

Virginia Genetics Advisory Committee
Wednesday, October 28, 2009
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):

- | | |
|--|---|
| <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 type="checkbox"/> Arti Pandya, VCU, VEHDIP Adv Cmt |
| <input checked="" type="checkbox"/> Nancy Bullock, VDH | <input type="checkbox"/> James Pearson, DCLS |
| <input type="checkbox"/> Mary Ann Discenza, DMHMRSAS | <input checked="" type="checkbox"/> Ginny Proud, CHKD |
| <input checked="" type="checkbox"/> Laura Duncan, VCU | <input type="checkbox"/> Jene O. Radcliffe-Shipman, VDH |
| <input type="checkbox"/> Mary Claire Ikenberry | <input checked="" type="checkbox"/> Charlie Stevenson, DCLS |
| <input type="checkbox"/> Anil R. Kumar, VCU | <input checked="" type="checkbox"/> Bill Wilson, UVA |
| <input type="checkbox"/> Sara Long, MOD | <input 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, Staff - NB Subcmt |
| <input type="checkbox"/> Heather Creswick, Lead Staff - SGP/PH Subcmt | <input checked="" type="checkbox"/> Rafael Randolph, Staff - VaGAC |
| | <input checked="" type="checkbox"/> Sharon Williams, Lead Staff - Contractors Subcmt |

VaGAC Ad Hoc Members:

- | | |
|--|--|
| <input type="checkbox"/> Joanne Boise, VDH | <input type="checkbox"/> Ruth Frierson |
| <input type="checkbox"/> Joan Corder-Mabe, VDH | <input type="checkbox"/> David Suttle, VDH |

Additional Subcommittee Members / Interested Parties:

- | | |
|--|---|
| <input 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 checked="" type="checkbox"/> Valerie Luther, Partnership, VCU | <input type="checkbox"/> Cliff Schroeder, Parent |
| <input type="checkbox"/> Paula Miller, Parent | <input type="checkbox"/> Holly Tiller, VDH |
| <input type="checkbox"/> Kathleen Moline, VDH | <input type="checkbox"/> Heather Trammell, Parent |
| <input checked="" type="checkbox"/> Jana Monaco, Parent | <input type="checkbox"/> Susan Ward, VHHA |

Guests: Joe Spontarelli, CART Provider

Recorders: Nancy Ford and Rafael Randolph

1. Welcome: J. Bodurtha
 - a. A moment of recognition was held for two of our colleagues who passed away since our last meeting: Thaddeus I. (Thad) Kelly, MD, PhD, and Loucendia (Lou) R. Givens-Lambert.
 - b. Introductions: Completed.
 - c. Minutes of 4/28/2009 Meeting: Approved as written.
 - d. Agenda: No changes
 - e. Membership: Circulated for corrections

- f. Travel Reimbursement Reminder: See Rafael Randolph to receive a travel reimbursement form.
2. Public Comments/Other: J. Bodurtha
 - a. No public comments
 - b. N. Ford recognized J. Bodurtha for being selected to receive the “2009 Outstanding Achievement Award” from the Association of University Centers on Disabilities (AUCD). J. Bodurtha was selected for her significant contributions to the association and the disabilities field.
 3. Review of VaGAC Infrastructure, if needed: N. Ford will now be chairing the VDH Contractors Subcommittee.
 4. Subcommittees Reports
 - a. Newborn Screening Subcmt – W. Andrews
 - (1) *Meetings*: Last October was the last face-to-face meeting and various topics were discussed at that time. Among the topics discussed were plans to purchase new tandem mass spectrometry equipment (which has been purchased), standardization of terminology, formation of a workgroup, and the formation of a “core” workgroup that meets monthly.
 - (2) *Membership*: Continue to work on expanding membership to reflect all areas of interest related to newborn bloodspot screening; will consider recommendation to draft a core letter to “reinvigorate” membership to sustain continuity.
 - (3) *Minutes*: Communication was another issue that arose and the idea that basic minutes could be taken to solve the problem. Plan: VDH staff available to take minutes, and after minutes are approved by subcommittee, minutes will be emailed to all VaGAC members.
 - b. Birth Defects Prevention Subcmt – T. Causey
 - (1) *Multi-Vitamin Task Force*: Over the last couple of months, T. Causey has been involved with the State Health Commissioner’s Multi-Vitamin Task Force. The state has ordered 100,000 bottles of multi-vitamins, and the task force is charged with creating a method to distribute and track the measures of these activities. Public service announcements are currently being developed.
 - (2) *Infant Mortality*: The State Health Commissioner’s Infant Mortality Work Group, which is attended by J. Bodurtha or T. Causey, reported that the state’s infant mortality rate had dropped significantly in 2008, to the lowest level in Virginia’s history.
 - c. State Genetics Plan and Public Health Subcmt – J. Bodurtha: The Virginia State Genetics Plan for Public Health has been placed on hold due to other priorities within DCAH.
 - d. VDH Contractors Ad Hoc Work Group – N. Ford
 - (1) *Chair*: Responsibilities have been transferred from S. Williams to N. Ford.
 - (2) *Contracts*: Management of the genetics and metabolic treatment centers contracts has been transferred from S. Williams to N. Ford. Invoices and quarterly reports should now be sent to N. Ford (instead of S. Williams).
 5. Updates: Agencies, Organizations, and Grants
 - a. VDH Genetics and Newborn Screening – N. Ford
 - (1) *Grants*:

