

**Critical Congenital Heart Disease (CCHD)
Subcommittee Meeting Minutes
January 26, 2018
10:00 a.m.
Conference Call**

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Scott McLean, MD (Chair of Subcommittee)	P		Joseph Schneider, MD	P	
Tiffany McKee-Garrett, MD	P		Linda Zediana, RN	P	

Yes: Indicates attended the meeting **No:** Indicates did not attend the meeting **P:** Indicates participated by phone

Table 2: Newborn Screening Unit and other guest attendance.

HHS/Other STAFF NAME	YES	NO	HHS/Other STAFF NAME	YES	NO
Debra Freedenberg, MD, PhD, Medical Director	Yes		Carriston Hendricks, MSN-FNP	P	
Beth Rider, RHIA, NBS Program Specialist	Yes		David Martinez, Unit Mgr.	Yes	

SUBCOMMITTEE MEETING NOTES:

The meeting was called to order at 1:07 p.m. by Subcommittee Chair, Dr. Scott McLean. This meeting was held via conference call and was audio recorded. Dr. McLean greeted everyone and requested attendees introduce themselves. For transparency, Dr. Joe Schneider disclosed that he has a vested interest in the Texas Early Hearing Detection and Intervention (TEHDI) system.

Recap of Last Subcommittee Meeting:

The last meeting was held on December 5, 2017, and minutes were distributed via email by Ms. Rider. Dr. McLean reminded the members that the product is to advise the agency on any policy, strategies, rules, and services that address methods for improving the quality of CCHD screening. The discussion last meeting included the underreporting of CCHD and the difficulty in measuring this. Additional articles were sent to the members after the meeting.

Subcommittee Meeting Discussion:

Dr. Schneider reviewed the current CCHD reporting form and suggested we continue to discuss finding a mechanism for reporting screening results electronically although the law doesn't support that currently. Dr. McKee-Garrett seconded the need for an electronic reporting mechanism. Perhaps this could be included as part of the "report card." Dr. McLean mentioned there isn't an actual percentage of babies missed for screening. The

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timeliness is what is reported on the report card. The committee discussed that the CCHD screening is mandated, but only the confirmed cases are mandated to be reported to the agency. The committee also discussed other state mandates for screening, which included New Jersey. New Jersey collects data on failed screens from a CCHD screening module built into the birth defects registry with a follow up to hospitals for clarification as needed. New Jersey collects individual level CCHD screening data on all live births through the electronic birth certificates. The committee discussed the historical information regarding the possible use of the TEHDI Management Information System (MIS). Mr. Martinez stated the legislation didn't authorize the agency to utilize that system and only diagnosed cases were mandated to be reported. Dr. Freedenberg reiterated that the care for an infant is needed immediately and the agency wouldn't be in the middle of prompt patient care. We share data with birth defects but the information is not real-time. The general number for heart disease is one percent of the population and the CCHD is 20-25 percent of that one percent.

The committee discussed the possibility of advising that a quality research study be conducted, and include a sample of cases screened to determine that screening is done appropriately. Dr. McKee-Garrett mentioned the TxPOP includes an algorithm to allow for re-screening. Dr. Freedenberg replied that there are specific guidelines for pulse oximetry use to meet the CDC criteria.

Dr. McLean suggested a recommendation to make the observation to the agency that CCHD screening is less than ideal and further study via NBS Unit or consultants is warranted to determine if there is a concern by taking an epidemiologic approach and include electronic reporting.

Ms. Carriston brought up the concern that there is not adequate education regarding the CCHD. The hope is birthing facilities do adequate education but maybe it's not standardized. The information is out there but not utilized, especially in rural areas. There is a pamphlet from TxPOP and is currently in the NBS CCHD toolkit. The challenge is new parents are receiving a lot of information and may not be retaining any educational materials regarding CCHD. The discussion included looking at education for parents prenatally. There was discussion on how to approach parents-to-be via digital or social media.

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Recommendations Next Steps/Ideas:

Based on a comparison of numbers of cases of CCHD reported to the Texas Department of State Health Services (DSHS) to the expected number of cases, as well as anecdotes that some infants are not being screened, the subcommittee members believe that it is reasonable to question that the CCHD newborn screening process is not working as ideally as it could. The subcommittee notes that current State policy does require universal, uniform CCHD screening; however, neither the universality nor the uniformity of the process can be measured, which brings the quality of information into question.

The subcommittee recommends further study, to include:

- 1) comparison of Texas CCHD data from the current form with the Texas Birth Defects Registry
- 2) comparison of Texas CCHD data with other states' program experiences
- 3) difference-in-difference analysis
- 4) detailed analysis of the process of conducting and documenting the point-of-care screening
- 5) sampling of quality measures
- 6) expand CCHD education efforts

Dr. McLean adjourned the meeting at 2:44 p.m.