

**Virginia EHDI Program Advisory Committee Meeting
Friday, November 9, 2007
10 a.m. – 3 p.m.**

**Children’s Hospital of Richmond
Auditorium
2924 Brook Road
Richmond, VA 23220-1298
(804) 321-7474**

MINUTES

Members (check=present)		Ex Officio Members
<input type="checkbox"/> Frank Aiello, MD, FAAP	<input type="checkbox"/> Ronald Lanier	<input checked="" type="checkbox"/> Nancy Bullock, RN, MPH
<input type="checkbox"/> Barbara Allen, RN	<input type="checkbox"/> Jacqueline Meeks	<input checked="" type="checkbox"/> Fredia Helbert, AuD
<input type="checkbox"/> Jeaninne Beden	<input checked="" type="checkbox"/> Stephanie Moody-Antonio, MD	<input checked="" type="checkbox"/> Claire Jacobson, AuD, CCC-A
<input type="checkbox"/> Nancy Bond, RN	<input checked="" type="checkbox"/> Casey Morehouse, MEd, CCC-A	<input checked="" type="checkbox"/> Roger Ruth, PhD
<input checked="" type="checkbox"/> Robert Boyle, MD	<input type="checkbox"/> Walter Nance, MD	Staff
<input type="checkbox"/> Deana Buck	<input type="checkbox"/> Walter Nance, MD	<input checked="" type="checkbox"/> Nancy Ford, MPH, RN
<input type="checkbox"/> Jackie Busa	<input checked="" type="checkbox"/> Debbie Pfeiffer	<input checked="" type="checkbox"/> Michelle Ballard, MPH
<input checked="" type="checkbox"/> Mark Campano, MEd	<input type="checkbox"/> Leslie Prince	<input type="checkbox"/> Darlene Donnelly
<input checked="" type="checkbox"/> Brian Campbell	<input type="checkbox"/> Teresa Robinson	<input checked="" type="checkbox"/> Ruth Frierson
<input type="checkbox"/> Craig Derkay, MD	<input checked="" type="checkbox"/> Ellen Rolader, MA	<input checked="" type="checkbox"/> Lou Lambert
<input type="checkbox"/> Mary Ann Discenza	<input type="checkbox"/> Terrence Schulte	<input checked="" type="checkbox"/> Rafael Randolph (for Darlene Donnelly)
<input type="checkbox"/> Leslie Ellwood, MD, Co-Chair	<input checked="" type="checkbox"/> Barry Strasnick, MD, Chair	
<input type="checkbox"/> Sally Frasier, RNC	<input checked="" type="checkbox"/> Beth Tolley	
<input checked="" type="checkbox"/> Ann Hughes, MA	<input type="checkbox"/> Linda Wallace	
	<input type="checkbox"/> Susan Ward	
	<input type="checkbox"/> Dana Yarbrough	
Guests: Susan Tlusty, Policy Analyst VDH; Karen Knox (guest of C. Morehouse); Allison Cleland (guest of S. Moody-Antonio); Sandra Woodward, Blue Ridge-Care Connection for Children.		
Recorders: Nancy Ford, Rafael Randolph		

1. Welcome: N. Ford

- A. Introductions: Completed.
- B. Approval of 5/11/07 Minutes: Reviewed and approved as written.
- C. Agenda: Reviewed, comments added:
 - D. Pfeiffer added children born with midwives that may not be screened. N. Ford recommended that this item be deferred to the appropriate Subcommittee.
 - N. Ford added SIDS to new business items.
 - E. Rolader has concerns about how information is presented to parents. N. Ford recommended that this item be deferred to the appropriate Subcommittee.
 - E. Rolader reported that the Web site listed in the VEHDIP Hospital Protocol for “How to Present to Parents” is invalid. Plan:
 - VEHDIP** staff will make corrections in the next version of the protocol.
- D. Membership: Circulated for corrections.

2. VEHDIP Regulations: S. Tlusty

The VEHDIP regulations are undergoing review. The VEHDIP Advisory Committee was invited to advise VDH on updating the regulations through a special ad hoc task force or subcommittee to be established during the later proposed infrastructure discussion.

A regulation is a general rule governing people's rights or conduct that is promulgated by a state agency and has the force of law. Agencies promulgate regulations in order to administer and enforce specific state laws and to implement general agency objectives. Regulations have to be reviewed every 4 years to make sure they are still valid or if changes need to be made. As a state agency, VDH is allowed 90 days following close of public comment to make a recommendation or change.

