



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.

AUGUST 2011

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FROM YOUR CHAIR



A BIG thank you. I want to thank each and every one of you that has or will be participating in the EHDI Chapter Champion regional conference calls. I cannot stress enough the importance of frequent and on-going communication between all EHDI stakeholders. This type of forum allows us to engage in real time information sharing, brainstorming, and solution-finding through a collaborative, team approach. We all know that the EHDI system is complex and includes a variety of professionals which is its beauty as well as its difficulty. We can never do too much to ensure that there is enough communication amongst all of these partners.

As the AAP Chairperson for the Task Force on Improving the Effectiveness of Newborn Hearing Screening, Diagnosis and Intervention (EHDI Task Force) and more importantly as the lead for Region (VIII), I found the experience of facilitating and participating on the call extremely valuable. It was great to hear from the Champions and State Coordinators in the region what their individual successes have been and what challenges they are struggling with. We had great dialogue amongst each other about how to celebrate our successes and how to overcome our challenges. We learned what others were doing and considered if that might work for us. We had a stage and an audience where we could 'toot our horn' and know it was being well received—which is something we can seldom do with so many competing priorities. But, most importantly, we came together as a unified team that was looking to improve the EHDI system, one state at a time. And, that is the key to our success as an EHDI professional and the success of our EHDI programs.

I want to encourage this teamwork and collaboration. I want to encourage each of you to continue to organize such calls or opportunities to get together and continue the discussion. We will do our best from the national/AAP level to help organize and facilitate this conversation but I urge you to take the lead as well. Take every chance you get to exchange ideas and talk through your obstacles. And, do not be limited to only those in your state or region. Think bigger. Talk to people across the country. Talk to anyone who is interested in listening and willing to share. You will find that you always learn something new and something useful.

Be sure to look forward to the highlights of the calls to be shared in the coming weeks.

- Albert Mehl

UPCOMING EVENTS

Event	Date	Location	Details
Play it by Ear: Interventions Strategies and Techniques to Improve Outcomes for Children with Hearing Loss	October 14, 2011	Philadelphia, PA	Web site
AAP National Conference and Exhibition (NCE)	October 15-18, 2011	Boston, MA	Web site
EHDI Partnering for Progress Trio of Conferences	October 26-28, 2011	Raleigh, NC	Web site

SALIVA IS EFFECTIVE IN SCREENING FOR CMV INFECTION IN NEWBORNS



Research published in the *New England Journal of Medicine*, finds that swabbing a newborn's mouth for saliva can be used to quickly and effectively screen for cytomegalovirus (CMV) infection, a leading cause of hearing loss in children. CMV is the most common infection passed from a mother to her unborn child. Of the 20,000-30,000 infants who are born infected with CMV each year, roughly 10-15 percent are at risk for developing hearing loss.

The multicenter research project, led by University of Alabama (UAB) researchers Suresh Boppana, MD, and Karen Fowler, DrPH, was seeking to find the most effective screening test for CMV infection in newborns. They found that saliva correctly identified every baby born with the infection when liquid samples were used and 97.4 % of babies when the samples were dried. "We now know that we have a test with saliva that works," said Dr. Boppana. "The challenge is, unlike the dried blood spot, which is already used for newborn screening in hospitals across the country, we don't have a system in place for the collection of saliva. But we've shown that if you wanted to test a lot of babies for congenital CMV infection, it can be done."

The researchers are now looking to find out how much congenital CMV infection contributes to overall hearing loss at birth and between the ages of 3 1/2 to 4 years old. For this reason, infants who tested positive for CMV infection in the study are being enrolled in a follow-up program to monitor their hearing every six months until they are four years of age.

The research was funded by the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health. Read more details here: <http://www.sciencedaily.com/releases/2011/06/110601171608.htm>.

