FROM YOUR CHAIRPERSON

I joined the Grandparent Club earlier this month, for the very first time. Just one more piece of evidence that I am a card-carrying member of the old-farts society, as you will recall from a previous column. Joining the club is a great feeling. If you are in the club, you know this already. If you are not yet in the club, I can tell you it is expansive and loving and heart-warming.

Of course, I hadn’t anticipated one other requisite of being a member of the club. A grandparent, just like a parent, has some obligatory worrying with which to deal. Worrying came pretty quickly with Sweet Grandbaby James, as he managed to spend some time in the NICU despite being full term. But he’s back on track, and home now with two fully competent but completely inexperienced young parents. The three will find their way, I am sure.

Years ago, my daughter (the new grandchild’s mother) was just in her pre-teens when we started universal hearing screening for newborns at Boulder Community hospital in the early 1990s. And just a few years later, she herself was performing newborn hearing screening as a summertime hospital volunteer using automated-ABR equipment. She seemed to enjoy making her own little contribution to the growing movement toward universal newborn hearing screening in the United States and around the world.

After the new grandbaby's discharge from the hospital, this Grandpa (from long-distance) had the tiniest moment of panic, realizing he hadn’t heard if the baby had completed a hearing screening test. “Of course,” the young mother laughed on the other end of the telephone connection, and then reassured me that Sweet Grandbaby James had indeed passed his newborn hearing screening.

The worry for this Grandpa is perhaps more complex than for most. You see, we have measured in Colorado that the group of babies most likely to be lost to follow-up after a “did-not-pass” screening result are the babies from the NICU. That didn't make any sense to me at first; this group has already become well-connected to the medical establishment. How could these children be inadequately re-evaluated, knowing that NICU graduates are at higher risk of being diagnosed as deaf or hard of hearing when compared to the infants who go home from the well-baby nursery?

Maybe some of these children have completed a re-evaluation, and are just lost to documentation. Maybe these families have too many other issues about which to worry, and the exhausted parents can’t bring themselves to complete one more appointment. Maybe the information about the “did-not-pass” screen is actually lost information. Maybe the families do not yet have a primary care physician to shepherd their journey and become their medical home. Maybe... maybe who knows?

Sweet Grandbaby James spent more than five days in the NICU. According to the Joint Committee on Infant Hearing, that is a risk factor for delayed-onset hearing loss, even if he passed his hospital-based hearing screening. A re-screening of hearing in the next 2 years or so is the current recommendation for a baby with this risk factor, and the same recommendation applies for a whole list of other risk factors.

I wonder if James’ two inexperienced parents have been told about this recommendation. I wonder if their pediatrician knows about this recommendation. I wonder if the audiology department at his birth hospital knows about this recommendation.

Worry, worry, worry...

- Albert Mehl, MD

UPCOMING EVENTS

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<tr>
<th>Event</th>
<th>Date</th>
<th>Location</th>
<th>Details</th>
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<td>2013 Annual EHDI Meeting</td>
<td>April 14-16, 2013</td>
<td>Glendale, AZ</td>
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FIRST INFORMATION PARENTS RECEIVE AFTER UNHS DETECTION OF HEARING LOSS

An Australian study First Information Parents Receive after UNHS Detection of Their Baby’s Hearing Loss, recently published in The Journal of Deaf Studies and Deaf Education, examined how the first information parents receive after referral through Universal Newborn Hearing Screening (UNHS) has a significant impact on care-related decisions they make later for their deaf child. The results of this 11-interview study conducted with a representative sample of the Flemish services providers showed that parents receive diverse information, depending on the reference center to which they are referred. The study also showed that the providers’ assumptions and beliefs concerning deafness and care also impacted the outcomes.


IMPACT OF THE WORDS WE USE

The impact of the words used and the way information is presented can be significant—especially as trusted providers of care. A recent Hands & Voices newsletter featured a 7-minute YouTube video Early Intervention: The Missing Link focused on the words used in the early intervention world and their potential to influence the way parents/families react to the news about their child’s hearing loss and future decision making. Watch this short video to learn how you can change a few small words to make a big difference!

DIABETIC PATIENTS HAVE HIGHER PREVALENCE OF HEARING IMPAIRMENT

A new study Diabetes and Risk of Hearing Impairment in Adults: A Meta-Analyis, published in the Endocrine Society’s Journal of Clinical Endocrinology & Metabolism (JCEM) found that patients with diabetes have an increased prevalence of hearing impairment than patients without diabetes. This study was a meta-analysis of thirteen previous cross-sectional studies (20,194 participants and 7,377 cases). In this study it was found that individuals with diabetes had more than two times higher prevalence of hearing impairment than those without the disease regardless of age. In light of these results, the authors are encouraging diabetic patients be screened for hearing impairment from an earlier age as compared to non-diabetics.


