

**Virginia Genetics Advisory Committee
Tuesday, April 4, 2006
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: Allison Schreiber, MS-VDH/VCU; Audrey Greene, RN-VDH; Charlie Stevenson, MS—DCLS; David Suttle, MD—VDH, Gwen Smith, RN, MSN—DOE; Heather Creswick—VDH/VCU; Jana Monaco—parent; Jene O. Radcliffe-Shipman—VDH; Joann Bodurtha, MD, MPH, Chair—VCU; Kathy Orchen—VDH; Laura Duncan, MPH, RD, VCU; Melody Persinger Yeargin—CHKD; Nancy Ford, MPH, RN—VDH; Rafael Randolph—VDH; Sara Long—MOD; Sarah Elsea, PhD, FACMG—VCU; Sharon Williams; MS, RN—VDH; Susan Ward—VHHA; Theresa Taylor—VDH; Vicki Hardy-Murrell, RN—parent; Virginia (“Ginny”) K. Proud, MD—CHKD; Walter Nance, MD, PhD—VEHDIP Adv Cmt.; William (“Bill”) G. Wilson, MD—UVA Health Sciences Center; Willie C. Andrews—DCLS

Absent: Arti Pandya, MD, MBA—VCU; James Pearson, DrPH, BCLD—DCLS; Joan Corder-Mabe, RNC, MS, OGNP—VDH; Joanne Boise, MSPH—VDH; Lynette Bartlett, RN—VDH; Mary Ann Discenza—DMHMRSAS; Nancy Bullock, RN, MPH—VDH; Ramona Schaeffer—VDH; Valerie Luther, VDPPPD

Recorder: Rafael Randolph

1. **Welcome: J. Bodurtha**
 - a. Introductions: Completed.
 - b. Revised minutes of 10/04/05: Approved as written. Final minutes will be posted on the VDH Minutes Calendar Web site <http://www.vdh.state.va.us/minutes/minutes.asp> and the Virginia Regulatory Town Hall Web site <https://www.townhall.state.va.us/>.
 - c. Agenda: Reviewed, no new items added.
 - d. Membership: Future updates will be done via e-mail.

2. **Pre-Lingual Hearing Loss and Recommendations for Improving Universal Newborn Hearing Screening Programs: W. Nance**
 - a. The embargoed article “Newborn Hearing Screening: A Silent Revolution,” by Cynthia C. Morton, PhD, and Walter I. Nance, MD, PhD, was distributed and reviewed. According to the authors, the best way to detect late-onset prelingual hearing loss would be to conduct molecular genetic tests via newborn dried-blood-spot screening tests on all infants for just four import causes of hearing loss: DFNB1, SLC26A4, congenital Cytomegalovirus (CMV) infection, and mitochondrial 12S rRNA. Plan:
 - (1) W. Nance will provide copy of slide presentation to W. Andrews.
 - (2) W. Andrews, as chair of the VaGAC Newborn Screening Subcommittee, will include this issue on a future agenda item for further discussion, including possible implications for Virginia Newborn Screening Services.

3. Subcommittees and Work Groups

a. **Genetics and Public Health Subcommittee: J. Bodurtha**

State Genetics Education Plan Work Group: The handout “State Genetics Plan Activities” was distributed and reviewed. The March of Dimes, Virginia Chapter, has provided funding to VCU for the 2003-2005 Statewide Assessment of Needs and the resultant final report, “Virginia GeneSEAN: Genetic Services and Education—An Assessment of Needs.” Assessment findings will be used by the VaGAC State Genetics Education Work Group for the purpose of addressing the identified priority need: consumer and provider genetics education. Next steps: recruitment of members; develop timeline, goals, and objectives; develop state genetics education plan with champions and funding possibilities; coordinate Genetic Evenings in the Libraries, and develop and implement an evaluation plan. Plan:

(1) J. Bodurtha will complete recruitment of members and convene the State Genetics Education Plan Work Group.

