



## EHDI E-MAIL EXPRESS

This is an e-mail communication from the American Academy of Pediatrics (AAP) "Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention through the Medical Home" project funded through cooperative agreements with the Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA) and the Centers for Disease Control and Prevention (CDC), National Center of Birth Defects and Developmental Disabilities (NCBDDD). It is designed to provide AAP Early Hearing Detection and Intervention (EHDI) Chapter Champions with resources and current clinical and other information. The EHDI E-Mail Express is sent on a monthly basis. Please feel free to share the EHDI E-Mail Express with colleagues working on or interested in childhood hearing detection and intervention issues. Distribution information appears on the last page.

### MARCH 2011

#### In this issue:

- Message from your Chair
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- Learn about the AG Bell LOFT Program
- Reducing LTF/D in Kentucky
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### FROM YOUR CHAIR



Dear EHDI Champions and Colleagues,

With the EHDI Conference behind us, I find myself continuing to think about how we keep the energy alive to address the work that remains. The annual conference is always the highlight of the year and each year I see more and more excitement during the event with new ideas and plans on how to tackle challenges such as loss to follow-up, late-onset

hearing loss, auditory neuropathy etc. But, when we return to our daily lives and practices, that vigor sometimes gets lost. So I offer you some simple but effective ways in which you can continue to move the needle for EHDI. Consider the following:

- ◆ Meeting with your Chapter President and/or Chapter Executive Director to update them about the activities that you are involved in related to the EHDI project. Ask about chapter needs in terms of providing members with education, information and/or resources related to EHDI (ie, a newsletter article, list of state resources, information on reporting requirements, a presentation at the chapter annual meeting, etc).
- ◆ Arranging a phone or in-person meeting with your state EHDI coordinator ([contact list](#)) to discuss plans and activities for 2011.
- ◆ Contacting your state organization representing family physicians ([AAFP Chapter Contacts](#)) or pediatric nurse practitioners ([NAPNAP Chapter Contacts](#)) to begin a dialogue regarding collaboration on EHDI going forward. Offer yourself as a resource.
- ◆ Plan to touch base with your region's AAP EHDI Task Force member and/or Chapter Champions to talk through any concerns you may have or celebrate a success. You can find their information in your EHDI Chapter Champion Resources packet or by contacting the AAP EHDI Program Manager, Faiza Khan, [fkhan@aap.org](mailto:fkhan@aap.org).

The bottom line—do something because every step, no matter how small, counts! Contact your region expert or AAP staff for more ideas or to discuss any ideas you may already have.

Albert Mehl MD

### UPCOMING EVENTS

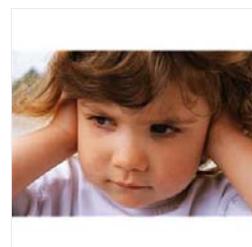
Event	Date	Location	Additional information
11th International Congress of the European Society of Pediatric Otorhinolaryngology	May 20—23, 2011	Amsterdam, the Netherlands	<a href="#">Web site</a>
AG Bell Listening and Spoken Language Symposium	July 21 –23, 2011	Washington, DC	<a href="#">Web site</a>
AAP Future of Pediatrics Conference	July 29—31, 2011	Chicago, IL	<a href="#">Web site</a>

## UNHS TESTS MISS LATER ONSET HEARING LOSS

Dr Nancy Young and colleagues at Children's Memorial Hospital in Chicago reported their findings on late-onset sensorineural hearing loss (SNHL) in the March issue of Archives of Otolaryngology–Head & Neck Surgery. According to the new research, screening infants for hearing loss at birth may fail to detect children with later-onset sensorineural hearing loss (SNHL) who will require implants. Universal newborn hearing screening (UNHS) legislation was passed in Illinois in 1999 in an effort to "achieve early identification of and enable timely intervention for infants born with hearing loss"; the legislation mandated that hospital-based programs become effective by January 1, 2003. Before passage of this legislation, only children with known risk factors were typically screened before hospital discharge.

According to the researchers, although universal screening successfully lowered the age at which many children with hearing loss were identified, many parents of children with cochlear implants report that newborn hearing screening failed to identify hearing loss in their child. The current study sought to determine the effect of the UNHS programs and to understand how often delayed-onset hearing loss limited the ability to provide early identification and implantation among infants and young children.

Also according to researchers, many causes of childhood hearing loss are associated with progressive loss (ie, are not detectable with screening at birth). Authors conclude that "at present, delayed onset of SNHL limits our ability to achieve early implantation of a significant number of deaf children. The current UNHS programs, by their very nature and design, will not solve this dilemma. This situation raises the issue of whether repeating mandatory hearing screening for all children before 1 year of age would be beneficial. [This is an] issue of...public policy...that requires further research and consideration".



Read the full article and details about the study at: <http://www.medscape.com/viewarticle/739353>

## CDC TELECONFERENCE: DELIVERING EHDI SERVICES TO DIVERSE POPULATIONS



Join the CDC Teleconference, Delivering EHDI Services to Diverse Populations, on April 21, 2011 from 4-5 pm ET/3-4 pm CT. The teleconference will provide detailed survey results from state EHDI coordinators which will help programs better understand barriers faced by culturally and linguistically diverse families of children with hearing loss when accessing EHDI services. Forty-two (42) states provided the information, which can be used to develop strategies tailored to help these vulnerable EHDI populations.

