



EHDI E-MAIL EXPRESS

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.

JUNE 2011

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FROM YOUR CHAIR



This month let's put the focus back on families—isn't that who we are in the business to serve? Families are critical to the work we do and the type of care we provide to our patients. Particularly as we push forward with becoming true medical homes, we need to consider how to engage and encourage parents and families to be involved in their child's care. To be a medical home, we need to be 'family-centered' and work in partnership with a child and the child's family to assure that all of the medical and non-medical needs of the patient are met. Through this partnership the pediatric care team can help the family/patient access, coordinate, and understand specialty care, educational services, out-of-home care family support, and other public and private community services that are important for the overall health of the child and family*.

There are a number of organizations that do a superb job of putting families at the forefront. Have you heard of Hands & Voices?

Hands & Voices is a nationwide, parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. This organization provides support activities and information concerning deaf and hard of hearing issues to parents and professionals that may include outreach events, educational seminars, advocacy, lobbying efforts, parent to parent networking, and a newsletter. Hands & Voices strives to connect families with resources and information to make informed decisions around the issues of deafness or hearing loss. A five-step plan for establishing a Hands & Voices chapter in your state as well as state contact information are also available from Hands & Voices on the organization's Web site at <http://www.handsandvoices.org/>. Be sure to visit the site and spend some time looking through the many resources they have such as: Guide By Your Side, A to Z Communication Considerations, and Supporting Families Without Bias.

Parents and families are as critical to the success of EHDI as are all the other professionals that touch the lives of children with hearing loss. Without them the medical home is incomplete.

Albert Mehl MD

* www.medicalhomeinfo.org

UPCOMING EVENTS

Event	Date	Location	Details
AAP Future of Pediatrics Conference	July 29 –31, 2011	Chicago, IL	Web site
NASHP 24th Annual Health Policy Conference	October 3-5, 2011	Kansas City, MO	Web site
EHDI Partnering for Progress Conference	October 26-28, 2011	Raleigh, NC	Web site
2012 National EHDI Conference	March 5-6, 2012	St. Louis, MO	Web site

HEARING HIGHLIGHTS FROM THE CDC NCBDDD 2011 ANNUAL REPORT

The Centers for Disease Control (CDC) National Center on Birth Defects and Disabilities (NCBDDD) released its 2011 Annual Report in April. This is a way for the center to share important information about their work and ways that they are collaborating with partners to improve the health of children, people with disabilities, and prevent death and disability associated with blood disorders.

The center has made great collaborative efforts towards improving newborn hearing screening rates and advancing the goal of meeting 1-3-6. In its report, the NCBDDD outlines that the center has “collaborated with state-based EHDI coordinators to recommend benchmark standards which have been incorporated into a new results-centered report designed to help states focus their intervention efforts. This new report will be distributed by Directors of the Speech and Hearing Programs in State Health and Welfare Agencies (DSHPSHWA).” Further, “to enhance reporting systems, the NCBDDD is partnering with organizations such as the Public Health Data Standards Consortium on the interoperability of clinical electronic health records and the public health EHDI information system.”

As background, the NCBDDD was established in April 2001 as a result of *The Children's Health Act of 2000*. Since its establishment, the center, as mentioned above, has continued to bring a public health focus to the fields of birth defects, child development, blood disorders, and disability across the lifespan.

In 2011, NCBDDD and its partners are launching a series of events and activities spanning the year to honor the achievement of milestone of progress “10 Years of Service”, and showcase the exceptional work of our collective organizations. To learn more and to participate in relevant events visit: <http://www.cdc.gov/ncbddd/tenyears/index.html>.



OKLAHOMA CITY CAMP FOR DEAF CHILDREN TEACHES CONFIDENCE



Christopher Lee learns dance moves during a class taught by two Thunder Girls at the Oklahoma City Museum of Art. The dance class was one of many activities of the weeklong Hearts for Hearing summer camp in downtown Oklahoma City this week.

The 10th annual Hearts for Hearing is a summer camp designed to help children practice hearing and speech. Hearts for Hearing is a non-profit health care provider that helps children and adults develop their hearing and speech skills. All the children in this camp are either deaf or nearly deaf and do not use sign language as their mode of communication—they speak. The camp goers are typically between the age of 5 to mid-teens, and volunteers are mostly graduates of the program.

A speech therapist at the camp, Lindsay Hanna, said “the goal of the summer camp is to encourage the students and catch any lingering or creeping speech problems that might crop up during the summer months.” The children have either hearing aids, cochlear implants or one of each. Some have used the aids since birth, while some have developed hearing loss later in life and are still adjusting to using the new technology.

Camp Counselor Connor Sullivan sums it up like this: “It's kind of like peer pressure, but in a positive way. They need to see that you can turn out positive. The students need to see that this is possible.” Most of the children look forward to this camp every year in the hopes of seeing their friends again. Read more at: <http://newsok.com/oklahoma-city-camp-for-deaf-children-teaches-confidence/article/3580097#ixzz1Qh1ptBBk>

