



EHDI E-MAIL EXPRESS

The monthly newsletter of Early Hearing Detection and Intervention Program



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.

JANUARY 2012

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FROM YOUR CHAIR



"We spend January 1 walking through our lives, room by room, drawing up a list of work to be done, cracks to be patched. Maybe this year, to balance the list, we ought to walk through the rooms of our lives... not looking for flaws, but for potential" – Ellen Goodman

What a great thought to start off 2012. Let's commit this year to focusing on potential, not on limitations. Let's think about barriers as opportunities. Let's approach challenges with optimism and vigor.

What are some of the challenges facing EHDI? Consider these...

- Reducing/eliminating loss to follow-up/documentation (LTF/D)
- Integrating hearing screening into electronic health records
- Increasing the understanding of risk factors and delayed-onset of hearing loss
- Addressing noise-induced hearing loss
- Better understanding the role of genetics
- Strengthening medical homes for children with hearing loss

While these challenges may seem to be many and may seem overwhelming, take a moment to also recognize how much effort is already underway to address them. At the AAP the Task Force and its subcommittees (the subcommittee on loss to follow-up and documentation and the education subcommittee) are working to address each of these challenges from the pediatricians perspective. We are also working with our partners to identify gaps in the EHDI system and develop approaches that are team-based and comprehensive. And, while we may not have all the answers today, we are optimistic that by continued hard work, increased collaboration, and a willingness to try things that may not necessarily end up in success as we had hoped, we will be able to make a positive change in the lives of children and families with hearing loss — and that is the most important outcome we can ask for.

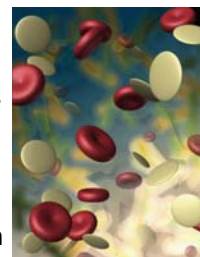
So, in the words of Oprah, lets say "cheers to a new year and another chance to get it right".
- Albert Mehl, MD

UPCOMING EVENTS

Event	Date	Location	Details
The NYS EHDI Program: What's New	February 13, 2012	Rochester, NY	Web site
22nd Audiology Conference by Mayo Clinic	February 18, 2012	Salt Lake City, UT	Web site
2012 EHDI Meeting	March 5—6, 2012	St Louis, MO	Web site

FIRST EVER STEM CELL CLINICAL TRIAL FOR HEARING LOSS IN CHILDREN

Children's Memorial Hermann Hospital and Cord Blood Registry® (CBR) are launching the first FDA-approved, Phase I safety study on the use of cord blood stem cells to treat children with sensorineural hearing loss. The study, which will use patients' stem cells from their own stored umbilical cord blood, is the first-of-its-kind, and has the potential to restore hearing. This follows evidence from published laboratory studies that cord blood helps repair damaged organs in the inner ear.



The year-long study will follow 10 children, ages 6 weeks to 18 months, who have sustained post-birth hearing loss. Children who are deaf as a result of a genetic anomaly or syndrome are not eligible. To ensure consistency in cord blood stem cell processing, storage, and release for infusion, CBR is the only stem cell bank providing clients for the study.

Parents will be interviewed by phone to determine eligibility of their children for the study. Those who meet the criteria will be admitted to Children's Memorial Hermann Hospital to undergo a series of blood tests, hearing and speech tests, and an MRI that will view the tracts that send signals from the inner ear to the brain.

Researchers will obtain and process the patients' stored cord blood for treatment. The cells then will be given to the patients via IV infusion, and patients will be observed for several hours in the hospital. Patients will return to the hospital to repeat all tests except the MRI at one month and one year, and all tests with an MRI at six months.

The Principal Investigator is Samer Fakhri, M.D., surgeon at Memorial Hermann-Texas Medical Center and associate professor and program director in the Department of Otorhinolaryngology – Head & Neck Surgery at UTHealth. Linda Baumgartner, MS, CCC-SLP, Auditory-Verbal Therapist, is a co-investigator.

The study is supported by CBR and TIRR Foundation. For information on participation in the study, visit www.cordblood.com/hearingloss.

HAVE YOU HEARD THE ECHO?

