

JANUARY 2015

EHDI E-MAIL EXPRESS

The monthly newsletter of AAP Early Hearing Detection & 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.

In this issue:

- New EHDI Leadership Structure
- Hands & Voices—2014 Seaver Vision Award, Susan Wiley, MD, FAAP
- EHDI E-Book from NCHAM
- Upcoming Events
- Physician Survey: Addressing EHDI Misconceptions
- Encouraging Follow-up Hearing Evaluations for Newborns
- AG Bell Family Needs Assessment Webinar
- The Impact of Universal Newborn Hearing Screening on Long-term Literacy Outcomes: A Prospective Study

NEW EHDI LEADERSHIP STRUCTURE—EXCITING TIMES!

As you know from previous communications, the American Academy of Pediatrics (AAP) Early Hearing Detection and Intervention (EHDI) program has undergone a change in its leadership structure.

Since 2001, the AAP has administered an EHDI program focused on promoting the medical home in coordinating efforts between pediatricians, health care professionals, state health departments, hospitals, and others. The Academy's program has focused on supporting the implementation of newborn hearing screening programs in states and improving identification of—and care for—infants and children who are Deaf or Hard of Hearing (D/HH).

The main goals of the new leadership restructure are two-fold. First, a new Leadership Team has been created, replacing the original Task Force on Improving the Effectiveness of Newborn Hearing Screening, Diagnosis, and Intervention. The Leadership Team will provide enhanced strategic direction and guidance to the overall program. Second, a new Regional Network Liaison structure has been created in order to improve the support and enhance the impact of the current AAP EHDI Chapter Champions that work with primary care pediatricians, state EHDI programs, and other EHDI stakeholders to further EHDI goals in their respective states and AAP chapters.

In order to provide some insight into the structural changes with the AAP program, the following is a brief overview of some of each group's roles and responsibilities.

EHDI Leadership Team

- A 6 member team of AAP experts from various pediatric disciplines that will provide overall strategic guidance for the AAP EHDI program
- Each leadership team member has agreed to assume leadership responsibilities for at least one activity/initiative under the AAP EHDI program including the following: the Regional Network Liaisons and Chapter Champions; educational opportunities; program communications; and Quality Improvement projects
- Each leadership team member also has agreed to serve as a point of contact for at least one internal or external partnership including the following: the National Center for Hearing Assessment and Management (NCHAM); the Centers for Disease Control and Prevention; state EHDI coordinators; the National Association of Pediatric Nurse Practitioners; Hands & Voices; and internal AAP partnerships with the Section on Otolaryngology as well as other AAP entities

EHDI Regional Network Liaisons

- A leadership group with 1 member from each of the 10 AAP districts
- Will provide hands-on support and mentorship for AAP Chapter Champions
- Will act as a liaison between the Leadership Team and Chapter Champions

EHDI Chapter Champions

- Provide ongoing guidance and education to primary care pediatricians and other health care professionals on meeting the 1-3-6 EHDI goals, identification of risk factors for hearing loss, and the appropriate referrals for infants who are diagnosed with, or at risk for, hearing loss
- Collaborate with state EHDI programs and take part in state EHDI Hearing Screening Advisory Committee meetings

We are pleased to welcome the new EHDI Leadership Team and Regional Network Liaisons as the AAP continues to move forward in efforts supporting care for D/HH infants and children and their families.

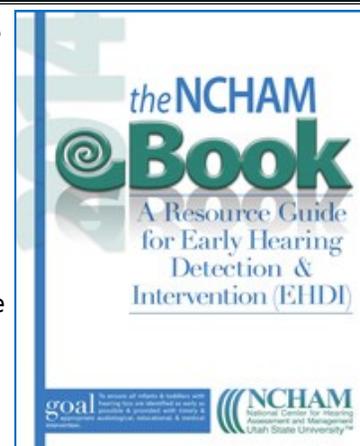
HANDS & VOICES—2014 SEAVER VISION AWARD, SUSAN WILEY, MD, FAAP

At the Hands & Voices Leadership Conference in September 2014, Dr Susan Wiley—long standing AAP Ohio Chapter Champion and Leadership Team member—was awarded the Seaver Vision Award. The Seaver Vision Award is given annually to a parent, professional, organization, or agency that exemplifies the values and commitment to the Hands & Voices vision by making significant contributions to family support for the field of deafness and hearing loss.

