

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 2008

The year 2008 marks the 8th year of Universal Newborn Hearing Screening in the State of Maryland. Our Program is now well-established but, along with the rest of the country, our challenge remains in the area of follow-up for those newborns who do not pass or who miss the Level 1 screening. Nationally, statistics show that as many as half of those babies who fail the Level 1 screen do not receive appropriate follow-up care to either confirm the presence of hearing loss and/or to begin appropriate intervention services.

Screening is only the first step

This newsletter focuses on what happens after an infant fails the hospital hearing screening. The goal of Maryland's Universal Newborn Hearing Screening Program is based on the Joint Committee on Infant Hearing's recommendation that screenings be completed by age 1 month, diagnosis be completed by age 3 months, and intervention be initiated by age 6 months. Our job is to ensure that any infant who fails the hospital hearing screening is guided through the rest of the process as quickly as possible, so as to promote the best possible outcome for the infant with hearing loss. This requires the combined efforts of many different professionals as well as the parents. On the next page, we have reprinted an open letter from the editor of *The Hearing Review* that captures what may be a large contributing factor to the issue of so many of these infants being "lost to follow up."

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Parents need the Hard Facts

Anyone who has ever cared for a child knows the kind of emotional investment and responsibility that comes with it. So many of your hopes and dreams “for the better world to come” are tied up in those goofy never-at-rest little bodies. For most of us when we shuffle off this mortal coil, our personal or professional accomplishments will inevitably pale in importance compared to the job we did influencing (for better or worse, I suspect) the lives of others, especially those of children.

Recognizing this, and assuming that it’s a fairly universal sentiment, it seems shocking that between one-half and one-third of all newborns who are determined at risk for hearing loss by newborn hearing screening programs are not brought back for follow-up testing. In other words, the parents are informed that their child might have a serious hearing impairment, but they do nothing to confirm or rule out the disability. I understand that much of this could be due to the factors I described above: the parents have so much emotional investment in their kids that they enter a state of denial when facing the possibility of a “physical disability” in their perfect baby. How many times have we all wondered how we’d react to getting this type of news? Even though most (maybe as much as 80%) of rescreenings show that the infant has normal hearing, it would be a scary trip to the hospital, indeed.

Similarly, in all cases of childhood hearing loss, the evidence is clear that children need early intervention and a multiprofessional approach. One can get into a fairly heated debate about the responsibilities of parents and the appropriate lines that healthcare professionals must toe when dealing with these situations. However, the article by Kochkin et al in this edition of *HR* suggests that there may not be enough urgency being transmitted to parents. Although it should be acknowledged that the study represents subjective comments from only 225 parents, the article suggests that there are cases of misinformation (or misinterpretation of information) from hearing care professionals, lack of knowledge or trivialization about hearing loss by pediatricians, ineffective public healthcare policy for the provision of hearing aids, and a general lack of urgency and advocacy by parents.

Karen Anderson, PhD, wrote an article in the November 2002 *HR* called, “The Magic Ingredient for Successful Child Outcomes.” In a nutshell, Anderson’s “magic ingredient” is parental involvement, and she cites nine things that parents have to “buy into” for the intervention process to work: 1) Their young child really has a hearing loss; 2) The hearing loss will really cause the child to develop or learn differently from other children if no intervention is obtained; 3) The hearing loss will not go away; 4) Hearing loss typically means having some useful hearing (ie, not totally deaf); 5) Having some hearing loss does not mean that the child can learn to “get by” without intervention just because he or she is a smart or exceptional child; 6) There is more to intervention than putting hearing aids on the child; 7) The hearing loss will still be an issue in how the child is able to access communication in different listening situations; 8) *Communication access* is the real issue, not the hearing loss; 9) Parents, caregivers, and peers are the “magic ingredients” that ensure the communication access that will allow the child to develop at as normal a rate as possible.

No one in our field would disagree that, with pediatric patients, there is a need for everyone in the chain—UNHS programs, pediatric and educational audiologists, pediatricians, educators, government programs for the provision of hearing aids, and the children’s parents and support networks— to look at the problem seriously, understand it, then step up and deliver the required services.

But the most important link in the chain is the parent. A parent’s job is to be *the* advocate for their child. In order to make informed decisions about their child’s hearing care, parents need to know the cold, hard facts: A lack of communication access is a serious problem that must be dealt with urgently, or it may negatively impact virtually every aspect of their child’s life.

Karl Strom, Editor-in-Chief *The Hearing Review* September 2007

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Delivering the Hearing Screening Results

Are you responsible for counseling parents regarding their infant's hearing screening results? What do you say? While every situation is different, if the infant does not pass the screening, there are some "always and never" guidelines that should be followed.



ALWAYS:

- Be sure that parents are informed by a well-trained staff person,
- Explain that permanent hearing loss can only be confirmed by further testing,
- Provide educational materials as appropriate – brochures are available for downloading at <http://www.fhamd.org/infanthearing>,
- Provide a written plan for any follow-up services required, and
- Stress the importance of the next test, and the importance of timely evaluation. Delays in testing may cause delays in intervention that can impact the infant's communication development and future academic success.



