



## Loss to follow-up threatens success of newborn hearing screening programs

**E**arly Hearing Detection and Intervention (EHDI) programs are currently screening 86% of the 4 million babies born each year in the United States. Unfortunately, according to data collected by Centers for Disease Control and Prevention (CDC), only half of those newborns who do not pass the hearing screen are known to receive an audiological evaluation.

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To put this problem in perspective, nearly 3,500,000 babies had their hearing screened in 2002.

Assuming there are about 3 babies per 1,000 in the general population

born with permanent hearing loss, there would be about 10,500 babies with hearing loss in this group. Assuming a 2% refer rate, about 70,000 babies did not pass the hearing screening prior to hospital discharge and should have received an audiological evaluation. However, according to CDC, half of these babies (35,000 babies) were lost to follow-up!

Particularly alarming is that these babies are at significantly higher risk for hearing loss than babies in the general population, because they have already failed a hearing screening test. In other words, if we assume that the babies who pass the screening all have normal hearing, then the incidence of hearing loss among the 2% who do not pass the hearing screen would be 3 per 20 instead of 3 per 1,000! This means that among the 35,000 for whom we have no evidence that they received an audiological evaluation, there would be about 5,250 babies with permanent hearing loss. Even though these babies are being screened, the fact that they apparently don't come back for an audiological assessment means that they are missing the benefits associated with newborn hearing screening!

The National Institutes of Health considered the problem of loss to follow-up in newborn hearing screening programs so serious that they convened a panel of experts to identify the problems and make recommendations (the panel's report is at [www.nidcd.nih.gov/funding/programs/hb/hearingreport.pdf](http://www.nidcd.nih.gov/funding/programs/hb/hearingreport.pdf)).

Some of the most serious problems identified by the work group included:

- **Transportation barriers.** Families who rely on public transportation could easily require 1+ hours in commuting time to arrive at a follow-up appointment; while those in rural areas may not have access to transportation of any kind.
- **Funding barriers.** When budgets are tight, hospital staff have enough difficulty caring for the patients who check in for treatment, much less the ones who should but don't. Many hospitals are not equipped to track every infant who needs to be scheduled for a follow-up examination and make sure that it happens.
- **Staffing barriers.** Large caseloads and frequent rotations among health-care providers has created an environment in which parents receive information that is spotty and incomplete.
- **"Lost messages" and ineffective communication.** Poor communication contributes to a large number of no-shows. If an infant is transferred to a neonatal intensive care unit in another facility, caregivers may not see parents for several days. This increases the chance that follow-up information won't be relayed.
- **Language and literacy barriers.** Language and literacy barriers are a major problem. In the United States, 329 languages are spoken or signed, and nearly 18% of the population—more than 40% in some

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# AROUND THE WORLD . . . A Universal Newborn Hearing Screening program in Poland

by Marzanna Radziszewska-Konopka

Newborn hearing screening was done in a few hospitals in Poland in the 1960s using behavioral techniques. In the 1990s, efforts were made to expand newborn hearing screening under the leadership of the Institute of Pathology and Physiology of Hearing, but only limited success was had. The possibility of implementing Universal Newborn Hearing Screening in Poland appeared in 2001 with the initiative of The Great Orchestra of Christmas Charity Foundation. The Foundation was established in 1993 to raise money for helping children. In 2001, its members decided to devote the money they collected that year to newborn hearing screening. The result was very successful with more than \$6 million collected on January 7, 2001.

Shortly after the money was collected, a team of experts (neonatologists, otolaryngologists, audiologists, speech therapists, and engineers) developed an implementation plan for a national Universal Newborn Hearing Screening program based on the guidelines published by the European Consensus Conference and the Joint Committee on Infant Hearing. International experts Dr. Ferdinando Grandori (Italy) and Dr. Karl White (USA) consulted with the project.

The team of experts set the following program goals:

- Every newborn will receive a hearing screening test.
- Babies who do not pass will complete a diagnostic evaluation before 3 months.
- Babies with confirmed hearing loss will receive appropriate intervention by 6 months.
- Infants with late onset hearing loss will be diagnosed and receive appropriate intervention as soon as possible.
- A computerized tracking and data management system will be created.
- An evaluation system will be used to continually improve the quality of the program.

