



# EHDI E-MAIL EXPRESS

The monthly newsletter of Early Hearing Detection and Intervention Program



NOVEMBER 2013

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.

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## FROM YOUR CHAIRPERSON



Friends,

It's that time of year, the time for giving thanks. And I'm giving thanks to you!

On behalf of the not-yet-born baby in the womb who is hard of hearing, and who is already falling weeks and months behind in the recognition of the mother's voice when compared with the other unborn babies in the waiting room of the obstetrician... I am thanking you for maintaining a hospital-based screening program that is ready to screen the baby in the first days of life and provide the necessary follow-up.

On behalf of the baby who is born at home or in a birthing center with no ability to perform newborn hearing screening... I am thanking you for finding ways to get that baby's hearing screening completed, somewhere, somehow.

On behalf of the baby who does not pass the first hearing screening... I am thanking you for making an appointment before the baby leaves the hospital, for tracking the completion of that appointment, for finding that family if the appointment goes uncompleted, and for insisting that they return when the odds are stacked against you.

On behalf of the baby who does not pass the outpatient re-screening... I am thanking you for helping to get that baby seen promptly by an audiologist experienced in testing tiny babies, and for getting the diagnostic testing completed promptly.

On behalf of the baby who is found to have normal hearing at that complete audiologic evaluation but who nevertheless has a risk factor for delayed onset hearing loss... I am thanking you for educating parents and for educating physicians about the importance of careful language development surveillance and the importance of arranging timely rescreening.

On behalf of the baby who is diagnosed as hard of hearing and is a candidate for amplification... I am thanking you for leveraging your influence to make sure that an examination and clearance for amplification by the ear specialist happens promptly, not just eventually.

On behalf of the baby who is hard of hearing and who begins amplification... I am thanking you for assisting in a simplified and timely entry into effective early intervention programs and parent support programs.

On behalf of the baby who, through timely testing, is identified as deaf... I am thanking you for your sensitive approach to discussing communication options and offering deaf mentor programs and deaf role model examples.

And, on behalf of the members of the American Academy of Pediatrics Task Force on Improving Newborn Hearing Screening, Diagnosis, and Intervention... I am thanking all of you for all the things that you do, every day, to support newborns who are deaf or hard of hearing, and to support their families.

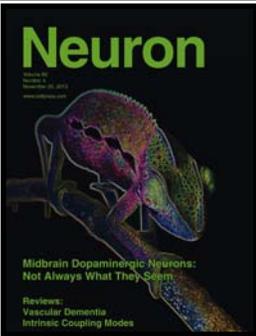
For all these reasons, have a safe... and thankful... holiday!

~AI

## UPCOMING EVENTS

Event	Date	Location	Details
Association of Maternal & Child Health Programs (AMCHP) 2014 Conference	January 25—28, 2014	Washington, DC	<a href="#">Web site</a>

## NEW RESEARCH CHALLENGES HOW HUMANS PERCEIVE SOUND



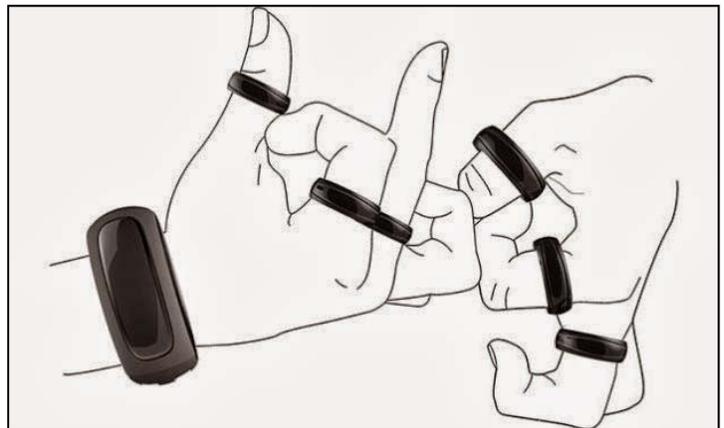
The study *Adaptation of Mammalian Auditory Hair Cell Mechanotransduction Is Independent of Calcium Entry* published in *Neuron* by researchers at the Stanford University School of Medicine challenges a key piece of the scientific model used for the past three decades to explain how humans perceive sound. The theory of “adaptation” or how humans can hear both low frequency and high frequency sounds without pain or damage to the ear is being overturned by this new research. The study was conducted to better understand how the adaptation process works by studying the machinery of the inner ear that converts sound waves into electrical signals. The traditional explanation—based on research of frogs and turtles— indicates that adaptation is controlled by complex cellular mechanisms both requiring calcium entry through a specific, mechanically sensitive ion channel in auditory hair cells. This new study finds that calcium is not required for adaptation in mammalian auditory hair cells and implies that one of the two previously described mechanisms is absent in auditory cochlear hair cells. Understanding how adaptation works can have a significant impact on future research for treating hearing loss.

Source: Peng A, Effertz T, Ricci A. *Adaptation of Mammalian Auditory Hair Cell Mechanotransduction Is Independent of Calcium Entry*. *Neuron* 2013; 80: 960-972.

## NOVEL INVENTION: THE SIGN LANGUAGE RING

Japanese designers from Asia University in Tokyo have developed a novel concept in the form of jewelry that can assist in the communication of those with hearing loss and those that do not understand sign language. Inspired by Buddhist prayer beads, the *Sign Language Ring* is a set of six rings and a bracelet that can translate sign language into either voice or text.

