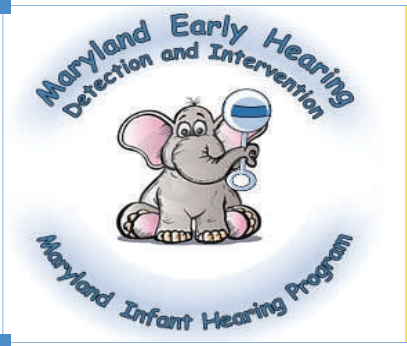
INFANT HEARING PROGRAM
Maryland Department of Health and Mental Hygiene
Family Health Administration
Office for Genetics and Children with Special Health Care Needs
201 West Preston Street, Room 423 A, Baltimore, MD 21201
Martin O'Malley, Governor
Anthony G. Brown, Lt. Governor
John M. Colmers, Secretary



Infant Hearing News January 2010

MD EHDI

This year marks a full decade of Universal Newborn Hearing Screening in the State of Maryland. For a Program of this magnitude, there has been a remarkable amount of progress in a short amount of time. The many people and facilities who are Maryland EHDI have laid a strong foundation for this Program's success. As we move into the future, it is the collaboration of the many stakeholders in the system that will determine its continued success. It was to that end that the Infant Hearing Program invested in and initiated use of the OZ Systems' eSP™ online database. This system is available to any Maryland professional involved in early hearing detection and identification, including hospital staff, audiologists, pediatricians, otolaryngologists, and early intervention specialists. Those who are using this system can take advantage of instant access to each infant's demographics, screening and audiological evaluation history, provider contacts and any other pertinent information previous caregivers have noted. In 2010 we will continue to add users to the system so that each infant's file is updated as quickly and accurately as possible. As always, our goal is to facilitate the process so that all infants with hearing loss are identified and receive intervention services by age six months. If you are a Maryland EHDI provider and would like access to this system or more information, please contact the Infant Hearing Program at 410-767-5803 or *HWharton@dhmh.state.md.us*.

Inside this issue:

Delayed-Onset Hearing Loss 2
Risk Factors for Delayed-Onset Hearing Loss 3
For our eSP system users 4
Cochlear implant support group 5
Distance Learning for Parents
Upcoming Conferences 6
News from NICHQ 7
Welcome BWMC
Infant Hearing Program - Resources and contact information 8

Delayed-Onset Hearing Loss

White and Munoz (2008) revealed that more than 25 times as many school children have hearing loss as do newborns. This means that there are a significant number of children who develop hearing loss in the first months or years of life. Parents and primary care providers may disregard their concerns about hearing in these children because, as infants, they passed the newborn screen. Although not all children who develop late-onset hearing loss have risk factors, there are some health conditions or medical history factors that put a baby at particular risk for delayed onset hearing loss.

The risk factors designated by the Joint Committee on Infant Hearing (JCIH) are listed on page three. Several of these are actually postnatal risk factors, but the committee included them as a guide for primary care providers to help decide which children need audiological referral, along with on-going medical and speech-language surveillance. The committee recommends that babies with risk factors should be seen by an audiologist by six months or at least once by 24 to 30 months of age (depending on the risk factor) and, of course, sooner if hearing loss is suspected or speech or language milestones are delayed. Children who have risk factors that are highly associated with delayed-onset hearing loss should receive more frequent audiological assessments. Those risk factors that are usually known at birth, and are highly associated with delayed onset hearing loss are a family history of permanent childhood hearing loss, extracorporeal membrane oxygenation (ECMO), confirmed congenital cytomegalovirus infection (CMV), and syndromes associated with late onset hearing loss.

Participants in newborn hearing screening and follow up can help identify these infants in many ways. Foremost, notify families that the child has a risk factor and explain that a hearing assessment will be needed at a later date. It is also vitally important to mark risk factors in eSP (the Maryland EHDI database) records. The Infant Hearing Program sends letters to families of infants with risk factors to remind them to schedule a monitoring evaluation. These letters are only sent to those with risk factors marked in eSP. Please also make sure the risk factors are correct and confirmed, and that the name of the PCP who will see the child after discharge from the hospital is in the file.

Did you know?

The JCIH 2007 statement includes the recommendation that for any infant who is readmitted in the first month of life when there are conditions associated with potential hearing loss (e.g., hyperbilirubinemia requiring exchange transfusion or culture-positive sepsis), a screening ABR should be performed before discharge.