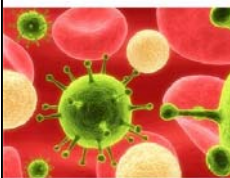
INDIVIDUALIZED EDUCATION PROGRAMS (IEP) TIPS AND STRATEGIES

AG Bell recently conducted a survey for both parents and professionals asking for their tips for successful Individualized Education Program (IEP) meetings. Parents stressed the need to prepare for these meetings and be ready to advocate for your child. As one parent, stated, "I always make sure that I talk with my child's liaison...well before the IEP is even scheduled, to let them know what I am thinking. I never want to blindside anyone at the IEP." Professionals hoped to remind parents to know their rights and understand that accommodations are compulsory, not optional, emphasizing that many children still have hearing loss even with cochlear implants, that all children with hearing loss have different needs and that hearing loss is not a learning disability. As one professional stated: "Meetings that go well include a team of professionals that understand the needs of children with hearing loss...it includes parents who are vested and who have a certain amount of trust in the educational team... [and] also requires the support of the administration to ensure that teachers, audiologists, and [speech-language pathologists] have the support they need to meet the needs of the students."

Additional results will be published in an upcoming edition of *Volta Voices*. To learn more about the IEP process, consider taking AG Bell's [Parent Advocacy Training](#) course. This program is offered for free through the AG Bell website and provides a wide range of information for securing appropriate access for children with hearing loss.



AAP RECEIVES FUNDING TO INCREASE PROVISION OF GENETIC MEDICINE



The American Academy of Pediatrics (AAP) is pleased to announce it has been awarded the *Genetics in Primary Care Institute* (GPCI) cooperative agreement—a 3 year award from the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB).

The overarching vision of the GPCI is to increase primary care providers' knowledge and skills in providing genetic-based services. Through the GPCI, the Academy will work with primary care providers to enhance such things as understanding of basic genetic principles, collection and interpretation of family history, education regarding new and emerging technologies and tests, navigation of ethical considerations regarding genetics-related issues, and integration of genetic medicine into health information technology.

To learn more about the GPCI including how to become involved, contact Michelle Esquivel, MPH, Director, AAP Division of Children with Special Needs, at mesquivel@aap.org or visit: <http://www.medicalhomeinfo.org/GPCI.aspx>.

REDUCING LOSS TO FOLLOW-UP & DOCUMENTATION (LTF/D) IN NORTH DAKOTA

In an effort to reduce loss to follow-up and documentation (LTF/D), the North Dakota (ND) EHDI program partnered with *Right Track* to encourage families to return for any necessary hearing screening follow-up. The ND EHDI team is working with all hospital staff to encourage utilization of their local *Right Track* staff for any follow-up efforts.

Right Track is a free program that provides in-home developmental screening for children from birth to three years of age. It is a family-centered program offered to every child so they can experience the "best start" in physical, social, emotional, and intellectual development. Their mission is to see every baby born in ND and provide a free developmental screening. The program is completely voluntary. *Right Track* is funded through the ND Department of Human Services, and available throughout the state.

Provided services include:

Home Visits

- Providing information about child growth and development; what to expect from the child at a specific age
- Discussing childhood concerns such as sleeping problems, nutrition, potty training, language development, and managing behaviors
- Offering ideas for activities to enrich a child's development
- Providing support to parents

Developmental Screenings

- Assessing children's skills in all areas of development
- Monitoring of children at risk for developmental delays and referrals for further testing if needed
- Assessing children's performance on various age-appropriate tasks

Information and Referral

- Providing information and resources to families about community programs and services

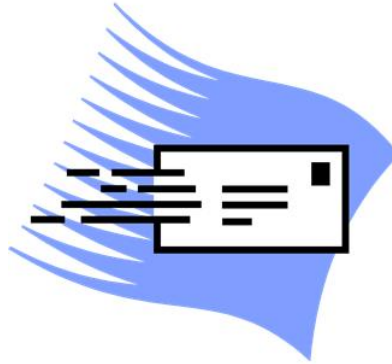
The program has proven successful in helping reduce LTF/D with a greater number of children with hearing loss now receiving timely follow-up and early intervention services. To learn more about the ND EHDI program and *Right Track*, contact, AAP Chapter Champion—Bernard Hoggarth (bhoggarth@gra.midco.net) or State EHDI Implementation Coordinator, Sue Burns (sburns@nd.gov). Find out if your state might have a similar program!



WORDS OF INSPIRATION...



The tragedy of life doesn't lie in not reaching your goal. The tragedy lies in having no goals to reach. - Benjamin Mays



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.