

Virginia Genetics Advisory Committee
Tuesday, April 20, 2010
10:00 a.m. – 12:00 Noon

Division of Consolidated Laboratory Services
Training Room T-23
600 North 5th Street
Richmond, VA 23219
Telephone (804) 648-4480

MINUTES

VaGAC Members (check = present):

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| ☒ Willie Andrews, DCLS | ☒ William Owen, EVMS/CHKD |
| ☒ Joann N. Bodurtha, VCU (VaGAC Chair) | ☐ Arti Pandya, VCU, VEHDIP Adv Cmt |
| ☐ Nancy Bullock, VDH | ☐ James Pearson, DCLS |
| ☐ Mary Ann Discenza, VDBHDS | ☒ Ginny Proud, CHKD |
| ☒ Laura Duncan, VCU | ☒ Charlie Stevenson, DCLS |
| ☐ Mary Claire Ikenberry | ☒ Theresa Taylor, VDH |
| ☐ Anil R. Kumar, VCU | ☒ Bill Wilson, UVA |
| ☒ Sara Long, MOD | ☒ Eileen Coffman, CHKD |
| ☐ Walter Nance, VEHDIP Adv Cmt | |

VaGAC and Subcommittee Staff:

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| ☒ Nancy Ford, Lead Staff - VaGAC & Steering Cmt | ☒ Rafael Randolph, Staff - VaGAC |
| ☒ Audrey Greene, Lead Staff - NB Subcmt | ☒ Sharon Williams, Lead Staff - Contractors Subcmt |
| ☒ Jennifer Macdonald, Staff - NB Subcmt | |

VaGAC Ad Hoc Members:

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| ☐ Joanne Boise, VDH | ☒ Ruth Frierson |
| ☐ Joan Corder-Mabe, VDH | ☐ David Suttle, VDH |

Additional Subcommittee Members / Interested Parties:

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| ☐ Stephen Braddock, UVA | ☐ Rees Lee, NMCP |
| ☐ Bonny Bukaveckas, VCU | ☐ Phil Poston, DCLS |
| ☒ Tahnee Causey, VCU | ☐ Alice Schroeder, Parent |
| ☒ Sarah H. Elsea, VCU | ☐ Cliff Schroeder, Parent |
| ☒ Valerie Luther, Partnership, VCU | ☐ Holly Tiller, VDH |
| ☐ Paula Miller, Parent | ☐ Heather Trammell, Parent |
| ☒ Jana Monaco, Parent (via conf call) | ☐ Susan Ward, VHHA |
| ☐ Vicki Hardy-Murrell | ☒ Rachel Arculin, Parent |
| ☒ Jane Juusola, VCU | |

Guests: Joe Spontarellio, CART Services; Dr. Tom Hickey, DCLS; Megan Farley, Genetic Counselor Student

Recorders: Rafael Randolph and Nancy Ford

1. Welcome: J. Bodurtha
 - a. Introductions: Completed.
 - b. Minutes of 10/28/2009 Meeting: Approved as written.
 - c. Agenda: No changes.
 - d. Membership: Circulated for corrections.
 - e. Travel Reimbursement Reminder: See Rafael Randolph to receive a travel reimbursement form.

FINAL

2. Public Comments: N. Ford
There were no public comments.
3. Review of VaGAC Infrastructure, if needed.
There were no changes.
4. Subcommittees and Groups Reports
 - a. Newborn Screening Subcmt – W. Andrews
Reminder that the Newborn Screening Subcmt will meet after today's VaGAC meeting. Lab purchased a new mass spectrometer; the instrument is not yet in production as it is being validated. Subcommittee continued to discuss reorganization within VDH's newborn bloodspot and hearing screening programs; concerns were raised about the ability to meet workload for newborn screening bloodspot testing, especially in the event that new diagnoses are added to the panel. DCLS continues to submit data to the Region 4 Collaborative project regarding diagnosed cases and associated levels. At the last Subcommittee meeting, Dr. Phil Poston gave a presentation and solicited the help of the metabolic specialists to determine if additional or different markers are needed to identify the disorders.
 - b. Birth Defects Prevention Subcmt – N. Ford
On hold until the new Preconception Health Coordinator position is filled; this is a new position within VDH Division of Women's and Infants' Health (DWIH).
 - c. State Genetics Plan and Public Health Subcmt – J. Bodurtha
As reported in the last meeting, the plan has been placed on hold due to other priorities within the VDH Division of Child and Adolescent Health (DCAH). (Note: Following the VaGAC meeting, the VaGAC/State Genetics Plan and Public Health Subcmt Chair (J. Bodurtha) and Subcmt staff (S. Williams and N. Ford) made a decision to disband the Subcmt and reconvene it in the future if indicated, if needed.)
 - d. VDH Contractors Ad Hoc Work Group – N. Ford
As reported in the last meeting, management of the genetics and metabolic treatment centers contracts has been transferred from S. Williams to N. Ford. Members are working on developing a FY 11 Annual Report and revising the quarterly report form via conference calls and emails. The next conference call is scheduled for April 28 at 2 p.m. In process of renewing the three genetic and metabolic treatment contracts (EVMS, UVA, and VCU) and the prenatal genetics contract (Genetics and IVF).
5. Updates: Agencies, Organizations, and Grants
 - a. VDH: Organizational Changes, Grants – N. Ford
 - (1) VDH and DCAH Organization: Dr. Suttle, Director of the Office of Family and Health Services (OFHS), is retiring at the end of the month; Dr. David Trump, who is currently the health district for Peninsula Health District, will be the Acting OFHS Director. An updated DCAH organizational chart was distributed and reviewed.
 - (2) VISITS II: The new Virginia Infant Screening and Infant Tracking System (VaCATPIP II) was released statewide on April 12. VISITS II is a component of the Virginia Vital Events and Screening Tracking System (VVESTS), which also includes the new Electronic Birth Certificate. Eight statewide trainings were held for hospital users. Training materials are available online at <http://vrfhs.vdh.virginia.gov/training.htm>.

