Final

Virginia Genetics Advisory Committee
Tuesday, October 7, 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

VaGAC Members (check = present):

- ☑ Willie Andrews, DCLS
- ☑ Joann N. Bodurtha, VCU (VaGAC Chair)
- ☐ Nancy Bullock, VDH-CSHCNP
- ☑ Eileen Coffman, CHKD
- ☐ Mary Ann Discenza, DMHMRSAS-Part C
- ☑ Laura Duncan, VCU
- ☐ Mary Claire Ikenberry, DOE
- ☐ Anil R. Kumar, VCU
- ☐ Sara Long, MOD
- ☐ Walter Nance, VEHDIP Adv Cmt
- ☑ William Owen, EVMS/CHKD present via conf call
- ☐ Arti Pandya, VCU, VEHDIP Adv Cmt
- ☐ James Pearson, DCLS
- ☑ Ginny Proud, CHKD
- ☐ Jene O. Radcliffe-Shipman, VDH
- ☑ Charlie Stevenson, DCLS
- ☑ Bill Wilson, UVA

VaGAC and Subcommittee Staff:

- ☑ Tahnee Causey, Lead Staff - CP/PI Subcmt
- ☐ Heather Creswick, Lead Staff - SGP/PH Subcmt
- ☑ Nancy Ford, Lead Staff - VaGAC & Steering Cmt
- ☑ Audrey Greene, Lead Staff – NB Subcmt
- ☑ Jennifer Macdonald
- ☑ Rafael Randolph, Staff - VaGAC
- ☑ Sharon Williams, Lead Staff - Contractors Subcmt

VaGAC Ad Hoc Members:

- ☐ Joanne Boise, VDH
- ☐ David Suttle, VDH

Additional Subcommittee Members / Interested Parties:

- ☐ Stephen Braddock, UVA
- ☐ Heather Bryant, DCLS
- ☐ Bonny Bukaveckas, VCU
- ☑ Karen Durst, DMHMRSAS-Part C
- ☑ Yasser El-Gohary, VCU
- ☑ Sarah H. Elsea, VCU
- ☑ Vicki Hardy-Murrell, Parent
- ☑ Gayle Jones, VDH-VEHDIP
- ☑ Valerie Luther, VCU-Partnership
- ☐ Paula Miller, Parent
- ☐ Kathleen Moline, VDH-DWIH
- ☐ Jana Monaco, Parent, Organic Acidemia Assoc
- ☑ Phil Poston, DCLS
- ☐ Alice Schroeder, Parent
- ☐ Cliff Schroeder, Parent
- ☐ Holly Tiller, VDH-DCDPC
- ☐ Heather Trammell, Parent
- ☐ Susan Ward, VHHA

Guests:
Recorders: Rafael Randolph, Sharon Williams, and Nancy Ford

1. **Welcome: J. Bodurtha**
   a. Introductions: Completed.
   b. Minutes of 04/01/08 Meeting: Approved as written
   c. Agenda: No changes.
   d. Membership (revised 4/1/08): Circulated for corrections
   e. Travel Reimbursement Reminder: R. Randolph reported that physical addresses are now required on the reimbursement form and only original forms will be accepted.

2. **VaGAC Infrastructure**
   a. Results of VaGAC Educationsl Sessions Survey: N. Ford
   During recent meetings, VaGAC discussed the merits of continuing the educational sessions that have been conducted at the beginning of meetings. At the last meeting, a decision was made for N. Ford to develop and send a VaGAC Educational Sessions Survey to members and interested parties. Completed surveys were summarized and the results were e-mailed to VaGAC on October 3, 2008. There was a 50% return rate—mostly by people who attend the meetings. Highlights of survey results:
   - Question 1. The major of respondents (76%) indicated that given our mission, it would be appropriate to provide educational sessions at a VaGAC meeting.
   - Question 2. The majority of respondents (62%) indicated that educational sessions should take place during the meeting (instead of after the meeting).
   - Question 3. The majority of respondents (57%) indicated that if educational sessions were provided during meetings, the sessions should last 30 minutes.
   - Question 4. If educational sessions were provided after meetings, 43% of respondents indicated that the sessions should last 30 minutes.
   - Question 5. If educational sessions were provided after meetings, 67% of respondents indicated they would be willing to pay for their lunch and 53% indicated they would be willing to bring their lunch.
   - Question 6. More that 50% of respondents indicated they would be most interested in learning more about the following topics: (1) newborn screening conditions that might be added to the nationally recommended panel; (2) genetic ethical, legal, and social issues; (3) genetic testing; (4) genetic counseling; and (5) genetics education in Virginia, grades K-12.

