



Wisconsin Association for  
Perinatal Care

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## EHDI in Wisconsin

In June 2000 WAPC published the first issue of the Universal Newborn Hearing Screening (UNHS) newsletter. The purpose of the newsletter was to keep health care providers and other interested personnel informed of the status of newborn hearing screening in Wisconsin and to provide suggestions, information and resources for those who were implementing or administering UNHS programs. While the purpose remained constant, in 2002 the newsletter took on an expanded focus on the status of not only newborn hearing screening, but also intervention activities in Wisconsin. The name of the newsletter changed to the Early Hearing Detection and Intervention (EHDI) newsletter. This final issue of the newsletter provides an opportunity to reflect on the accomplishments of the past 3-1/2 years.

This newsletter is funded by the Perinatal Foundation and a Title V MCH Block Grant through the Maternal and Child Health Bureau of the Health Resources and Services Administration, U.S. Department of Health and Human Services to the Wisconsin Association for Perinatal Care.

The first issue featured a program model, an ideal of how we wanted newborn hearing screening and intervention to go in Wisconsin. The model was developed over a period of time by multiple partners—the Wisconsin Hospital Association; the Wisconsin Speech, Hearing, and Language Association; the Wisconsin Division of Public Health; the Birth to 3 Program; the Wisconsin Association for Perinatal Care; and others. That model served as the master plan that called for screening 100% of newborns by hospital discharge, with an outpatient diagnostic evaluation done by 4 weeks of age on all infants who failed the screening. Further, children with confirmed hearing loss were to receive intervention services by 6 months of age. Finally, there was a requirement that the results of the screening program would be reported, making the ongoing evaluation of the program possible.

The data reporting and collection function has been a key component of the program's success. It allowed documentation of the gradual increase in the number of hospitals that initiated screening as well as the number of infants screened. Early data collection was done through yearly surveys of hospitals, but has recently been augmented by an electronic data collection program, known as WE-TRAC.

As we celebrate our success in making newborn hearing screening a standard of care in Wisconsin, we acknowledge the challenges before us. One of the most critical is the need to demonstrate the value of early intervention to the infant's communication, social and emotional development. Wisconsin has a legion of dedicated parents who will continue to work for their children's success and a legion of providers who are committed to improving health systems so all children with hearing loss or deafness will have the opportunity for optimal development.

On the following pages you will find articles about success stories of infants who were identified early and received intervention services, the role of the primary care provider in being the "case manager" for the family with a child with a hearing loss or deafness, how the role of the audiologist has changed, creative educational efforts for children with hearing loss or deafness, parent educational and support groups, and the growth of Birth to 3.

***EHDI in Wisconsin continued from page one.***

On behalf of the Wisconsin Association for Perinatal Care and the Wisconsin Sound Beginnings Program, thank you to all who have made newborn hearing screening and intervention a standard of care that benefits all infants in Wisconsin!

**UNHS**  
Universal Newborn Hearing Screening

Things I Should Have Learned In Kindergarten  
About Universal Newborn Hearing Screening



The reason to screen is to intervene.  
Anticipating how it might be is easier than explaining how it will.  
There is no such thing as a simple hearing test.  
Worry doesn't go away by someone saying,  
"There's nothing to worry about."  
Parents want to do the best for their child.  
Offer a chair. Offer a beverage. Take a chair.  
Make sure it's accurate the first time.  
Say it often in many different ways.  
It's not the machine.  
Everything matters.  
A baby is a baby.  
Be nice.



The work group that planned the first series of regional forums in 2000 compiled a list of truisms about universal newborn hearing screening and published it in a poster format. The truisms served us well over the past four years and continue to serve as a reminder that at the heart of our efforts to institutionalize a standard of care is an infant and a family.

## MADISON'S STORY

The following three articles are personal stories about children with hearing loss and their families. **Madison's story** was written by Christine Kometer from the Center for the Deaf & Hard of Hearing. **Maggie's story** was written by Amy Ryan, Community Relations Coordinator for Sauk Prairie Memorial Hospital where her daughter Maggie was born. The last story, a mother's perspective, was written by Connie Stevens.

When Madison was born, her parents were concerned about the trauma she experienced during birth with the necessary use of forceps and a lung problem. The lung problem corrected itself within a couple days of being on oxygen in the NICU. However, her parents were then presented with the information that she had not passed her hearing screening. It turns out this would not correct itself in a few days.

Her parents, Matt and Leah, took Maddie to Children's Hospital of Wisconsin for further testing. After an auditory brainstem response evaluation at the age of one month, they were told that she had a moderately severe to severe hearing loss bilaterally. Maddie was fit with hearing aids by the time she was 2 months old. Right from the start, she wore them almost full-time. By 4 months old, she was enrolled in Birth to 3 services at the Center for the Deaf and Hard of Hearing (CDHH).

