

**Critical Congenital Heart Disease (CCHD)
Subcommittee Meeting Minutes
September 20, 2018
12:00 p.m. – 1:00 p.m.
Conference Call**

Table 1: CCHD Subcommittee member attendance at the Thursday, September 20, 2018 meeting.

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		X

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

Table 2: Newborn Screening Unit (NBS) and other guest attendance.

NBS STAFF NAME	YES	NO	GUEST NAME	YES	NO
David Martinez	Yes		Carriston Hendricks, MSN-FNP	P	
Aimee Millangue	Yes		Benna Timperlake, RN	P	
Patricia Lanfranco	Yes				

BACKGROUND OF SUBCOMMITTEE:

The CCHD Subcommittee was created at the October 27, 2017 Newborn Screening Advisory Committee (NBSAC) meeting. The subcommittee met twice previously, on December 5, 2017 and January 25, 2018.

During the July 16, 2018 NBSAC Meeting, Chair Dr. Charleta Guillory asked that the subcommittee meet for a third time. Prior to the meeting, Dr. McLean sent an e-mail to subcommittee members and subject matter experts summarizing the CCHD reporting discussion from the meeting.

SUBCOMMITTEE MEETING NOTES:

The meeting was called to order at 12:05 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.

Dr. McLean gave an overview of the presentations and discussion on CCHD reporting from the July 16 Meeting. Dr. Debra Freedenberg, Medical Director, Newborn Screening Unit, and Dr. Charles Shumate, Birth Defects and Surveillance Branch, presented data and analyses comparing the Texas CCHD data from the current form to data from the Birth Defects Registry. The data shows a decline in the number of cases being reported through

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newborn screening from 2015-2017 and an uneven response rate among institutions. The number of cases reported are also not close to approximating the number of cases investigated and tracked through the birth defects surveillance system, which seems to indicate underreporting and non-compliance with the reporting requirement. As a result, the NBSAC Chair, Dr. Charleta Guillory, gave the subcommittee the charge to work on guidelines on how to increase reporting on CCHD.

Subcommittee Meeting Discussion:

- About 40% of CCHD cases are detected prenatally and 30% are clinically detected within the first 24 hours. Even if CCHD newborn screening through pulse oximetry only has a 75% sensitivity rate, the intent of the screening to find the remaining 30% of babies so they receive necessary care in a timely way.
- There are issues with the current law as it is written since it only requires reporting of diagnosed cases.
- It is not clear who is responsible for reporting CCHD, such as those attending the birth, and it is not mentioned in Texas law or rule.
- Considering a law change may result in unintended adjustments or statute changes that could adversely impact the newborn screening program.
- Possible reason for facilities not complying with reporting requirement may be that the current reporting form on DSHS website is two pages and must be printed, completed, and faxed, a total manual process.
- CCHD differs from other conditions on the Texas Newborn Screening Panel in that it is a point of service test, so cases are not sent to DSHS for follow up by DSHS staff.
- The current system is not designed to capture cases since the intent of point of service testing is to necessitate immediate management of care. Reporting of data for case management by the state may delay a referral to cardiology or other action, which makes a difference when urgent care is needed.
- While it may be helpful to streamline processes through a website or web-based system, CCHD reporting is not currently linked to the other point of service newborn screen, hearing screening.
- By law, hearing screening is captured in the Texas Early Hearing Detection and Intervention (TEHDI) Management Information System (MIS). Current state mandates do not provide support for the use of the TEHDI MIS for CCHD reporting.
- The current vendor for the TEHDI MIS offers individual hospitals the option to independently purchase a module to document CCHD

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screening. However, there is concern that there can be miscommunication about which modules are required by DSHS and lead to confusion regarding hearing screening requirements and CCHD reporting.

- David Martinez, NBS Unit Manager, can try to get more information how the module is working out for hospitals who have adopted it.
- An idea - possible evaluation of the CCHD module. Analyze if the numbers indicate better quality and quantity of CCHD reporting.
- A suggestion was made to have DSHS recognize hospitals who adopt a “best practice” in CCHD reporting.
- There was also a question of whether CCHD screening reporting may be necessary at all. If reporting alone is the goal, is it possible the data from the birth defects registry satisfies the intent of requiring CCHD reporting. If so, the minimum requirement of the law is met, and no further resources are needed for implementation and enforcement.
- If increasing CCHD reporting is still the goal, it may be helpful to target education to and get the insights about reporting and quality from the hospital staff who treat CCHD and have a stake in the outcomes, such as cardiologists, cardiac and NICU/PICU/CCU nurses, advanced practice nurses, and cardiothoracic surgeons.

Recommendations/Next Steps/Ideas:

- Mr. Martinez will find old fiscal note from the proposed legislation regarding the cost of a component/module that would capture CCHD information for the TEHDI MIS.
- Subcommittee agreed to continue discussion over e-mail and put together a report for the full NBSAC committee at the October 19 meeting.

Dr. McLean adjourned the meeting at 1:02 p.m.