The VEHDIP review process needs to make sure that the definitions are correct and the rules ensure that the VEHDIP objectives are met (e.g., making sure regulations are consistent with Joint Committee of Infant Hearing when feasible given current resources) in addition to meeting Executive review requirements (e.g., regulation is consistent with statutory authority; clearly written and easily understandable to the regulated community; essential to protect public health, safety, and welfare; and is the least burdensome and intrusive regulation possible). For more information about the regulatory process, see the Virginia Regulatory Town Hall Web site at <http://www.townhall.state.va.us/>. See Item 7 for further discussion on involving Advisory Committee in the regulatory review process.

3. Group Announcements

- A. **F. Helbert:** The early training on the National Center for Hearing Assessment and Management's (NCHAM) Early Childhood Hearing Outreach (ECHO) initiative, which focuses on "echo-ing" successful newborn hearing screening efforts by extending the benefit of periodic hearing screening to children 0 – 3 years of age in a variety of settings including Head Start settings, has been completed.
- B. **D. Pfeiffer:** The Virginia Association of the Deaf accepted nominations for the Joe Turner award. The Guidelines for Working with Student Who are Deaf or Hard of Hearing document is in the final states of editing.
- C. **A. Hughes:** The first of three trainings ("Working with Parents") for educational professionals working with student who are deaf or hard of hearing has been completed by UVA; the next trainings will focus more on in-depth audiology training. There is a Hands & Voices meeting 11/12/07. Jennifer Hutson heads this non-profit, parent-driven organization that is dedicated to supporting families of children who are deaf or hard of hearing and supports non-biased communication methodologies and believes that families can make the best choices for their child if they have access to good information and support. A Hands & Voices Virginia Chapter is required to maintain a Guide By Your Side program in Virginia.
- D. **C. Morehouse:** The article "Molecular Screening for Children with Hearing Loss: Why Do It?" by Jace Wolfe and Walter Nance, published in *The ASHA Leader*, November 6, 2007, was circulated. The article is available online at <http://www.asha.org/about/publications/leader-online/archives/2007/071106/071106c.htm>
- E. **B. Strasnick:** On 08/9/2007, a comprehensive cooperative agreement between Old Dominion University and Eastern Virginia Medical School enabling the efforts of future Coalition for Hearing, Education and Research (CHEAR) projects was signed by the presidents of ODU and EVMS. The mission of CHEAR is to provide to the Hampton Roads community and its citizens comprehensive services for disorders of the ear, hearing and balance through identification, clinical care, research, rehabilitation, education, public awareness and advocacy. For more information about CHEAR, see its Web site at <http://chearvirginia.com/>.

4. **Hearing Aid Loan Bank (HALB):** S. Woodward distributed and reviewed a summary of the HALB *Highlights:*

- The HALB provides temporary aid until permanent aid can be found if necessary. Insurance companies do not cover hearing aids.
- The ages of children that have used or are using the HALB range from less than 1 year of age to 19 years of age.
- The number of weeks of use ranges from 2 weeks to 50 weeks, with 25 weeks being the average.
- Between June 2006 and November 8, 2007, 142 children have obtained devices: 25 children in 2005, 54 children in 2006, and 63 children in 2007.
- A parent survey was conducted to determine the effectiveness of the program; 75 surveys were sent out and 90% were returned. Parents found the program beneficial. The next survey will target audiologists.
- When a HALB referral is received by VDH, R. Frierson sends it to the HALB. The turn around time is about 48 hours. The devices are sent out for 6 months and then returned and refurbished.
- The HRSA EDHI grant that is managed by VDH and which funds the HALB ends August 31, 2008. The grant paid for 60 hearing aids and 15 FM systems. The cost of replacing hearing aids is \$100 and refurbish is free. Costs have gradually increased across the board.
- The HALB is managed by Blue Ridge-Care Connection for Children because it has the staff resources; however, it does not “own” the HALB.
- Phyllis Mondak, 619 Coordinator, Office of Special Education, Virginia Department of Education, has indicated that DOE *might* be able to provide future funding to maintain the HALB.

