

**Virginia Genetics Advisory Committee
Tuesday, April 1, 2008
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

Present: VaGAC Members (check = present):

- | | |
|--|--|
| <input checked="" type="checkbox"/> Willie Andrews, DCLS | <input checked="" type="checkbox"/> William Owen, EVMS/CHKD |
| <input checked="" type="checkbox"/> Joann N. Bodurtha, VCU (VaGAC Chair) | <input checked="" type="checkbox"/> Arti Pandya, VCU, VEHDIP Adv Cmt |
| <input type="checkbox"/> Nancy Bullock, VDH | <input checked="" type="checkbox"/> James Pearson, DCLS |
| <input checked="" type="checkbox"/> Karen Durst for Mary Ann Discenza,
DMHMRSAS | <input checked="" type="checkbox"/> Ginny Proud, CHKD |
| <input checked="" type="checkbox"/> Laura Duncan, VCU | <input checked="" type="checkbox"/> Jene O. Radcliffe-Shipman, VDH |
| <input checked="" type="checkbox"/> Mary Claire Ikenberry | <input type="checkbox"/> Charlie Stevenson, DCLS |
| <input type="checkbox"/> Anil R. Kumar, VCU | <input checked="" type="checkbox"/> Bill Wilson, UVA |
| <input checked="" type="checkbox"/> Sara Long, MOD | <input checked="" type="checkbox"/> Eileen Coffman, CHKD |
| <input type="checkbox"/> Walter Nance, VEHDIP Adv Cmt | |

VaGAC and Subcommittee Staff:

- | | |
|--|--|
| <input checked="" type="checkbox"/> Nancy Ford, Lead Staff - VaGAC & Steering
Cmt | <input checked="" type="checkbox"/> Audrey Greene, Lead Staff – NB Subcmt |
| <input checked="" type="checkbox"/> Tahnee Causey, Lead Staff - CP/PI Subcmt | <input checked="" type="checkbox"/> Jennifer Macdonald |
| <input checked="" type="checkbox"/> Lillie Chandler | <input checked="" type="checkbox"/> Rafael Randolph, Staff - VaGAC |
| <input type="checkbox"/> Heather Creswick, Lead Staff - SGP/PH
Subcmt | <input checked="" type="checkbox"/> Sharon Williams, Lead Staff - Contractors Subcmt |

VaGAC Ad Hoc Members:

- | | |
|---|--|
| <input type="checkbox"/> Joanne Boise, VDH | <input type="checkbox"/> Ramona Schaeffer, VDH |
| <input type="checkbox"/> Joan Corder-Mabe, VDH | <input type="checkbox"/> David Suttle, VDH |
| <input checked="" type="checkbox"/> Gayle Jones | |

Additional Subcommittee Members / Interested Parties:

- | | |
|--|---|
| <input checked="" type="checkbox"/> Stephen Braddock, UVA | <input type="checkbox"/> Vicki Hardy-Murrell |
| <input type="checkbox"/> Bonny Bukaveckas, VCU | <input type="checkbox"/> Rees Lee, NMCP |
| <input checked="" type="checkbox"/> Eileen Coffman, CHKD | <input checked="" type="checkbox"/> Phil Poston, DCLS |
| <input checked="" type="checkbox"/> Sarah H. Elsea, VCU | <input type="checkbox"/> Alice Schroeder, Parent |
| <input type="checkbox"/> Valerie Luther, Partnership, VCU | <input type="checkbox"/> Cliff Schroeder, Parent |
| <input type="checkbox"/> Paula Miller, Parent | <input type="checkbox"/> Heather Trammell, Parent |
| <input checked="" type="checkbox"/> Jana Monaco, Parent – present via conference
call | <input type="checkbox"/> Susan Ward, VHHA |

Guests: None

Recorder: Nancy Ford

1. Welcome: J. Bodurtha

- a. Introductions: Completed.
- b. Minutes of 10/16/07 Meeting: Approved as written.
- c. Agenda: Added item 2 e.
- d. Membership (revised 10/16/2007): Circulated for corrections.