   It was noted that a comment was made on the survey by VDH management staff that because VaGAC is advisory, it is inappropriate to include an educational agenda as this is going beyond the scope of what VDH should be staffing for an advisory committee. J. Bodurtha posed three questions: (1) Were there topics where being in the same room could lead to a level of understanding, dialog, or questioning that would not happen otherwise? (2) Are we poised to be more thoughtful in a state-wide genetics meeting? (3) How can we make our time together more effective? Plan:
   - ☐ **VaGAC Steering Committee** will include VaGAC mission-related updates (instead of formal educational sessions) that require in-person discussion on agendas when appropriate.
   - ☐ **J. Bodurtha** will periodically prepare written summaries of VaGAC mission-related updates that do not require in-person discussion and send to VaGAC via e-mail.

   b. Review of Infrastructure Summary (04/01/08): J. Bodurtha
   J. Bodurtha briefly reviewed the mission, and N. Ford asked members to consider joining a subcommittee if they are not on one already. There were no changes made to the VaGAC Infrastructure document. Plan:
   - ☐ **Subcommittee Chairs** will continue to send N. Ford new members' names for adding to the VaGAC Infrastructure Summary document.
   - ☐ **All VaGAC Members and Interested Parties** will contact subcommittee chairs if interested in joining a subcommittee as follows:
     - State Genetics Plan and Public Health Subcommittee: Contact Joann Bodurtha
     - Newborn Screening Subcommittee: Contact Willie Andrews
     - Birth Defects Prevention Subcommittee: Contact Tahnee Causey

- VDH Contractors Subcommittee: Contact Sharon Williams

3. **Subcommittees Reports**
   a. Newborn Screening Subcommittee: W. Andrews
      - The Subcommittee continues to hold quarterly meetings but has not been successful in getting endocrine and cystic fibrosis specialists to join. The last time the Subcommittee met was July 2008 via conference call. J. Bodurtha asked that if time permitted, could emergency preparedness and clinical contingency planning for newborn screening be added to the Subcommittee's agenda (e.g., building what is already in place at VDH, DCLS, and metabolic centers). Plan:
        ☐ **W. Andrews** will add newborn screening clinical contingency planning to a future Subcommittee agenda.

   b. Birth Defects Prevention Subcommittee: T. Causey
      - T. Causey reported that she is currently recruiting members for the Subcommittee. Invitations were sent to former members of the Virginia Folic Acid Council and VDH Fetal Alcohol Spectrum Disorder Task Force. Several responses were received. Plan:
        ☐ **T. Causee** will convene the first meeting of the Subcommittee after initial recruitment activities are completed.
      - J. Bodurtha reported that VCU is working on a request for Governor Kaine to proclaim November 2008 as Family Health History month.
      - T. Causee presented the Family Health History banner, which is available for use by stakeholders, including VaGAC members and interested parties. This is the second year of the Family Health History promotion contest in which young people have been asked to submit a poster. Several posters have been received so far.

