FROM YOUR CHAIRPERSON

Three cheers! Three cheers for the school audiologist!

With all of our mutual excitement about newborn hearing screening and early intervention over these last two decades, I am reminded this week of the many decades of important hearing screening that have been faithfully performed under the umbrella of the public school system.

Earlier this spring a seven-year-old in my pediatric practice had a routine hearing screening performed at school, just as millions of children have experienced over the years. He didn’t pass the screening. Nothing dramatic, but a quality screen performed in a quiet room, and an identified concern for his high frequency hearing thresholds in both ears. And the school audiologist made a timely request of the parents to discuss this new concern with the child’s doctor, me.

Next followed a visit in the office. Nothing dramatic, an evaluation of the ears and an assessment to assure that there was no concurrent middle ear effusion or smoldering ear infection. A confirmation that newborn hearing screening had been performed seven years earlier, and was normal. And then a timely request of the parents to continue the evaluation with a referral to a community audiologist and otolaryngologist.

Next followed a comprehensive audiology evaluation. Nothing dramatic. But the child was newly identified as being hard of hearing. A high frequency hearing loss was confirmed in both ears. And then an evaluation with the otolaryngologist. Nothing dramatic, but a thoughtful investigation concerning the cause of hearing loss, followed by a medical clearance for the fitting with hearing aids.

For me, it was an illustration that our system of school-aged screening was well-designed years ago and, in most places, well maintained over the decades. It reminded me that delayed onset hearing loss is real, and that hearing assessment doesn’t end when a newborn passes the hospital-based hearing screening. And it reminded me of how far we have come in addressing hearing screening early in life, and not waiting for the school-based screening to be the very first screening of hearing, as it was for many children years ago.

Though having a child newly identified as hard of hearing represents the beginning of an unexpected journey for this family, perhaps even these parents might look back someday and use the words “nothing dramatic.” No guilt about wondering if the hearing loss might have been present at birth. No angst about wondering how many bedtime stories were never heard clearly by the baby on the parent’s lap. Just a new journey of discovery about how to provide amplified hearing for this good boy.

We have all come to know many heroes along the path of early child hearing screening. For this family, their new hero is the school audiologist.

Mine too.

Al
**CYBER SAFETY FOR KIDS WITH SPECIAL NEEDS**

NetSmartz is an online resource and educational program of the National Center for Missing & Exploited Children® (NCMEC) to help parents and caregivers educate children with special needs on the safe use of the internet. NetSmartz houses a library of animated and live-action videos for kids ages 5-17 about online risks and teaches them effective strategies for protecting themselves. While NetSmartz resources were not created specifically for children with special needs, many of its materials employ the same teaching methods used with special needs children, such as role-playing, rhyme, and repetition. Follow the link above or go to [http://www.netsmartz.org/SpecialNeeds](http://www.netsmartz.org/SpecialNeeds).

**RAISING AND EDUCATING DEAF CHILDREN: A NEW EVIDENCE-BASED RESOURCE**

Raising and Educating Deaf Children: Foundations for Policy, Practice, and Outcomes, launched in early 2014, seeks to provide objective, evidence-based information for policy-making and practice associated with raising and educating deaf children. Posting new bulletins quarterly, it aims to reach the broad community of stakeholders, professionals, practitioners, policy-makers, and other parties interested in optimizing opportunities—and futures—for deaf children.

This site operates in association with the Journal of Deaf Studies and Deaf Education, published by Oxford University Press, and [www.educatingdeachildren.org](http://www.educatingdeachildren.org), administered by the Center for Education Research Partnerships at the National Technical Institute for the Deaf, with support from the William G McGowan Charitable Fund and the CVS Caremark Charitable Trust.

**2014 HANDS & VOICES LEADERSHIP CONFERENCE**

Mark your calendars for a conference for Hands & Voices Chapter Leaders, GBYS Programs, parents of children who are deaf or hard of hearing, and professionals who work with them!

This year’s topics will include:
- Why Do We Learn What We Do? Parents as Adult Learners
- Culture Eats Strategy for Breakfast: Best Laid Plans
- Overcoming Social Deafness
- I am Me – Identity Considerations for Families with D/HH children
- Parent Engagement: Helping Families to Understand the Importance of Getting Involved
- A Transition Plan for Parents
- And much more!!

If you are not involved in specific activities for Hands & Voices, this is still a fantastic conference featuring up to date information, fascinating conversations, and exploration of content in a new and exciting way. Consider attending and/or helping to spread the word to parents and professionals. For information about sponsoring, exhibiting, and registering for the conference, go to [http://www.handsandvoices.org/conference/2014/index.htm](http://www.handsandvoices.org/conference/2014/index.htm).

**CLERC CENTER COLLABORATION WITH AMERICAN SOCIETY FOR DEAF CHILDREN**

The Clerc Center has collaborated with the American Society for Deaf Children to provide Spanish and Mandarin translations to their publication, *Sign Language use for Deaf, Hard of Hearing, and Hearing Babies: The Evidence Supports It*. What was previously only available as a full report is now a colorful publication ready to share with families in three languages.
England implemented a national Newborn Hearing Screening Program in 2001. At the same time, the government undertook a study comprised of six discrete but complementary research projects to evaluate the program. A report of the first phase of the evaluation was published in late 2004, and a number of papers subsequently appeared on the findings of the evaluation.

In this month’s issue of the EHDI E-mail Express, we’d like to revisit two peer-reviewed articles published in 2008 resulting from a unique data set—the true case study—in which 45 parents/caregivers whose children received a confirmed diagnosis of deafness through the screening program were identified and agreed to participate in a qualitative, narrative interview on their experience with screening, early intervention and professional support, and their advice to professionals and other parents going through this process. The interview was structured around a “broad framework” that allowed researchers to collect information about comparable events while allowing parents to “set the criteria” for what they shared. The resulting qualitative data allow for the examination of a variety of different themes as expressed by these families.

Universal Newborn Hearing Screening and Early Identification of Deafness: Parents’ Responses to Knowing Early and Their Expectations of Child Communication Development examined how parents described feeling about having their child’s deafness identified very early. Simultaneous with a myriad of other emotions, most parents’ responses to an early diagnosis were positive. While they acknowledged having to confront their shock and grief, they felt reassured that their child would benefit from early interventions, that they could quickly take action on behalf of their child, and that they could prepare themselves for life with a family member who has special needs. Conversely, some parents wished they would have had a period of time free of the burden that the diagnosis brought, and others experienced frustration with the effectiveness of early intervention services. This paper also looked at parents’ expectations of language development and their perceptions of “normalization” for their children. The qualitative nature of the data and sensitive interpretation by the authors provide for a nuanced look at the parental experience of early newborn hearing screening.

Using the same narrative interview data, Universal Newborn Hearing Screening: Parental Reflections on Very Early Audiological Management looked at a variety of issues around the early management of hearing loss interventions from the parent perspective. Five themes were identified and explored: time and timing issues; conceptualization of early amplification; practical daily management; challenges specific to moderate hearing loss; and parental solutions to challenges in the delivery system. The authors note that the majority of these families were supportive of early detection and intervention services and that their reflections on the management of their children, within the context of their families, offer meaningful considerations for improvement of family-centered services.

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.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 Hollis Russinof, hrussinof@aap.org or (847) 434-4983. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.