At the beginning of 2001, only 17 out of 441 birthing hospitals were screening babies for hearing loss. The Great Orchestra of Christmas Charity Foundation purchased screening equipment, prepared informational materials, developed instructions for screening staff, and organized training programs. In May 2002, a pilot program was initiated to check the efficiency of personnel training, proper data flow, and any problems that might occur. Based on this pilot project, a two-stage training program for approximately 2,000 nurses and

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## THE WEB [www.infanthearing.org](http://www.infanthearing.org)

### Materials for EHDI information for parents

Over the past several years, states have been developing various materials for their EHDI programs. In the spirit of collaboration, many states have shared their materials with the National Center for Hearing Assessment and Management (NCHAM). These materials can be viewed on the NCHAM Web site at [www.infanthearing.org](http://www.infanthearing.org). Materials can be found in the EHDI/UNHS Resource Center and include areas such as parent and program information. Many materials have been translated into Spanish. There is no need to start from scratch. Visit the Web site and see what other states have done!

Each state EHDI coordinator has a CD of these materials for their use in future development of materials. If you are developing materials and would like to make them available to others, please send a copy to [webmaster@infanthearing.org](mailto:webmaster@infanthearing.org).

A particularly comprehensive resource for families of newly identified children with hearing loss has been developed by the Wisconsin EHDI program. The *Wisconsin's Babies & Hearing: An Interactive Notebook for Families With a Young Child Who Is Deaf or Hard of Hearing* can be found at <http://www.infanthearing.org/familysupport/wisconsin/index.html>.



**SOUND IDEAS, SEPTEMBER 2003, Vol. 5, No. 3.** *Sound Ideas* is a quarterly publication of the National Center for Hearing Assessment and Management (NCHAM). Its goal is to provide information to hospital staff, health-care providers, early interventionists, families, and public health officials to help in the establishment and expansion of successful newborn hearing screening and intervention programs.

#### WE'RE ELECTRONIC!

The newsletter is also available at our Web site, [www.infanthearing.org](http://www.infanthearing.org). Send us your e-mail address at [nchamhelp@coe.usu.edu](mailto:nchamhelp@coe.usu.edu), and we will e-mail you each time the newsletter is published. If you would like to submit an article, contact the editor, Karen Ditty, at [DittyKM@aol.com](mailto:DittyKM@aol.com).

## RESEARCH NEWS YOU CAN USE

### Risk of bacterial meningitis in children with cochlear implants

**A**lmost 10,000 children in the United States with severe-to-profound hearing loss have cochlear implants—a surgically implanted device with an electrode array that is inserted into the cochlea and enables most recipients to perceive sounds and learn to speak. In July 2002, the maker of one of the three brands of cochlear implants available in the U.S. reported to the Food and Drug Administration (FDA) that 15 recipients of their device had been identified with post-implantation bacterial meningitis. Within a short time, cases of meningitis were also reported for recipients of cochlear implants from the other manufacturers.

These reports raised concerns among many people that cochlear implants may be causing meningitis—a serious and potentially deadly disease. In response to these reports, a recent article by Reefhuis and colleagues [2003, July 31. **Risk of bacterial meningitis in children with cochlear implants.** *New England Journal of Medicine*, 349(5), pp. 435-445] investigated the incidence of and risk factors for meningitis among young implant recipients. The study examined 4,264 children younger than 6 years of age in the United States who had received cochlear implants between January 1, 1997, and August 6, 2002. The incidence of meningitis among this group was investigated by reviewing the FDA's Adverse Event Reporting System, sending surveys to the parents of all children who had received implants during this time period, and contacting public health officials in every state.

Among the 4,264 children included in the study, 26 had contracted meningitis following an implant. The incidence of meningitis caused by *Streptococcus pneumoniae*

was 138.2 cases per 100,000 person/years—more than 30 times the rate in same-age children in the U.S. general population. Although a better comparison group would have been severe-to-profoundly deaf children who did not receive cochlear implants, no data on the incidence of meningitis among this group are available. The authors concluded that the risk of meningitis was greatest for cochlear implants with a positioner and for patients with a malformation of the inner ear or cerebrospinal fluid leak. Although meningitis was more common in the perioperative period (within 30 days of the surgery), the risk continued for the 6-year duration of follow-up considered in the study.

The benefits of cochlear implants are well documented. Even though the risk of meningitis among cochlear implant recipients is relatively low (99.4% of the recipients did not contract meningitis), the seriousness of the disease and the increased risk of meningitis compared to the general population emphasizes the need to take preventive measures. The authors recommend that all cochlear implant recipients, regardless of age, should receive pneumococcal vaccine and caretakers should monitor recipients and promptly treat any bacterial infections.