(2) J. Bodurtha will send final GeneSEAN report to VAGAC.

b. **Newborn Screening Subcommittee: W. Andrews and S. Williams**

Virginia Newborn Screening Services expansion began March 1, 2006. All who have and are involved in the expanded program were recognized. Metabolic treatment centers reported that all of the preparations, such as setting parameters and trainings, have paid off in that the expanded panel screenings are proceeding smoothly. Metabolic consultants have conducted a variety of educational events on the newborn screening expanded panel. New VDH staff/positions: Angela Johnson, RN, newborn screening nurse, and Rafael Randolph, full-time VaCARES technical support staff. Recent DCLS/VDH collaborative activities:

(1) Five on-site and five “webinars” were completed; participant evaluations were very positive.

(2) Three trainings have been scheduled for April and more trainings are being planned, including, pending available funding, online training modules. Targeted audience includes physicians, Care Connection for Children coordinators, hospital and physician office nurses, public health nurses, laboratory staff, and regional perinatal councils. The April training schedule was distributed.

(3) The resource manual “Virginia Newborn Screening Services: Healthcare Practitioner Manual” was completed, published online (<http://www.vahealth.org/genetics/pubsgp.htm>), and sent to printer. The manual was circulated.

(4) The parent brochure “Screening Tests for Your Newborn Baby,” which was revised by the VaGAC Parent Involvement Work Group, was completed, published online (<http://www.vahealth.org/genetics/pubsgp.htm>), and distributed to testers. Future plans are to distribute the brochure more widely, such as to obstetrician offices. The brochure was distributed.

(5) Parent fact sheets, which were reviewed by the VaGAC Parent Involvement Work Group, were completed and published online (<http://www.vahealth.org/genetics/pubsgp.htm>).

(6) Professional fact sheets were included in the Healthcare Practitioner Manual and published individually online (<http://www.vahealth.org/genetics/pubsgp.htm>).

(7) A one-page parent fact sheet was developed for inclusion in the Parent Tool Kit (new parents usually receive the kit at the hospital or through a local community group) and is being translated into Spanish. The fact sheet was distributed.

(8) A VDH news release, March 1, 2006, generated 10-12 media contacts. The news release is available online (<http://www.vdh.state.va.us/news/PressReleases.asp>).

c. **Parent Involvement Work Group: A. Schreiber**

Parents were thanked for their work on reviewing various parent materials. Two new members, who were speakers at the January 2006 National Birth Defects Prevention Network annual meeting, were invited to join the Work Group. Recent Work Group/VDH collaborative activities:

(1) VaCARES parent brochure, “For Families of Infants and Toddlers with Special Health Care Needs,” was completed and published. It is available in English and Spanish and will be sent

- to parents of children identified under VaCARES. The brochure was distributed during the meeting.
- (2) VDH, DCAH, PSGS fact sheet letterhead stationary was completed and printed. The letterhead is available in English and Spanish and will be used for printing VaCARES and VNSS fact sheets.
- d. **VDH Contractors Subcommittee: S. Williams**
A meeting is being planned.
4. **Updates: Agencies, Organizations, Grants**
- a. **VDH: Pediatric Screening and Genetic Services**
- (1) **PSGS Grants: N. Ford**
Virginia Congenital Anomalies Tracking and Prevention Improvement Project (VaCATPIP) II: This is a five-year, CDC-funded “Population-Based Birth Defects Surveillance Program” cooperative agreement, which began 3/1/06 and focuses on birth defects quality surveillance and prevention; VDH submitted a year-2 application, which was awarded by CDC. Virginia Child Health Information Systems Project (VaCHISIP): This is a three-year, CDC-funded “Early Hearing Detection and Intervention Tracking, Surveillance and Integration” cooperative agreement, which began 7/1/05 and focuses on the redesign of VISITS; VDH submitted a year-2 application to CDC. Virginia Early Hearing Detection and Intervention Program: This is a three-year, HRSA-funded “Universal Newborn Hearing Screening” cooperative agreement, which began 9/1/05 and focuses on follow up; VDH will submit a year-2 application.
- (2) **Family Health History: H. Creswick**
The form “Family Health History,” which was drafted by H. Creswick based on focus group comments from an earlier draft, was circulated for comments. VaGAC members were invited to provide comments to H. Creswick (comments can be sent via email to Allison Schreiber, Allison.Schreiber@vdh.virginia.gov). Plan:
(a) H. Creswick will contact C. Bodkin, VDH Resource Mothers Coordinator, for review by resource mothers.
- b. **VDH: Virginia Sickle Cell Awareness Program: J. Radcliffe-Shipman**
Contracts for pediatric comprehensive sickle cell services are in the process of being renewed for the Children’s Hospital of The King’s Daughters, VCU Health System, INOVA Fairfax Hospital, and University of Virginia. Dr. Kamar Godder is the new division chairman for Pediatric Hematology/Oncology at VCU. They are currently recruiting for a Nurse Practitioner/Case manager for the sickle cell program. A Phase III clinical trial for pain in pediatric patients is currently underway at VCU.
- c. **DCLS: W. Andrews**
The information system STARLIMS, which began under newborn screening, is being implemented throughout DCLS on a phase-in basis. DCLS is determining the feasibility of implementing a process for physicians to access newborn screening results via Internet and working to increase data exchange opportunities, such as partnering with VDH to connect with WebVISION.
- d. **Virginia Council on Folic Acid: K. Orchen**
National Folic Acid Awareness Week was January 9-15, 2006. A VDH news release, March 1, 2006, generated several media contacts. The news release is available online (<http://www.vdh.state.va.us/news/PressReleases.asp>). The news release was translated into Spanish. Folic acid distribution through VDH family planning clinics in health districts with the highest rate of NTDS, which began 7/1/05, continues and includes an evaluation component that will determine if a woman’s intake of folic acid will increase if it is supplied. Three new folic acid materials, which were circulated during meeting, are being finalized: brochure, bookmark, and poster. Three folic acid TV ads are being developed and will be broadcast in late 2006, pending available funding.