Leah has two first cousins who were born profoundly deaf. They were not identified until the age of two-years and one-year, respectively. She said the younger cousin did not even start talking until she was about 3 years old. If Madison had not had UNHS, "we might not have found out until the age she is now or later, and by that time, her speech and language would've been so far behind. Her communication is so great! It's amazing, between her words and her signing, she communicates even better than some hearing kids I've seen!" She wishes that the newborn hearing screening could have been available for other families, especially her cousins.

Matt and Leah decided to use a Total Communication approach with Maddie, and they enrolled in sign language classes. They also learned from Leah's cousins. Maddie is now 20 months old, is participating in a Communication Playgroup at CDHH, and her communication skills are within the 18-24 month age range. She communicates using both sign and speech, and her parents and entire extended family couldn't be happier with their energetic bundle of joy!

## MAGGIE'S STORY

It was in early May of 2000 when I met with the Auxiliary president, Dianna Woerpel and Obstetrics manager, Alice Hutter. I took a picture of them posing with a Natus Algo Hearing Screener, which the Auxiliary had just purchased for the hospital for nearly \$11,000.

Little did I know that this small piece of equipment would one day make a big difference in my child's life. One year later my daughter, Margaret, was born. Maggie, as we call her, came 10 days early weighing 6 pounds, 8 ounces. It was a relatively quick and easy labor and delivery with no complications. The next day, the nursing assistant came into our room. Because Maggie was sleeping, she said it would be a good time to do her hearing screening. She did the screening by placing small sensors on Maggie's head, and earphone-like cups on her ears. While Maggie slept, the machine sent soft clicking sounds through the ear cups. The sensors measured how Maggie's brain responded to the clicks.



When the nursing assistant returned with Maggie, she told us that our baby had "referred" on the hearing screening. She told us not to worry - Maggie may just have fluid in her ears - and our doctor would follow-up and have her see an audiologist. We didn't worry—at first. But after going home, I began to wonder. What if she does have a hearing loss? Could it be possible?

***Maggie's Story continued on page four.***

## ***Maggie's Story continued from page three.***

It was possible. In fact, follow up with an audiologist confirmed that Maggie had a severe to profound hearing loss in both ears.

The news left my husband and me briefly stunned. So stunned that I don't even remember asking many questions before we left the audiologist's office that day. As we drove home, our emotions, thoughts and questions began to flow. I remember saying that I was glad we knew about her hearing loss so early. The thought of finding out when she was 2, after possibly getting frustrated with her because we were unaware that she could not hear us was heartbreaking to me. When sharing the news with family and friends, I made the same comment. They assured us that we would have figured it out. But I have since learned that the average age when parents realize their child is hearing impaired is between 2 and 3 years of age when they do not start talking at the same rate as their peers. But unfortunately, by that time, the child has already missed out on much of the critical period for speech and language development.



I understand that it can be difficult for rural hospitals to implement newborn hearing screening programs because of the expense involved. Our community was very fortunate that the hospital's auxiliary donated the funds for the equipment. Maggie is nearing her third birthday now. She has been wearing hearing aids and working with a speech therapist through Sauk County's Birth-3 program since she was 3 months old. Hearing tests show that she benefits somewhat from hearing aids and she does babble more when wearing them.

This past summer my husband and I made the difficult decision to pursue a cochlear implant for Maggie. After doing our own research, which included sifting through conflicting information and talking with other families and professionals, we felt that it was the best opportunity for her. The surgery was performed in early December and we are anxiously awaiting the mapping appointment scheduled for early January, in which her audiologist will program the device and we will watch her respond to it for the very first time.

Words cannot express how grateful we are that Maggie's hearing loss was detected at birth. We have learned so much since that day in the audiologist's office nearly three years ago. Having this time to learn about, accept and work with Maggie's hearing loss has been invaluable to us. Today she is a happy, inquisitive, funny little girl, and I often think that had we not learned of her hearing loss when we did, her early experiences in life may have been very different.

## **UNEXPECTED NEWS: A MOTHER'S STORY**

Until five years ago the field of deafness and the importance of communication was foreign to me, but it is no longer. Yes, I had previously met deaf people and remembered the sign language alphabet from seventh grade. But I was unprepared for the news that Tess, my younger daughter, was profoundly deaf. My family was already reeling from the unexpected news at her birth that she had Down Syndrome.

