American Academy of Pediatrics
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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.

AUGUST 2015

In this issue:

IMPROVING THE ROLE OF THE PRIMARY CARE PHYSICIAN IN EHDI—A REFLECTION BY BOB CICCO, MD, FAAP

Improving quality at the practice level has been and will continue to be an essential strategy for reducing Early Hearing Detection and Intervention (EHDI) lost to follow up. Unfortunately, few quality improvement (QI) initiatives have focused on primary care practice improvement that will assure newborns at risk for hearing loss will be referred and diagnosed as early as possible.

However, over this past year, the AAP EHDI program, in cooperation with the Health Resources and Services Administration (HRSA), has launched a QI initiative designed to develop practice changes that both identify children at risk, as well as assure appropriate referral and follow up for children who may be Deaf or Hard of Hearing (D/HH).

The specific aims of this this project include assuring the following:

- Hospital hearing screening results are received by the primary care office and documented in the chart
- Newborn screening results are discussed with families
- Newborns not passing hearing screening complete an audiological evaluation by 3 months of age
- Newborns who have passed their newborn hearing screen but have risk factors for hearing loss are identified and an individualized surveillance plan is put into place

This project is utilizing the Learning Collaborative model that allows practices to implement small tests of change, measure the impact of these changes, and share with others in order to develop best practices. An Expert Group including pediatricians, a QI expert, a representative from the National Center for Hearing Assessment and Management (NCHAM), a family leader and AAP staff have been overseeing the project. This group collaborated on developing a number of process and outcome measures that practices could track as change strategies to be tested.

Pediatric practices were recruited to participate in the project and the six practice teams that were selected met at the end of June for a two-day Learning Session. Prior to this meeting all the participating practices reviewed their current processes in following babies after newborn hearing screening and were able to share barriers and successful strategies they employ in their current practice. Representatives from the Expert Group participated in the Learning Session and it is fair to say that all involved were impressed with the degree of brainstorming, innovation, and passion that went into the discussions.

The practices are now in their second Action Period of testing change ideas and are performing chart review to measure improvements around their stated aims and measures. In addition to the work being done in their individual work settings, the practices are communicating on a monthly basis with each other to share successes and challenges in order to achieve a collaborative learning experience. These monthly sessions also have an educational component and, as such, include presentations on specific EHDI topics. Some of these topics include the following: developing individualized plans for babies with risk factors; the medical home's role after a diagnosis of hearing loss is made; and monitoring interventions for effectiveness.

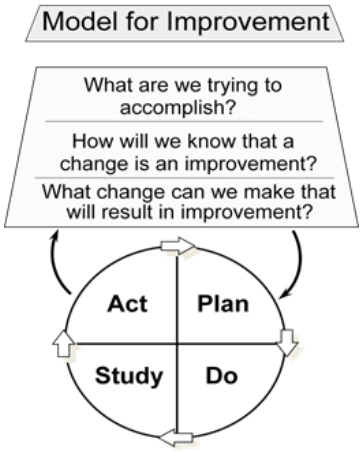
At the end of five Action Periods, there are plans to compile and disseminate the best practices identified throughout the project. The project has been approved for Maintenance of Certification (MOC) credit and, once completed, we hope to make this process available for other practices wishing to implement a QI project in their own practice setting.

UPCOMING EVENTS

Event	Date	Location	Details
12th Annual Hands & Voices Leadership Conference	September 18-20, 2015	New Braunfels, TX	Website
Early Hearing Detection and Intervention: Doing the Right Thing in Primary Care Practice	September 29, 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

NATIONAL CENTER FOR HEARING ASSESSMENT AND MANAGEMENT—EHDI QUALITY IMPROVEMENT

Early Hearing Detection and Intervention (EHDI) relies on the efforts of multiple team members to successfully identify and provide appropriate interventions for children who are Deaf or Hard of Hearing (D/HH). From the primary care clinician and medical sub-specialist, to the audiologist, to the family—all play an important role.



Parent-to-parent support is often identified as one of the most valuable aspects of the EHDI journey for families. Several states, including the Indiana EHDI program, have been using Quality Improvement (QI) efforts to identify ways to decrease their loss to follow up rates. Through Plan, Do, Study, Act (PDSA) cycles, the Indiana EHDI team has found that when a parent consultant contacts the family after a failed newborn hearing screen, the rate of follow-up for diagnostic evaluation increases.

The QI initiative in Indiana has led the EHDI program to develop a new data management and follow-up system. A parent consultant is now alerted directly when an infant does not pass the hearing screen so they can immediately contact the family. The parent consultant supports the family by encouraging them to follow through with any referrals for additional screening and provides additional assistance such as scheduling the diagnostic assessment, if necessary. When the audiologist enters the diagnostic test results into the electronic database, an alert is sent to the follow-up coordinator if a D/HH diagnosis is made. The EHDI follow-up coordinator can then work with the local Guide by Your Side (GYBS) Program Coordinator to assign a Parent Guide (Consultant) to the family; this person provides ongoing support and discusses early intervention options.