Anyone knowing of additional cases of bacterial meningitis in cochlear implant recipients should report them to CDC by calling 1.877.232.4327 (voice), 1.800.232.7672 (TTY).

## TECHNIQUES AND TIDBITS

### Enhancing screener performance and motivation through communication

**T**here are many challenges to coordinating an effective EHDI program. The Joint Committee on Infant Hearing (JCIH) Year 2000 position statement stipulates:

- 95% of babies be screened prior to hospital discharge.
- <4% referral rate to diagnostic testing.
- Documented efforts to obtain follow-up on 95% of infants referred to diagnostics and ideally a return-for-follow-up rate of 70% or more.

Effective communication among program stakeholders is one of the keys to a successful EHDI program. One way of improving communication is to create a newsletter that can be sent regularly to people involved with the program. What kind of information could be included in such a newsletter?

One possibility for such a newsletter is to report outcome statistics about your screening program. Such statistics are routinely monitored by most program coordinators and can be quickly and easily shared in a periodic newsletter. Such a newsletter can also be used to communicate program goals, testing tips, EHDI updates and news, recognition of effort, and success stories about babies identified with hearing loss (assuming you have the parents' permission to share the information).

As a result of such communication, screeners and others involved in the EHDI process will better understand the importance of early identification and intervention of hearing loss while gaining a better appreciation of their contribution to the process.

To see example newsletters created by one hospital in Illinois, go to [www.infanthearing.org/statenewsletters](http://www.infanthearing.org/statenewsletters).

## CENTe-R: Collaborative Early Intervention National Training e-Resource

The rapid expansion of newborn hearing screening means that many more infants with hearing loss are being identified and consequently require early intervention during the first few months of life. The Joint Committee on Infant Hearing (JCIH) Year 2000 stated that infants and toddlers who are deaf and hard of hearing and their families should begin intervention before 6 months of age. The mission of CENTe-R is to train early interventionists to better meet the needs of newly identified infants with hearing loss. CENTe-R's mission is "to inform and support graduate-level professionals serving families with infants and toddlers who are deaf/hard of hearing through Web-based training that embraces transdisciplinary approaches and connections among ongoing learners." More information about the project that is funded by the United States Department of Education, Office of Special Education Programs, can be found at <http://center.uncg.edu>. CENTe-R has the following goals:

- Develop a program of study focusing on the acquisition of professional standards in the areas of child development, communication, socialization, cognition, cultural sensitivity, medicine, and technology.
- Partner with state agencies, medical communities, parent organizations, professional and advocacy groups, colleges, and universities.
- Develop, field-test, and disseminate Web-based modules in early intervention for preservice professionals.
- Establish ongoing training activities via on-site, distance education, and consultation.
- Provide an electronic and print media clearinghouse featuring topics in early intervention and hearing loss.

CENTe-R has recruited a broad audience of "partners and experts" who represent a variety of perspectives and disciplines from across the United States. A complete listing of these "partners" can be found on their Web site. Instructional modules have been created to augment course work offered in university settings and include outlines, objectives, research-based content, discussion, review, investigative questions, personal perspectives (videos and narratives), pre- and post-self-report, and a bibliography of online resources. Examples of some of the modules that have been created include: Learning Theories, Prenatal and Perceptual Development, Developmental Milestones, Social/Physical Environments, and a Cultural Issues module.

You can tour the available modules at <http://center.uncg.edu/training/modules/tour/indexmain.html>. If you want to use the modules for training, contact Rosalyn Proctor, CENTe-R Director, at 336.256.1082 or [rsprocto@uncg.edu](mailto:rsprocto@uncg.edu).

## 2004 National EHDI meeting

The 2003 National EHDI Conference attracted over 400 participants, including parents, audiologists, physicians, nurses, early interventionists, EHDI program administrators, and state/federal officials. Participants evaluated the meeting very positively and the 2004 National EHDI Conference promises to be even better.

The conference is co-sponsored by the Maternal and Child Health Bureau, the Centers for Disease Control and Prevention, the American Academy of Pediatrics, and the National Center for Hearing Assessment and Management. It will be held at the Renaissance Mayflower Hotel in Washington, DC, February 18-21, 2004. The theme for this year's conference is "Communication Counts: Optimizing Outcomes for Children With Hearing Loss."

The planning committee for the conference is inviting proposals for workshops, roundtables, or instructional sessions to be presented at the meeting. Anyone interested in making a presentation can obtain details at [www.infantheating.org](http://www.infantheating.org). Abstracts must be submitted by October 30, 2003.