In a nomination letter for Dr Susan Wiley, it was noted, “Dr Wiley has been motivational and inspirational to Ohioans and the others throughout the nation who work with D/HH children. She has served as the EHDI Chapter Champion in Ohio for many years, sits on the Universal Newborn Hearing Screen Sub-committee (Ohio EHDI Advisory Board), and runs a clinic that specializes in the care of children who are D/HH and Deaf plus. Dr Wiley has always been a professional who ‘gets deafness.’ She is able to work with and help parents and families without a bias around their choices.”

EARLY HEARING DETECTION & INTERVENTION E-BOOK FROM NCHAM

This month, we continue to offer a glance at the NCHAM eBook, a comprehensive online resource. In [Chapter Nine](#) authors Jessica Stich-Hennen, AuD, PASC and Gabriel Amme Bargen, PhD provide an overview of the risk factors for late onset hearing loss. The authors begin by providing a brief history of development of the standard list of risk factors by the Joint Committee on Infant Hearing (JCIH) which first published the high-risk criteria for late onset hearing loss—along with the recommendation for increased monitoring of infants that fell into this category—in 1973. The risk criteria have grown since their inception and beginning in 2000, the JCIH developed separate risk factors for neonates and infants. In 2007, emphasis on “high-risk” factors that are of greater concern for late onset hearing loss were identified by the JCIH; the authors of this chapter describe each of the risk factors in detail. As risk factor monitoring has become more widespread, high-risk monitoring programs have been implemented and the chapter highlights the different roles that medical homes, birthing centers, audiologists, and hospitals play in the ongoing surveillance and identification of children who are Deaf or Hard of Hearing (D/HH). The authors suggest that state EHDI programs should have a system in place to track and monitor infants and children who are at risk for late onset hearing loss. However, the authors also emphasize the importance of ongoing education for all EHDI stakeholders in order to successfully identify these individuals and provide the appropriate interventions.



UPCOMING EVENTS

Event	Date	Location	Details
NCHAM Move the Needle Webinar: Is Meeting the Needs of Physicians in Support of EHDI	February 11, 2015	Webinar	Web site
2015 National EHDI Meeting	March 8-10, 2015	Louisville, KY	Web site
American Academy of Audiology: AudiologyNOW! Conference	March 25-28, 2015	San Antonio, TX	Web site

PHYSICIAN SURVEY: ADDRESSING EHDI MISCONCEPTIONS

The National Center for Hearing Assessment and Management (NCHAM)—along with support from state EHDI coordinators and the American Academy of Pediatrics (AAP)—conducted a self-report survey with pediatricians and other clinicians who provide care for infants and young children. The purpose of this survey, conducted in 2012, was to:

- Understand the degree to which medical homes are engaged in EHDI activities
- Update our understanding of physician attitudes and knowledge regarding EHDI since the 2005 survey conducted on this topic
- Drive strategies to support physicians in their role within EHDI systems

In upcoming editions of the EHDI E-Mail Express, we will review some of the questions presented in the survey and the results that pediatricians provided. We hope to identify and examine what gaps in understanding and practice, if any, still persist.

Question: List any specialist to whom you would routinely refer the family of a child with a confirmed permanent hearing loss (open ended):

Results: Percentage of Physicians Reporting by Year

Specialty	2005	2012
ENT/Otolaryngology	75.6%	73.4%
Geneticist	8.8%	9.3%
Ophthalmologist	0.9%	2.2%
Audiologist	41.2%	53.0%
Speech Language Pathologist	22.9%	27.0%
Early Intervention	11.4%	12.0%
Neurologist	7.0%	5.6%

As shown in the table, not all physician respondents are making these important referrals on a routine basis. Moreover, there has been little improvement in this sphere of physician practices since 2005. Following diagnosis of permanent hearing loss, it is critical to identify etiology and to ensure that entry into Early Intervention happens as quickly as possible. It is recommended by the Joint Committee on Infant Hearing (JCIH, 2007) that this occur before 6 months of age.

