DRAFT

Virginia EHDI Program Advisory Committee Meeting
Friday, May 29, 2009
10 a.m. – 3 p.m.

Virginia Hospital and Healthcare Association
4200 Innslake Drive
Glen Allen, VA 23060
(804) 965-1227

MINUTES

ATTENDANCE

Barbara Allen
Nancy Bond
Deana Buck
Nancy Bullock
Regina Craig
Darlene Donnelly
Leslie Ellwood
Christine Evans
Ruth Frierson
Fuwei Guo
Kristen Harker
Fredia Helbert
Ann Hughes
Gayle Jones
Loucendia Lambert
John Mangiaratti
TyJuana Person
Debbie Pfeiffer
Susan Ward
Rebecca Wikers

1. **Welcome: L. Ellwood**
   A. Introductions: Completed
   B. Review of Agenda: Reviewed and corrected where necessary
   C. Membership: Circulated for corrections.
   D. Travel Reimbursement: Complete and return to Darlene Donnelly

2. **JCIH Recommendations**

   Discussion at the last Early Hearing Detection and Intervention (EHDI) Advisory Committee (AC) meeting resulted in a number of suggestions to the adoption of the JCIH recommendations. Due to the number and extent of suggestions, everything could not be adopted.

   HEARING SCREENING AND RESCREENING PROTOCOLS
   Separate protocols are recommended for NICU and well infant nurseries. NICU infants admitted for more than 5 days are to have auditory brainstem response (ABR) included as part of their screening so that neural hearing loss will not be missed.

   EHDI will support ABR for NICU infants that are admitted more than 5 days regardless of procedures and risk indicators due to the fact that

current resources/staff do not support the ability to monitor certain risk indicators as previously mentioned.

MEDICAL MANAGEMENT

Every infant with confirmed hearing loss should be evaluated by an otolaryngologist who has knowledge of pediatric hearing loss

Every infant with profound hearing loss should at least one examination to assess visual acuity by an ophthalmologist who is experienced in evaluating infants.

Both recommendations will be added to the EHDI protocols.

DIAGNOSTIC AUDIOLOGY EVALUATION

The timing and number of hearing re evaluations for children with risk factors should be customized and individualized depending on the relative likelihood of a subsequent delayed onset hearing loss. Infants who pass the neonatal screening but have a risk factor should have at least 1 diagnostic audiology assessment by 24 months of age.

At this time, EHDI will continue to support the recommendation of "at least 1 diagnostic audiological assessment by 24 months of age" due to letters having been written and translated based on this recommendation. Current funding does not allow for the translation of new letters.

RISK INDICATORS

Neonatal indicators (Assisted ventilation, Exposure to ototoxic medications, intensive care more than 5 days, Hyperbilirubinemia that requires exchange transfusion, ECMO)

Neonatal indicators will be adopted as written.

Syndromes associated with progressive hearing loss (Type 2 Neurofibromatosis, Osteopetrosis, Usher, Jervell, Lange-Nielson, Alport, Pendred, Waardenburg, White Forelock)

Type 2 NF will be used to reduce unnecessary costs associated with Type 1 NF.

Toxic chemotherapy

Toxic chemotherapy will be adopted.

Craniofacial anomalies (Atresia of ear, Ear Canal, Cleft Palate, Pinna, Temporal bone anomalies, Choanal Atresia, Microtia)

Craniofacial anomalies will be accepted as is with the removal of preauricular ear tag or pit/sinus.

Discussion continued with S. Ward expressing concern regarding updating the protocols with the adopted JCIH recommendations before regulations are finalized. N. Bullock pointed out that the process is already in progress, but it could be about a year before it is done. L. Ellwood explained that S. Tlusty wanted an idea of what the protocols would contain in order to align the regulations and the protocols. R. Frierson stated that many audiologists were already implementing the JCIH recommendations and since risk indicators are presently covered in the regulations, an update of protocols would just be an expansion of what is already there.

N. Bond presented concerns that hospitals would make an investment in implementing the updated protocols and then later learn that approved regulations did not support them. S. Ward and N. Bond also expressed concern regarding the amount of time that would be hospitals would be given to comply with regulations. Both S. Ward and N. Bond felt that hospitals should have an opportunity to weigh in on the changes being made become any changes become regulations.

F. Helbert suggested that protocols that are currently on the website remain and list the new ones as "Proposed" so hospitals, audiologists, and primary care providers (PCPs) can anticipate what is coming.

3. Website Review

EHDI staff decided through public and private feedback that the current website needs to be updated. The planned revisions were distributed to those in attendance for review and suggestions. Changes will be made on a schedule and should be seen as soon as the end of June 2009.

Suggestions included: List of approved audiologists be added to the PCP module; link to Hands & Voices (H&V); posting a notice to inform users that changes were being made and to return to the website soon; having parents test the changes to the parent page for feedback; and the ability for anyone to provide feedback to EHDI on any part of the process regarding the provision of services.

