

Critical Congenital Heart Disease (CCHD) Workgroup
Tuesday, April 2, 2013
11:00a.m. – 3:00p.m.

University of Virginia
The Inn at Darden
100 Darden Blvd.
Charlottesville, VA 22903

MINUTES

CCHD Workgroup Members (check = present)

Jann Balmer, UVA	Dr. Paul Matherne, UVA (Chair)
Dr. Robert Boyle, UVA	✕ Dr. Manuel Peregrino, Pediatrix Med. Group
Elizabeth Bradshaw, CNMC	Chris Ramos, AMA
Tammy Eberly, UVA	Aimee Siebert, The Hillbridge Group
✕ Cathleen Grzesiek, AHA	Susan Ward, VHHA
✕ Dr. William Harp, DHP	Dr. James Thompson, Pediatrix Med. Group
✕ Karen Hendricks-Munoz, VCU	Dr. John North, Inova Fairfax
✕ Delegate Patrick Hope,	Dr. William Moskowitz, VCU
✕ Ann Hughes, MSV	✕ Dr. Robert Shor, Virginia Heart
✕ Dr. Jamil Kahn, CHKD	✕ Paul Speidell, VHHA
Jodi Lemacks, Mended Little Hearts	✕ Dr. Herbert Whitley, Carilion Clinic
Sara Long, MOD	✕ Dr. Kent Willyard, TPMG
	✕ Cal Whitehead, Whitehead Consulting, LLC

Recorders: Cathy Cornelius and Rafael Randolph
Guests: Shahid Hafidh, VDH
VDH Staff: Cathy Cornelius, Kathy Moline, and Rafael Randolph

- 1) Welcome and Introduction: K. Moline
 - a) Attendees stated their names and affiliations.
- 2) Review of Minutes: K. Moline
 - a) Minutes were approved.
- 3) Public Comments: K. Moline
 - a) No public comments
- 4) Lessons learned from the first six months of the grant: P. Matherne
 - a) Site Preparations – Cathy Cornelius
 - (1) Challenges identified are:
 - (a) Data Collections
 - (b) Data Entry
 - (c) Submission of data to VDH

- (2) The biggest challenges concerning data are:
 - (a) Staff time demands to perform data entry
 - (b) Compatibility with internal programs and VDH tool
- (3) Other challenges are:
 - (a) Staff Education
 - (b) Parental Education
 - (c) Implementing additional screening while maintaining Baby Friendly certification
- b) Data – Shahid Hafidh
 - a) Discussion of the development and refinement of the data collection tool and review of site data collections of CCHD screening results.
 - b) Discussion and review took place of raw data results from state-wide survey of all birthing centers to assess the state’s capacity for CCHD screening.
- c) HRSA Meeting in Atlanta – Kathy Moline
 - a) Several states were in attendance and discussions were had on the issues and challenges with implementing CCHD screening.
 - b) Virginia stands slightly above average when compared to the rest of the nation. There are some data issues that we are dealing with that some other states did not.
 - c) All of the requirements for year one of the grant have been fulfilled.
- 5) Data Collection and lessons we are learning: S. Hafidh
 - a) Findings from the first two months of data collection (January/February 2013) were shared with the group. Data from Martha Jefferson Hospital (MJH), Winchester Medical Center (WMC), and University of Virginia Hospital (UVA) were presented on total number of pulse oximetry screens entered into the CCHD Data Entry form compared to total births during the time period; and average time after birth, in hours, in which newborn screening is conducted.
 - b) There were no positive screens reported during this time period. The average time after birth in which screens were conducted for all three reporting hospitals was 29.77 hours when combined. A question was raised as to how to define “according to protocol” when measuring the appropriate time for conducting screening after birth.
 - c) Additional training/follow-up with demonstration site staff was identified as a need to ensure proper data entry, specifically in relation to time and date entry, and ensuring that multiple screen data is entered in one newborn record, and not duplicating data entry for the same newborn.
- 6) Education – T. Eberly
 - a) Discussed CCHD screening webinar for professionals (physicians, nurses, and other staff) which took place on March 28, 2013. The webinar was offered to all of Virginia’s birthing centers at no cost and fifty-five (55) individuals attended from thirty-three(33) different urls. The webinar will be archived and available for future use for one year. <http://eo2.commpartners.com/users.uva>

- b) VDH and UVA are collaborating to create a Newborn Screening educational platform continuing medical education (CME) and continuing education units(CEU) accreditation for all newborn screening (metabolic and CHHD).
- 7) Parent Education – C. Cornelius & J. Lemacks
- a) Discussed the edits made to the CCHD parental education fact sheet which was recommended at the previous workgroup meeting.
 - b) Results from the workgroup
 - a) The workgroup recommended the use of the parental education fact sheet once final edits are made.
- 8) Hospital Survey – P. Matherne & S. Hafidh
- a) The fact that close to 90% participation was recorded on the March 2013 Statewide Survey to assess the extent to which CCHD is being screened via pulse oximetry in Virginia Hospitals was shared. All survey findings were reviewed. Consensus was heard among workgroup members that since nearly all Virginia hospitals are currently screening, VDH should focus its efforts on ensuring a standardized approach to screening among birthing centers. Findings currently show varying definitions of what constitutes a failed screening, and what to do in the event of a failed screen.
 - b) Workgroup unanimously agreed to pursue the option to enter CCHD screening results on the birth registry.
 - c) Workgroup discussed sustainability of CCHD newborn screening.
- 9) Next Steps
- a) Proceed to add CCHD screening information on birth certificates.
 - b) After minor edits to the parental fact sheet the fact sheet is approved.
- 10) Meeting adjourned at 1:25p.m.