**SEPTEMBER 2011** 

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# **EHDI E-MAIL EXPRESS**

American Academy of Pediatrics

DEDICATED TO THE HEALTH OF ALL CHILDRI

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.

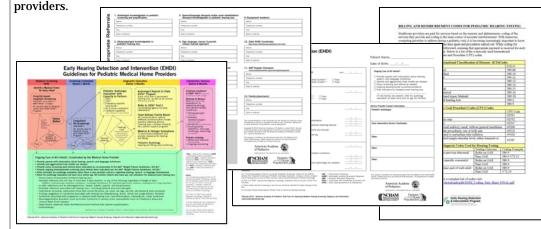
### FROM YOUR CHAIR



As we continue to work towards developing more and improved resources, let's not forget some of the effective tools we already have at our disposal. Do you have a patient with hearing loss in your practice? Are you scheduled to present at grand rounds or to a residency program in the near future? If yes, AAP staff can send you multiple copies of the AAP Early Hearing Detection and Intervention Guidelines for Pediatric Medical Home Providers Algorithm or Patient Checklist for Pediatric

Medical Home Providers.

These materials were recently reprinted and provide guidance on EHDI issues and appropriate referrals and allow health care professionals to track hospital-based inpatient hearing screening results, outpatient hearing screening results, information from the pediatric audiologic evaluation, ongoing audiologic services, enrollment in early intervention services, and medical evaluation results in one place in their patient's chart. The checklist also includes an easy-to-use guide to ensure that the child is linked with appropriate services and that the necessary evaluations are coordinated. It also provides space for you to record relevant service provider contact information. The reprinted algorithm with some common billing codes (below) was also included as an insert into AAP members' newsletter, *AAP News*, in August which reached over 60,000



Please continue to use and promote this available tool and contact Faiza Khan, fkhan@aap.org, to request copies for your next event. You can also download the guidelines and checklist at http://medicalhomeinfo.org/how/clinical\_care/hearing\_screening/.

- Albert Mehl, MD

#### **UPCOMING EVENTS** Event Date Location Details Child Health Day October 3, 2011 Web site AAP National Conference and Exhibition (NCE) October 15-18, 2011 Boston, MA Web site Raleigh, NC EHDI Partnering for Progress Trio of Conferences October 26-28, 2011 Web site



## EXOME SEQUENCING: DEFINING HEREDITARY DEAFNESS

Exome sequencing (also known as targeted exome capture) is an efficient strategy to selectively sequence the coding regions of the genome to identify novel genes associated with rare and common disorders. Understanding the role of genetics is critical to precise diagnosis of disease and developmental syndromes. Most cases of early onset hearing loss are genetic in origin but there are many different forms. Therefore, it has been difficult to identify the gene responsible for the hearing loss of each affected child, because the critical mutations differ among countries and populations.

New research published in BioMed Central's open access journal *Genome Biology* has identified six critical mutations in Israeli Jewish and Palestinian Arab families. Mutations in one gene - TMC1- was found in 38% of children with genetic hearing loss in the Moroccan Jewish population.



To read more about the findings visit: <u>http://www.sciencedaily.com/releases/2011/09/110914073203.htm</u>.

## **REINTRODUCING ONE OF OUR PARTNERS: NCHAM**

Since some of our readers may be new and unfamiliar with our partners, we'd like to reintroduce one of our important ones – the National Center for Hearing Assessment and Management at Utah State University (NCHAM). Under a cooperative agreement with the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), the goal of NCHAM is to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. NCHAM's research, training, and technical assistance activities contribute to this goal by working to achieve the following objectives:

- Every child born with a hearing loss is identified before 3 months of age and provided with timely and appropriate intervention by 6 months of age.
- Every family of an infant with hearing loss receives culturally-competent family support as desired.
- All newborns have a medical home.

NCHAM serves as the National Technical Resource Center for all state-based Early Hearing Detection and Intervention (EHDI) programs in the United States. State Departments of Health have effective newborn hearing screening tracking and data management systems that are linked with other relevant public health information systems.

NCHAM is also a key member of the national American Academy of Pediatrics (AAP) Task Force on Improving the Effectiveness of Newborn Hearing Screening, Diagnosis, and Intervention (EHDI Task Force) and takes the lead on organizing the annual national



agnosis, and Intervention (EHDI Task Force) and takes the lead on organizing the annual national EHDI Conference along with its co-sponsors MCHB, Centers for Disease Control and Prevention (CDC), and the AAP.

To learn more about NCHAM and access a wealth of resources, be sure to visit their website at <u>www.infanthearing.org</u>, and follow them on facebook: http://www.facebook.com/pages/The-National-Center-for-Hearing-Assessment-and-Management-NCHAM/109285292471141.

#### AAP WEB-BASED EDUCATIONAL PROGRAM ON HEARING

The American Academy of Pediatrics still offers a web-based educational program for physicians about early identification of hearing loss. The next time you send information to primary care physicians in your state, discuss EHDI issues at meetings or presentations, or if you are contacting an individual physician concerning a child who has been diagnosed with a hearing loss, consider sending information about the EHDI Pedialink module to help further the concept of "just in time" learning, i.e., providing educational tools, materials, and resources just at the time that a primary care provider needs them.

