Newborn Critical Congenital Heart Disease – Pulse Oximetry Testing (4:40)

TEXAS PULSE OXIMETRY PROJECT

Mom of baby with congenital heart disease: I was 29 years old and we were finding out that we were having our first child. She arrived beautiful as can be; full head of black hair; and we're both just crying with tears of joy meeting her for the first time. We brought her home, thinking everything was okay. She gained enough weight to where she was growing out of one set of size clothes. So she was healthy. We thought she was healthy. I went to Target one day. We came home, and I was holding her in her room, and she made this sound that didn't sound right to me. When I looked at her, she felt limp in my arms, and that's when I knew things aren't okay. I saw labored breathing and I immediately started CPR, and called 911. The ambulance arrived, and they just grabbed her, and ran to the ambulance. I just remember the number four, so let's start ruling it out. Do all the tests so you can rule out seizure disorder. Do all the tests for the metabolic disorders. What did I do wrong? How did I not know that my child was so sick? That same night around 11 o'clock, the doctor said, "We need to sit down and talk. She has a heart defect." Nobody talked to me about screening. Nobody gave me the option. Nobody told me it was the most common defect. Otherwise, I wouldn't have taken that risk to take her home without her being tested. She stopped breathing for long enough to cause significant brain damage. She was struggling, even though she was intubated and they were breathing for her. They kept running tests, and I just remember hearing – sitting beside her, wanting to hold her, and hearing the machines go off because something was wrong. Something was wrong with the machines to alert the nurses and doctors. And we went through that all night long. We held her when she took her last breath. And I remember kissing her and all her jet black hair. We left the hospital with the car seat that was empty.

(2:47)

Alice Gong, MD, Professor of Pediatrics, UT Health Science Center, San Antonio: I'm a neonatologist at the University of Texas Health Science Center at San Antonio. I'm here to tell you about a new newborn screen that is done on apparently healthy babies, and involves the use of pulse oximetry. If we find a low reading on the pulse oximeter, then the baby is referred to get diagnosis. With diagnosis, we may be able to pick up a group of conditions called critical congenital heart diseases. You've heard Vee Kennedy's heartbreaking story about her daughter, Taren, who died of an unidentified total anomalous pulmonary venous return, TAPVR, a critical congenital heart disease that could have been found through screening, although the information about the screen was not available at the time of Taren's birth. Screening should be done after 24 hours of a newborn's life. Because of this screening, we recently found an apparently healthy newborn before discharge with the same life-threatening condition. Miss Fruella's baby, Abe, was able to have corrective surgery before discharge from the hospital, and is doing fine now.

Spanish-speaking mom (English subtitles): I gave thanks to God for everything, and for the fact that the surgery was a success.

Mom of baby with congenital heart disease: I would say to all moms out there, before bringing your baby home, after they've been born for 24 hours, ask the hospital, ask your pediatrician; "I want pulse ox on my baby, and I want you to follow the rules set by the American Academy of Pediatrics, along with the American Heart Association.

(credits roll at 4:30)