

FINAL

Virginia EHDI Program Advisory Committee Meeting
Friday, February 20, 2009
10 a.m. – 3:15 p.m.

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

MINUTES

ATTENDANCE

Frank Aiello
Barbara Allen
Michelle Ballard
Nancy Bond
Deana Buck
Nancy Bullock
Brian Campbell
Regina Craig
Darlene Donnelly
Leslie Ellwood
Christine Eubanks

Christine Evans
Nancy Ford
Ruth Frierson
Kristen Harker
Claire Jacobson
Gayle Jones
Loucendia Lambert
TyJuana Person
Debbie Pfeiffer
Lisa Powley
Susan Thlusty

1. Welcome: L. Ellwood

- A. Introductions Completed.
- B. Review of Agenda.
- C. Travel Reimbursement: Complete and return to Gayle Jones.

2. JCIH Recommendations

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. Separate protocols are recommended for NICU (excerpt from JCIH Year 2007 Position Statement: Principles & Guidelines for EHDI Programs).

Discussion of this topic presented the following concerns:

The requirement of an ABR on NICU babies would create a resource and financial drain on organizations with a larger number of annual births.

The JCIH Year 2007 Position Statement allows the child's physician to make a decision regarding the particular screening test.

Being too broad or too general in reference to the testing methods would create more problems.

The recommendation of ABR testing conserves resources in that an abnormal ABR would flag both cochlear and neural hearing losses and send the child directly to diagnostic testing rather than re-screening.

The timing and number of hearing 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 one diagnostic audiological assessment by 24 months (excerpt from JCIH Year 2007 Position Statement: Principles & Guidelines for EHDI Programs).

Discussion of this topic presented the following concerns:

Prior recommendations for screening every 6 months until 3 years of age created a burden for parents and audiologists because this could not always be accomplished.

Children with a risk indicator considered to be of low risk should have at least one assessment by 24 months of age. This recommendation could change if the primary care physician found new concerns in reference to hearing. However, the outside range of 24 months was considered too long to wait. Screening done that late would delay diagnosis of hearing loss to where significant delays would be unavoidable.

Virginia does not have the resources to commit to going beyond what the national recommendations are and voiced concerns regarding legal issues.

Pediatric surveillance and evaluation is not sufficient. Pediatricians need to receive more education and become more involved in the newborn hearing screening process.

Re-evaluation was proposed for infants with risk indicators at 6 and 18 months of age. Also expressed was the need to consider the overall status of the child.

The following risk indicators were considered of greater concern for delayed onset of hearing loss:

- ❖ Caregiver concern regarding hearing, speech, language, or developmental delay
- ❖ Family history of permanent childhood hearing loss
- ❖ Neonatal intensive care of more than 5 days or any of the following regardless of length of stay: ECMO, assisted ventilation,

exposure to ototoxic medications, and hyperbilirubinemia requiring exchange transfusion

- ❖ CMV
- ❖ Syndromes associated with hearing loss or progressive or late onset hearing loss.
- ❖ Neurodegenerative disorders
- ❖ Culture positive postnatal infections associated with sensorineural hearing loss.
- ❖ Chemotherapy
- ❖ Head trauma

The following were of less concern:

- ❖ Craniofacial anomalies
- ❖ Physical findings

Minor craniofacial abnormalities such as pits should be monitored through developmental screening and should not be considered a risk indicator to be monitored regularly.

Craniofacial anomalies should include cleft palate.

Under syndromes, it should specify type 2 Neurofibromatosis because type 1 presents less of a risk for hearing loss and the testing would be an unnecessary burden on families and audiologists.

Every infant with confirmed hearing loss should be evaluated by an otolaryngologist who has knowledge of pediatric hearing loss and have at least one examination to assess visual acuity by an ophthalmologist who is experienced in evaluating infants (excerpt from JCIH Year 2007 Position Statement: Principles & Guidelines for EHDI Programs).

Discussion of this topic presented the following concerns:

It is not practical to request the services of an ophthalmologist based on the failure of a newborn hearing screen due to there being a very small number of pediatric ophthalmologists. An ophthalmologic evaluation is only needed for profound hearing loss.

For any degree of hearing loss, an otolaryngologist should be involved.

Continued discussion of JCIH Recommendations presented the following concerns:

It was recommended that the letters that are sent out should be revised to address the services that the child should receive in relationship to the risk indicator.

In reference to exposure to ototoxic medications, it was suggested that toxic chemotherapy be specified due to the differences in chemotherapy. In addition, it was suggested that some examples of ototoxic medications are listed, but that it is stated “including but not limited to”.

To address hospitals taking a less invasive approach to treating hyperbilirubinemia, it was recommended that the wording be revised to state “hyperbilirubinemia at a level where exchange transfusion would be considered”.

3. Coalition for Hearing, Education, and Research (CHEAR)

CHEAR is comprised of medical, educational, and social institutions in Virginia to include, but not limited to Old Dominion University and Eastern Virginia Medical School (EVMS). The mission of CHEAR is to provide the citizens of Hampton Roads the highest quality and comprehensive services for disorders of the ear. This goal is achieved through programs for identification, clinical care, research, rehabilitation, education, public awareness, and advocacy.

