

Critical Congenital Heart Disease (CCHD) Workgroup
Tuesday, August 21, 2012
10:00a.m. – Noon

Virginia Housing Authority
Henrico Room B
4224 Cox Rd.
Glen Allen, VA 23060
Telephone (804) 915-3200

MINUTES

CCHD Members (check = present):

Aimee Siebert,	Dr. William Moskowitz, VCU
Dr. Paul Matherne, UVA (Chair)	Dr. John North, Inova Fairfax
Dr. Robert Boyle, UVA	Chris Ramos,
Elizabeth Bradshaw, CNMC	Susan Ward, VHHA
Dr. Alexander Ellis, CHKD	Cal Whitehead,
Sara Long, MOD	Dr. Herbert Whitley, Carilion Clinic
Elaine Yeatts, DHP	
✕ Dr. William Harp, DHP	

VaGAC and Subcommittee Staff:

Kathleen Moline, Staff - VaGAC & Steering Cmt	Dr. Diane Heletjaris, VDH
Joanne Boise, VDH	Rafael Randolph, Staff – VaGAC
Dr. Cornelia Ramsey, VDH	Dev Nair, VDH

Recorders: Rafael Randolph and Joanne Boise

- 1) Welcome and Introduction: K. Moline
 - a) Attendees stated their names and affiliations.
 - b) Overview of Newborn Screening was given. There are two aspects of Newborn Screening in Virginia.
 - i) Inborn errors of metabolism or physiology
 - ii) Hearing loss
 - c) CCHD (CCHD) was added to the national Recommended Uniform Screening Panel in 2011.

- 2) Overview of CCHD Issue: P. Matherne
 - a) Dr. Matherne gave an overview on screening for CCHD.
 - b) Out of the 4,000,000 births in the U.S. per year, 40,000 are born with Congenital Heart Disease, and out of that 40,000; 8-10,000 are CCHD.
 - c) Somewhere between 2-4% of all babies with CCHD will be discharged undiagnosed.
 - d) Pulse oximetry can identify CCHD in these infants.

FINAL

- i) Detects 100% of infants with pulmonary duct dependent circulation and when combined with routine clinical examination detects 92% of all infants with duct dependent circulation before hospital discharge, and has a higher detection rate than physical examination alone.
 - e) Simplified Protocol
 - i) A pulse oximetry reading in the right hand and either foot after 24 hours of life or before discharge.
 - ii) Screening is normal if oxygen saturation is 95% or higher in either extremity or there is less than a 3% difference between the hand and foot.
 - f) Summary
 - i) Painless
 - ii) Quick
 - iii) Simple
 - iv) Low Cost Supplies
 - v) Life-saving
 - vi) Disability-reducing
 - vii) The right thing to do.
- 3) Executive Directive #4 and HRSA CCHDDP Grant: D. Helentjaris
 - a) The HRSA Critical Congenital Heart Disease Demonstration Project (CCHDDP) grant establishes this workgroup as a subcommittee of the Virginia Genetics Advisory Committee.
 - b) The purpose of this workgroup is to advise the Virginia Department of Health (VDH) on developing clinical protocols for screenings, referral practices that would ensure diagnosis and treatment, public education regarding signs and symptoms, guidelines for training healthcare professionals, and developing estimates of cost. Also, input for screening and referral protocols, how the data are reported to the VDH, and processes for communicating screening results to healthcare providers and follow-up.
- 4) General Discuss – Member Concerns: All
 - a) The HRSA three year demonstration project was awarded to establish protocols, training and data indicators to be reported to VDH. The demonstration project involves a neonatal birth center, UVA, which was chosen because of its existing relationships with Virginia Baptist Hospital, Augusta Health, Martha Jefferson, Rockingham Memorial, and Winchester Medical Center.
 - b) Two things that should make this process less daunting
 - i) Many people are already doing it – so one task is to get some uniformity.
 - ii) Care systems are already defined - so how do we track it?
 - iii) Need to be careful in defining cost of screening, differentiating from costs associated with treatment.
 - c) Cost
 - i) How much will it be?
 - ii) Who will be responsible for it?

FINAL

- d) What to do about Birth Centers?
 - i) Invite a midwife to the workgroup
 - e) VDH has to report to Governor McDonell by Dec. 1st on the actions of the workgroup.
 - f) Fairfax had been doing this for about a year and the pulse oximetry measurements are taken around 24 hours in the nursery.
- 5) Review of CCHDDP Work Plan, Year One: K. Moline
- a) Need to establish a demonstration project through contractual arrangement.
 - b) Incorporate the CCHD screening and reporting at the provider and state level.
 - i) VaCARES – Virginia Congenital Anomalies Reporting and Education System. The system keeps track of birth defects in Virginia up to 2 years of age. It is still to be determined if the system is suitable for CCHD reporting. The system already tracks CCHD when it is diagnosed and reported.
 - ii) VVESTS – Virginia Vital Events and Screening Tracking System. Information system that is built on birth certificates.
 - c) Developing and delivering educational programs with UVA.
 - d) Establish how follow-up will be conducted.
 - e) Where do we go next after working with UVA, Virginia Baptist Hospital, Augusta Health, Martha Jefferson, Rockingham Memorial, and Winchester Medical Center?
- 6) Review of CCHDDP Evaluation Plan, Year One: D. Nair
- a) Four Primary Objectives
 - i) Building an infrastructure for developing our CCHD data reporting system. In year one it will be UVA, Virginia Baptist Hospital, Augusta Health, Martha Jefferson, Rockingham Memorial, and Winchester Medical Center.
 - ii) Using some assessment tools to guide our development in education and training programs.
 - (1) Surveys of the year one participating hospitals.
 - (2) Surveys of specialty and subspecialty birthing centers.
 - (3) Surveys of pediatric cardiology capacity.
 - iii) To develop a multisite data collection system for the participating hospitals.
 - iv) Utilize the data collected for education and training.
- 7) Next Steps: P. Matherne and K. Moline
- a) To gather all the points discussed during this workgroup.
 - b) To think of some barriers we haven't thought of yet.
- 8) Public Comments: K. Moline
- a) None

FINAL

- 9) Next Meeting: K. Moline
 - a) Date: September 25, 2012
 - b) Time: 2:30-4:30 p.m.
 - c) Place: Perimeter Center

- 10) Adjourn: K. Moline
 - a) Meeting adjourned at 11:58a.m.