- (3) CDC Birth Defects Grant: The Virginia Congenital Anomalies Tracking and Prevention Improvement Project (VaCATPIP II) ended February 28, 2010, and the VaCATPIP II final report, which is due May 31, is being completed. The VDH application to CDC to fund VaCATPIP III was recommended for approval but did not rank high enough to be funded. If awarded, the grant would have funded a 1500-hour genetic counselor or similarly skilled staff position and birth defects prevention activities. A thank you was extended to everyone who wrote a letter of support. Birth defects prevention responsibilities have been transferred to the to-be-hired DWIH Preconception Health Coordinator. VaCARES quality improvement responsibilities have been transferred to the recently hired DCAH Surveillance and Evaluation Coordinator.
- (4) VEHDIP: The vacant Virginia Early Hearing Detection and Intervention Program (VEHDIP) Manager position was filled by Ruth Frierson, who had been serving as the Acting VEHDI Program Manager and Follow-up Coordinator. VEHDIP continues to support the Virginia Hearing Aid Loan Bank and Guide By Your Side family-to-family support program. Virginia has had over 200 matches for family-to-family support. VEHDIP also continues to manage two cooperative agreements (CDC and HRSA) that support the part-time (wage) Data Manager Coordinator, Follow-up Analyst, and Quality Assurance Coordinator positions; a full-time Follow-up Specialist position; and six VEHDIP learning collaborative sites.
- b. VDH: Virginia Sickle Cell Awareness Program – T. Taylor
Jean Radcliffe Shipman has retired. Virginia Sickle Cell Awareness Program responsibilities will be under the to-be-hired Preconception Health Coordinator.
- c. VDH: CSHCN Program, including CCC and CDCs – N. Bullock
No report. (Children continue to be referred from Virginia Newborn Screening Program to Care Connection for Children.)
- d. VDH: DWIH – K. Moline
No report.
- e. Division of Consolidated Laboratory Services –W. Andrews
 - (1) National Laboratory Week: Reminder that it is National Medical Laboratory Professionals Week, which provides the profession with a unique opportunity to increase public understanding of and appreciation for, clinical laboratory personnel.
 - (2) Virginia State Furlough Day: The Newborn Screening Lab will be operational during furlough day, May 28.
 - (3) DCLS-VDH Conference Calls: About one year ago, the newborn screening follow-up and laboratory team started having monthly conference calls; these calls continue and have been very beneficial in terms of staying connected and addressing issues as they occur.
 - (4) CDC Epidemiology and Laboratory Capacity (ELC) Grant: Funds are available for developing a standardized data exchange between DCLS and hospitals. VDH Department of Epidemiology would need to sponsor the grant on behalf of DCLS. While the primary focus is not newborn screening, it could be a component of the exchange. This is the first funding made available to public health labs for electronic data exchange. So far, letters of support have come in from UVA, VCU, and Sentara hospitals.
- f. March of Dimes – S. Long

