



NEWBORN SCREENING FOR CRITICAL CONGENITAL HEART DISEASE (CCHD)  
IN NEVADA

Testimony on behalf of the  
March of Dimes  
Before the Interim Health Committee

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My name is Michelle Gorelow. I am the Director of Program Services, Advocacy, and Government Affairs for the March of Dimes Nevada Chapter. I am here to discuss SB92, which was passed during the 2013 legislation session. SB92 will require all birthing hospitals to screen for critical congenital heart disease using pulse oximetry as part of the newborn screening program.

Newborn screening program is a public health program designed for early identification of disorders in newborns shortly after birth that are not evident and can affect their long term health including brain damage, organ damage, and even death. Early detection, diagnosis, and treatment can lead to a significant reduction of death, disease, and associated disabilities.

Newborn screening programs in the United States began with the work of Dr. Robert Guthrie, a March of Dimes funded researcher who in the 1960's developed a screening test for phenylketonuria, also known as PKU. PKU is a rare condition in which the baby is born without the ability to breakdown certain amino acids. When undetected, it can lead to irreversible mental retardation.

Over the last 40 plus years, other tests have been added to the program. The 90's saw a large expansion of tests due to advances in technology. The Uniform Panel increased from 11 tests to 29, and now with the addition of a few more conditions, the panel recommends each state screen for 31 conditions.

In 2010, critical congenital heart disease screening using pulse oximetry was recommended to be added to the panel. CCHD account for 7 different diseases: Hypoplastic left heart syndrome, pulmonary atresia w/ intact septum, Tetralogy of Fallot, Total anomalous pulmonary venous return, Transposition of the great arteries, Tricuspid atresia, and Truncus

arteriosus. These are considered rare with only 7,200 babies a year being born with one of the conditions or 18 out of 10,000 babies.

I would like to share a story of a family that had a child with a CCHD.

Cora's story – (this was shared by Cora's family with the CDC and copied from the CDC website): After a healthy and normal pregnancy, I gave birth to my daughter, Cora, on November 30, 2009. Two days later we took her home, after getting a clean bill of health at the hospital. The next 3 days were spent cuddling, getting to know each other, and waking every few hours to feed her.

“One early morning my husband handed Cora over to me because she seemed hungry. I started to feed her and everything was going great. I looked up at my husband to tell him I loved him. When I looked back down, Cora was pale, gray, and not breathing. We raced to the hospital, which was no more than 5 minutes away, but it was too late. Cora was gone. We learned from the coroner that she had an undetected congenital heart defect. Neither of us had ever even heard the term.

“We later learned about a type of screening—pulse oximetry—that might have helped identify Cora's heart defect before it was too late. While we'll never know for sure if it would have made a difference for Cora, we sure wish she'd had the simple screening. Cora's story is extremely sad, but it's also full of hope. In Indiana, where we live, a new law requiring newborn heart screening with pulse oximetry is named after her and is known as Cora's Law.

“As for now, I hope for a day when no mother finds out about her child's heart defect from a coroner. I hope that undetected congenital heart disease becomes a thing of the past. And, ultimately, I hope that one day congenital heart disease can be prevented and that no baby is born with a broken heart.”

Although Nevada hasn't had any Cora's stories, that doesn't mean that critical congenital heart disease isn't happening to Nevada's babies. With the high rate of women not receiving prenatal care, it is only a matter of time before Nevada does have a story like Cora's.

Besides screening for critical congenital heart disease, pulse oximetry is also finding several secondary conditions.

Per Dr Andy Ewer from the UK – “Just wanted to let you know that we picked up an undiagnosed congenital diaphragmatic hernia on the postnatal wards last week. Baby was essentially asymptomatic but has sats in low 80s, screened at 6 hours. Now ventilated and on Nitric oxide but stable. Could have easily collapsed on the wards if not picked up. An added

benefit of CCHD screening using pulse ox is that it saves babies like this one as well as those with critical congenital heart disease!

Per Lisa Horn, RN, Esq. from Children's National Heart Institute - The list of secondary targets continues to grow as more and more babies are being screened...recently I've heard about GB strep pneumonia, hemoglobinopathy and other non-CCHD forms of CHD all detected as a result of CCHD screening implementation. Exciting that we are identifying them earlier!

And lastly from Dr. Darshak Shanghavi from the Engelberg Center for Health Care Reform at the Brookings Institution and Associate Professor of Pediatrics at the University of Massachusetts Medical School - "From a public health perspective, neonatal infection, sepsis and pneumonia can all be treated more effectively if the conditions are detected early. Incorporating routine pulse oximetry as a universal 'vital sign' in newborns could be an important global life-saving tool."

Without screening, some newborns with CCHD might be missed, because the signs might not be evident until after the baby has been discharged from the hospital. It is estimated that about 300 infants with an unrecognized CCHD are discharged every year from newborn nurseries in the United States. I ask the committee to continue to support CCHD screening, and continue to require that all Nevada's babies are screened before discharge using pulse oximetry.

Thank you for your time and allowing the March of Dimes to testify.

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