



“Taryn’s Story” – 4-minute video

4-minute video script - Produced by UTHSCSA Academic Technology Services Department, on behalf of Texas Pulse Oximetry Project, a joint educational initiative of UTHSCSA Department of Pediatrics, Baylor College of Medicine/Department of Pediatrics and Texas Department of State Health Services

Link to “Taryn’s Story”:

<http://www.youtube.com/watch?v=2lM8hFHUMI4&feature=youtu.be>

Vi Kennedy: I was 29-years-old and we found out that we were having our first child. She arrived beautiful as can be, full head of black hair, and we were 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 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 4, so let's start ruling it out. Do all the tests you can rule out, seizure disorder, do all the tests for the metabolic disorders. What did I do wrong? How, how do 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. And 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, 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, you know, something was wrong. Something was wrong to alert the machines, to alert the nurses and doctors.

And we went through that all, all night long.

We held her when she took her last breath (crying).

(Silence)

And I remember kissing her and all her jet black hair.

We left the hospital (pause) with the car seat, and it was empty.
(Silence)

Dr. Alice Gong: 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. It involves the use of pulse oximetry. If we find a low reading on the pulse oximeter, then the babies are 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 Vi Kennedy's heartbreaking story about her daughter, Taryn, who died of an unidentified total anomalous pulmonary venous return, TAPVR, a critical congenital heart disease that could have been found through a screening, although the information about this screen was not available at the time of Taryn's birth. Screening should be done after 24 hours of a newborn's life.

Because of this screening, we recently found an apparently healthy baby before discharge with the same life-threatening condition. Ms. Varale's baby, Abe, was able to have corrective surgery before discharge from the hospital and is doing fine now.

Ms. Varales (Speaking Spanish) I gave thanks to God for everything, and for the fact that the surgery was a success.

Vi Kennedy: 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.