- (a) CDC Birth Defects Grant: The five-year CDC Birth Defect Surveillance and Evaluation grant will end February 28, 2010. The application for the next round, which will be competitive for all states, is not out yet.
- (b) Year 2 of the 3-year CDC Early Hearing Detection and Intervention grant began July 1, 2009.
- (c) Year 2 of the 3-year HRSA Universal Newborn Hearing Screening grant began September 1, 2009.
- (2) *Organizational Changes:* The Genetics and Newborn Screening organizational chart was distributed. Highlights:
 - (a) “Pediatric Screening and Genetic Services” (PSGS) has been renamed “Genetics and Newborn Screening” (GNS). N. Ford’s title has changed from “PSGS Director” to “GNS Director.”
 - (b) The name “Virginia Genetics Program” has been discontinued.
 - (c) “Virginia Newborn Screening Services,” which was under the Virginia Genetics Program, has been renamed “Virginia Newborn Screening Program” (VNSP). S. Williams will continue to manage VNSP; her title has changed from “Virginia Genetics Program Manager” to “VNSP Manager.”
 - (d) VaCARES, which was under Virginia Genetics Program, has been moved to “Birth Defects Surveillance and Evaluation” (BDPSE), which is managed by N. Ford. BDPSE also includes VaCATPIP II.
 - (e) G. Jones, then Virginia Early Hearing Detection and Intervention Program (VEHDIP) Manager, resigned July 15, 2009. R. Frierson is the Acting VEHDIP Manager.
 - (f) VNSP and VEHDIP Managers are now required to work 50% as direct staff, and N. Ford has absorbed some of their former administrative and management activities, such as managing contracts, invoices, and budgets.
 - (g) A decision was made by DCAH Director with support by OFHS Director to not fill one of the newborn screening nurse positions. Several concerns were raised by VaGAC members related to sufficient number of qualified staff to perform complex VNSP follow-up functions.
- (3) *VDH Newborn Screening Database*
 - (a) VISITS II is still in production with a new release date of January 2010. The delay is contributed to the linkage with the Electronic Birth Certificate (EBC) system.
 - (b) The EBC is now complete and different regions are being phrased in. VISITS II cannot go live until EBC is implemented statewide.
- b. *VDH Virginia Sickle Cell Awareness Program – J. Shipman*
 - (1) J. Shipman at NYMAC so Dr. Owen spoke in her absence.
 - (2) Dr. Owen (CHKD) stated they are still trying to strengthen their transition program from the pediatric world to the adult world for their patients. They have also been affected by the state budget.
- c. *VDH CSHCN Program, including Care Connection for Children (CCC) and Child Development Clinics (CDCs) – N. Bullock*
 - (1) As of July 1, 2009, CDCs are funded (federal with state matching funds). A CDC was closed in Newport News. The rationale for the closing was there was a clinic in Norfolk that the clients could go to.
 - (2) VISITS II database will be linked to CCC database, which will enable automatic referrals of children with certain birth defects to CCC.