Seeking and receiving early intervention was not an easy task. We were coping with a loss that was hard to explain. We were experiencing many new things, besides raising two children for the first time - finding, meeting, and scheduling appointments with new doctors and professionals; welcoming therapists into our house and lives; learning new terminology and a new way of communication; finding financial help. I eventually resigned from my job, with health benefits, so I could manage our new life.



***Unexpected News continued on page five.***

## **Unexpected News: continued from page four.**

It was stressful. Looking back, I realize that my husband and I didn't fully celebrate our new family because we were taking on new roles and responsibilities that we did not choose. Overnight, we became students of many disciplines: medicine, audiology, speech therapy, deaf history and culture, sign language, education, law. People told us that as parents we would be our daughter's strongest advocate and case manager. I took the role seriously.

I gained information from as many sources as I could find and then documented it. I read voraciously and attended conferences and trainings. I contacted other parents and service organizations. I recorded Tess's use of hearing aids, problems encountered and sounds possibly heard. We immersed ourselves in sign language when Tess experienced continual ear infections and problems with her hearing aids. We bought sign language books and videotapes. We received Deaf Mentor Program services, attended Family Learning Vacations at Lion's Camp and became actively involved with Shore to Shore, a language group in Madison. I documented every new sign Tess expressed and motor skill accomplished. I communicated all this with our service providers and offered suggestions on how to better serve Tess, our family and others.

With the hope of helping other families and ourselves through the maze of feelings, information and services, I became involved in other activities across the state. I became a Wisconsin Sound Beginning's Birth to Three consultant. I co-authored the notebook titled, "Babies and Hearing Loss: An Interactive Notebook for Families with a Young Child Who is Deaf or Hard of Hearing" and use it through my work with Shore to Shore as a parent educator and now program coordinator. With other parents across the state, we are starting a state chapter of Hands and Voices.

It has been a wild trip. But I wouldn't trade it for anything. We have experienced wonderful times with Tess and our older daughter Grace. We have learned that communication can take many forms. We have expanded our network of supports and look forward to new adventures. Just last week, we went down another path. Tess underwent surgery for a cochlear implant. We are excited to see where this takes all of us. I feel very fortunate to have had the opportunity to give her all the supports that may benefit her. I am confident that with continuing services, Tess will grow up to become a literate and successful woman. Thank you to everyone who has been involved.



### **EHDI TRAINING AND TECHNICAL SUPPORT TEAM**

**The following people are available to provide training and technical support free of charge.**

#### **SHARON FLEISCHFRESSER, MD, MPH**

Sharon is the Medical Director for the State of Wisconsin Children With Special Health Care Needs Program in Madison. You can reach her at (608) 266-3674 and by email at [fleissa@dhfs.state.wi.us](mailto:fleissa@dhfs.state.wi.us).

#### **LILAH KATCHER**

Lilah is the WE-TRAC Project Manager with the Wisconsin Sound Beginnings Program and works closely with the University of Wisconsin Department of Information Technology to implement and support the WE-TRAC data system. You can reach her at (608) 261-9307 and by email at [katchlm@dhfs.state.wi.us](mailto:katchlm@dhfs.state.wi.us).

#### **ELIZABETH SEELIGER, MA, CCC-A**

Elizabeth is the Coordinator of the Wisconsin Sound Beginnings Program. She can be reached at [seeliel@dhfs.state.wi.us](mailto:seeliel@dhfs.state.wi.us) or by phone at (608) 267-9191.

#### **ANN-MARIE WINECKE, RN, BSN**

Ann-Marie is a Nurse Consultant in the State Children With Special Health Care Needs Program in Madison. She is available by phone at (608) 267-9190 and by email at [winecae@dhfs.state.wi.us](mailto:winecae@dhfs.state.wi.us).

## ROLE OF THE PRIMARY CARE PROVIDER IN A MEDICAL HOME

Sharon Fleischfresser, MD, MPH contributed the following article, with assistance from Joseph Kerschner, MD.

Each year an estimated 200 babies are born in Wisconsin with hearing loss. Studies show that early diagnosis and intervention can minimize developmental delays that arise from hearing impairment and that infants who receive intervention prior to 6 months of age maintain language development commensurate with their cognitive abilities through the age of 5 years. Therefore, early screening, follow-up, and treatment are critical. In 2000 the Joint Committee on Infant Hearing (JCIH) recommended that all infants be screened prior to hospital discharge, diagnosed by at least 3 months of age and enrolled in intervention by no later than six months.

Since release of the JCIH recommendations, Wisconsin has made tremendous progress. In 2003 all Wisconsin birthing hospitals had universal newborn hearing screening (UNHS) programs in place. But screening is only the first step. According to Joseph Kerschner M.D., a pediatric otolaryngologist and member of the Wisconsin UNHS Implementation Work Group, "the key is the infant is diagnosed, options are provided, and intervention begins early with a team that includes audiologists, Birth to 3, and physicians". The primary care provider plays a critical role in determining if a child receives timely diagnosis and intervention services.