   c. State Genetics Plan and Public Health Subcommittee: J. Bodurtha
      - J. Bodurtha reported that the draft State Genetics Plan for Public Health plan is reviewed. When completed, it will be sent to Subcommittee for review and advice to VDH.
      - L. Duncan reported that the Joint Legislative Audit & Review Commission (JLARC) has been assigned responsibility for conducting evaluations of mandated health insurance benefits in support of the Special Advisory Commission on Mandated Health Insurance Benefits by §2.2-2503 and §30-58.1 of the *Code of Virginia.* Of the bills being evaluated, two concern Mandated Coverage of Amino Acid-Based Formulas: House Bills 615 and 669 of the 2008 General Assembly. House Bill 615 would mandate health insurance for amino acid-based elemental formulas for various gastrointestinal (GI) and hypersensitivity diseases and disorders. House Bill 669 would mandate coverage for amino acid-based formulas for inborn errors of metabolism (IEM) and certain GI conditions. L. Duncan spoke as a medical expert concerning House Bill 615. The JLARC evaluation report for House Bills 615 and 669 is available online at http://jlarc.state.va.us/mhibeval.htm.

   d. VDH Contractors Subcommittee: S. Williams
      - The Subcommittee has not yet met this fiscal year.

4. **Updates: Agencies, Organizations, Grants**
   a. VDH, Grants: N. Ford

- VDH was awarded year-four funding (2/28/08 – 03/01/09) of the five-year CDC Birth Defects Surveillance cooperative agreement that supports the Virginia Congenital Anomalies Tracking and Prevention Improvement Project II (VaCATPIP II). Funds are being used to support continuation of the VDH-contracted genetic counselor positions (90% and 10%) along with geneticist consultation and VaGAC support. N. Ford continues to be the project director. In April 2008, a Family Health History Web page was created that includes a downloadable Family Health History form. The Web page URL is http://www.vahealth.org/psgs/FamilyHealthHistory.htm.
- Funding for the three-year CDC Early Hearing Detection and Intervention (EHDI) cooperative agreement that supported the Virginia Child Health Information Systems Integration Project I (VaCHISIP I), which involved the redesign and implementation of the Virginia Infant Screening and Infant Tracking System (VISITS II), ended June 30, 2008. However, a one-year no-cost extension to complete the redesign and implementation of VISITS II was awarded. N. Ford continues to be the project director. Because VISITS II will be integrated with the electronic birth certificate (EBC), VISITS II cannot be implemented until EBC is implemented. The target completion date for VISITS II to be running statewide is no later than June 2009.
- VDH was awarded year-one funding (7/1/08 – 6/30/09) of a three-year CDC EHDI cooperative agreement to support VaCHISIP II. Year-one funds will be used to (1) hire a part-time Project Coordinator, (2) hire a part-time VEHDIP Follow-up Analyst, (3) support a learning collaborative to test local EHDI processes and VEHDIP roles change for improving VEHDIP effectiveness and efficiency, and (4) support VISITS II database management and programming enhancements. G. Jones is the project director.
- Funding for the three-year Health Resources and Services Administration (HRSA) Universal Newborn Hearing Screening (UNHS) cooperative agreement that included support for VEHDIP follow up, Hearing Aid Loan Bank (HALB), and Guide By Your Side (GBYS) project ended August 30, 2008. G. Jones was the project director. HALB has moved from VDH to DOE management with eventual DOE funding; interim funding will be provided by VDH Children with Special Health Care Needs (CSHCN) Program. In addition, DOE will provide one more year of GBYS project funding through UVA.
- VDH was awarded year-one funding (9/1/08 – 8/31/09) of a three-year HRSA UNHS cooperative agreement. Year-one funding will be used to retain the current full-time VEHDIP Follow-Up Specialist and to hire a part-time Quality Improvement Coordinator. G. Jones is the project director.
- G. Proud asked if blood-spot screening results will be made available to providers via the DCLS Web site. W. Andrews responded that DCLS is working towards this, but there are many related questions that need to answered, data formats need to be unified, and system capability issues need to be worked out.

b. VDH, Virginia Sickle Cell Awareness Program: J. Shipman
   - No report.

c. VDH, CSHCN Program, including Care Connection for Children and Child Development Clinics: N. Bullock
   - No report.

d. DCLS: W. Andrews
   - As part of Governor Kaine's FY 2009 budget reduction plan**,** DCLS was required to submit 5%, 10% and 15% budget reduction proposals, as were other State agencies.