- (3) As the Virginia CSHCN Director, N. Bullock is participating in the VEHDIP Learning Collaborative, which is a component of the National Initiative for Children's Healthcare Quality (NICHQ) Learning Collaborative. The Virginia team is comprised of multidisciplines and parents. The team is focusing on how to improve VEHDIP's implementation of the CDC 1-3-6 Plan, which includes the following goals: (1) All newborns will be screened for hearing loss before one month of age, preferably before hospital discharge; (2) All infants who screen positive will have a diagnostic audiologic evaluation before 3 months of age; and (3) All infants identified with a hearing loss will receive appropriate early intervention services before 6 months of age.
- d. VDH Division of Women's and Infants' Health – K. Moline: No report.
- e. Division of Consolidated Laboratory Services – J. Pearson, W. Andrews
 - (1) Ongoing H1N1 testing.
 - (2) Dr. Tom Hickey is representing DLCS at NYMAC.
 - (3) Currently looking to fill four vacant scientist positions.
- f. March of Dimes – S. Long: No report.
- g. DMHMRSAS: Part C – M. A. Discenza: No report.
- h. NYMAC – J. Bodurtha: Did not attend last meeting; however, others on VaGAC did attend.
- i. Virginia Association of Genetic Counselors – T. Causey
 - (1) Election for board members begins November 2, 2009.
 - (2) Creating letter of intent for sunrise review of licensure.
- j. HRSA Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC) – J. Monaco. The 19th ACHDNC meeting was convened September 24-25, 2009. Highlights:
 - (1) *Newborn Screening Web Portal Concept* - Purpose is to improve the quality of care for newborns by enabling early detection and invention for the disorders. It would address both the importance of newborn screening as well as electronic data exchange possibilities. Presentation available online at <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/downing.pdf>
 - (2) *Internal Review Workgroup: Nomination of Alpha Thalassemia: Hemoglobin H Disease to The ACHDN'S Recommended Uniform Screening Panel* - The committee voted to recommend a full evidence review to the core panel. Presentation available online at: <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/frempong.pdf>
 - (3) *Use and Storage of Residual Blood Spots Workgroup: Briefing Paper Report* - A presentation on the use of storage of residual dried bloodspots was conducted. Family, laboratory, and public perspectives were given. The presentation was well attended with approximately 75 people in attendance and almost 300 on the webinar. A white paper on topic is being developed. Plan: J. Monaco will send power point slides to N. Ford for emailing to VaGAC. Presentation available online at <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/Monaco.pdf>
 - (4) *Committee Discussion on the Candidate Nomination of Krabbe Disease* - Voted not to add Krabbe disease to core panel because substantial evidenced is needed to show net benefit. Presentation available online at <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/Perrin.pdf>

- (5) *Policy Paper: Newborn Screening and Health Care Reform*: Presentation slides available online at <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/johnson.pdf>
 - (6) *Medical Foods Legislation*: Senator John Kerry is sponsoring the Medical Foods Equity Act of 2009, which will require medically necessary food and supplements to be covered by both federal health programs and private insurance plans. Presentation slides available online at <http://www.hrsa.gov/heritabledisorderscommittee/presentations/sep09/CBrown-NPKUA.pdf>
6. Updates: Virginia Genetics and Metabolic Centers
 - a. EVMS – G. Proud
 - (1) Virtual ground breaking for new research building just occurred and the Governor attended.
 - (2) Currently recruiting for fourth genetic counselor.
 - (3) Offered thanks to the DCLS newborn screening lab and VDH newborn screening nurses for their work.
 - b. UVA – B. Wilson
 - (1) Hired their fourth genetic counselor.
 - (2) Approval was given to hire a genetic counselor fellow. The fellowship will be a one year fellowship.
 - c. VCU – L. Duncan, J. Bodurtha
 - (1) BioMarin sponsored two family educational events this summer.
 - (2) UVA and VCU both had PKU picnics in September that were well attended.
 - (3) The first National PKU Alliance Conference will be held January 15-17, 2010, in Dallas. Information is available online at <http://npkua.org/index.php/conference-update>
 - (4) J. Bodurtha gave a report on genetics in Libya. A connection between Physicians for Peace and a foundation in Libya has been established. The medical schools in Libya have genetics as a priority. Libya is one of three countries in the Mediterranean region that does not perform newborn screenings.
 7. New Business
 - a. S. Williams - Followed-up on the Portsmouth Naval not reporting diagnosed cases. On September 30, 2009, S. Williams received a call from Portsmouth Naval saying they received a directive “from above” to share their diagnosis data with the health department.
 - b. V. Luther – The Virginia Deaf-Blind Project has a new director, Julie Durando. The Partnership for People with Disabilities will be celebrating their 25th anniversary in 2010.
 8. Next Meetings
 - a. Next VaGAC Meeting:
 - Date: April 20, 2010
 - Time: 10 a.m.-12 noon
 - Place: Division of Consolidated Laboratory Services
 - b. VaGAC Steering Cmt Meeting: Date and time to be announced.
 9. Adjourn: Meeting adjourned at 12 noon.