AMERICAN ACADEMY OF PEDIATRIC’S HEALTHYCHILDREN.ORG LAUNCHES NEW APP

HealthyChildren.org is the only parenting Web site backed by 60,000 pediatricians committed to the attainment of optimal physical, mental, and social health and well-being for all infants, children, adolescents, and young adults. HealthyChildren.org is now available on the go as a free app for iPhones and iPads and an Android version will be available next month.

With this application, parents can look up age-by-age health information for their children, check immunization schedules, access first-aid how-to information and other resources in a new format designed for tablets and smartphones. The app includes popular features from HealthyChildren.org, including the Find-A-Pediatrician tool and the “Ask the Pediatrician” advice column. Users can download the HealthyChildren app on the iTunes store. Automatic updates to the app will keep parents informed of new features, including the soon-to-be launched Healthy Children e-magazine and upcoming apps such as an ADHD tracker and a car seat checker.

SAVE THE DATE! DISABILITY AND HEALTH FEATURED IN THE NEXT CDC PUBLIC HEALTH GRAND ROUNDS: DECEMBER 18, 2012, 1:00 PM

The National Center on Birth Defects and Developmental Disabilities (NCBDDD) is pleased to announce that disability and health will be featured in the next month’s CDC Public Health Grand Rounds, on December 18, 2012, 1:00 pm ET. The NCBDDD Division of Human Development and Disability and four guest speakers will present data demonstrating health disparities of people with disabilities and talk about strategies and programs at a national and state level to improve the health of people with disabilities. Information regarding how to register for and access the grand rounds will be available soon from AAP EHDI program staff.
Accomplishing the EHDI mission of ensuring families are connected to needed follow up, diagnostic, intervention, and support services requires partnerships with others to help families find the right “doors” for accessing what they need. EHDI systems— which include pediatricians— can benefit from partnering with broader disability-related family resource entities such as Family Voices, Family-to-Family Health Information Centers, Parent Training and Information Centers, and Parent-to-Parent USA. These organizations have a lot to offer families. In tum, EHDI stakeholders can be an important resource to these organizations.

To better understand the role family organizations play in serving families who have hearing-related concerns, the National Center for Hearing Assessment and Management (NCHAM) conducted a national survey with the aforementioned groups. The results from over 127 respondents shine light on the number of families served, the type of information they provide to families based on their requests, the challenges they face in supporting families, and their relationship with the state EHDI program. The vast majority reported that families request help in finding where to go if they are concerned about their child’s hearing, finding intervention services or addressing education-related issues, getting connected with family support opportunities, and finding pediatric providers to perform hearing evaluations. The majority of respondents reported that they refer families to the EHDI program and condition specific organizations, such as Hands & Voices. According to the survey, the greatest challenges these organizations face in trying to help families of children with hearing-related needs are knowing about financial resources to cover hearing-related services, engaging families of children with hearing loss in their organization, and having materials available in languages other than English.

In accordance with the role of medical home, pediatricians can ensure that families are connected with needed resources and support. Family Voices and Family-to-Family Health Information Centers are particularly experienced in addressing health care financing issues, while the Parent Training and Information Centers historically specialize in education and early intervention-related needs. Parent-to-Parent USA provides emotional and informational support to families of children who have special needs most notably by matching parents seeking support with an experienced, trained ‘Support Parent’. A list of family support organizations can be found at http://www.infanthearing.org/familysupport/fslinks.html#support.

Pediatricians also have expertise to share with the state leaders of these family organizations. For example, pediatricians can assist these organizations in helping families understand the role of the pediatrician in addressing hearing-related concerns, and they can help identify pediatric providers who specialize in serving children with hearing loss.

Newborn screening saves and improves the lives of more than 12,000 babies in the United States each year. 2013 marks 50 years since newborn screening was initiated in the US. A new public service announcement (PSA) developed by the Association of Public Health Laboratories (APHL) will be promoted on a Jumbotron in Times Square, New York from November 2012 through January 2013. In order to help promote the word further, share this link http://www.aphl.org/aphlprograms/newborn-screening-and-genetics/50th-Anniversary-of-Newborn-Screening/Pages/What-is-Newborn-Screening.aspx with facts about newborn screening with parents, families, and other providers of care.

Words of Inspiration...

If you care at all, you’ll get some results. If you care enough, you’ll get incredible results.

~Jim Rohn
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.