A main focus of the AAP EHDI program is improving the role of the medical home in coordinating care for infants and children who are D/HH. As such, Chapter Champions should be aware of this pattern in pediatric physician practice and tailor education efforts to ensure that the appropriate referrals to specialty care are being made.

ENCOURAGING FOLLOW-UP HEARING EVALUATIONS FOR NEWBORNS

[The National Institute on Deafness and Other Communication Disorders Web site](#) provides practical information for health care providers on “how” they can encourage follow-up for hearing evaluations for newborns who do not pass the newborn hearing screening. The following are some materials and information included on the site:

- Why don't some parents return for a follow-up examination?
- What all parents need to know before they leave the hospital
- Free publications from the NIDCD
- Where parents can get more information

AG BELL FAMILY NEEDS ASSESSMENT WEBINAR

Alexander Graham Bell Association for the Deaf and Hard of Hearing has released a new webinar for health care professionals based on their 2013 Family Needs Assessment survey. The survey, given to families with children who are Deaf or Hard of Hearing (D/HH), sought to glean insight and assess families' experiences in regards to access and quality of services they received while seeking care for their child. The following are some of the topics covered in the survey that are also addressed in the webinar:

- Access to information
- Emotional and support resources
- Early Intervention services
- School-age years
- Financial Considerations
- Additional support

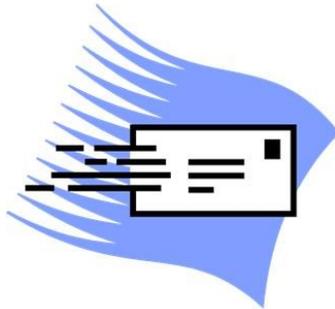
The webinar is free of charge for interested professionals, both AG Bell members and non-members. The [Family Needs Assessment webinar](#) and [survey results](#) can be found on the AG Bell Web site.

THE IMPACT OF UNIVERSAL NEWBORN HEARING SCREENING ON LONG-TERM LITERACY OUTCOMES: A PROSPECTIVE STUDY

This study sought to follow a cohort of children with permanent childhood hearing impairment (PCHI) for 17 years since birth in order to determine whether benefits of universal newborn hearing screening (UNHS) persist in the second decade of life. Of the 120 children with PCHI who were assessed for reading comprehension at 6-10 years of age, 76 (63%) were reassessed in their teenage years using the same metrics. The research found that teenagers who were exposed to UNHS and were identified with permanent hearing loss before nine months of age, had significantly higher adjusted reading comprehension and summarization scores than similar teenagers who were diagnosed with permanent hearing loss after nine completed months of age.

Although individuals born during periods with UNHS had improved reading comprehension scores over individuals born in periods without UNHS, the results were not statistically significant. However, the authors show that gains made by UNHS to improve early detection of hearing loss (before nine months of age) have a positive impact on reading comprehension in individuals who are Deaf or Hard of Hearing (D/HH) that lasts into their teenage years. Moreover, the gap in reading comprehension ability between individuals with earlier and later-identified hearing loss, had grown from a smaller disparity when assessed during childhood to a much larger disparity when assessed during teenage years. This research supports the mounting evidence that UNHS can improve early detection of hearing loss in infants and children and the positive reading comprehension outcomes that are associated with this early detection.

Source: Pimperton H, et al. The Impact of Universal Newborn Hearing Screening on Long-term Literacy Outcomes: A Prospective Study. *Arch Dis Child*. 2014;0:1-7.



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 Stephen Crabbe, scrabbe@aap.org or (847) 434-4738. If you would like to unsubscribe to the update, please notify staff by responding to this e-mail.