Children's Hospital: They can get really sick, really fast. They can go into what we call shock, where blood isn't flowing to different parts of their body. They can become what we call cyanotic, where their body isn't getting enough oxygen and they turn blue. So it's really scary. And it can go from non-life-threatening to life-threatening in a matter of hours.

Amy Gaviglio, Genetic Counselor, Minnesota Department of Health, Newborn Screening Program: And it's important to have that check before they leave the hospital for us to look and make sure that if there is something wrong, we know about it. We know about it as quickly as possible.

(2:09)

CONGENITAL HEART DISEASE IS A PROBLEM WITH THE STRUCTURE AND FUNCTION OF THE HEART THAT IS PRESENT AT BIRTH

CONGENITAL HEART DISEASE IS THE MOST COMMON BIRTH DEFECT

Dr. Jamie Lohr, MD, University of Minnesota, Amplatz Children's Hospital: About a third of the infants with congenital heart disease have very serious forms of congenital heart disease that require intervention as a newborn to prevent very serious consequences, and we call those critical congenital heart disease. And with those babies, we can intervene appropriately and really improve their outcomes, and the long-term outlook for their lives.

(2:45)

3% OF INFANT DEATHS EACH YEAR ARE DUE TO CONGENITAL HEART DEFECTS

Dr. Emily Borman-Shoap, MD, Medical Director for Newborn Care, University of Minnesota, Amplatz Children's Hospital: What we can do for babies with congenital heart disease is incredible, even compared to what it was 10 years ago, or even five years ago. And that's really, you know, when we say we're going to do a screening test, you want to know that you're going to be able to do something with that result that's gonna improve the health of that child.

(3:11)

EVERY NEWBORN SHOULD BE SCREENED FOR CRITICAL CONGENITAL HEART DISEASE

Dr. Jamie Lohr, MD, University of Minnesota, Amplatz Children's Hospital: The pulse oximetry screening that we do is done ideally when the baby is over 24 hours of age, but certainly right before discharge. It's meant mostly for asymptomatic babies who are in a normal nursery and haven't had any other problems with their heart. It's done with a light which detects the level of oxygen in the bloodstream. It's a very small probe that is wrapped around the baby's hand or foot. It's painless for the infant. Generally we get a very accurate reading very rapidly

(3:46)

Marylou Salzer, RN, Newborn Family Care Center, Amplatz Children's Hospital (speaking to birth mother): I'm coming in to do the test for the congenital heart defects. This is a screen that we do on all babies to detect...

Marylou Salzer, RN, Newborn Family Care Center, Amplatz Children's Hospital: Every family that I've worked with has been very happy to have this screen done on their baby. We screen babies at bedside because they're going to be most comfortable with the mom or dad. So, the best place to do it would be having the mom holding the baby, or in the bassinet in the room. We try to screen babies when they are calm and comfortable, and in not too much of a deep sleep, or moving around too much. The type of sensor we use is used on all babies. It doesn't matter what skin tone or color the baby is, or whether or not they're jaundiced. It is still going to give an accurate reading.

(4:37)

Shannon Youngberg, RN, Newborn Family Care Center, Amplatz Children's Hospital: We want the baby's skin to be preferably warm and dry. If they're cold, the sensor may not pick up as well and, if it's wet, the probe may not stick. For the screening, you should always use an appropriate size sensor and wrap. We screen babies using the right hand or either foot. We found that starting with the foot seems to be more helpful cuz once you get up to the hand, babies tend to get a little more fussy and close their hand. So you want to start with either foot, with the detector on the fleshy part, and the emitter on top. You want to place it on the outer thinnest portion of the foot. For the hand, you want to do the same sort of placement. When placing the sensor on the skin, there should be no gaps between the sensor and the skin. It takes maybe three minutes, maybe five minutes if you have a fussy baby, but it's very quick and very simple. Technology for screening varies, but it is recommended that the motion-tolerant pulse oximeters be used to achieve the highest accuracy in newborns. This protocol calls for either a reusable sensor or a disposable sensor. Either one is fine for the screening. If you are using reusable sensors, make sure you're cleaning them properly in between each use. So 97% is measurement of how much oxygen is in your baby's blood, which is a great number. A baby that is 95% or greater is an automatic pass. If a baby gets a reading between 90 and 94%, we repeat their procedure in an hour. If again they are between 90 and 94%, we repeat it in another hour. If they fail at that point, then we notify the primary care provider. Any baby who is 90% or less automatically fails and we notify the primary care provider at that point. If there is a 3-point differential between either extremity, that would call for a repeat also.

(6:48)

Becky Gams, RN, CNP, Perinatal Nurse Leader, University of Minnesota, Amplatz Children's Hospital: Parents are very reassured. They're taking their baby home and their baby has been screened to be healthy. You don't know that something couldn't go haywire still at home, and we hope that it doesn't, but at least we've gotten the screen. It's not a diagnostic tool. And that's something that we have to be careful to share with parents. Nurses are very happy to be able to offer this screening tool to our families. They know that they've offered one more thing to our families to make sure that their babies are going home to a safe environment. They

know that they're making a difference and a great contribution to our families that we take care of in our hospitals.

(7:21)

25% INCREASE IN DETECTION OF HEART PROBLEMS BY ADDING PULSE OXIMETRY SCREENING

Amy Gaviglio, Genetic Counselor, Minnesota Department of Health, Newborn Screening Program: That's the beauty of a universal screening program is that every child has the same opportunity for the same level of healthcare. And for those children who have abnormal or positive screens that they're quickly getting into a diagnostic setting. And that can be difficult. And that will be a big role for the state health departments in CCHD screening. That's where a big focus should be – is that follow-up. I think our story is very neat, and I think it illustrates a few things – the importance of building the collaborations with different specialists and your stakeholders, but also how screening is completely advocate-driven, and it has been since 1960's. And it's kind of a cool, cool story.

(8:16)

95% OF BABIES WITH HEART DEFECTS SURVIVE AND THRIVE WHEN DIAGNOSED EARLY

Annamarie Saarinen, Newborn Foundation & 1in100 Founder, CCHD Parent Advocate: We've got 40,000 kids a year being diagnosed with congenital heart disease – babies – you know, and we're losing 4,000 of them. And that number, that sort of 10%, just hasn't changed in a long time. And if we've got one simple thing that we can do, there's no reason not to do it. My daughter is a testament to that. I mean just today she had a routine checkup. She is a precocious, active, overactive 3-year-old that just goes in for routine cardiology visits. And thanks to early detection of her heart defect, she was able to get the right cardiac care, the right surgical intervention, and will lead a beautiful life.

(9:12 speech stops and slides with informational text continue until 10:01)