NEVER:

- Minimize the significance of a fail result, as this may prevent the parent from believing in the need for follow-up,
- Say to the parents it was *only* one ear; stress that while many children with hearing loss in one ear develop normal communication, one-third of them experience communication, language and academic delays,
- Generalize screening results to indicate permanent hearing loss; e.g., the baby is deaf because he did not pass the hearing screening, etc., and
- Delay forwarding the screening results to the pediatrician and DHMH as this will delay the follow-up and referral process.



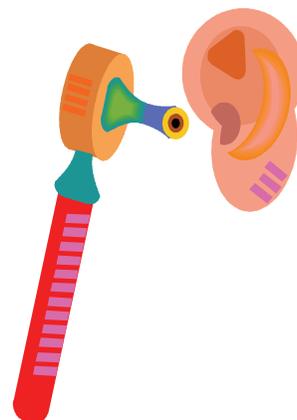
REMEMBER:

Approximately three in 1000 of the infants who pass the hearing screening at birth will go on to develop hearing loss by their fifth birthday. All parents should be encouraged to monitor their child's language development and to have their child retested by an audiologist if any concerns arise.

The Diagnostic Hearing Evaluation

Audiologists providing services to the infant and toddler population should have the necessary equipment (ABR with bone conduction and tone bursts, OAE, high frequency tympanometry, etc.) and be experienced in the assessment of infants. If the audiologist does not have the equipment or expertise they should refer the infant to a center with those skills. The following audiologic services should be available and provided as needed to infants referred for Level III diagnostic hearing tests:

- Otoscopic examination,
- Threshold click ABR - 25dBHL or lower each ear,
- Bone conduction ABR if click stimuli thresholds are elevated (above 25dBHL),
- Ear specific bone conduction ABR if thresholds are elevated bilaterally or asymmetric loss is suspected,
- Threshold tone burst ABR at 500Hz and 3,000 or 4,000Hz,
- Diagnostic OAE,
- Acoustic immittance using high frequency tone,



- Acoustic reflex thresholds 500Hz, 1,000Hz and 4,000Hz,
- Counsel parents on findings and recommendations,
- Make appropriate referrals– i.e., ENT, Parent-Infant-Toddler, etc. with parent's consent.
- Complete Level 3 Form and return to DHMH, and
- Schedule follow-up appointments for additional testing and any intervention indicated.

It is important to remember that diagnosis must occur long before age six months if the infant is to begin receiving services by age six months. All involved caregivers need to recommend that any infant who fails a second screen requires an immediate referral to an audiologist for diagnostic evaluation. Keep in mind, the timeline is short and there are relatively few facilities capable of performing diagnostic evaluations. Delaying diagnosis delays intervention and results in poorer outcomes for the infant with hearing loss. Delaying the diagnostic evaluation also creates the complication of necessitating the use of sedation to obtain ABRs on older babies. When infants receive the diagnostic evaluation at ages under 3 months, there is typically no need to sedate them in order to successfully complete the evaluation. Older infants, even when sleep-deprived (assuming you can do that during the car ride to the facility!) typically will not sleep long enough or deeply enough to permit a full test in one session.

Early Intervention Programs

Universal Newborn Hearing screening programs exist because treating infants with hearing loss prior to age six months allows them the best opportunity to develop communication skills normally. But who provides this treatment? And what does this treatment involve?

Every county in Maryland has an Infant and Toddler Program. This Program, a division of the Maryland State Department of Education, is staffed by specialists in early intervention. It is through these programs that the infant will receive language enrichment, developmental monitoring, counseling/training for the parents, and all the other services that are necessary for optimal outcomes.

“With very young infants, much of the time is spent teaching the parents about the hearing loss, helping them adjust to and accept the hearing loss and hearing aids, helping them deal with family, friend, and stranger’s reaction to the hearing loss/hearing aids, and helping them to realize that everything they do is a "language opportunity." They don't have to "create" special things to do or sit their child down for "lessons." Everyday life is full of the language they need to learn. The specialists model language they can use while bathing, diapering and dressing the infant, while cooking and grocery shopping, etc. Most of the parents have never personally known anyone with a hearing loss, so they may think their child will never talk, or that they must use sign language, etc. because their only experience with hearing loss is what they may have seen on television. Many parents don't understand that there are degrees of hearing loss, and that even children with significant hearing loss can develop speech and listening skills. Parents are shown that they can have high expectations for their children. There are parent groups, parent workshops and social activities so parents can meet each other, share experiences, support each other, and learn about a variety of topics (ex: learning about hearing loss, language development, deaf culture, assistive technology, cochlear implants, speech development) In the beginning, a lot of what we do really deals with the parents, but will help the child in the near future and in the long run, too.”

