

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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COLLABORATING TO ADDRESS LOSS TO FOLLOW-UP AMONG STATES WITH LARGE BIRTH COHORTS

Considerable progress has been made in early identification of infants with hearing loss. This is reflected by over 95% of all newborns being consistently screened in the United States and the over 5,500 infants with identified permanent hearing loss in 2013. However, challenges remain—with one-third of infants considered Loss to Follow-up (LFU)/Loss to Documentation (LTD) for diagnosis because hearing loss cannot be confirmed until the infant/child receives recommended diagnostic testing. A quarter of those infants with a permanent hearing loss are LFU/LTD for intervention. Reducing LFU/LTD is especially challenging in states that have a large number of births annually. To help address this issue, the Health Resources and Services Administration (HRSA), Centers for Disease Control and Prevention (CDC), and National Center for Hearing Assessment and Management (NCHAM), recently hosted a meeting with 5 states that have 150,000 or more births per year (California, Florida, Illinois, New York, and Texas).

During the meeting each state gave a brief presentation about their program; the presentations included an overview of how they collect and report data, their successes and challenges, how they are using Quality Improvement to address LFU/LTD, and how HRSA, CDC, and NCHAM can further support states. During the meeting the states expressed many commonalities in challenges they face due to the large number of births and how they manage their respective EHDI programs as a result. Several states noted that they address reporting, documentation and tracking hearing screening and follow up by recognizing the work of hospitals through regular report cards, making follow-up calls, scheduling follow-up appointments before discharge, and having the hospitals enter more data into the EHDI Information System. The meeting allowed staff and leaders working on EHDI in states to similar and unique activities, lessons-learned, and make new connections.

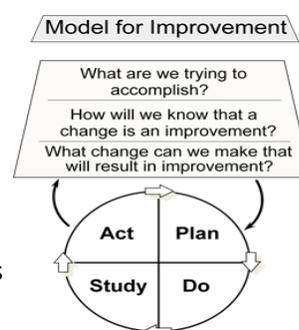
Following the meeting, CDC, HRSA, and NCHAM hosted a webinar with the 5 states to further discuss data standardization. During the webinar the states were asked to review a series of scenarios and determine how the data should be reported on the annual CDC data survey. This activity generated in-depth discussion around the classification of several scenarios, highlighted challenges in applying the survey definitions, and demonstrated the importance of open discussion. The CDC, HRSA, and NCHAM are now discussing next steps to build on the progress made and further support states in identifying and providing services to all children who are Deaf and/or Hard of Hearing.

UPCOMING EVENTS

Event	Date	Location	Details
Ototoxicity Monitoring as Part of Risk Monitoring in the EHDI System	October 8, 2015	Webinar	Website
6th Annual Coalition for Global Hearing Health	October 9-10	Washington DC	Website
AAP National Conference & Exhibition	October 24-27, 2015	Washington, DC	Website
2016 EHDI Meeting	March 13-15, 2016	San Diego, CA	Website

NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT—EHDI QUALITY IMPROVEMENT

Audiologists are key partners in the effort to reduce Loss to follow up (LTF) and loss to documentation (LTD). In Louisiana, the EHDI team has faced the issue of infants remaining “in process,” with no conclusive diagnosis, for much longer than is desired. In order to address this issue, they have developed a quality improvement strategy to specifically target two types of “in process” infants. The first type of “in progress” infants are those that are referred to a second, or multiple audiology facilities in order to receive diagnostic testing. The second type of “in progress” infants are those who have multiple rescheduled screenings at a single facility.



The state EHDI coordinator began the quality improvement efforts by simply trying to identify all infants who were caught in these “in process” cycles by sending faxes to two audiology practices requesting information on nine infants. The EHDI program received a response with information on five of the nine infants. They continued to use Plan, Do, Study, Act (PDSA) cycles in order to reach out to additional pediatric audiologists, each time increasing the number of audiology sites contacted. In the third cycle they received follow-up information on 24 out of 24 infants. Through this process of identifying which infants were ‘in process’, the state EHDI program was able to provide more targeted follow-up and reduce the number of infants who were “in process” from 7.7% to 2.0%.

The Louisiana EHDI team made progress on the following through this process:

- Identification of audiologists who tended to keep infants in the diagnostic process too long, for one reason or another. As a result, the Louisiana EHDI team began to offer webinars to audiologists regarding this issue and provide technical assistance with individual audiologists to improve the diagnostic process.
- Improvement of processes to identify audiologists who fail to report diagnostic results in a timely manner.
- Understanding the need for strengthening the referral protocols between audiology site, and making improvements regarding same.
- Greater involvement of primary care providers in the follow-up process and enhanced engagement of the primary care provider to ensure the medical home is more closely involved.

Quality improvement is a continuous effort to improve EHDI systems, individual medical care, and LTF/LTD. As state EHDI programs engage in quality improvement, the lessons learned and the opportunities can be shared with other states. The National Center for Hearing Assessment and Management (NCHAM) has developed a Virtual Learning Collaborative (VLC) that will allow states to collaborate and share quality improvement ideas, and EHDI best practices. For more information on the NCHAM quality improvement efforts or the VLC, contact [Alyson Ward, NCHAM Director of Quality Improvement](#).