### **What is the role as a primary care provider related to hearing screening?**

- ❖ Provide parents with information about hearing, speech, and language milestones.
- ❖ Assure all newborns in the practice have been screened, and parents are aware of the screening results.
- ❖ While most infants with a hearing loss will be identified through a universal newborn hearing screening, hearing loss may have an onset after the newborn period. A referral to an audiologist should be considered if a parent expresses concern about their child's hearing.
- ❖ Identify and refer for audiologic monitoring infants who have risk indicators for late-onset hearing loss.

### **What if an infant refers on screening?**

- ❖ Infants who refer on screening should receive prompt comprehensive audiologic assessment including infants with a unilateral refer.

### **What if an infant has a confirmed hearing loss?**

- ❖ All infants with confirmed hearing loss should be referred to an otolaryngologist.
- ❖ Referral for genetic evaluation is an important part of the diagnostic work-up for infants with bilateral moderate, severe, or profound sensorineural hearing loss; or children with a family history of hearing loss or other co-existing medical problems or birth defects.
- ❖ Refer to a pediatric ophthalmologist.
- ❖ Refer the infant to the Birth-3 Program. Call 1-800-642-STEP to find the phone number for your local program.
- ❖ Provide vision screening and referral as needed.
- ❖ Identify and aggressively treat middle ear disease.
- ❖ Provide ongoing developmental surveillance and referral to resources as needed.

*Babies and Hearing Loss: A Guide for Providers about Follow-up Medical Care* provides:

- ❖ A guide to best practices in follow-up medical services
- ❖ A list of publications for professionals
- ❖ A list of community, statewide, and national resources important to families with an infant who is deaf or hard of hearing

This document along with the companion *Babies and Hearing Loss: A Guide for Families About Follow-up Medical Care* (English and Spanish) and *Wisconsin's Babies & Hearing: An Interactive Notebook for Families With a Young Child Who Is Deaf or Hard of Hearing* can be downloaded at <http://www.medicalhomeinfo.org/screening/EHDI/.html#Wisconsin>.



## **WISCONSIN'S PEDIATRIC AUDIOLOGISTS: PAST, PRESENT, FUTURE**

**Laura Feldhake, Au.D., CCC-A, provided the following perspective on the evolving role of audiologists in EHDI.**

The field of pediatric audiology in the state of Wisconsin has experienced many changes during the last six years. In 1998, a handful of audiologists with the support of the Wisconsin Speech Language and Audiology Association (WSHA) began a grassroots endeavor to resurrect the idea of universal newborn hearing screening. Several states had laid the groundwork and the political climate was favorable. After several meetings, the WSHA workgroup was invited to attend a similar multi-disciplinary workgroup organized by the Wisconsin Health and Hospital Association and Wisconsin Association for Perinatal Care. This joint effort resulted in a bill introduced into the legislature that gave birthing hospitals the directive to screen all newborns for hearing loss before discharge. Audiologists and speech pathologists around the state supported the cause and called their representatives, went to fund-raising functions, tested hearing at the Capitol and took part in a 5 K walk around the Capitol Square.

After the passing of the bill into law, audiologists had a new role. We were suddenly testing, identifying and fitting children younger than ever before. Many audiologists were overwhelmed with the new role and sought out further education. In answer to this request, the Wisconsin Sound Beginnings Program coordinator and WSHA developed an intensive three-part training series for audiologists to further their knowledge of pediatric services to infants referred from UNHS programs. Forty audiologists completed all three segments of the training and are listed with Wisconsin First Step for referral sources.

Audiologists in the state continue to further their education in the area of pediatric assessment through doctoral programs, programs offered by our professional associations, and implementing the new protocols introduced by JCIH. The audiology community will continue to work toward obtaining further funding through legislation for intervention and follow-up programs for children identified with hearing loss for the ultimate goal of offering complete services to infants and their families.