You know that the National Center for Hearing Assessment and Management (NCHAM) supports effective newborn hearing screening, but did you know that they also provide expertise in screening older infants and toddlers? The Early Childhood Hearing Outreach (ECHO) Initiative is part of NCHAM, focusing on extending the benefit of periodic hearing screening to children 0 – 3 years of age in a variety of health and education settings. In particular, ECHO serves Early Head Start programs as the National Resource Center on Early Hearing Detection and Intervention in response to Early Head Start requirements for conducting objective hearing practices for children 0-3 years of age.

ECHO provides training and excellent online tools to effectively implement Otoacoustic Emissions screening (OAE's), track results, and communicate with EHDI partners. These online tools have also been adapted to meet the needs of health care providers, including pediatricians and their office staff. Tools include an OAE Hearing Screening Implementation Checklist, recommendations for selecting equipment, as well as partnering with pediatric audiologists and the state EHDI coordinators. The video demonstrations are particularly useful for training in the use of OAE's. Visit the ECHO website to access valuable resources to guide your efforts to ensure that the children you serve receive appropriate hearing screening: <http://www.infanthearing.org/earlychildhood/>.



HOPE: A COCHLEAR AMERICAS PROGRAM



HOPE is a Cochlear Americas program designed to support the entire cochlear implant (CI) community, including adult CI recipients, parents, children with CIs and the professionals who support them. The Web site: <http://hope.cochlearamericas.com/> has a number of resources that can help cochlear implant patients achieve their best outcome. Resources include online courses, listening tools, telephone training, and more.

SESSIONS PRESENTED BY CHAPTER CHAMPIONS TO ATTEND AT 2012 EHDI MEETING

This year's EHDI Meeting is full of exciting educational sessions many of which are being presented by our very own Chapter Champions. Below is the list of all the AAP EHDI Chapter Champion-led sessions:

Session	Time	Chapter Champion
Sunday, March 4		
EHDI and the Medical Home	1:00 – 5:00 pm	Jack Levine, Rachel St John
Monday, March 5		
NICHQ Improving Hearing Screening and Intervention Systems (IHISIS) Learning Collaborative: Connecting past work	11:05 – 12:05 pm	Susan Wiley
Case Studies in the Medical Home	2:00 – 3:00 pm	Jack Levine, Rachel St John
Tuesday, March 6		
Guidance for Hearing Re-screening in the Medical Home	9:40 – 10:10 am	Bradley Golner, Jack Levine
EHDI Program and Medical Home Partnership: Promoting Appropriate Follow-up Through 'Just In Time' Learning	9:40 – 10:40 am	Thiravat Choojitarom
The Role of the Medical Home in Reducing Loss to Follow Up	11:00 – 11:30 am	Jack Levine
Engaging the Medical Home in Connecting Babies with Hearing Loss to Early Intervention, Family Support, and Specialty Services	11:30 – 12:00 pm	Brenda Balch
Early Functional Skill Development in Children with Cochlear Implants and Additional Developmental Disabilities	11:30 – 12:00 pm	Susan Wiley
Understanding the Etiology of Hearing Loss: From Detection to Diagnosis	11:30 – 12:00 pm	Luis F Escobar
Providing Sound Beginnings for Children by Recognizing Risks of Delayed-Onset Hearing Loss	1:45 – 2:45 pm	Rachel St John
AAP EHDI Chapter Champion Lunch: Genetic Evaluation of Hearing Loss (<i>*by invitation only</i>)	12:10 – 1:30 pm	G. Bradley Schaefer
Plenary #4: The Genome and EHDI – A Fascinating Couple	3:55 – 4:45 pm	G. Bradley Schaefer

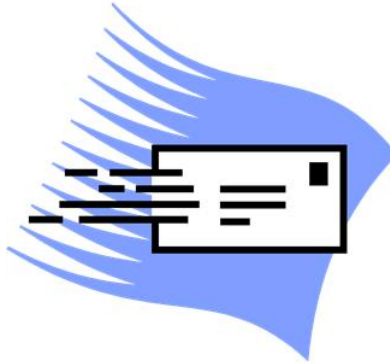
Find the full meeting agenda here: <http://ehdimeeting.org/schedule/Grid.cfm>.

WORDS OF INSPIRATION...



One resolution I have made, and try always to keep, is this: To rise above the little things.

- John Burroughs



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/. Previous e-mail updates are available upon request from Faiza Khan, 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.