2. **VaGAC Infrastructure: J. Bodurtha**

- a. Community Partnerships/Parent Involvement: Changing focus to birth defects prevention.
- b. Subcommittee Names: All subcommittees' task forces were abolished because each task force membership includes the same individuals who are on its subcommittee. The following subcommittee names were maintained or revised:
 - Newborn Screening Subcommittee (name maintained).
 - Birth Defects Prevention Subcommittee (formerly named the Community Partnerships/Parent Involvement Subcommittee).
 - State Genetics Plan and Public Health Subcommittee (name maintained).
 - VDH Contractors Subcommittee (name maintained).
- c. Subcommittee Membership: No changes.
- d. Mission Statement: No changes.
- e. Speakers: Discussion conducted on the merits of continuing to have a small presentation at each meeting as has been done at the beginning of the last several meetings. The following options were identified for use in a short needs assessment, which will be sent to VaGAC members.
 - Option 1: Conduct a topic-specific 15-minute presentation during each meeting (members would send a proposed topic and speaker's name to N. Ford) but do not conduct a lunch-time continuing education session.
 - Option 2: Conduct a lunch-time continuing education session but do not conduct a topic-specific 15-minute presentation during each meeting.
 - Option 3: Conduct a topic-specific 15-minute presentation during each meeting and conduct a lunch-time continuing education session (the later would "piggy-back" with Genetic Counselors meeting).
 - Option 4: Do not conduct a topic-specific 15-minute presentation during meeting and do not conduct a lunch-time continuing education session.

3. **Subcommittees Reports**

a. **Newborn Screening Subcmt: W. Andrews**

Quarterly meetings have been well attended. Expanded membership with Dr. Owen (expert on hemoglobinopathies) and Dr. Lee (expert on cystic fibrosis). Still working on having an expert on endocrinology join the subcommittee. Recent activities have included (1) P. Poston providing updates on the Public Health Laboratory Interoperability Project, which involves international data collection, and (2) addressing use of newborn screening data for research programs, which would only be allowed with informed consent. The handout "Virginia Newborn Screening Services Diagnosed Cases 10/16/07 – 3/31/08" was distributed. A subcommittee meeting will be convened today following the VaGAC meeting. Extra copies of the *Birth Defects Research Journal* that includes 2007 state congenital malformations surveillance reports were made available.

b. **Community Partnerships/ Parent Involvement Subcmt: T. Causey**

This has been an open committee. The subcommittee would like to have more parents join. The focus of the committee is changing to birth defects prevention and will incorporate the VDH-managed Virginia Council on Folic Acid and the VDH Fetal Alcohol Spectrum Disorders Task Force, both of which have been on hold. From now on, the name of the subcommittee will be Birth Defects Prevention Subcommittee. Currently, staff (T. Causey) has focused on completing the VDH Folic Acid Supplements Distribution Project, which has involved distributing remaining supplements by way of the following tiered system: (1st tier) 17 health districts that participated in the original project, (2nd tier) health districts that are participating in the "Saving Babies" project, and (3rd tier) all other health departments. Recommendation was made to add the following tiers:

(4th tier) Perinatal Councils, (5th tier) March of Dimes grantees, and (6th tier) Other (all VaGAC members invited to contact T. Causey for suggestions).

c. **State Genetics Plan and Public Health Submt: J. Bodurtha**

Most of the activities have been through the March of Dimes-funded State Genetics Education Working Group. The handout “Working Group Task Menu” was distributed. An issue that needs to be addressed is which entity should be responsible for state genetics education activities if the March of Dimes funding ends. National DNA Day is 4/25/08; it was created by the National Human Genome Research Institute to commemorate the completion of the Human Genome Project in April 2003 and the discovery of DNA's double helix.

d. **VDH Contractors Submt: S. Williams**

A conference call was convened 2/5/08, in which the following were discussed: (1) the New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC) Emergency Project—it was decided that emergency protocols do not need to be developed because all Virginia genetic centers have such protocols, and (2) site visits schedule. On 2/8/08, VDH, in collaboration with DCLS, conducted a pediatric grand round at Prince William Hospital on newborn dried-blood spot screening. Jennifer Macdonald is a new VDH Newborn Screening Nurse; she began in January 2008 and is from the Chickahominy Health District where she worked as an epidemiologist.