The three priority projects for CHEAR are an auditory/oral preschool for hearing impaired children, a mobile hearing van and hearing aid bank, and support for the hearing and balance center of EVMS.

The CHEAR preschool program has a maximum capacity of 6 children. This does not meet the needs of the children in that area. Parents come in one hour a week. Kindergarten teachers will attend sessions. Early Intervention (EI) will be asked to observe sessions. Classes are videotaped to be used for research and development. CHEAR would like the assistance of the VEHDIP Advisory Committee in achieving their goals. For further information, please visit www.hearvirginia.com

4. Standing Updates

Hearing Aid Loan Bank (HALB) L. Powley

The HALB is currently funded by the Virginia Department of Education (VDOE) serving children from birth to age 18, but most recipients are from birth to age 5. Since the creation of the HALB, 220 children have been loaned aids. It was expressed that the HALB cannot accept used aids because they are unable to refurbish them. New hearing aids are only slightly above the cost of refurbishing one. All HALB aids have warranties and are sent to be refurbished when returned. The only requirement for receiving aids from HALB is to be a resident of Virginia. Income is not questioned. EHDI has been able to identify 18 children with hearing loss through the use of the HALB.

Guide By Your Side (GBYS) D. Buck & R. Craig

D. Buck is the new principal investigator and R. Craig is the program coordinator for GBYS. Since October 1, 2008, GBYS has received 39 referrals, 27 matches with home visits, 7 phone support matches, and 5 pending referrals. There were 6 Spanish and 2 Korean families. Virginia GBYS has had the most matches of anyone in the nation.

A statewide training has been planned to insure uniform services. The guides have reported that most families choose cochlear implants. The next choice is hearing aids and then sign language.

As of September 30, 2009, GBYS will need funding.

Hearing Work Group D. Pfeiffer & G. Jones

The group met in January to discuss subcommittees and clarifications of functions. A concern was expressed about the Linkage and Intervention subcommittees overlapping.

G. Jones reported that EHDI had been invited to participate in a learning collaborative hosted by the National Initiative on Children's Healthcare Quality. Some of the members of the workgroup were requested to assist in locating pediatricians and audiologists who would be willing to participate. A team of specific members (pediatrician, audiologist, screening nurse manager, office manager) would need to be in place by March 2. There are three trips that would require team members to travel. VDH is responsible for all costs associated with each trip for each team member. There is no compensation for any team member's participation. The purpose of participating in the learning collaborative is to receive recommendations and implement quality improvement processes statewide.

Department of Medical Assistance Services (DMAS) B. Campbell

B. Campbell reviewed DMAS statistics and funds as it relates to hearing aids and reported that the dispensing of hearing aids is increasing. At this point, no cuts have been proposed for the hearing aid program.

If changes were to be made to Medicaid recipients, changes may include tightened utilization, pre authorization, or transfer costs. Assessment reimbursements are still low. DMAS has to maintain its current rate structure for assessments and evaluations.

Children in managed care and the State Children's Health Insurance Program are eligible for hearing aids through DMAS. It was

recommended that this information be better advertised. B. Campbell expressed that there is a fact sheet that can be provided for inclusion in mailing to providers. B. Campbell stated that finding audiologists and otolaryngologists who want to work with Medicaid has not been successful.

Partnership for People with Disabilities D. Pfeiffer

The Optimizing Auditory Learning for Students with Hearing Aids and /or Cochlear Implants will be held April 3-4, 2009 in Staunton, Virginia. It is sponsored by VDOE, the Partnership for People with Disabilities, and the Alexander Graham Bell Association for the Deaf and Hard of Hearing. Registration is already full.

Virginia Department of Health G. Jones

R. Frierson is expected to attend the EHDI Conference in Dallas this year. Of the three positions that were open, two have been filled. The Follow Up Analyst, T. Person, has already started working with R. Frierson and L. Lambert. The Quality Improvement Coordinator will begin work in late March or early April. The Data Management Coordinator position has not been filled as of yet.

EHDI received a call from a student in Chapel Hill regarding participation in a study assessing the services provided by EI. A survey will be prepared by UNC for parents for distribution in late fall. The survey will be for English speaking families only.

5. Group Announcements

N. Ford announced Electronic Birth Certificates (EBC) is expected to go live in May 2009. Virginia Infant Screening and Infant Tracking System II (VISITS) should go live not long after.

C. Eubanks: A parent run support group has started in Richmond for parents who have chosen spoken language for their children. It meets at Chattering Children on the second Monday of every month from 7-8:30pm.

Further education to primary care providers is needed in order to increase the addressing issues that EHDI has such as lost to follow up.

There is a need to fill the insurance representative position on the VEHDIP Advisory Committee. B. Strasnick volunteered to get an insurance representative.

Next meeting: May 29, 2009

Location: TBA