Risk Indicators Associated with Permanent Congenital, Delayed-Onset or Progressive Hearing Loss in Childhood

1. Caregiver concern* regarding hearing, speech, language, or developmental delay (Roizen, 1999).
2. Family history* of permanent childhood hearing loss (Cone-Wesson et al., 2000; Morton & Nance, 2006).
3. Neonatal intensive care of >5 days, or any of the following regardless of length of stay: ECMO,* assisted ventilation, exposure to ototoxic medications (gentamycin and tobramycin) or loop diuretics (furosemide/lasix), and hyperbilirubinemia requiring exchange transfusion (Fligor et al., 2005; Roizen, 2003).
4. In-utero infections, such as CMV,* herpes, rubella, syphilis, and toxoplasmosis (Fligor et al., 2005; Fowler et al.,1992; Madden et al., 2005; Nance et al., 2006; Pass et al., 2006; Rivera et al., 2002).
5. Craniofacial anomalies, including those involving the pinna, ear canal, ear tags, ear pits, and temporal bone anomalies (Cone-Wesson et al., 2000).
6. Physical findings, such as white forelock, associated with a syndrome known to include a sensorineural or permanent conductive hearing loss (Cone-Wesson et al., 2000).
7. Syndromes associated with hearing loss or progressive or late-onset hearing loss,* such as neurofibromatosis, osteopetrosis, and Usher syndrome (Roizen, 2003). Other frequently identified syndromes include Waardenburg, Alport, Pendred, and Jervell and Lange-Nielson (Nance, 2003).
8. Neurodegenerative disorders,* such as Hunter syndrome, or sensory motor neuropathies, such as Friedreich ataxia and Charcot-Marie-Tooth syndrome (Roizen, 2003).
9. Culture-positive postnatal infections associated with sensorineural hearing loss,* including confirmed bacterial and viral (especially herpes viruses and varicella) meningitis (Arditi et al., 1998; Bess, 1982; Biernath et al., 2006; Roizen, 2003).
10. Head trauma, especially basal skull/temporal bone fracture* requiring hospitalization (Lew et al., 2004; Vartialnen et al., 1985; Zimmerman et al., 1993).
11. Chemotherapy* (Bertolini et al., 2004).

* Risk indicators that are marked with an asterisk are of greater concern for delayed-onset hearing loss.

Reference: Joint Committee on Infant Hearing. (2007). *Year 2007 position statement: Principles and guidelines for early hearing detection and intervention.*

Did you know?

Congenital CMV is strongly associated with late-onset hearing loss: In symptomatic newborns, about 16% will have congenital hearing loss with 36% having hearing loss by 6 years of age. In asymptomatic newborns, 3% will be born with hearing loss and 11% will have permanent hearing loss by age 6.

J Am Acad Audiol. 2000 May;11(5):283-90.

For our eSP system users

Here are some tips for helping us ensure that Maryland EHDI does the best possible job of identifying, diagnosing, and initiating intervention services by age six months for infants with hearing loss.

Please enter the infant's permanent name as soon as it has been determined. Many medical home facilities cannot search for infants by mother's name, so follow-up can be delayed or permanently stopped if that is the only name we have. You will not "lose" this file if your site only records the mother's name. You can search for any infant by the mother's name under the demographics button of the search page.

Please confirm demographic and pediatrician data at every visit to your facility. Families with newborns often move, change pediatricians, etc. in the first few months after a baby's birth. We need the most current information to provide the timeliest follow-up.

Please do not make up names for the primary contact. If the mother is not the primary contact for the child, please enter the mother's contact information and uncheck the box "primary contact." If the mother does not have custody of the infant, enter the primary contact as "Foster Parent", "Social Services," "Adoption Parent," etc. We must have genuine contact information to follow-up on these infants. Case notes can certainly be utilized when there are extenuating circumstances requiring sensitivity.

Please choose the risk factor that reads "NICU > 48 hours" only when the infant is in the NICU for more than five days. The standard changed after the software was developed - the next upgrade will correct the option to read "NICU > 5 days."

Please search for all infants who are transferred to your hospital from another facility. You should never create a file on an infant who was not born at your facility. If you cannot locate the file of an infant who has transferred to your site, contact the EHDI Program staff for assistance.

Please add the receiving hospital to the file of all infants who transfer out of your hospital as soon as possible. The receiving hospital is responsible for completion of the birth screen record, and needs access to the file upon receiving the infant.

Cochlear implant support group

Families with children who have cochlear implants have a new support group opportunity. The Family Support and Resource Center, a statewide support service for families who have deaf or hard of hearing children, has started a Cochlear Implant Parent Support Group. This group meets monthly and provides parents and professionals with a variety of topics and supports. Presenters from around the country have spoken to this group on topics such as mapping, classroom technology, parent experiences, student experiences, and resources. The support group is open to any family or professional in Maryland. The January meeting will be held at the Maryland School for the Deaf, Frederick Campus. The topic will be Reading Skills and Strategies. The February meeting will be held at the Maryland School for the Deaf, Columbia Campus, and will focus on Understanding the IEP Process. For more information about these meetings or to sign up for this group, please contact Cheri Dowling at 410-480-4597 or *partners@msd.edu*.

