

**Presentation to the Interim Health & Human Services Committee
October 3, 2013, at New Mexico Junior College, Hobbs, New Mexico
on Critical Congenital Heart Disease, and Post-natal screening.**

Presenters are:

Sheridan Gluff,- parent, CCHD Advocate, Roswell, NM
Dr Ron Reid, -State Director Program Services & Gov't
Affairs, March of Dimes, New Mexico Chapter
Kathy Cooper, -RN, BSN, Lovelace Regional Hospital, Roswell

-Dr Reid will make a brief introduction of presenters, and give a short overview of Critical Congenital Heart Disease.

- Sheridan Gluff will speak of her experience with losing a child because screening is not mandatory. Mrs Gluff will summarize her research on CCHD, and how other states deal with this screening. She will speak to the prevalence of testing as it already exists in New Mexico, and the range of costs with obtaining the equipment, and administering the screening.

- Kathy Cooper, RN, BSN, will relate her experiences as a nurse in the Neonatal Unit at Lovelace Regional Hospital in Roswell, NM. She will explain how the screening is done, and the benefits of the screening. She can answer any medical questions the Committee may have.

- Dr Ron Reid, MoD, NM, will tell of the March of Dimes involvement in supporting implementation of post-natal CCHD screening, both in New Mexico and nationally. He will speak of both the success, and some of the concerns that have been had as other states have addressed this issue, and how the March of Dimes has worked with concerned parties to make the necessary changes for successful legislation.

All three will be available to answer any questions the Committee may have.

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Congenital Heart Disease in the Newborn

The Problem

3 out of every 1,000 babies born every year have a severe form of Critical Congenital Heart Disease. This is our most common birth defect. 23% can be diagnosed with Prenatal Testing and Fetal Ultrasound with only 50% diagnosed with a Physician Exam. The remainders go home as Healthy Newborns but later are identified as Failure to Grow and develop normally, or in Cardiogenic shock or death.

Another Diagnostic Tool

O2 Sat monitoring on every baby in the State of New Mexico after 24 hours of age or right before discharge on those babies going home with an earlier discharge. The Oxygen Saturation is done on the right hand and on a foot. The normal finding is both extremities are above 90. But if one or both extremities is below 90 or if there is a greater than a 3% difference between the 2 readings than we wait an hour and repeat O2 Saturations. If then the findings are again below 90 or greater than 3% difference.... again wait 1 hour and Repeat. If there is a failed O2 Saturation 3 times than this is considered a Great Concern. The next step is Echocardiogram with reading by a Pediatric Cardiologist to determine the severity of these results.

Pros

Very easy. This test takes 4 - 10 minutes to accomplish. There is no need for additional Hospital Staff. Low in cost - about \$6.28 cents for the Oxysensor with a machine that certainly all hospitals have in house to monitor patients.

Cons

Certainly for our State of New Mexico there is a concern over the accomplishment of the Echocardiogram. At this moment only the 3 major Hospitals in Albuquerque are set up to do infant echocardiograms with 24 hour 7 days capability of being read by a Pediatric Cardiologist. In just days to a couple of weeks Farmington, Las Cruces and Roswell will have that capability. What about the outlying regions?? How do we make access available to every newborn with a failed O2 Sat? One thought would be to send every baby with a failed O2 Sat reading to a regional area by road ambulance. At this center the echo could be done, read by a Pediatric Cardiologist and the severity

of a defect determined. At this point this precious baby would be either flown to Albuquerque or scheduled for follow up as necessary according to any defects found.

Concerns for liability in regard to the accepting Doctor at the Regional Center.

The capability of the Regional Hospital to care for the Echocardiogram findings.

Who would organize this in our State??

Does our State have the number of Pediatric Cardiologists to read the Echocardiograms and to provide the necessary care??

I have been a Registered Nurse in Roswell caring for Newborn Babies for 34 years. Certainly it is the one of our happiest days of our entire life to welcome a new baby into our Family. This is a job that has brought me a great amount of Joy. To some families this Day represents one of the saddest days of their lives. I have certainly been a witness to this and can testify of the deep tragedy that affects everyone involved. In my own individual case in Roswell in the past 5 years, I know of 3 infants an O2 Sat would have been able to recognize a severe congenital heart disease. One, is our precious Ryan the March of Dimes Baby of the year, the second baby came into our hospital in severe cardiogenic shock, close to death who came in at 2 weeks, flown to Albuquerque then flown immediately to Stanford where surgery was performed. The 3rd one picked up at the Dr. office at 2 days of age, flown to Albuquerque with surgery: doing well before and after surgery. The o2 sat monitoring is so easy to perform and research proven to be so effective in recognizing cardiac defects. I wish every hospital was using such a simple diagnostic tool. I recognize the problem is the next step of echocardiograms. I am thankful to be living in Roswell where we will soon have the capability of providing echocardiograms with 24 hour 7 days a week reading of results by a Pediatric Cardiologist.

Thank you with all my heart for listening and evaluating this very Heartfelt need.