4. Funding Opportunity

Additional funding from Health Resources and Services Administration (HRSA) was announced 05/22/09. The hearing focus is on the reducing lost to follow up. The amount that could be received is $150K from 2009

to 2012. To participate, EHDI would have to have a proposal ready by June 12, 2009 for approval. The final proposal would have to be submitted to HRSA by June 22, 2009. The following people volunteered to assist with the proposal: L. Ellwood, C. Evans, D. Pfeiffer, D. Buck, F. Helbert, & R. Craig. Handouts providing information of the grant proposal focus were given to those in attendance and included specific ideas and interventions provided by HRSA and the National Center for Hearing Assessment and Management (NCHAM).

Discussion continued regarding the use of funding. R. Frierson pointed out that evaluations have shown that PCPs need more education about EHDI, there are gaps in the information given to families by hospitals, and that there is a need for more locations to receive follow up services. Education can address some of these gaps. R. Frierson expressed that when advised that a PCP is not supportive of the EHDI goals, she gets the name of the PCP from the parent and then calls that PCP to provide education and answer any questions.

Changes have been made to the EHDI system to improve follow up. Calls are being made to parents in the evenings every week in order to catch parents after work hours. With the addition of staff, every parent receiving a letter will also receive a phone call a week later to provide information on the process. Upon implementation of VISITS II, every child who fails a second time will receive a letter and a call to encourage them to go back for a diagnostic evaluation. Parents of children with hearing loss will continue to receive guidance about resources from EHDI.

Regional resources for parents would be a great asset to EHDI. G. Jones suggested use of local health departments. R. Craig suggested using parents from Guide By Your Side (GBYS) to be associated with each region. F. Helbert suggested having audiologist associated with each local health department do screenings on non-hospital children. In addition, F. Helbert recommended more training and education for audiologists and PCPs on guiding the family through the system. It was suggested that GBYS may be able to assist with this. A. Hughes explained that there needed to be some focus on getting better information to the parent before being discharged from the hospital. L. Ellwood supported getting a second or third contact to help with locating families.

In addition, L. Ellwood expressed a need to spend time working with border states to develop a better method of exchanging information. G. Jones explained that there are 64 reporting hospitals in Virginia, but children born at home, in birthing centers, and with midwives are not connected to EHDI. Midwives and birthing centers are able to order brochures. EHDI staff is currently gathering information on midwives to address educational issues. D. Pfeiffer expressed having spoken with

Peggy Franklin of the Commonwealth Midwife Alliance last year and Peggy expressed interest in the hearing screening process. L. Ellwood suggested using the Board of Nursing to identify midwives in Virginia.

H&V is creating a DVD for parents entitled "Loss and Found" that explains the importance of screening and what parents need to do in the event that their child does not pass. States are represented in the DVD and receive unlimited copies if they agree to the cost of producing it which is $10K per state. Hospitals could distribute the DVD to families at discharge and the DVD could be played on closed circuit televisions in waiting rooms and physician offices.

There was a question about the funding status of the Hearing Aid Loan Bank (HALB) being able to benefit from the funding proposal. Due to the strict funding proposal focus, it could not be determined how HALB could be included. F. Helbert suggested putting it under Audiology/Diagnostics with the intention of a child being able to try out the hearing aid device before committing to purchasing a device or find another alternative.

D. Pfeiffer suggested the use of webcams to help families who have received a diagnosis of confirmed hearing loss connect with other families. Webcam use could be limited to certain hours, certain days, and available through the public library system. F. Helbert inquired about a live chat session on the EHDI website or a feature to connect to a live person.

There was also an inquiry about funding for interpreters and printed materials. In addition, C. Evans expressed interest in including Early Intervention.

Suggestions were narrowed down to focus on regional representation and education of health professionals.

5. Updates

Learning Collaborative

There was an inquiry about the amount of funds associated with the learning collaborative. G. Jones explained that there was $25K provided for the learning collaborative, but that it must remain with collaborative objectives.

F. Guo discussed the National Initiative on Children's Healthcare Quality (NICHQ) learning collaborative session held May 12 – 13, 2009 in Atlanta, Georgia. F. Guo, C. Evans, L. Ellwood, and N. Bullock attended. The purpose of the collaborative is to define problems, develop solutions, test them through pilot programs, and share results with other hearing programs. Currently, 13 states are involved and each state has a team.

Virginia's team has ten members which includes an audiologist, PCP, one social worker and two parents. The collaborative is expected to end around May 2010.

To further explain some of the activities, F. Guo talked about a recent visit to Sentara Norfolk General Hospital (SNGH) and Children's Hospital of the King's Daughters (CHKD). Children born at SNGH who fail their newborn hearing screening (NBHS) are referred to CHKD for follow up testing. The nurse at SNGH would call CHKD and set up the appointment. Only 40% of the time are SNGH nurses able to speak with someone at CHKD. Usually the nurses leave a message. As a result incomplete information is often received. There was a decision to create a referral form that could be faxed in order to capture complete and necessary information without duplication. Audiologists and nurses are working together to create this form. When the form is ready it will be tested at a pilot site for evaluation and feedback.