The online module, *Childhood Hearing: A Sound Foundation in the Medical Ho*me, is now available on <u>www.PediaLink.org</u> for registration. The module content was developed by nationally and internationally renowned pediatricians and audiologists, and is presented in an interactive and informative manner, including engaging vignettes, multimedia, and resources you can personalize and download for your own office. Providers can participate in this module from the convenience of their own office or home.

Through the module, pediatric health care providers learn about different types of hearing loss; screening methods for hearing loss; medical and genetic risk factors; the importance of early recognition and ongoing surveillance; and the role of the medical home in hearing screening. Physicians can earn a maximum of 5 AMA PRA Category 1 credits. Registration fees are as follows: AAP Member, \$80; non-member, \$96.

For more information about this module, or if you have any questions, please contact Faiza Khan at fkhan@aap.org.





#### **REDUCING LOSS TO FOLLOW-UP BY STRENGTHENING EHDI PROGRAMS**

The Alexander Graham Bell Association for the Deaf and Hard of Hearing (AG Bell) released a monograph that presents the findings of a groundbreaking analysis that applies a widely used business strategic planning tool to gain new insights into the strengths, weaknesses, opportunities, and threats of statewide early hearing detection and intervention programs (EHDI) across the nation. The results provide a guideline for strengthening EHDI systems in each state to provide comprehensive care to infants and young children with hearing loss.

The monograph presents the findings of a 2009 survey in which state EHDI coordinators responded to an online survey of 12 major areas within their EHDI systems. Each EHDI coordinator was asked to identify at least one strength, weakness, opportunity, and threat for use in strategic planning.

The survey used a strengths, weaknesses, opportunities, and threats (SWOT) analysis, a well established strategic planning tool, to identify the internal factors (strengths and weaknesses) of the EHDI system, as well as external ones (opportunities and threats) that could affect the system. The 12 areas surveyed include EHDI components such as newborn hearing screening, professional development, collaboration, and loss to follow-up. A panel of experts in the field reviewed the results and categorized them into common themes in each of four strategic planning areas.

Jackson Roush, Ph.D., professor and director of the Division of Speech and Hearing Sciences at the University of North Carolina School of Medicine, served as guest editor of the monograph. "This monograph will be an excellent resource for EHDI stakeholders and a valuable tool for analyzing strengths and needs of state EHDI programs," said Dr. Roush.

The project was supported by the National Center for Hearing Assessment and Management (NCHAM), which serves as a national resource center to ensure that all infants and toddlers with hearing loss are identified as early as possible and provided with timely and appropriate audiological, educational, and medical intervention. *The Volta Review*, AG Bell's 120-year old scholarly journal, was selected as a publication venue for the groundbreaking comprehensive analysis.

Monograph articles underwent a rigorous, peer-review process that included blinded review of all articles. Peer reviewers were selected for their high level of expertise, objectivity, and diversity of background.

"This report will go a long way in building a better EHDI system," said Kathleen Treni, AG Bell president and the principal of the pre-kindergarten through 12<sup>th</sup> grade programs for students who are deaf and hard of hearing in Bergen County Special Services District in Northern New Jersey. "A well-functioning EHDI system is critical to improving the communication outcomes of children who are deaf and hard of hearing. I am delighted that AG Bell has been able to support this project through *The Volta Review*, our peer reviewed journal."

NCHAM Founding Director Karl White, Ph.D., a professor of Psychology at Utah State University and an internationally recognized expert on EHDI, applauded efforts on the monograph. "This monograph is a tremendous step forward in the quest to improve and increase the effectiveness of EHDI," said Dr. White. "These strategies should be carefully considered by national and state level EHDI stakeholders to continue improvement to state EDHI programs so that children with hearing loss and their families benefit from the advances made in recent years and the opportunities now available."

The monograph can be accessed on the AG Bell website at <u>www.agbell.org</u>. AG Bell members may access the full version online by <u>clicking here</u> (you must log-in first). Printed copies may be purchased from the AG Bell Bookstore by <u>clicking here</u>.

AG Bell has developed a comprehensive summary of the strategic analysis of EHDI programs. <u>Click here</u> to download this free summary (PDF).

#### About the AG Bell Association

The Alexander Graham Bell Association for the Deaf and Hard of Hearing helps families, health care providers and education professionals understand childhood hearing loss and the importance of early diagnosis and intervention. Through advocacy, education and financial aid, AG Bell helps to ensure that every child and adult with hearing loss has the opportunity to listen, talk and thrive. With chapters located in the United States and a network of international affiliates, AG Bell supports its mission: *Advocating Independence through Listening and Talking*!

(AG Bell Press Release 09/08/11)

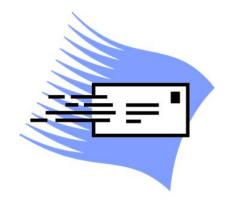
#### WORDS OF INSPIRATION...



"Don't say you don't have enough time. You have exactly the same number of hours per day that were given to Helen Keller, Pasteur, Michaelangelo, Mother Teresea, Leonardo da Vinci, Thomas Jefferson, and Albert Einstein."

- Life's Little Instruction Book, compiled by H. Jackson Brown, Jr.





#### **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 <a href="http://www.medicalhomeinfo.org/how/clinical\_care/hearing\_screening/">http://www.medicalhomeinfo.org/how/clinical\_care/hearing\_screening/</a>. 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.

