

Report from the CCHD

[Critical Congenital Heart Disease]

Subcommittee

For the Texas Newborn Screening Advisory Committee
Friday, October 19, 2018

1

Subcommittee Members

- Benna Timperlake, BSN
- Carriston Hendricks, FNP-C
- Joe Schneider, MD
- Linda Zediana, RN
- Scott McLean, MD (chair)
- Tiffany McKee-Garrett, MD

2

Background

- Charge: “to evaluate methods for improving the quality of the Texas CCHD screening program.”
- NBSAC meeting July 2018
 - Dr. Freedenberg and Dr. Schumate presented data and analyses
 - The number of cases of CCHD reported to TDSHS annually between 2015 and 2017 has been steadily declining
 - There is very uneven reporting across institutions in Texas

3

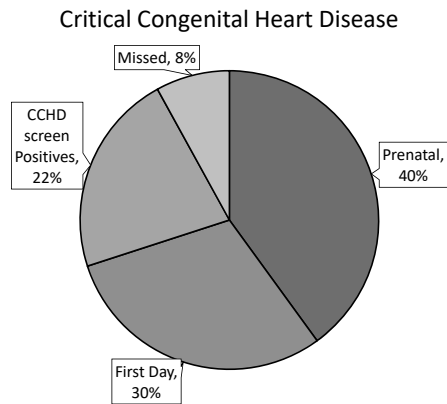
Background, continued

- The average number of cases of CCHD ascertained by active birth defects investigations is about **700 per year** over the past 17 years
- Texas newborn screening for CCHD, using the reporting methodology in place, is picking up about a quarter of that – **174 during our best year** in 2015
- Consequently, Dr. Guillory requested that the CCHD Subcommittee “work on guidelines of how to increase reporting” of CCHD.

4

Reporting

- The reporting of confirmed diagnoses of CCHD to the Texas Newborn Screening Program is required by statute
- **40%** of cases are detected prenatally
- Another 30% are clinically detected within the first 24 hours of life
- CCHD is attempting to detect the remaining 30% of cases
- Pulse oximetry has 75% sensitivity
- A specific Reporting Form **must be mailed or faxed** to the CCHD Program to the Texas Department of State Health Services Newborn Screening Genetics Branch



5

Alert! Warning! Danger!

- **Reporting of confirmed cases of CCHD is not to be confused with reporting that CCHD screening was accomplished.**
- Though these are linked, they are separate and distinctly different events. We (I) sometimes confuse them in our discussions!



6

CCHD Quality Metrics

- Reporting of confirmed cases per se should be understood to be just one of several ways to measure the quality of CCHD screening
- What we would also like to measure would be how efficiently CCHD screening identifies CCHD that is not clinically diagnosed during the prenatal and perinatal periods.
- The metrics that would be most useful would be
 - A. the percentage of newborns that have CCHD screening
 - B. the percentage that have technically correct screening
 - C. the percentage of positive screens that are acted upon appropriately
- Texas Administrative Code (Chapter 37 §37.75 – 37.79) does not include any requirements for communicating this data to the Texas Newborn Screening Program.

7

CCHD subcommittee Telephone Conference 9/20/2018

- CCHD screening can be documented via TEHDI
 - Requires purchase of the module by individual hospitals.
 - Some hospitals do use the CCHD module now.
 - Mr. Martinez was going to see if he can find more information.
- Can reporting confirmed cases of CCHD via the birth defects registry satisfy reporting requirements?
- The big question – what are we trying to accomplish?
 - The law as currently written may be so weak that it would be futile to devote a significant amount of resources to enforcing its implementation.
 - However, if the TEDHI CCHD screening documentation module works, maybe changing the law should be considered.

8

Telephone Conference

- TDSHS is unable to measure CCHD screening and is unable to enforce the reporting of confirmed cases.
- Might other entities have roles to play?
 - In encouraging universal, uniform, technically adequate pulse oximetry screening (A, B, and C)
 - In setting a community standard that confirmed cases must be reported



9

Telephone Conference

- Who would dare step forward to serve as Texas' CCHD Screening Champion?
 - Pediatricians via TPS
 - Neonatologists
 - Texas Neonatal Regional Advisory Committees
 - TMA
 - THA
 - Texas Hospital Association (THA)
 - Webinar on Oct. 9: Best Practices to Improve Newborn Screening
 - Cardiologists
 - Nurses



10

Options for improving the reporting of confirmed diagnoses of CCHD to the Texas Newborn Screening Program

Optimize the percentage of newborns that have timely, technically accurate pulse oximetry screening that is acted upon appropriately

Consider requiring documentation using the TEDHI CCHD module

- Assess efficacy in current users of the TEDHI CCHD module
- Consider pilot project to assess the efficacy of the TEDHI CCHD module in a larger and more representative cohort of locations that obtain newborn screening
- Would require changes to the Administrative Code
- Would increase costs

Find and support a Champion that could promote CCHD screening and reporting quality

- Nurses
- Cardiology
- Neonatology
- Pediatrics
- Hospitals