## **PUBLIC PRESCHOOL EDUCATIONAL OPPORTUNITIES FOR CHILDREN WHO ARE DEAF OR HARD OF HEARING**

**Marcy Dropkin and Carol Schweitzer provided the following information. For more information about these educational opportunities, please contact Marcy at 262-787-9540 or [marcy.dropkin@wesp-dhh.wi.gov](mailto:marcy.dropkin@wesp-dhh.wi.gov) or Carol at 608-266-7097 or [carol.Schweitzer@dpi.state.wi.us](mailto:carol.Schweitzer@dpi.state.wi.us).**

School districts throughout the state support an array of preschool educational options for children ages 3 to 6 who are deaf or hard of hearing. Decisions about the type of educational setting and the type and amount of services to be provided to the child are determined by the Individual Education Program (IEP) team. Parents are key players on the IEP team along with school district staff who are knowledgeable about the child's disability and typical early child development. Information from the Birth to 3 providers who know the child is also included in the discussion that determines appropriate early educational services. The Individuals with Disabilities Educational Act (IDEA) supports a continuum of preschool educational placements to meet the differing early needs of children with

***Public Preschool Educational Opportunities continued on page nine.***



## **EARLIER INTERVENTION WITH EARLY IDENTIFICATION—THE BIRTH TO 3 CONNECTION**

Jean Nothnagel, with the State's Birth to 3 Program and Linda Tuchman, PhD of the Waisman Center Early Intervention Center provided the following update.

The challenge of identifying infants with hearing loss is being met by hospitals and midwives every day in Wisconsin. At the same time in Wisconsin Birth to 3 Programs have increased their capacity to provide supports, and early intervention for infants and toddlers who are deaf or hard of hearing and their families is improving.

The Wisconsin Birth to 3 Program and the Wisconsin Personnel Development Project (WPDP) have been partners with the Wisconsin Sound Beginnings Program (WSB) in the effort to develop strategies that identify, refer, serve and advise families with children who have been confirmed as deaf or hard of hearing.

### **Are More Infants and Toddlers Being Served by Birth to 3 Programs?**

Between 2001 and 2002 we know the number of deaf or hard of hearing children identified in Birth to 3 Programs increased over 50% statewide. Some of the increase was the result of improved county reporting of hearing impairment as a secondary finding in children who have other diagnoses or delays. Some of the increase is due to the successful program to confirm hearing loss in infants and very young children, and the consequent referral to Birth to 3. Early detection of hearing loss is becoming the standard of practice. Now Birth to 3 looks forward to seeing a new standard of referral processes that results in a shorter time gap between confirmation of hearing loss and referrals. Earlier referrals will help families begin the process of exploring communication options and strategies to create communication environments for their child at a younger age. Results of research have demonstrated the impact of early communication intervention on academic performance in early elementary education.

### **What Has Birth to 3 Accomplished to Prepare for Earlier Referrals?**

Participation in collaborative WSB efforts has thus far resulted in offering extensive statewide training to hundreds of participants, from parents to providers. The "Where Do We Begin?" series offered awareness training to a large number of early intervention providers, and the Intensive Birth to 3 Consultant Training provided in depth training to a small group of motivated partners. Parents voiced their ideas about successes and challenges for the future at the statewide Parent Summit that resulted in numerous actions, including the new Guide-By-Your-Side program. Additional outlets to distribute current information have been available with contributions to the WAPC EDHI newsletter and Birth to 3 web site publications. The development and distribution of Principles for Best Practices and dissemination of Birth to 3 eligibility guidelines specific to hearing loss contributes to the ability of Birth to 3 staff to provide direct services and supports.

### **What's Next for Birth to 3?**

Birth to 3 and WPDP will continue collaborations with old partners and new, welcoming and exploring new methods to reach families early, elevate the knowledge and abilities of Birth to 3 programs and contribute to new standards of practice.

### **Additional Information**

For additional information see the following:

<http://www.waisman.wisc.edu/birthto3/EARLYHEARINGDET.HTML> and

<http://www.perinatalweb.org/association/unhs.html>

## **Public Preschool Educational Opportunities continued from page seven.**

disabilities. Preschool support for young children who are deaf or hard of hearing should focus on language development and communication skills.

Most deaf and hard of hearing preschoolers participate in their local school and/or community programs along with needed support as identified in their IEP. Educational services/programs can range from in-home speech and language instruction and audiology support, to a day care setting where the teacher of deaf and hard of hearing students provides instruction and consultation to the day care provider. Children may receive support from their local school district in Head Start programs or in early childhood, special education classrooms, or preschool classrooms for children with and without disabilities.

In southeastern Wisconsin, there are some unique preschool programs for deaf and hard of hearing children. The Milwaukee Sign Language School (MSLS) provides an educational environment where children who are deaf or hard of hearing attend classes along with children with typical hearing peers. Sign language is taught to all of the students as well as speech and listening skills. MSLS, as a PK-8 school, continues to support sign communication amongst all students, including students without a hearing loss, as well as all staff. The model includes classrooms where students who are deaf and hearing and students with typical hearing are team taught by a regular education teacher and a teacher for the deaf/hard of hearing.