- (1) March for Babies: The Richmond March for Babies fundraiser walk is planned for May 2 at Monroe Park.
 - (2) Prematurity Campaign: The March of Dimes Prematurity Campaign is in its seventh year. The national rates for preterm births did drop a little in 2008 and 2009. The campaign has two goals: (1) to raise public awareness of the problems of prematurity and (2) to decrease the rate of preterm birth in the U.S. (15 percent reduction in rate). As part of a national effort to save babies from premature birth, the March of Dimes has designated November as Prematurity Awareness Month. The third annual Premature Birth Report Card will be released around November 18, 2010, which has been designated Prematurity Awareness Day. It was noted that Dr. Jerome Strauss, dean of the VCU School of Medicine, identified a gene variant related to increased risk of premature rupture of the fetal membranes, a common cause of premature birth; the gene variant is much more common among African-American women (2006).
- g. VDBHDS: Part C – M. A. Discenza
No report.
- h. NYMAC – J. Bodurtha
The New York-Mid-Atlantic Consortium (NYMAC) for Genetic and Newborn Screening Services recently went through a process of review of grants. They included transitions particularly for children with genetic conditions, emergency preparedness, laboratory technical issues, and how to continue to improve communication medical home management issues. If you have interest in any of these areas, some small funds may be available. For more information, contact Katharine Harris, NYMAC Project Manager, phone: (518) 474-7148, e-mail kbh02@health.state.ny.us.
- i. Virginia Association of Genetic Counselors – T. Causey
The second round of elections was conducted on November 2, 2009. The Fourth Annual Virginia Genetics Education Conference will be held on May 25, 2010, in Falls Church, Virginia. Additional information is available from the VaAGC web site <http://www.vaagc.org/>. Continue to work on licensure.
- j. HRSA Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) – J. Monaco
(1) Last Meeting: The 20th ACHDNC meeting was held January 21-22, 2010. The minutes are available online at <http://www.hrsa.gov/heritabledisorderscommittee/meetings/>. Meeting highlights:
(a) The Internal Nomination Review and Prioritization Workgroup recommended to the Advisory Committee that the nominations of neonatal **hyperbilirubinemia** and **critical congenital heart disease** be forwarded for an evidence review by the Evidence Review Workgroup.
(b) The Advisory Committee recommended adding **severe combined immunodeficiency disorder** (SCID) to the uniform newborn screening panel and recommended adding other T-cell lymphocyte deficiencies to the list of secondary targets as a comprehensive entity. (Post meeting note: On May 21, 2010, Kathleen Sebelius, Secretary of Health and Services, announced the addition of SCID to the core panel of 29 genetic disorders as part of her recommendation to adopt the national Recommended Uniform Screening Panel. SCID is the first nominated condition to be added to the core panel of disorders.)

- (c) The Newborn Screening Saves Lives Act of 2008 called for the Health Resources and Services Administration (HRSA) to establish and maintain a **clearinghouse** of current materials, resources, research, and data related to newborn screening. In late 2009, HRSA awarded a five-year, \$3.75 million cooperative agreement to the Genetic Alliance to develop such a clearinghouse.
 - (d) The second draft of the Advisory Committee white paper on national policies regarding the **retention and use of dried blood spots** after newborn screening was presented for the Advisory Committee's review. The final white paper will be published.
 - (e) The report from the Sickle Cell Disease Association of America's (SCDAA) Workshop on Carrier Screening was discussed, including the National Athletic Trainers' Association consensus statement promoting **screening for sickle cell trait** (SCT). It was decided that Dr. Howell (Committee Chairperson) will contact the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) about possibly collaborating on some work in developing recommendations pertaining to ethical, legal, and social issues related to carrier screening.
 - (f) It was noted that the Evidence Review Workgroup had revised its report on **Krabbe disease** and was planning to submit it to Genetics in Medicine for publication. (Note: During the September 2009 meeting, the Advisory Committee recommended not adding Krabbe disease to the recommended newborn screening panel at the present time.)
- (2) Next Meeting: The 21st ACHDNC meeting will be held May 13 -14, 2010.
6. Updates: Virginia Genetics and Metabolic Centers
- a. EVMS – G. Proud and W. Owen
Recruited fourth genetic counselor and he/she will start in June. A new dean is coming; the current dean is moving to be the head of research at EVMS. Sickle cell program recently hired a new social worker.
 - b. UVA – B. Wilson
Genetic counselor fellow Lindsey Paule started in early April.
 - c. VCU – L. Duncan, J. Bodurtha
Subsequent to the end of the VDH VaCATPIP II grant, Tahnee Causey joined the VCU genetic counseling team. Various student projects are on-going. Had an excellent recruitment year in which 25 students were interviewed. There is a particular interest in this year in the genetic counselor PhD combined program. They currently have two PhD genetic counseling trainees.
7. New Business
- a. Virginia Newborn Screening Program – S. Williams
Distributed 2008 Virginia newborn screening data, which are a component of the VDH MCHB Title V Block Grant application: Number and Percentage of Newborns and Others Screened, Cases Confirmed, and Treated.
 - b. No other new business reported.
8. Next Meetings

FINAL

- a. VaGAC Meeting:
Date: Tuesday, October 5, 2010
Time: 10 a.m. - 12 p.m.
Place: DCLS
 - b. VaGAC Steering Cmt Conference Call:
Date: Tuesday, September 14, 2010
Time: 10 a.m.
Contact Information: N. Ford will send.
9. Adjournment
Meeting adjourned at 12 p.m.