4. **Updates: Agencies, Organizations, Grants**

a. **VDH: VaCATPIP II (CDC), VaCHISIP (CDC), EDHI (HRSA): N. Ford**

The five-year CDC Birth Defects-funded grant that supports VaCARES began its 4th year 3/1/08. The three-year CDC Early Health Detection and Intervention (EHDI)-funded grant that supports VISITS redesign will complete its final year 6/30/08. The VISITS redesign will most likely extend beyond the end of the grant year through a no-cost extension agreement with CDC EHDI. VDH plans to apply for a new CDC EHDI grant; it is due 4/28/08. The three-year HRSA Universal Newborn Hearing Screening (UNHS)-funded grant that supports Guide By Your Side and Virginia Hearing Aid Loan Bank will complete its final year 8/31/08. VDH applied for a new HRSA UNHS grant; it was due 3/21/08.

b. **VDH: Virginia Sickle Cell Awareness Program: J. Shipman**

The 2008 General Assembly sickle cell budget cut was reinstated for 2009-2010 for provision of community services. A request for proposal (RFP) will be put forth, which will include southwest Virginia.

c. **VDH: CSHCN Program, including CCC and CDCs: N. Bullock**

No Report.

d. **DCLS: J. Pearson, W. Andrews**

The Abington laboratory is closing due to budget changes; there will be no impact on genetic services. DCLS is implementing the Laboratory Information Management System (LIMS) in a variety of ways. Health care providers will be able to access their patients' newborn screening results via LIMS.

e. **March of Dimes: S. Long**

The Tidewater Area project is distributing baby t-shirts with newborn screening information materials. MOD is planning a grand round at Virginia Beach Hospital on preconception as part of the MOD's preconception education campaign. The 2008 General Assembly approved an increase for FAMIS MOMS (Family Access to Medical Insurance Security) program to 200% of the federal poverty level, but its implementation will be delayed for one year.

f. **DMHMRSAS: Part C: M. A. Discenza**

No report.

g. **Dept. of Education: T. Campbell**

Although school nurse are not mandated in Virginia, there is a least one school nurse in every

school division. DOE produces reports on students with chronic health conditions based on findings of annual surveys. VaGAC would like to receive copies of the next report; the next survey will take place September 2009. VaGAC agreed that it would be appropriate for T. Campbell to contact VaGAC members to conduct presentations at future School Nurse Coordinator meetings; the meetings are convened three times a year.

5. Updates: Virginia Genetics and Metabolic Centers

a. EVMS: G. Proud

EVMS will be recruiting for two genetic counselors. A presentation on metabolic disorders will be conducted at the October 2008 pediatrics-at-the-beach conference. G. Proud continues to be involved in NYMAC.

b. UVA: B. Wilson

UVA continues to participate in the BioMarin expanded access program for the product sapropterin. A presentation on newborn hearing screening will be conducted 6/6/08, by Dr. John Kerry, who is a medical geneticist from Utah.

c. VCU: A. Pandya, J. Bodurtha, L. Duncan

Paul Fisher, PhD, will be entering as the new chair of the VCU Department of Human Genetics. On 5/10/08, a PKU Walk-A-Thon will take place in Dorey Park, Henrico County. J. Bodurtha continued to be involved in NYMAC. A new PKU treatment was approved.

6. New Business:

The following items will be added as standing agenda updates: NYMAC by J. Bodurtha; Genetic Counselors Network by T. Causey; and HRSA Advisory Committee on Heritable Disorders and Genetic Diseases in Newborns and Children by J. Monaco.

7. Next Meetings

Date: Tuesday, October 7, 2008

Time: 10 AM – 12 Noon

Location: Division of Consolidated Laboratory Services

8. Adjournment

Meeting adjourned at 12:00 PM