The preschool program in Waukesha for children who are deaf or hard of hearing is housed at Lowell Elementary School. This school provides an auditory-oral program. Students in this program are given a variety of opportunities to learn through structured activities that support and enhance the development of audition and speech skills by knowledgeable staff.

A third unique program is at the Wisconsin School for the Deaf (WSD), in Delavan. This program is in a state-supported school that offers a bilingual-bicultural program where class content is taught using American Sign Language with English instruction in written form. WSD has a residential program for children ages 6–21. Children ages 3–6 must live in the area in order to attend school at WSD.

The Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH) is a program within the Department of Public Instruction (DPI). WESP-DHH includes an Outreach Program. The Outreach Program employs a variety of specialists including a Diagnostic/Educational Specialist, Speech-Language Consultant, Educational Audiology Consultant, Sign Communication Specialist, Deaf-Blind Coordinator and a Birth to Six Services Coordinator. The Outreach staff work with local Birth to 3 Programs and school districts to provide student observation/assessment, participation in the development of a student's Individualized Educational Plan (IEP)/Individualized Family Service Plan (IFSP), consultation to educational professionals, training and staff in-service. This program provides support at no charge.

There are also several programs available to support families of children who are deaf or hard of hearing. The *Deaf Mentor Project* is a program that works with families of children who are deaf or hard of hearing up to age 6 by providing in-home sign language instruction by a Deaf adult who has been trained to work with families and early child language. In collaboration with *Wisconsin Sound Beginnings* and *Wisconsin Hands and Voices*, the newly established *Guide-by-Your-Side Program* will provide immediate in-home parent-to-parent support when a child is diagnosed with a hearing loss.

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## **Professional Services continued from page eleven.**

### **Publication Ordering Process**

To order the materials on page ten and eleven (except those labeled N/A), please use the following process:

- Complete form DMT-25, "Form / Publication Requisition." Because it is a multi-PLY form, it is not available on this site. To order this form, you may call 608-267-7172 or email your request to: [rundhmm@dhfs.state.wi.us](mailto:rundhmm@dhfs.state.wi.us).
- Please DO NOT remove carbon between white and yellow copy on the DMT-25 form. Retain blue copy for your records. When providing your mailing address, include an appropriate address such as a street address. The United Parcel Service (UPS) will not deliver to a P.O. Box.
- Send completed form (DMT-25) to:  
Cris Caputo, Room 250, P.O. Box 2659, Madison WI 53701

The materials you have ordered will then be shipped directly to you.

## RESOURCES

Elizabeth Seeliger, MA, CCC-A, provided the following list of resources about hearing loss, professional services, or parent-to-parent support groups. If a resource has only a TTY number listed, please contact the Wisconsin Relay System at 711.

### State & Local Organizations

#### Center for the Deaf and Hard of Hearing (CDHH)

3505 N. 124th Street  
Brookfield, WI 53005  
(262) 790-1040 Voice  
(262) 790-0584 TTY  
(262) 790-0580 Fax  
Dorothy Kerr, Executive Director

#### Cochlear Implant Club of Wisconsin

119 Oconomowoc Square  
Oconomowoc, WI 53066  
(262) 267-9621 Voice (work)  
(262) 832-6332 (home)  
Carol Burns, President  
Work e-mail:  
burnsca@dwd.state.wi.us  
Home e-mail: burnsca@chorus.net

#### Office for the Deaf and Hard of Hearing (BDHH)

Central Administration Office  
PO Box 7851  
1 W. Wilson St., Room 451  
Madison, WI 53707-7851  
(608) 266-3118 Voice/TTY  
(608) 264-9899 Fax  
Linda Huffer  
Internet: www.dhfs.state.wi.us/sensory

#### Wisconsin Association of the Deaf (WAD)

111 W. Wilson, #302  
Madison, WI 53703  
(608) 250-6076  
Linda Russell, President  
E-mail: linda\_russell@sbcglobal.net  
(or) russelm@dhfs.state.wi.us  
Internet: www.wi-deaf.org

#### Wisconsin Educational Services Program for the Deaf and Hard of Hearing (WESPDHH)

Alex Slappey, Director  
309 W. Walworth Avenue  
Delevan, WI 53115  
(262) 740-2066 v/tty  
E-mail: alex.slappey@dpi.state.wi.us  
• Wisconsin School for the Deaf  
309 W. Walworth Avenue  
Delevan, WI 53115  
Internet: www.wsd.k12.wi.us/