- e. **March of Dimes: S. Long**
Two pamphlets, “WalkAmerica” and “Share. An Online Community for NICU Families,” and diaper for micropremies (i.e., extremely premature, 27 weeks gestational age or less) were distributed. Focusing on preconceptual health. Grant line will be available soon. April is “Walk America” month. Walk America’s proceeds will go toward defeating prematurity.
 - f. **DMHMRSAS: Part C of IDEA: Infant & Toddler Connection of Virginia: Mary Ann Discenza**
No report.
 - g. **DOE: G. Smith**
Currently conducting business under the acting Superintendent of Public Instruction, Patricia I. Wright. The manual “Virginia School Health Guidelines” is being revised (available online <http://www.pen.k12.va.us/VDOE/Instruction/Health/home.html>). Beginning to work on changing special education regulations pursuant to federal 2004 changes.
5. **Updates: Virginia Genetics and Metabolic Centers**
- a. **EVMS: V. Proud**
EVMS is close to having full staff and there is a new genetic counselor. A second metabolic nutritionist is being trained by M. Persinger Yeargin. The metabolic center was invited to submit a request for new office space at CHKD.
 - b. **UVA: W. Wilson**
Transition has been relatively smooth. Reports an increase in phone calls but not as high as what was expected. Recruiting for two new faculty members.
 - c. **VCU: J. Bodurtha**
A children’s hospital will start at former eye and ear clinic.
6. **New Business: All**
- a. **D. Suttle:** Announced that funding was obtained that will help resource mothers and the MCHB Title V Block Grant: funding was reduced by about 3%.
 - b. **T. Taylor:** Informed members that she is attending today’s meeting as a representative to the Virginia Fetal Alcohol Spectrum Disorder (FASD) Task Force, which has recently been convened by VDH, Division of Women’s and Infants’ Health. Announced there is a new Web site on Perinatal Depression <http://www.perinataldepression.org/>.
 - c. **K. Orchen:** Announced that she will soon be resigning from her position at VDH.
 - d. **N. Ford:** Announced that **J. Bodurtha** was one of fifteen faculty members who were chosen from Virginia’s public and private colleges and universities as winners of the Outstanding Faculty Awards, which are administered by the State Council of Higher Education. Two Richmond Times Dispatch articles that featured J. Bodurtha were circulated.
7. **Future Meeting: J. Bodurtha**
- a. Virginia Genetics Advisory Committee:
Date: Tuesday, October 3, 2006
Time: 10:00a.m. – 12:00 p.m.
Location: Division of Consolidated Laboratory Services
 - b. VaGAC Steering Committee Conference Call
Date: Thursday, September 21, 2006
Time: 1:00 p.m. – 2:00 .m.
Call-in information: N. Ford will set up conference call and send in information to Steering Committee.
8. **Adjourn: J. Bodurtha**
Meeting adjourned at 12 p.m.