Distance education for parents

The John Tracy Clinic (JTC) is offering a free Distance Education Program for parents of children with hearing loss; with separate courses for babies and pre-schoolers. Both courses are available in English and Spanish. The Baby Course consists of ten lessons with information about families, deafness, child development and communication. The lessons discuss the stages of language development including looking and listening, responding and initiating, and exploring and expressing. All of the lessons discuss communication, development, language building, and learning through play. The material is designed to encourage parent-child activities and communication. The course can be adapted to a child's interest and skill level and can be used with any language, including sign language, but the emphasis is on spoken language and listening. The course for pre-school children follows a similar format.

When parents submit an enrollment form to JTC, they are given an enrollment number and a password to access lessons. If the family chooses to do the course through the mail, material is sent to them. When a report form is submitted after a lesson, the next lesson is immediately available online or mailed to the family. Personal letters are sent responding to the reports to answer questions and provide suggestions. Enrollment in the courses also automatically provides access to an online Learning Library containing JTC publications on parent priorities.

For more information, or to enroll in the courses, contact the John Tracy Clinic: *http://www.jtc.org/services/distance-education/index.html* or 800-522-4582

Upcoming Conferences

2010 EHDI Conference

The 2010 Early Hearing Detection & Intervention Conference will be held
at the Intercontinental Chicago O'Hare Hotel in Chicago, IL
on March 1–2, 2010
http://ehdiconference.org

AudiologyNOW! 2010

The annual conference for the American Academy of Audiology
will be held April 14, 2009
in San Diego, California
http://www.audiologynow.org

AG Bell 2010 Biennial Convention

will be held June 25-28, 2010
at the Hilton Orlando Bonnet Creek
in Orlando, FL
http://www.agbell.org/

NHS 2010 Beyond Newborn Hearing Screening:
Infant and Childhood Hearing in Science and Clinical Practice

will be held June 8-10, 2010
Cernobbio, Italy
http://www.nhs2010.org/

News from NICHQ

The National Initiative for Children's Healthcare Quality (NICHQ) recognizes that timely intervention for children with special healthcare needs can lead to improved quality of life. This organization is now conducting a virtual learning collaborative with audiologists around the country to reduce waits and delays in accessing both primary care and specialty services, and to enhance access to ENT and audiology services. This work is being undertaken as a component of the Improving the System of Care for Children and Youth with Special Healthcare Needs Program, a three-year program supported by the US Maternal Child Health Bureau (MCHB).

To learn more, contact Carolyn Anderson at *canderson@nichq.org*

Welcome

Baltimore-Washington Medical Center
became Maryland's newest birth hospital
with its first delivery on October 2, 2009.

Please join us in welcoming Kathe Campbell, R.N.
and her staff to Maryland EHDI

Did you know?

Researchers at Uppsala University Hospital in Uppsala, Sweden have grown a human auditory nerve from stem cells and human tissue obtained from donated cochleae. The researchers hope that in a few years cell transplants will be a real treatment alternative or complement to cochlear implants.

www.uu.se/news/news_item.php?typ=pm&id=587

Resources

We have a number of resources available on our website:

www.fhamd.org/infant hearing

Some of these resources include:

- Infant Hearing Newsletters – past and current editions
- Informational pamphlets and brochures – some available in Spanish
- Patient Education forms
- Guidelines and Checklists
- Links to other helpful sites

As always, the staff at Maryland DHMH is happy to assist you in any way we can. The Infant Hearing Program toll free phone number is 800-633-1316, our toll free TTY number is 866-635-4410, and the office fax number is 410-333-5047. Individually, we can be reached by phone or email:

Linda Vaughan, Program Director

410-767-6432 *LSVaughan@dhmh.state.md.us*

Erin Filippone, Program Audiologist

410-767-6762 *EFilippone@dhmh.state.md.us*

Theresa Thompson, Follow-up Coordinator

410-767-5093 *TThompson@dhmh.state.md.us*

Stephanie Hood, Follow-up Coordinator

410-767-6659 *SHood@dhmh.state.md.us*

Hope Wharton, Administrative Assistant

410-767-5803 *HWharton@dhmh.state.md.us*

This newsletter is intended to serve as a communication vehicle for all UNHS stakeholders. If you have any patient interest stories, photos, announcements, helpful hints, questions, or any information you would like to share with your Maryland colleagues, please email them to Erin Filippone at *EFilippone@dhmh.state.md.us.*

WORKING TOGETHER… EARLY HEARING DETECTION AND INTERVENTION

THE KEY TO COMMUNICATION SUCCESS

The services and facilities of the Maryland Department of Health and Mental Hygiene (DHMH) are operated on a non-discriminatory basis. This policy prohibits discrimination on the basis of race, color, sex, or national origin and applies to the provisions of employment and granting of advantages, privileges, and accommodations.

The Department, in compliance with the Americans With Disabilities Act, ensures that qualified individuals with disabilities are given an opportunity to participate in and benefit from DHMH services, programs, benefits, and employment opportunities.