- Outreach Program-WESPDHH  
Marcy Dropkin, Outreach Director  
19601 W. Bluemound Road  
Brookfield, WI 53045  
(262) 787-9540 v/tty  
E-mail: marcy.dropkin@wesp-dhh.wi.gov
- Deaf Mentor Project  
WESPDHH-Outreach Program  
Marika Kovacs-Houlihan,  
Project Co-Coordinator  
Bonnie Eldred, Project Co-Coordinator  
E-mail: deafmentor@wesp-dhh.wi.gov

#### Wisconsin Relay System

Western Tower Building  
8383 Greenway Blvd., Suite 90  
Middleton, WI 53562  
(800) 283-9877 TTY  
(800) 395-9877 Voice, VCO  
(608) 827-0402 Fax  
E-mail: wirelay@hamilton.net  
Internet: www.hamilton.net/relay/wi

### National Organizations

#### Alexander Graham Bell Association for the Deaf and Hard of Hearing (AGBell)

3417 Volta Place NW  
Washington, DC 20007  
(202) 337-5220 Voice  
(202) 337-5221 TTY  
(202) 337-8314 Fax  
Internet: www.agbell.org

#### American Academy of Audiology (AAA)

8300 Greensboro Dr., Suite 750  
McLean, Virginia 22102  
(800) AAA-2336 Toll-Free  
(703) 790-8466 Voice  
(703) 790-8631 Fax  
Internet: www.audiology.org

#### American Society for Deaf Children

P.O. Box 3355  
Gettysburg, PA 17325  
(717) 334-7922 Business V/TTY  
(717) 334-8808 Fax  
(800) 942-ASDC Parent Hotline  
E-mail: asdc@deafchildren.org  
Internet: www.deafchildren.org

#### American Speech-Language-Hearing Association (ASHA)

EXEC. DIRECTOR: Frederick T. Spahr, Ph.D.  
10801 Rockville Pike  
Rockville, MD 20852  
Helpline: (800) 498-2071 (Voice/TTY)  
(301) 897-5700 TTY  
(301) 571-0457 Fax  
John E. Bernthal, President  
E-mail: actioncenter@asha.org  
Internet: www.asha.org

#### Cochlear Implant Association, Inc.

5335 Wisconsin Avenue, NW  
Suite 440  
Washington, DC 20015-2052  
(202) 895-2781  
(202) 895-2782 Fax  
Internet: www.cici.org

#### Families For Hands and Voices

P.O. Box 371926  
Denver, CO 80237  
(303) 300-9763  
(866) 422-0422 Toll Free  
Internet: www.handsandvoices.org

#### National Association of the Deaf (NAD)

814 Thayer Avenue  
Silver Spring, MD 20910-4500  
(301) 587-1788 Voice  
(301) 587-1789 TTY  
(301) 587-1791 Fax  
E-mail: NADinfo@nad.org  
Internet: www.nad.org

#### National Information Center for Children and Youth with Disabilities (NICHCY)

P.O. Box 1492  
Washington, DC 20013  
(800) 695-0285 V/TTY  
(202) 884-8200 V/TTY  
(202) 884-8441 Fax  
E-Mail: nichy@aed.org  
Internet: www.nichcy.org

#### National Institute on Deafness and Other Communication Disorders

National Institutes of Health  
31 Center Drive, MSC 2320  
Bethesda, MD USA 20892-2320  
Internet: www.nidcd.nih.gov

Resources continued on page eleven.

## Resources continued from page ten.

### Laurent Clerc National Deaf Education Center and Clearinghouse

Gallaudet University  
800 Florida Ave. NE  
Washington, DC 20002  
Kendall Demonstration Elementary School  
Internet: [www.clerccenter.gallaudet.edu/InfoToGo](http://www.clerccenter.gallaudet.edu/InfoToGo)

### Self Help for Hard of Hearing People, Inc. (SHHH)

National Chapter  
7910 Woodmont Ave-Suite 1200  
Bethesda, Maryland 20814  
(301) 657-2248 Voice  
(301) 657-2249 TTY  
(301) 913-9413 Fax  
E-mail: [National@shhh.org](mailto:National@shhh.org)  
Internet: [www.shhh.org](http://www.shhh.org)  
Wisconsin First Step Hotline

## Additional Resources

### National Center for Hearing Assessment and Management (NCHAM)

[www.infantheating.org](http://www.infantheating.org)

This site contains a wealth of information on resources for families and professionals. It has links to many of the national organizations listed above as to many of the publications and resources available in Wisconsin. This site will continue to be updated with WI activities and publications.

### Hands & Voices–Wisconsin Chapter

"What works for your child is what makes the choice right"

Hands & Voices is a newly developed parent organization dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology. They are a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Their focus is on outreach activities, parent/professional collaboration, and advocacy focused on enabling Deaf and Hard of Hearing children to reach their highest potential.