How does it work? When the rings are worn on the fingers of a person using sign language, they are able to pick up on the person’s motions and translate those into words. The words are then sent to the bracelet which contains a text panel that displays spoken words so the user can read them. Sign language users can also pre-record their customized gestures and assign appropriate words.



Learn more about this invention by visiting <http://www.medicalnewstoday.com/articles/269253.php>.

## DIALOGUE WITH STATE ELDI COORDINATOR ABOUT PHYSICIAN SURVEY RESULTS



As reported in earlier issues of the *EHDI Express*, the “Physician Survey Regarding Newborn and Infant Hearing Screening” was developed by the National Center for Hearing Assessment and Management (NCHAM) at Utah State University and Boys Town National Research Hospital, with support from the American Academy of Pediatrics (AAP). Twenty-seven EHDI coordinators who chose to participate in the study administered the survey in 2012/2013. Some states also conducted the earlier survey in 2005; comparisons across these time frames have been provided for these states.

In recognition as one of the key partnerships that exists to achieve optimal developmental outcomes for children who are deaf or hard of hearing, NCHAM and the AAP are working to facilitate communication among state EHDI coordinators and the AAP pediatrician chapter champions about these survey results. Chapter champions and state coordinators are encouraged to have an open dialogue about the “state” of EHDI within their state/chapter focusing the discussion on how these results can drive future goals and team efforts. Chapter champions and EHDI coordinators from states that participated in the most recent survey will receive a discussion guide along with a summary of their state’s results from NCHAM in the coming days.

## ATTEND AMCHP AND LEARN MORE ABOUT THE PHYSICIAN SURVEY

The 2014 Association of Maternal and Child Health Programs (AMCHP) annual conference is scheduled for January 25-28, 2014 in Washington, D.C. For those who have never attended an AMCHP Conference before, it is a great opportunity to understand how EHDI and the medical home fits within the broader system of care to improve the health of women, children, youth and families, including those with special health care needs.

Next year's conference will feature a presentation by Dr Jack Levine from the AAP EHDI Task Force and Diane Behl from NCHAM on Monday, January 27 titled *Opportunities for the Medical Home to Support Early Hearing Detection and Intervention (EHDI) Programs*. This session will present results from the 2012/2013 *Physician Survey on Newborn and Infant Hearing Screening* along with useful tools developed by AAP to support the role of the pediatrician in hearing screening and monitoring. Consider attending this conference to show support and ensure that EHDI is a partner in future efforts to build a strong health care system. Go to <http://www.amchp.org/Calendar/Conferences/amchp-conference/Pages/default.aspx> to learn more.

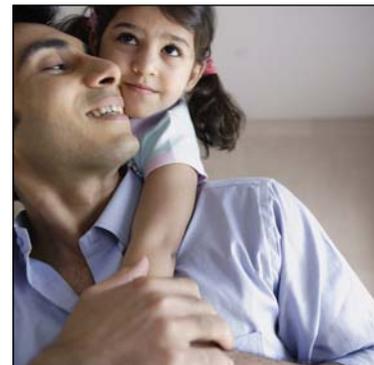


## THE IMPORTANCE OF PARENT PARTNERSHIP AND HELPFUL RESOURCES

"Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-centered care is the standard of practice which results in high quality services." - National Center for Family-Centered Care

Parent and/or family partnership is not only a key pillar of the medical home but it has been proven over and over again that their involvement results in improved patient care. The National Initiative for Children's Healthcare Quality (NICHO) provides the following [tips and tools on how to engage with patient representatives](#):

- Publically share patient stories to increase buy-in
- Establish a parent and family advisory council
- Involve patients and families from the beginning
- Ask patients and families to share with their networks
- Look for professional "Parent Partners" such as Hands and Voices



Watch this brief video on ["The Value of Parent Partners"](#).

## AG BELL PARENT ADVOCACY TRAINING COURSE



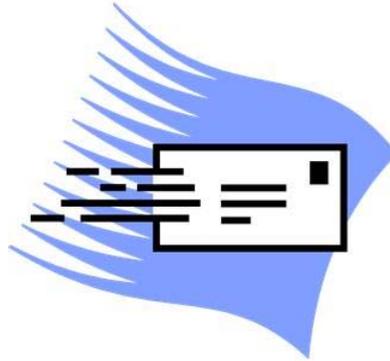
Participate in a [free online training course](#) offered by the Alexander Graham Bell (AG Bell) Association that helps parents and educators learn about ways to become advocates for children who are deaf or hard of hearing. This course focuses on Part B of the Individuals and Disabilities Education Act (IDEA) and the Individualized Education Program (IEP). At the end of the course participants will be able to:

1. Demonstrate parents' critical role in the IEP process and describe the legal framework of IDEA
2. Utilize the 4-step process for creating the IEP
3. Apply the Know-Act-Do (KAD) Negotiation Model for deaf or hard of hearing children

## Words of Inspiration ...

Not what we say about our blessings, but how we use them, is the true measure of our thanksgiving.

~ W.T. Purkiser



***Distribution Information:***

*The AAP EHDl Program implementation staff send this e-mail update to the Academy's EHDl Chapter Champions, other interested AAP members, staff and state EHDl coordinators. For additional information on hearing screening and to access previous editions of the EHDl E-mail Express, click on the following link <http://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/PEHDIC/Pages/Early-Hearing-Detection-and-Intervention.aspx>. 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.*