Presenters include Susan Chacon who is the New Mexico Title V Director for Children's Medical Services, Children and Youth with Special Health Care Needs program which includes oversight of the Newborn Hearing and Newborn Genetic Screening programs and Claudia Gaffney who joined the EHDI team in 2004 and has developed materials and programs to help educate minorities and expand a public health initiative within hard-to-reach populations.

No registration is required but space is limited so be sure to join the call promptly at 4 pm EDT! To join the call:

1. Dial (866) 842-6975
2. Enter passcode 218840#
3. Click on <https://www.livemeeting.com/cc/cdc/join>
4. Copy and paste the required information:  
Meeting ID: 7HW628  
Entry Code: 5RD;`^-Ds  
Location: <https://www.livemeeting.com/cc/cdc>

For more information and to request captioning contact Steve Richardson at [SRichardson4@cdc.gov](mailto:SRichardson4@cdc.gov).

## HELP TEENS WITH HEARING LOSS SHARE A MEMORABLE LEADERSHIP EXPERIENCE



In 1995 the AG Bell Association started the Leadership Opportunities for Teens (LOFT) program for adolescents with hearing loss. The 4-day program is designed for participants to develop skills in individual leadership, teamwork, understanding group dynamic and communication, public speaking, and self advocacy. The program provides a supportive and structured environment in which participants increase their self confidence and understanding of their own strengths and abilities through activities designed to challenge them to work outside of their comfort zone. To learn more and support this program visit <http://agbell.org/NetCommunity/Page.aspx?pid=640>

## REDUCING LOSS TO FOLLOW-UP IN KENTUCKY

WHO'S INVOLVED?	WHERE CAN THEY BE REACHED?
AAP EHDI Chapter Champion: Dan L Stewart	E-mail: danstewart@louisville.edu
KY State EHDI Coordinator: N. Carolyn Kisler	E-mail: Ncarolyn.Kisler@ky.gov

### WHAT HAVE THEY ACCOMPLISHED RECENTLY?

- ⇒ Expansion of the electronic online semi-integrated database KY CHILD (Certificate of Birth, Hearing, Immunization and Lab Data) to allow audiologists providing services to infants and young children to report follow-up electronically to Early Hearing Detection and Intervention (EHDI) Program within the Commission for Children with Special Health Care Needs (CCSHCN)
- ⇒ Training of the audiologists statewide to enter audiology follow-up in KY CHILD
- ⇒ Expanding the hours of the EHDI follow-up coordinator position to full-time
- ⇒ Passage of House Bill 5 which has a condition of inclusion on the state's Infant Audiological Assessment and Diagnostic Centers that they must report follow-up audiological findings to EHDI/CCSHCN
- ⇒ Completion of a Memorandum of Agreement with Part C (Kentucky First Steps) that includes CCSHCN audiologists (15 statewide) to be the primary referral source for audiology services and improved data exchange that will allow individual data to be collected on those diagnosed as Deaf or Hard of Hearing to be submitted to EHDI for improved tracking of the 1-3-6 National EHDI guidelines

These efforts have resulted in a reduction of loss to follow-up/loss to documentation (LTF/D) in KY. The numbers of infants born in 2009, currently documented as LTF in Kentucky are: 1) between hospital and outpatient screening: 526 of 2160 or 24%; 2) between outpatient screening and audiologic diagnosis: 144 of 526 or 27% and 3) between diagnosis and entry into early intervention: 43 of 82 or 52%.

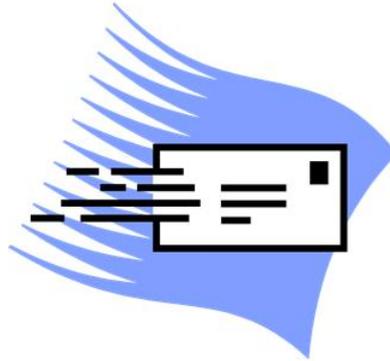
### WHAT ARE THE FUTURE PLANS/ACTIVITIES?

- ⇒ Annual site visits to all birthing hospitals to communicate current EHDI status in KY; monitor compliance with written policies/procedures; review KY CHILD submissions and provide technical assistance as warranted
- ⇒ Ongoing follow-up through contacting families when follow-up after referral from physiologic newborn hearing screenings is not received by EHDI/CCSHCN
- ⇒ In November 2010 submitted a grant proposal to MCHB-HRSA to further address Loss to Follow-up following referral on Newborn Hearing Screening for \$900,000 over next three years
- ⇒ Anticipated participation in NICHQ collaborative if awarded MCHB/HRSA funding
- ⇒ Currently working on CDC FOA related to technical and data systems targeted to reduce loss to follow-up following referral on Newborn Hearing Screening – due in March 2011

## WORDS OF INSPIRATION. . .



*In everyone's life, at some time, our inner fire goes out. It is then burst into flame by an encounter with another human being. We should all be thankful for those people who rekindle the inner spirit. —Albert Schweitzer*



***Distribution Information:***

*The AAP EHDI Program implementation staff send this e-mail update to the Academy's EHDI Chapter Champions, other interested AAP members, staff and state EHDI coordinators. For additional information on hearing screening and to access previous editions of the EHDI E-mail Express, click on the following link [http://www.medicalhomeinfo.org/how/clinical\\_care/hearing\\_screening/](http://www.medicalhomeinfo.org/how/clinical_care/hearing_screening/). Previous e-mail updates are available upon request from Faiza Khan, [fkhan@aap.org](mailto:fkhan@aap.org) or (847) 434-4924. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.*