Suggestions were made for areas that could be tested under the learning collaborative. C. Evans would like the H&V DVD to be included in one of the testing cycles so that the benefits of using it could be noted. EHDI letters could be reviewed by parents who have gone through the process. Parents of children having their hearing tested be given beepers so they would not have to be paged when the child has completed testing.

Hearing Aid Loan Bank (HALB)
From January 2009 to May 18, 2009, 34 children obtained devices. Currently, the HALB has 90 old aides and 11 fm systems and 39 new aides and 8 new fm systems.

Guide By Your Side (GBYS)
Funds are needed to continue the level of support they are now providing. 73 total referrals with 54 from EHDI and 19 from other sources. There have been 58 matches and 12 are pending. One family declined as not interested and two declined an immediate match due to medical situations but will consider a match later. Training will be held July 31, 2009 through August 1, 2009. They have six new guides for that training, 3 from Northern Virginia, 2 from Norfolk and 1 from Richmond who also happens to speak Spanish. Training will be for the new as well as current guides. Speakers will come from different service sectors. The program has a new data reporting system which will be used to develop graphs to chart their progress. On May 30, they will be distributing information on GBYS and the HALB at Kings Dominion.

Hearing Work Group
The focus of the last meeting was funding for GBYS and the HALB. C. Eubanks has taken on researching grant opportunities. A. Hughes

mentioned attempting to obtain funding from Richmond Eye and Ear and exploring whether there are similar regional agencies around the state that could be approached for funds. G. Jones stated that approximately $32K was written into the HRSA continuation application for the HALB; however, no feedback has been received as of yet.

Other Announcements
L. Ellwood announced the Virginia Commonwealth University 31st Annual Pediatric Primary Care Conference "Pediatrics at the Beach" will be held July 17-19, 2009. It will be a combined meeting with the Virginia Chapter of the American Academy of Pediatrics. This course is designed for physicians, physician assistants, and other health care professionals who deliver primary care to children and adolescents. Each day's program will be devoted to one of the following subject areas: emergency medicine, primary care, and developmental pediatrics.

Debbie Pfeiffer reminded the board of Dr. Strasnick's presentation on the Oral Preschool Program at Old Dominion University. Dr. Montero and Dr. Strasnick's, representing his group, the Coalition for Hearing, Education and Research (CHEAR), got Old Dominion University interested in the program. The Department of Education (DOE) joined in the project, and provided funding for it (to modify, supply and staff the classroom). Students started in February 2009 with 6 students age 3-5. D. Pfeiffer visits about once a month to support professional development efforts for staff members of local school divisions. It's exciting to see students' progress.

The Council of American Instructors of the Deaf (CAID) 2009 National Conference will be held June 22 – 26, 2009, at Gallaudet University in Washington DC. It will include keynote speakers, round table discussions, poster sessions, and a variety of presentations and workshops relevant to teachers, educational interpreters, counselors and other professionals who work with deaf and hard of hearing students.

Cue Camp Virginia (CCVA) will be meet August 27-30, 2009, at the 4 H Center in Front Royal Virginia

Radford University has scheduled two sessions for its Summer Institute for Professionals/Pre Service Teachers Working with Students Who Are Deaf and Hard of Hearing. Information will be provided on strategies and techniques that facilitate auditory learning of spoken language by children who are deaf or hand of hearing, July 14-15, 2009. The theoretical foundations of the school neuropsychological assessment model as applied to the population of learners who are deaf or hard of hearing will be provided July 16-17, 2009.

John Eisenberg is now the Director of Instructional Support and Related Services for DOE. This office will focus on the needs of students who are deaf/hard of hearing; blind/visually impaired; deaf-blind; have severe cognitive challenges; and/or traumatic brain injury. The Office will also focus on related services and assistive technology initiatives.

H&V is planning its second annual picnic in July; actual date to be announced.

A one day conference is being held August 4, 2009 in Roanoke and August 11, 2009 in Richmond for teachers for the deaf/hard of hearing, related service providers, and all who work with students who are deaf/hard of hearing. The conference is entitled "Opening Doors-Unlocking Potential". This conference is in conjunction with DOE's I'm Determined project which promotes self determination and self advocacy skills for students with special needs.

The Virginia Network of Consultants (VNOC) for professionals working with children who are deaf or hard of hearing has a website. www.vcu.edu/partnership/vnoc

EHDI is expecting a visit during the summer from the Centers of Disease Control and Prevention (CDC) to evaluate the program and offer assistance.

6. **Next Meeting**
   Date: October 2, 2009
   Location: Children's Hospital of Richmond
   Time: 10 a.m. – 3 p.m.