THE PARENT PERSPECTIVE—HANDS & VOICES SPANISH LANGUAGE RESOURCES

Did you know that Hands & Voices has a Spanish Resource section on their Web site? Hands & Voices has been working with their chapter leadership who provide support to Spanish speaking families to begin including [needed and relevant resources in Spanish](#). Professionals and families can find resources such as Glossary of Audiological and Deafness Terms, articles and links to videos and other resources in Spanish. Hands & Voices staff encourage you to familiarize yourself with this section of the Web site and refer families to same as appropriate.

RISK OF SENSORINEURAL HEARING LOSS AND BILIRUBIN EXCHANGE TRANSFUSION THRESHOLDS

While high bilirubin levels are associated with sensorineural hearing loss, there is little known about the relative and excess risk associated with bilirubin levels at or above exchange transfusion thresholds (ETT). [This research examined the risk of sensorineural hearing loss \(SNHL\)](#) in a subset of the Late Impact of Getting Hyperbilirubinemia or phototherapy (LIGHT) cohort. This subset consisted of infants born in Northern California between 1995 and 2011, whose total serum bilirubin (TSB) reached the ETT recommended by the American Academy of Pediatrics (AAP). Patients with diagnoses of conditions that could indicate congenital hearing loss, were not included in the study. For this study any TSB level at or above the AAP ETT was considered exposure and the outcome was confirmed SNHL.

The crude risk for patients was found to be 6.0 per 1000 newborns in the exposed cohort, compared to 2.3 per 1000 newborns in the unexposed patients. When analyzing TSB levels according to the amount they exceeded AAP ETT, only levels greater than 10 mg/dL above ETT exhibited a statistically significant increase in risk of SNHL. Overall the study found that elevated TSB levels that are around, or just above the AAP ETT, levels that are typically considered concerning, were not associated with increased risk of SNHL. These findings may have implications for current practice recommendations concerning the treatment of hyperbilirubinemia.

Wickremasinghe, AC, Risly, RJ, Kuzniewicz, MW, et al. Risk of sensorineural hearing loss and bilirubin exchange transfusion thresholds. *Pediatrics*. 2015;136(3):505-512.

SENSITIVITY OF THE AUTOMATED AUDITORY BRAINSTEM RESPONSE IN NEONATAL HEARING SCREENING

In a 2-stage neonatal hearing screening protocol, if an infant fails the first-stage screening with an otoacoustic emissions test, an automated auditory brainstem response (ABR) test is performed. [The purpose of this study was to estimate the rate of hearing loss](#) detected by the first-stage otoacoustic emissions test but missed by second-stage automated ABR testing. The screening results for a cohort of 17,078 infants born between January 2013 and June 2014 were reviewed. All patients with a failed otoacoustic emissions test were referred for a follow-up evaluation at a hearing clinic, regardless of automated ABR result. The study found that 24% of infants who failed the otoacoustic emissions test and also passed the automated ABR, were eventually diagnosed with hearing loss (22/90). This group comprised more than half of the infants who were eventually diagnosed as Deaf or Hard of Hearing (D/HH) and 36% of the infants that were diagnosed with a hearing loss considered moderate to profound in at least one ear (8/22). These results suggest additional evaluation is necessary to confirm the sensitivity of automated ABR testing and review current screening protocols in order to ensure children who are D/HH are identified as early as possible.

Levit, Y, Himmelfarb, M, Dollberg, S. Sensitivity of the automated auditory brainstem response in neonatal hearing screening. *Pediatrics*. 2015.136(3);642-647.

YELLOW DOT PROGRAM—A TOOL FOR FIRST RESPONDERS

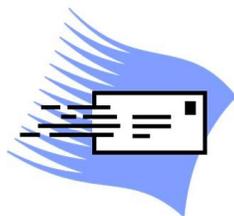
The national [Yellow Dot](#) safety program is a tool to provide first responders with information about a disability and/or a health issue that can help them save lives, particularly in that first "golden hour" following a car crash or other medical emergency.

A yellow dot decal placed on the driver's side rear window of a car would let first responders know that additional emergency information can be found in the glove compartment. For people who are D/HH, this could provide crucial information to guide the care that first responders and emergency room personnel provide. Examples of when the yellow dot program could provide assistance in the case of an emergency involving someone who is D/HH are if someone uses cochlear implants and cannot have an MRI or uses hearing aids, making emergency personnel aware about a potential need for additional communication options and accommodations. This program has been adopted in several states and more detailed information regarding [the Yellow Dot program is available](#).

CYTOMEGALOVIRUS IN PREGNANCY—CLINICAL MANAGEMENT GUIDELINES

The American College of Obstetricians and Gynecologists recently released [a practice bulletin](#) to provide background and clinical recommendations for several infections that affect women, and potentially their newborns, during pregnancy. The bulletin's section on cytomegalovirus (CMV) will be of particular interest to chapter champions, pediatric clinicians, and other EHDI stakeholders due to the increased risk of hearing loss due to infection. The clinical management guidelines provide an in depth overview of CMV, its transmission and possible outcomes. Additionally, the clinical guidelines review possible methods of diagnosis as well as future diagnostic and treatment options. The guidelines conclude that due to the current absence of any proven diagnostic protocols or treatment therapies for CMV infection, routine screening of pregnant women for CMV infection is not recommended at this time.

Committee on Practice Bulletins-Obstetrics. Practice Bulletin No 151: Cytomegalovirus, Parvovirus B19, Varicella Voster, and Toxoplasmosis in Pregnancy. *Obstetrics & Gynecology*. 2015;125(6):1510-1525.



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.