- In September 2008, DCLS Newborn Screening Lab recognized and celebrated National Newborn Screening Awareness Month.
- The May 2008 PKU Walk-A-Thon, which was sponsored by Ryan's PKU Foundation of Virginia, raised about $4,000.

e. March of Dimes: J. Bodurtha (for S. Long)
- VCU submitted another MOD grant, which focused on a developing a Virginia genetics questions and answers Web site, but the application was not awarded because March of Dimes is only funding projects that focus on preterm labor this year.
- VCU plans to meet with MOD to determine what plans MOD has in relation to genetics.

f. DMHMRSAS, Part C: Karen Durst (for M. A. Dicenza)
- Governor Kaine has transferred Part C from DMHMRSAS to VDH, effective July 1, 2009. Part C will be located in the Office of Family Health Services, Division of Child and Adolescent Health.

g. Virginia Department of Education: J. Bodurtha and N. Ford (for M. C. Ikenberry)
- DOE has requested comments from VaGAC on modifying the DOE Chronic Health Conditions Report (see report that was mailed to VaGAC previously). This report is sent to all school divisions each January to determine the total number of students that have certain chronic conditions and to identify factors that may require the consideration of school divisions to provide trained staff to perform medical procedures that involve such devices as medical shunts tracheostomy tubes, gastrointestional tubes, urinary catheters, and central venous lines. Plan:
  - ☐ **N. Ford** will send a brief survey to VaGAC that asks (1) What items would you recommend be added to the DOE Chronic Health Conditions Report? and (2) Would you be interested in participating in a conference call with DOE concerning the results of the VaGAC recommendations and what, if any, modifications will be made to the Chronic Health Conditions Report?
- L. Duncan and A. Pandya reported that they spoke to a group of school nurses on October 6, 2008, to educate them about some of the newborn screening conditions, including diagnosis and treatment.

h. New York-Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC): J. Bodurtha
- L. Duncan, who is on the NYMAC Transition Work Group, reported that staff in Florida developed a short instructional video for teens and young adults on how to assume responsibility for their own healthcare. The Work Group is in the process of developing grants that will fund the creation of transition programs.
- J. Bodurtha, who is on the NYMAC Medical Home Work Group, reported that there have been no new accomplishments in the Work Group
- S. Williams, who is on the NYMAC Newborn Screening Standardization Work Group, reported that the Work Group will convene a conference call October 16, 2008.

i. Virginia Association of Genetic Counselors (VaAGC): T. Causey
- VaAGC is an organization that was developed in the fall of 2007 by a group of genetic counselors representing various regions in Virginia as an outgrowth of conversations begun at various state meetings. The intended purpose of the organization is to facilitate communication among counselors in Virginia and to serve as a resource for relevant information to the public. VaAGC has a working group of

eight individuals, and an email was sent out calling for nominations for officers. For more about VaAGC, visit its Web site at http://www.vaagc.org/.