## NCHAM goes to Hollywood

You can now view some of your favorite videos without going to the video rental store! NCHAM has added streaming videos to their Web site at [www.infantheating.org](http://www.infantheating.org)/videos. The site includes videos related to newborn hearing screening, diagnosis, and intervention produced by various state EHDI programs, professional organizations, and commercial companies.

All the videos can be viewed for free over the Internet (a high-speed connection is best, but it works with a modem connection), some can be downloaded for free, and others have information on how they can be purchased.

So the next time you are looking for a cheap date, grab some popcorn and go to the movies for free!

**Loss to follow-up threatens success . . .**  
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cities—speaks a language other than English as a first language. According to the most recent National Assessment for Adult Literacy, 23% of American adults cannot answer fairly straightforward questions about a newspaper article they’ve just read.

We can (and should) be proud of our accomplishments in EHDI over the past several years. It is easy to point proudly to those children who have successfully navigated the system and are experiencing all the benefits that early intervention has to offer. It is important to remember, though, that EHDI programs are not successful for those children who are missed or lost to follow-up. Even though most babies are being successfully screened, we must improve the follow-up and tracking of those infants that are missed or do not pass the screen. This will ensure that EVERY baby born with a hearing loss is diagnosed before 3 months and enrolled in early intervention before 6 months of age!

**Around the world . . .**  
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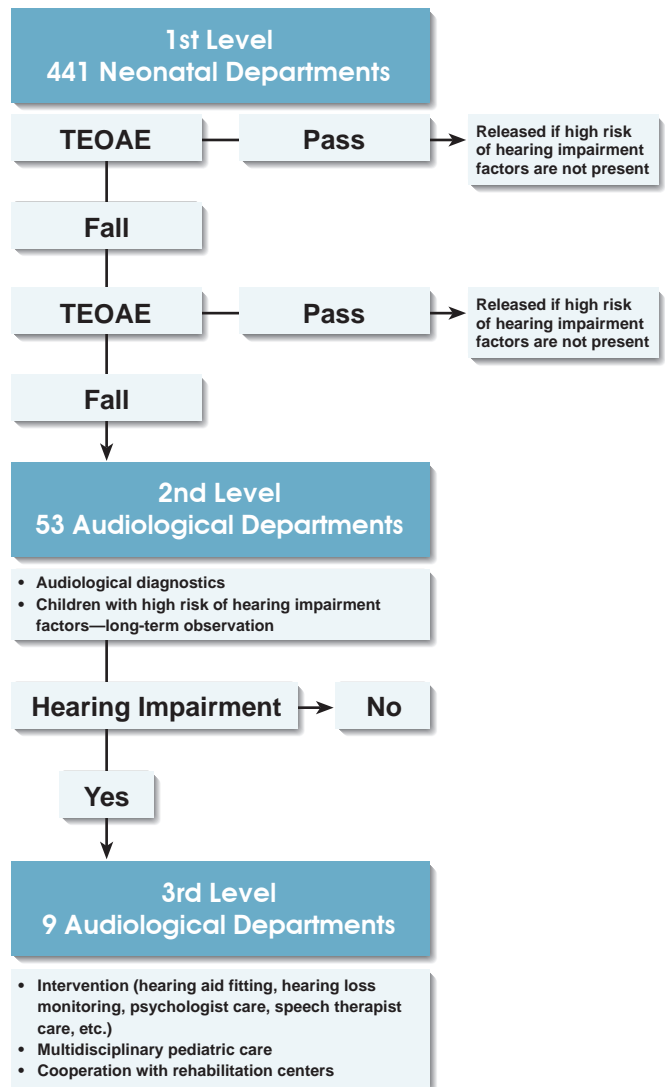
doctors started in Fall 2002. By the end of November 2002, all neonatal and audiological departments joined the national newborn hearing screening program.

Newborn hearing screening is now conducted in all 441 public hospitals, and a number of private hospitals are expected to join soon. In Poland, newborns are typically released after 48 hours. Although there is no national law requiring newborn hearing screening, almost 100% of newborns in Poland are now being screened. Every parent, regardless of the screening result, receives a brochure that provides milestones for auditory and speech/language development. Babies who do not pass at least one ear and/or who have risk factors for hearing loss are referred to 1 of 53 audiological departments in Poland. Infants with confirmed hearing loss are referred to 1 of 9 audiological centers, where they are enrolled in an early intervention program.