5. **Standing Update**

- A. ***Guide By Your Side (GBYS) Program and the Partnership for People with Disabilities:*** Ann Hughes distributed and reviewed a summary of the GBYS program. The FY 08 Principal Investigator for the FY 07 GBYS program was Ann Hughes; the current PI is Tera Yoder. The number of Family Guides in Northern Virginia has decreased from five to two. The importance of maintaining a Hands & Voices Virginia Chapter was emphasized because GBYS is short term support while the Hands & Voices organization is for long-term parent support. VDH funding for the GBYS program ends August 31, 2008. Phyllis Mondak, 619 Coordinator, Office of Special Education, Virginia Department of Education, has indicated that DOE *might* be able to provide future funding to maintain the GBYS program.
- B. ***Hearing Work Group:*** Beth Tolley reported that during its first year, the VEHDIP Advisory Committee’s Hearing Work Group focused on developing and implementing Guide By Your Side. During its second year, the work group focused on educating those who serve families, including development of a fact sheet and distributing it to all 40 local early intervention systems. Future activities will include developing a curriculum for online training opportunities and establishing a permanent home for the Guide By Your Side program (e.g., Virginia Department for the Deaf and Hard of Hearing).
- C. ***Virginia Department of Medical Assistance Services:*** Brian Campbell reported that amendments in the Virginia State Plan for Medical Assistance to provide for changes to the Amount, Duration and Scope of Medical and Remedial Services and the Methods and Standards for Establishing Payment Rates – Other Types of Care are now in the second draft stage for DMAS management review. The changes clarify that Medicaid covers hearing aids for children (individuals under 21 years of age) under EPSDT; the changes

are to be effective January 1, 2008. The changes are in response to the 2007 Appropriation Act, which directs DMAS to modify reimbursement for pediatric hearing aids to reimburse the actual cost of the device within the limits set by the Department, plus provides a fixed rate dispensing fee and fitting fee. Various means will be implemented to inform stakeholders of the changes, including March 2008 presentation and a WebEx online presentation. Decisions regarding if DMAS will preauthorize hearing aids are in another project.

D. ***Virginia Department of Health:***

- ***Follow-Up Services:*** Ruth Frierson reviewed the conclusions and recommendations of the final report “An Evaluation of Loss to Follow-Up in State EHDI Programs: Findings from the Virginia EHDI Program,” June 2007, prepared by Research Triangle Institute International, North Carolina. Highlights:
 - Efforts to examine the shortage of audiologists more closely and identify the appropriate programmatic and policy solutions are warranted.
 - Continuing education and promotion of the benefits of EHDI are needed to reinforce the training of younger physicians and to dispel the outdated notions of an older generation of physicians.
 - Education and counseling activities should extend beyond the immediate family to significant others so that they can offer support that is informed, positive, and empowering.
 - More effort should be directed to ensuring that all pregnant women receive education counseling on hearing screening.
 - It will be useful to more rigorously assess the education materials that are presented and to assess the nature of their presentations (e.g., comprehension and appeal).
 - Education and counseling in the prenatal period, both written and oral confirmation of test results, and more intensive counseling and education during the hospital stay could potentially address the lack of understanding of test results.
 - Effort should be directed at ensuring that all non-English speakers receive the results of the hearing screening in their native language.
 - Identification of families that have no established link to a health care provider for their infant should be done prior to discharge so that they can be tracked and supported more intensively, which may prevent or mitigate loss to follow up.
 - Additional supports such as scheduling appointments prior to discharge and reminder calls and letters could promote timeliness for those high-risk families who face various barriers to accessing health care.
 - Post-test counseling should address parental concerns and worries but should do so in a way that stresses the importance of follow up.
 - Links to family support networks appear to be largely lacking and need to be improved.
- ***Surveillance and Evaluation:*** Michelle Ballard distributed and presented a summary of the VEHDI Program 2006 Annual Report, elaborated on R. Frierson’s introduction regarding the number of infants without a medical home, and cited the 2007 Joint Commission on Infant Hearing’s statement that “...hospitals should ensure that each infant is linked to a medical home.” If the hospital cannot link the infant to a medical home, it is the responsibility of the VEHDI Program’s staff to do so.
- ***Grants:*** Nancy Ford reported that the HRSA EHDI grant, which funds the Guide By Your Side program, Hearing Aid Loan Bank, and VEHDIP Follow-Up Specialist ends August 31, 2008, and the CDC EHDI grant, which funds the redesign of the

Virginia Infant Screening and Infant Tracking System (VISITS) ends June 30, 2008, which is also the deadline for VISITS to be implemented statewide.