j. HRSA Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC): J. Monaco
   - J. Monaco reported on Project Quilt, which honors those born with inborn errors of metabolism. The quilt was displayed during the meeting. It was made from squares that were made by various individuals. This is an ongoing project in which new quilt squares will be added. The motto of Project Quilt is "All In This Together." The project symbolizes two groups: Organic Acidemia Association and Fatty Acid Oxidation Family Support Group.
   - ACHDNC convened its 15th meeting on October 1-2, 2008, in Washington, DC. Agenda items included (1) Decision Criteria and Process Workgroup; (2) Evidence Review Workgroup: Report on the Candidate Nomination (Pompe Disease); (3) Public Comment; (4) Financial Reimbursement and Insurance Coverage for Medical Foods (they are doing surveys in different groups to find out exactly what insurance groups cover); (5) Subcommittee Sessions: (a) Laboratory Standards and Procedures, (b) Education and Training, and (c) Follow-Up, and Treatment; (6) Personalized Healthcare Workgroup: (a) Newborn Screening Health IT Standards and Use Case Recommendations and (b) Use Case Process and Community Input); (7) Emergency Preparedness and Contingency Planning for Newborn Screening: (a) HHS National Contingency Plan for Newborn Screening, (b) Newborn Screening Preparedness/ Contingency Planning Framework: A White Paper by the Association of Public Health Laboratories, and (c) Emergency Preparedness for Newborn Screening and Genetic Services: A Report by the Regional Collaboratives' National Coordinating Center; and (8) Subcommittee Reports: (a) Laboratory Standards and Procedures, (b) Education and Training (in the process of reviewing proposals to see who would become the an educational clearing house), and (c) Follow-Up and Treatment). In addition to Pompe Disease, KRAB-A (Krüppel-associated box-A), and SCADD (short-chain acyl-CoA deficiency) are being reviewed. For more information about ACHDNC, visit its Web site at http://www.hrsa.gov/heritabledisorderscommittee/default.htm.

5. **Updates: Virginia Genetics and Metabolic Centers**

a. EVMS: G. Proud
   - Three weeks ago EVMS hired a full-time clinical geneticist, Nicole Safina, and recruited a third genetic counselor.
   - Last weekend a workshop was conducted in Williamsburg.
   - EVMS was part of a PKU awareness event when a man ended up in Yorktown after bicycling across the country to bring attention to PKU. One of their families suggested that they should be part of the medical mystery series.
   - Dr. Owen reported that a new staff member joined the sickle cell program. Last month was sickle cell awareness month; they had a lot of media exposure especially with their transition program.

b. UVA: B. Wilson
   - UVA continues to be busy, and Danielle Dawn is back as genetic counselor.
   - Workload continues to increase with the enzyme replacement program and the cancer genetic program.

- A genetic counselor meeting was convened in May 2008, and they held their 15th annual PKU picnic in June.
- Dr. Kelly has retired.

c. VCU: J. Bodurtha
- L. Duncan reported that Kuvan, a medication for PKU is being tested. Kuvan is currently not to be used during pregnancy.
- S. Elsea reported that Rick Guidotti, a former fashion photographer who founded Positive Exposures, is coming to speak in January 2009. Positive Exposures challenges the stigma associated with difference by celebrating the beauty and richness of human diversity. Rick travels around the world taking pictures of individuals with various genetic disorders. He has done some amazing work in promoting diversity and acceptance for individuals with genetic disorders. S. Elsea will send out information regarding time and place. For more information about Positive Exposures, visit its Web site at http://www.positiveexposure.org/.
- J. Bodurtha reported that Margie Jaworski has moved over to pediatrics to work with the new child development center in Southside. Colleen Kraft, M.D., Immediate Past President of the Virginia Chapter-American Academy of Pediatrics, was not elected President of the American Academy of Pediatrics.

6. **New Business**
- V. Murrell reported that if you would like to announce such activities as walk-a-thons, fundraisers, and subcommittee meetings, please send her an email as she can pass this information along to families.
- J. Bodurtha proposed that a letter of thanks be sent to Walter Nance and Thad Kelly for their many years of service to the Virginia genetics community. Plan:
  - ☐ **J. Bodurtha** will write a thank you letter on behalf of VaGAC to W. Nance and T. Kelly that recognizes both of them as "Founding Fathers" of genetic services and education in Virginia.

7. **Next Meetings**

a. VaGAC Meeting:
- Date: Tuesday, April 28, 2009
- Time: 10 AM – 12 Noon
- Location: Division of Consolidated Laboratory Services

b. VaGAC Steering Committee Conference Call:
- Date: Tuesday, March 31, 2009
- Time: 10 AM
- Call-in Information: N. Ford will send before the conference call.

8. **Adjournment**
- Meeting adjourned at 12:00 PM