

FINAL

**Virginia Genetics Advisory Committee
Tuesday, November 6, 2012
10:00 a.m. – 12:00 Noon**

Virginia Hospital & Healthcare Association
4200 Innslake Dr.
Glen Allen, VA 23060

MINUTES

VaGAC Members (check = present):

Willie Andrews, DCLS	Anil R. Kumar, VCU
☒ Arti Pandya, VCU	Sara Long, MOD
☒ Tia Campbell, DOE	Jana Monaco, Parent
Eileen Coffman, CHKD	☒ Walter Nance, VEHDIP Adv Cmt
Karen Durst, VDBHDS	William Owen, EVMS/CHKD
Laura Duncan, VCU	Ginny Proud, CHKD
☒ Eric George, VHF	Anthony Vilella, CBD
Tom Hickey, DCLS	Bill Wilson, UVA
Jan Kuhn, VBD	

VaGAC and Subcommittee Staff:

Kathleen Moline, Staff - VaGAC & Steering Cmt	Jennifer Macdonald, Staff – NBS Subcmt
Lillie Chandler, Staff	Rafael Randolph, Staff - VaGAC
Sidnee Dallas, VDH	

VaGAC Ad Hoc Members:

Joanne Boise, VDH	Ruth Frierson, VDH, VEHDIP Adv Cmt
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Additional Subcommittee Members / Interested Parties:

☒ Rachel Arculin, Parent	Valerie Luther, Partnership, VCU
☒ Stephen Braddock, UVA	☒ Paula Miller, Parent
☒ Sarah H. Elsea, VCU	☒ Alice Schroeder, Parent
☒ Cynthia Epstein, M.D., EVMS	☒ Cliff Schroeder, Parent
☒ Vicki Hardy-Murrell, Parent	☒ Heather Trammell, Parent
☒ Jane Juusola, VCU	☒ Susan Ward, VHHA
☒ Rees L. Lee, M.D., NMCP	☒ Joel Schmidt, M.D., VCU
☒ Deborah K. Froh, M.D., UVA	☒ John P. Osborn, M.D., FNA
	☒ Beth Harkness, RN, BSN, CNMC

Guests: Margie Jaworski, Veronica Kirkland, Jennifer Madden , & Greg Scott

Recorders: Jennifer Macdonald and Rafael Randolph

1. Welcome: B. Wilson
 - a. Introductions: Completed
 - b. Minutes of 05/01/2012 Meeting: Approved as written.
 - c. Agenda: No changes
 - d. Membership
 - e. Travel Reimbursement Reminder (members only): Travel Reimbursements were available for pick up.

2. Public Comments: B. Wilson
 - a. None

3. CF Update with information about UVA grant: J. MacDonald, T. Hickey, & B. Wilson
 - a. Ms. Macdonald went over follow-up data. Mr. Hickey reviewed lab data. Lab plans to investigate to see whether 4% floating cut-off should be increased to 5%. Meeting participants discussed reporting process and the role of consultants in process. Dr. Wilson described UVA's CF grant as a 2 year QI grant sponsored by the CF Foundation to increase the involvement of genetic counseling to diagnosed carriers' families, and to develop educational materials. Parents will be anonymously surveyed to monitor the quality of services that have been given.

4. SCID Update: W. Andrews
 - a. SCID workgroup currently in the middle of data gathering for the regulatory process. Details of September 20-21 meeting were shared. Participants in meeting included pediatric immunologists from around the state, NBS lab, NBS follow-up, Virginia Hospital Association, medical representatives from Roanoke, Northern Virginia, Eastern Virginia Medical School, UVA and VCUHS, Chantilly Pediatric Specialty Center, DMAS, VDH Policy and Evaluation and Barb Ballard from SCID Foundation. The first day was dedicated to creating testing and follow-up algorithms and identifying services for diagnostic follow-up and treatment. The second day was dedicated to discussing the logistics of the regulatory process, length of time needed to implement program and funding issues. Notice of Intent of Regulatory Action (NOIRA) has been initiated and will be introduced at the December Board of Health (BOH) meeting. Cathy Cornelius has been hired as the SCID project nurse on the follow-up team.

5. CCHD update: K. Moline
 - a. CCHD workgroup currently working on the HRSA 3 year demonstration project. VDH is partnering with UVA and there have been 2 meetings with state-wide stakeholders to create algorithms, education plans and data indicators. Group is also developing state-wide reporting system, surveying facilities on current practices, capabilities especially regarding neonatal echocardiograms and transfer agreements, and technology capabilities. Grant progress is currently in Phase 1 and will start with 5 hospitals in the Western/Central part of state that frequently partner with UVA. On Dec 15, 2012 education plans will start to be implemented. Phase 2 will include identifying the next centers that can participate based on lessons learned from Phase 1. Phase 3 goal is to have a reporting system in place and support statewide screening. CCHD workgroup progress report has been written and is due in the Governor's office on December 1, 2012.

6. Bleeding Disorders: J. Kuhn
 - a. Ms. Kuhn described the Virginia Bleeding Disorders Program and members discussed the inclusion of this group into the VaGAC. Services were described as supporting a network of care coordination, providing pool of funds for medication obtainment, health insurance consultation, contracts with Patient Services, Incorporated, to provide health insurance premium assistance to eligible persons, and provide leadership through public health assessment, assurance, leadership and policy development, Ms. Kuhn also detailed the group's projects that reflected assessment, assurance, policy development and leadership since 1996.

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7. CSHCN Update: Sidneé Dallas
 - a. Ms. Dallas had the opportunity to go to the US Dept of Health & Human Services to meet with staff there to review VDH's Maternal and Child Health block grant. Currently working on meeting objectives and outcome measures. The 3 main objectives include: 1) Work with centers to coordinate ongoing care for children with special health care needs (CSHCN) on a daily basis 2) All CSHCN have access to care and 3) CSHCN transition to adult care and independence. Barbara McCall is in transition to oversee management of the Virginia Bleeding Disorder Program. Marcus Allen was hired in July to manage the state-wide sickle cell program.
8. 50th Anniversary Celebration: B. Wilson & K. Moline
 - a. 2013 is the 50th anniversary of NBS. Call for volunteers made to assist in planning state events such as press conference at next VaGAC meeting, celebrations, press releases, etc. Volunteer list made.
9. Metabolic formula/food: J. Madden
 - a. Ms. Madden discussed VDH's formula program and the current analysis of the program's usage. Program is being underutilized by current participants. In January 2013 survey will be sent out to families asking about their usage and understanding of the program and any insurance issues they may face. Ms. Madden will share data at next meeting.
10. New Business: B. Wilson
 - a. Sara Long stated that the March of Dimes is celebrating its 75th anniversary in 2013. Jan 15, 2013 is Advocacy Day and they hope to have 75 partners attend event.
11. Next Meetings: B. Wilson
 - a. Tentatively scheduled for April 30, 2013, 10a-12n, location TBD.
 - b. VaGAC Steering Cmt Conference Call–TBD
12. Adjournment: B. Wilson
 - a. Meeting was adjourned at 11:50a.m.