EARLY HEARING DETECTION AND INTERVENTION WEBINAR: DOING THE RIGHT THING IN PRIMARY CARE PRACTICE, BY RACHEL ST JOHN, MD, FAAP

Although 95% of infants receive newborn hearing screening, up to one-third in some states are "lost to follow-up," which can cause significant delays in language and communication development. Rachel St John, MD, FAAP, will highlight the role the medical home, as well as offer strategies and tools to improve clinical practice for children who are Deaf or Hard of Hearing. This webinar will take place on Tuesday, September 29 at 6 pm CT. Additional information and registration for the webinar is available here.

THE PARENT PERSPECTIVE—HANDS & VOICES COMMUNICATIONS CONSIDERATIONS A TO Z™

Hands & Voices Communication Considerations A to Z™ is a series from Hands & Voices that is designed to help families and the professionals working with them access information and further resources to assist them in raising and educating children who are Deaf or Hard of Hearing. Through this series, experts share insights on the many diverse considerations that play into communication modes and methods, as well as the many other variables that are part of informed decision making. Informed decision making and empowerment of families are vital elements to support the motto of Hands & Voices— *"what works for the child is what makes the choice right".*

At the Communication Considerations A to Z™ section of the Hands & Voices website, articles are available in alphabetical order and include topics such as American Sign Language (ASL), Cochlear Implants, acoustical adaptations, research, self-advocacy for teens. All topics are concisely written by reputable authors who answer the following four specific questions:

1. What is the selected *Communication Considerations* topic?
2. What issues are at the forefront?
3. What should every parent or professional know?
4. Where else can I find information about this subject? *(Author/expert provides up to three recommended resources including books and/or websites)*

RISK INDICATORS FOR CONGENITAL AND DELAYED-ONSET HEARING LOSS

This article aims to evaluate risk indicators for congenital and delayed onset hearing loss and the Joint Committee on Infant Hearing's (JCIH) recommendations on requirements for ongoing monitoring of infants identified as at risk for hearing loss. From 2001 to 2007, the authors identified and followed a cohort of 26,341 newborns who underwent newborn hearing screening in Michigan. Logistical regression analysis was used to evaluate the risk indicators for congenital and delayed onset hearing loss as well as to estimate the cost burden of ongoing monitoring due to the presence of risk factors.

A permanent hearing loss was documented in 90 infants, including 16 infants who were diagnosed with delayed-onset hearing loss, giving a prevalence rate of 3.4 per 1,000. In the first analysis conducted, all risk indicators identified by the JCIH, except for congenital diaphragmatic hernia, showed statistically significant association with the identification of hearing loss. Due to the fact that in many circumstances, multiple risk indicators were identified for a single patient, an additional analysis was conducted to control for other indicators. This new analysis found that a stay in the neonatal intensive care unit (NICU) for more than 5 days, loop diuretic exposure, low birth weight, and congenital diaphragmatic hernia were not associated with increased odds of identification of hearing loss. The authors also found that risk indicators such as family history of childhood hearing loss, hyperbilirubinemia requiring exchange transfusion, syndromic conditions, and meningitis were most strongly associated with delayed-onset hearing loss. Cost estimates for ongoing monitoring of infants and children identified with risk factors for congenital and delayed-onset hearing loss are given, but the authors caution that these estimates should be weighed against the cost savings that occur when hearing loss is identified and interventions are implemented early in a child's life.

Resource: Kraft, CT, Malhotra, S, Boesrt, A, Thorne, MC. Risk indicators for congenital and delayed-onset hearing loss. *Journal of Otology & Neurotology*. 2014;35:1839-1843.

MITOCHONDRIAL MUTATION M.1555A>G AS A RISK FACTOR FOR FAILED NEWBORN HEARING SCREENING IN A LARGE COHORT OF PRETERM INFANTS

The mitochondrial m.1555A>G mutation has been found in an estimated 1 in 500 children and is associated with a high rate of permanent hearing loss when aminoglycosides are given. This study investigated a cohort of preterm infants who had the m.1555A>G mutation to evaluate the elevated risk for a failed newborn hearing screening. Additionally, mothers of infants with the mutation were screened in order to determine whether genetic screening for m.1555A>G would be feasible to prevent postnatal aminoglycoside treatment of infants who carry the mutation.

Between 2003 and 2012, infants from 46 NICUs were identified and received genotyping. Only 0.2% of infants were found to carry the m.1555A>G mutation, and of those, three out of ten who received aminoglycoside antibiotics failed their newborn hearing screen. Patients treated with furosemide were statistically more likely to fail their newborn hearing screening. As aminoglycoside treatment is standard for suspected sepsis in newborns, general avoidance of this treatment may not be feasible or reasonable. However, this data may suggest that screening mothers in preterm labor for the m.1555A>G mutation may be beneficial to determining whether treatment plans alternative to aminoglycosides should be identified in order to decrease the risk of permanent hearing loss.

Gopel, W, Berkowski S, Preuss M, et al. Mitochondrial mutation m.1555A>G as a risk factor for failed newborn hearing screening in a large cohort of preterm infants. *BMC Pediatrics.* 2014;14:210.

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.