6. **Lunch and Networking**

7. **Proposed VEHDIP Advisory Committee Infrastructure Draft 1**

- A. **Chair vs. Co-Chairs:** Recommendation made to keep co-chairs positions instead of changing to one chair position to ensure at least one Adv. Cmt head is present during a meeting. There appeared to be consensus on this recommendation.
- B. **Membership and Voting:** Recommendation made to have one representative for each affiliations required by Code. These members would be the voting members. Additional affiliation representatives would be considered non-voting members. There appeared to be consensus on this recommendation.
- C. **Representative from Virginia Genetics Advisory Committee:** Recommendation to invite Arti Pandya, MD, MBA, Associate Professor, Department of Human Genetics, Virginia Commonwealth University, to represent VaGAC along with its current representative, W. Nance.
- D. **Maintaining Membership:** Recommendation made that to maintain membership, an individual needs to attend 50 percent of meetings over a one year period. There appeared to be consensus on this recommendation.
- E. **Meeting Schedule:** Recommendation made to maintain the same schedule of meeting four times a year. There appeared to be consensus on this recommendation.
- F. **Mission:** Need to review original mission. Plan:
 - N. Ford** will search files for original mission statement and include in Draft 2 Proposed Infrastructure
- G. **Decision Making and Quorum:** There appeared to be consensus on the proposal sent forth in the Draft 1 Proposed Infrastructure.
- H. **Types of Meeting:** Recommendation made to continue in-person Advisory Committee meetings instead of alternating with audio-conference calls with Subcommittees choosing what would best fit their needs (e.g., via email, audio-conference calls, in-person). There appeared to be consensus on this recommendation.
- I. **Steering Committee:** There appeared to be consensus on the proposal sent forth in the Draft 1 Proposed Infrastructure.
- J. **Subcommittees:** Suggestions were made to replace the proposed subcommittees set forth in Draft 1 Proposed Infrastructure with ones that more closely tie in with the components of the EDHI process. For example:
 - Identification Subcommittee, which would focus on such issues as how to best present diagnosis, screening techniques, Joint Committee on Infant Hearing Screening position statement.
 - Linkage Subcommittee, which would focus on such issues as follow-up, referrals to Care Connection for Children, VDH follow-up letters sent to primary care physicians and parents.
 - Intervention Subcommittee, which would focus on audiological components.
 - Funding Subcommittee, which would focus on leveraging additional funding for VEHDIP, such as grant applications.
- K. **VEHDIP Regulations:** Recommendation made to convene an ad hoc subcommittee to review current VEHDIP regulations and proposed changes to VDH, especially in view of the new Joint Commission on Infant Hearing position statements.
- L. **Draft 2 Proposed Infrastructure:** Plan:
 - N. Ford** will prepare Draft 2 based on discussion and send to B. Strasnick for review and edits.

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- B. Strasnick** will review Draft 2 and return edits N. Ford.
- N. Ford** will send edited Draft 2 Proposed Infrastructure to Advisory Committee before next meeting.
- Advisory Committee** will review final Draft 2 Proposed Infrastructure during next meeting.
- N. Ford** will invite A. Pandya to co-represent VaGAC (along with W. Nance).
- M. Ballard** will facilitate establishment of an ad hoc VEHDIP Regulations Review Committee to meet via audio-conference call, which will be lead by Susan Tlusty, Policy Analyst, VDH.

8. **New Business**

- A. **Constituent's Proclamation Request:** May 2008 EHDI Awareness Month: Members decided not to pursue at this time, but perhaps, it could be followed up by a Subcommittee.
- B. **SIDS and Newborn Oto-Acoustic Emission Hearing Screening Tests:** Prior to meeting, members were send several articles on this topic and several members participated in the 10/30/2007, CDC EHDI ad hoc teleconference call on this topic. Members decided not to pursue at this time given the current status of research on this topic.

9. **Next Meeting**

- A. **Date:** Friday, February 8, 2008
- B. **Time:** 10:00 AM – 3:00 PM
- C. **Location:** Children's Hospital of Richmond, Auditorium, 2924 Brook Road, Richmond, VA 23220-1298.

10. **Adjournment:** Meeting adjourned at 2:15p.m.