For more information or to become a member contact Molly Martzke at [mpmartzke@yahoo.com](mailto:mpmartzke@yahoo.com)

### Wisconsin First Step Hotline

[www.mch-hotlines.org](http://www.mch-hotlines.org)  
(800) 642-7837 voice/TTY

Callers get information on a full range of services and programs for children with special needs, birth to 21. They can provide connection to parent-to-parent networks. This hotline is available 24 hours a day, 365 days of the year.

### Wisconsin Sound Beginnings Publications List (see instructions for ordering on page nine)

*A Sound Beginning for Your Baby: Newborn Hearing Screening* (brochure) Revised 02/02.

Purple brochure that describes the importance of screening baby's hearing at birth, referral services, and tips on enjoying your baby. Order #: PPH 4512.

*Un comienzo optimo para su bebé: Examen de audición del recién nacido* (brochure) Revised 02/02.

Purple brochure that describes the importance of screening baby's hearing at birth, referral services, and tips on enjoying your baby.- Spanish Language. Order #: PPH 4512S.

*Babies and Hearing Loss: A Guide for Families on Follow-Up Medical Care* (brochure) Printed 10/02.

Describes the steps in the process that a family would take and the professionals they might see if their baby were identified as deaf or hard of hearing. Order #: PPH 40055.

*Los bebés pérdida auditiva: Una Guía Para Familias Sobre Buidado Médico Continuo* (brochure) Printed 10/02.

Describes the steps in the process that a family would take and the professionals they might see if their baby were identified as deaf or hard of hearing - Spanish Language. Order #: PPH 40055S.

*Babies and Hearing Loss: A Guide for Providers about Follow-Up Medical Care* (booklet) Printed 8/03.

Glossy color booklet that clearly identifies and describes the various provider roles and responsibilities for each phase of follow up for a child with hearing loss. Order #: PPH 40058.

*Early Hearing Detection and Intervention in Wisconsin* (periodic newsletter). Periodic newsletter to keep health care providers and other personnel informed of status of early hearing detection and intervention news in Wisconsin. Printed and distributed by WAPC. Call Elizabeth Seeliger to obtain back issues: 608-267-9191. Order #: N/A.

*Babies and Hearing Loss: An Interactive Notebook for Families with a Young Child who is Deaf or Hard of Hearing*

(3-ring binder) Printed 02/03. 3 ring color binder that is a keepsake/record keeper full of easy to understand information on hearing loss issues and services for the young child. Distributed through audiologists to families of infants who are newly diagnosed with deafness/hearing loss. Contact Elizabeth Seeliger for more information: 608-267-9191. Order #: N/A.



DIVISION OF PUBLIC HEALTH

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**State of Wisconsin**  
Department of Health and Family Services

608-266-1251  
FAX: 608-267-2832  
dhfs.wisconsin.gov

December 16, 2003

Ann E. Conway, RN, MS, MPA, Executive Director  
Wisconsin Association for Perinatal Care & Perinatal Foundation  
McConnell Hall, 1010 Mound Street  
Madison, Wisconsin 53715

Dear Ann:

On behalf of the Wisconsin Universal Newborn Hearing Screening (UNHS) Implementation Work Group, I would like to express our appreciation to the Wisconsin Association for Perinatal Care and the Perinatal Foundation for their strong commitment to early hearing detection and intervention (EHDI).

Early in the course of Wisconsin's implementation of universal hearing screening, the Wisconsin Association for Perinatal Care and the Perinatal Foundation assumed a leadership role. An invitational stakeholder meeting was held and recommendations for next steps were published. This was followed by a series of regional forums where the concepts of EHDI were presented. A "champions" meeting then committed partners to action. These activities played an instrumental role in promoting EHDI statewide.

The Perinatal Foundation made funds available to hospitals to assist with the purchase of screening equipment. This grant program enabled a guild of midwives and seven small hospitals, many rural, to initiate a newborn hearing screening program. In 2003, all Wisconsin birthing hospitals had universal hearing screening programs in place.

Over the past five years, Wisconsin has progressed from a state with few infants screened to nearly all newborns. This growth has been the result of an incredible public and private partnership under the stewardship of the Wisconsin Association for Perinatal Care, the Perinatal Foundation, and the Wisconsin Sound Beginnings Program in the Division of Public Health.

While there is more work to be done to achieve full implementation of early hearing detection and intervention programming, Wisconsin is well on its way. Thank you.

Sincerely,

Sharon Fleischfresser M.D., M.P.H.  
Medical Director, Wisconsin CSHCN Program



Wisconsin Association for  
Perinatal Care

McConnell Hall  
1010 Mound Street  
Madison, Wisconsin 53715

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