Data from the hearing screening and diagnostics are recorded electronically and on paper. A unique (and very secure) data transmission system was developed. Computers in each hospital and center are equipped with GSM modems connected to a dedicated network. The medical coordinator in the Children’s Memorial Health Institute (in Warsaw) supervises the entire system. This data analysis and reporting system enables program staff to follow the progress made by each child at all levels of the program.

Since the beginning of the program, 270,000 newborns have been tested, which corresponds to an average rate of 1,500 daily hearing tests countrywide. About 6% of newborns have been referred to audiological departments. Children with risk factors account for 6.2% of the population; however, over 70% of them passed the screening test. Thus, 11% of all newborns are currently referred to the second-level centers, but this number is continually decreasing.

The screening tests are now free of charge. All operational costs (except for the staff) are covered by the foundation, and the health-care staff conduct the tests as a part of their daily routine. The diagnostic centers are funded by the state, but unless there is additional funding, they will soon be insufficient. Adequate reimbursement for hearing aids is an emerging problem, but so far, all the children with confirmed hearing loss have been given hearing aids. Early intervention takes place in existing speech therapy centers, but work is being done to expand the services of these programs. The screening and diagnostic protocol used in Poland is shown below.



**WE'RE ELECTRONIC!!!**

This newsletter is  
primarily distributed  
electronically at  
[www.infanthearing.org](http://www.infanthearing.org).

To have a printed copy sent,  
register at [www.infanthearing.org](http://www.infanthearing.org).  
HEAR's to early hearing screening  
for all babies!

## UPCOMING EVENTS

- October 3, 2003 • A Child With Hearing Loss: Communication, Amplification, and Education**, Mobile, AL. A 1-day continuing education seminar for parents and professionals. *Sponsored by* The Alabama Ear Institute. **Contact:** [tonya@alabamaearinstitute.org](mailto:tonya@alabamaearinstitute.org) or [www.alabamaearinstitute.org](http://www.alabamaearinstitute.org)
- October 10, 2003 • New Technologies Workshop in Audiological Assessment: Multiple Auditory Steady-State Response (ASSR) and Stacked ABR**, Chicago, IL. A continuing education activity. *Sponsored by* Health Stream with funding from Biologic Systems Corp. **Contact:** [www.eddesign.com/calendar/index.html](http://www.eddesign.com/calendar/index.html)
- October 19-22, 2003 • National Symposium on Childhood Deafness, "The Roads to Literacy for Deaf Children Utilizing Collaboration and Partnerships,"** Sioux Falls, SD. **Contact:** Joseph J. Innes, Program Director, National Association of the Deaf, 814 Thayer Avenue, Silver Springs, MD 20910-4500 or [www.c-s-d.org/CSD/NSCD2003\\_call.pdf](http://www.c-s-d.org/CSD/NSCD2003_call.pdf)
- October 23-24, 2003 • 24th Annual Fall Conference on Mainstreaming Students With Hearing Loss: Developing Self-Advocacy**, Springfield, MA. **Contact:** [www.Clarkeschool.org](http://www.Clarkeschool.org)
- October 24, 2003 • New Technologies Workshop in Audiological Assessment: Multiple Auditory Steady-State Response (ASSR) and Stacked ABR**, Dallas, TX. A continuing education activity. *Sponsored by* Health Stream with funding from Biologic Systems Corp. **Contact:** [www.eddesign.com/calendar/index.html](http://www.eddesign.com/calendar/index.html)
- October 30-31, 2003 • Linking Early Identification to Early Intervention Following Newborn Hearing Screening: Audiological Evaluation, Management, and Family Counseling**, Central Michigan University, Mt. Pleasant, MI. Will provide participants with state-of-the-art tools for early audiological intervention for infants with hearing loss. **Contact:** [www.infanthearing.org/resources/20031030\\_audiology.pdf](http://www.infanthearing.org/resources/20031030_audiology.pdf)
- November 8, 2003 • Advances in Early Hearing Detection and Intervention**, Columbus, OH. A continuing education activity. *Sponsored by* Health Stream with funding from Biologic Systems Corp. **Contact:** [www.eddesign.com/calendar/index.html](http://www.eddesign.com/calendar/index.html)
- November 13-15, 2003 • American Speech, Language, and Hearing Association Convention, "Exploring New Frontiers in Biology,"** Chicago, IL. **Contact:** <http://professional.asha.org/events/>