JOEY MCINTYRE ON HEARING LOSS

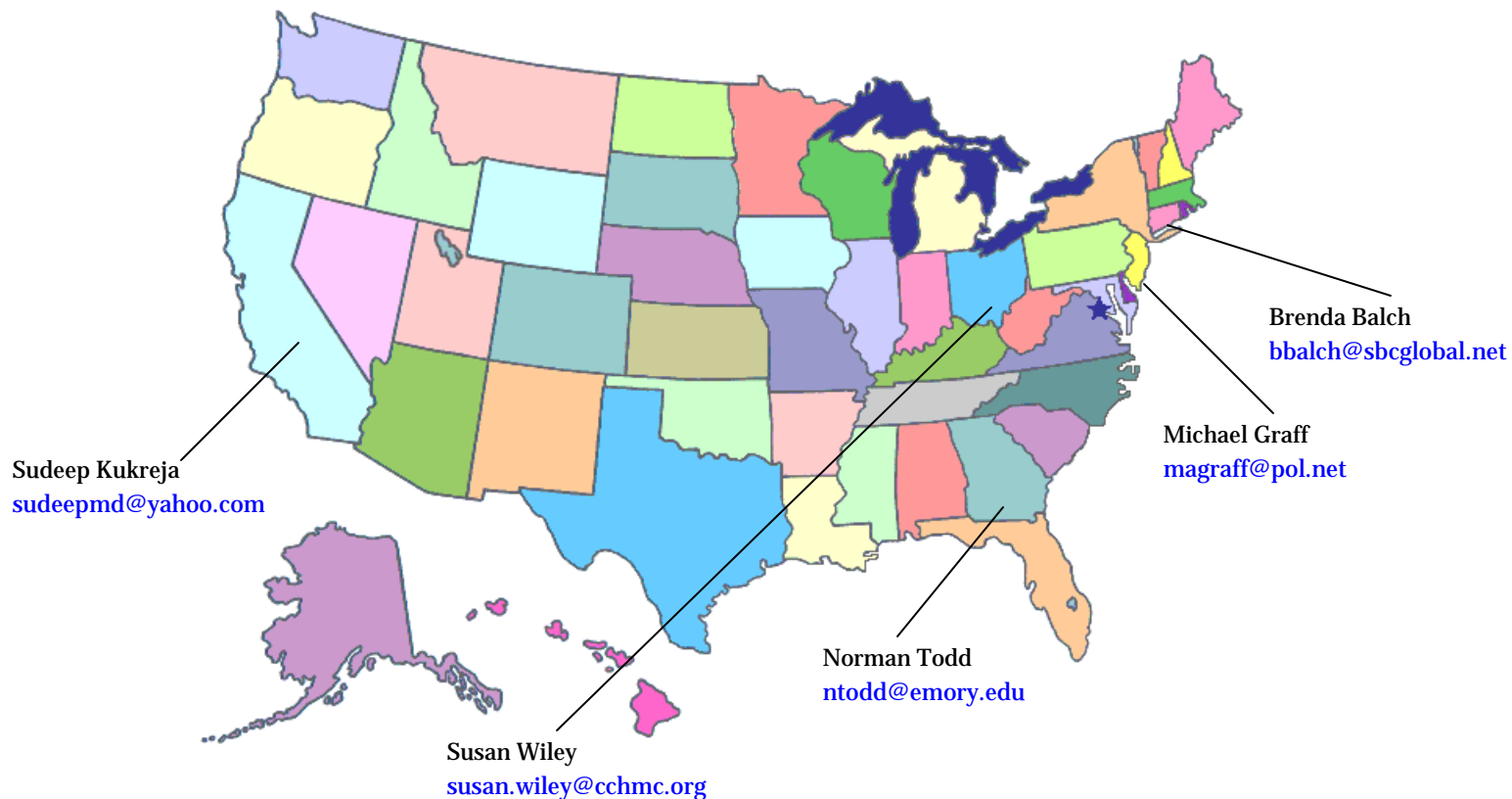


Watch this 30 second video: http://infanthearing.org/flashplayer/index.htm?file=http://www.infanthearing.org/flashvideos/featured/Joey_McIntyre_captioned.mp4

featured on the NCHAM web site with a powerful message from signing sensation, Joey McIntyre of the New Kids On The Block, about the importance of newborn hearing screening and follow-up. Be sure to check out all the other featured videos on NCHAM's web site monthly.

REDUCING LOSS TO FOLLOW-UP THROUGH EDUCATION

The AAP EHDI Program recently announced a call for volunteers from within the AAP EHDI Chapter Champion network to serve on the AAP EHDI Education Sub-committee. This committee is being convened to address the need for continuing education and professional development of pediatric professionals to ensure consistent and ongoing education regarding EHDI and related topics. The committee will assist specifically in the development of pediatric hearing related educational opportunities for EHDI Chapter Champions, state EHDI coordinators, medical home providers, and other EHDI stakeholders. Below are the final members for this committee:



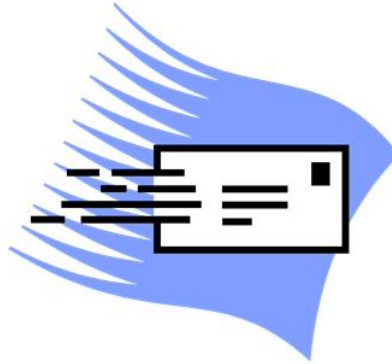
Educating medical home providers and related EHDI stakeholder on ways to reduce loss to follow-up will be a top priority for this committee. Further, the AAP EHDI Program will be sending out a call for EHDI Chapter Education Training Grants in early July. These educational grants of up to \$2500 will be awarded to five Chapter Champions through their respective chapter. The purpose of the grants is to empower EHDI Chapter Champions to work with state EHDI stakeholders and their respective AAP chapter to conduct EHDI specific training and education for members of their chapters and other EHDI providers of care. The session(s) will be used to increase provider knowledge regarding newborn hearing screening and the EHDI system, provide practical strategies for improving office systems regarding newborn screening/surveillance, review current screening/surveillance methodologies, address lost to follow up/documentation issues, and link systems within the state.

Chapter Champions must partner with their AAP chapter to develop and submit the application. The chapter must review, approve, and sign the final application as it will serve as the fiscal agent for the grant. Watch for additional details of the grant when the call goes out.

WORDS OF INSPIRATION...



Life can be pulled by goals just as surely as it can be pushed by drives.
- Viktor Frankl



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.