- Donna Cain, Teacher of the Deaf and Hard of Hearing, PG County

Single Point of Entry

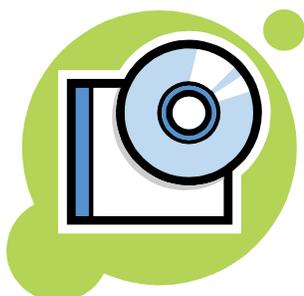
<u>County</u>	<u>Infants & Toddlers</u>
Allegany	301/689-0466
Anne Arundel	410/222-6911
Baltimore	410/887-2169
Balt City	410/396-1666
Calvert	410/535-5400x388
Caroline	410/479-4419
Carroll	410/876-4437
Cecil	410/996-5444
Charles	301/609-6808
Dorchester	410/221-0837
Frederick	301/600-1612
Garrett	301/334-1189
Harford	410/638-3823
Howard	410/313-7017
Kent	410/778-7038
Montgomery	240/777-3997
Prince George	301/985-3811
Queen Anne	410/758-2403x180
Somerset	410/651-1485
St. Mary	301/475-4393
Talbot	410/820-0319
Washington	301/766-8217
Wicomico	410/543-6920
Worcester	410/632-2582x233



The Family Support and Resource Center

Have You Heard About the Family Support and Resource Center?

The Family Support and Resource Center is a resource center for families and schools. Each local school system, including the Maryland School for the Deaf and the Maryland School for the Blind, have resource centers for families. However, the Family Support and Resource Center is focused on helping families around Maryland who have Deaf or Hard of Hearing children ages birth through 21. The Center is staffed by a parent/educator team. The team assists families, students, and educators by providing support, unbiased information and resources on disabilities, technology, and community services.



The Center has a lending library of over 2,000 books, video's, DVD's, and games available to families. The Center provides information and referrals as requested, parent to parent support, a monthly newsletter and presents workshops on various topics such as Understanding the IEP Process, Transitioning from an IFSP to an IEP, Procedural Safeguards, Signing to Hearing Children, Advocacy, School Records, and much more. All services are provided at no cost.

The Goals for the Family Support and Resource Center are: to assist families in resolving concerns, to help them make informed decisions regarding their child's education, and to help increase parent involvement and partnership between families and professions.



The team consists of Pat Timm, Education Coordinator, and Cheri Dowling, Parent Coordinator. The Center is located in the Steiner Building, Room #100 at the Maryland School for the Deaf, 8169 Old Montgomery Road, Ellicott City, MD 21043. The TTY/Voice number is 410-480-4597 and the fax number is 410-480-4598. The center's email address is partners@msd.edu.



The Center has been open since October 1999 and is very active throughout the State. If you would like more information, or to be added to the mailing list, please contact Cheri or Pat.

Did you know?

ANY type or degree of hearing loss makes an infant eligible for the services provided by the Maryland State Department of Education Infant and Toddler Program and ANY clinician, physician, parent or healthcare provider can make the referral by calling the county Infant and Toddler phone number list on the previous page.

Updates at DHMH

In December, Hope Wharton joined us as our new Administrative Assistant. Hope can be reached by email at *HWharton@dhmh.state.md.us* or by phone at 410-767-5803.

JCIH Year 2007 Position Statement

JCIH's new position statement was released in September 2007. The full text can be found at <http://www.cdc.gov/ncbddd/ehdi/>

The updates include changes in the following categories:

1. Definition of Targeted Hearing Loss,
2. Hearing Screening and Rescreening Protocols,
3. Diagnostic Audiology Evaluation,
4. Medical Evaluation,
5. Early Intervention,
6. Surveillance and Screening in the Medical Home,
7. Communication, and
8. Information and Infrastructure.

Additionally, the risk factors for congenital and acquired hearing loss have been combined in a single list (see page 8) rather than grouped by time of onset.

Did you know?

NCHAM and A.T. Still University, Arizona School of Health Sciences have announced the availability of "Diagnosis and Amplification for Infants and Toddlers" in Mesa, Arizona on March 3-6, 2008. This workshop is designed to provide audiologists with the information and experience necessary to serve infants referred from newborn hearing screening programs. This workshop features a combination of didactic instruction along with practical clinical experiences.

For more information on the workshop, please visit their website at www.infanthearing.org



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.



Resources

We have a number of resources available to assist you on our website:

[http://www.fhamd.org/infant hearing](http://www.fhamd.org/infant_hearing)

Here you will find:

- Infant Hearing Newsletters – past and current editions
- Informational pamphlets and brochures – some available in Spanish
- Patient Education forms
- Level 2 and 3 screening forms
- Guidelines and Checklists
- Links to other helpful sites

Please also note our toll free phone number 800-633-1316 and our toll free TTY number 866-635-4410.

As always, the staff at Maryland DHMH would be happy to assist you in any way we can. We can be reached by phone:

Linda Vaughan, Program Director	410-767-6432
Erin Filippone, Program Audiologist	410-767-6762
Theresa Thompson, Follow-up Coordinator	410-767-5093
Stephanie Hood, Follow-up Coordinator	410-767-6659
Hope Wharton, Administrative Assistant	410-767-5803

Or by mail: Infant Hearing Program
Maryland Department of Health and Mental Hygiene
201 W. Preston Street, Room 423A
Baltimore, MD 21201
Fax: 410-333-5047

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@dhhm.state.md.us.

WORKING TOGETHER...EARLY HEARING DETECTION AND INTERVENTION THE KEY TO COMMUNICATION SUCCESS

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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.