

Oregon EHDI Newsletter

July 2010



In this issue

Newborn Hearing Screening News:

EHDI Converts to OVERS & Screening Tips *

New Features at the EHDI Page! *

Free Infant and Toddler Hearing Screens *

First Hands & Voices Parent Conference a Great Success *

Guide By Your Side: An Invaluable Resource for Families *

National and Oregon Trail to Early Hearing Detection and Intervention *

Scientific Research Brings Breakthrough About Inner Ear Cells *

Oregon Deafblind Project *

August SUMMIT for Educators of the Deaf and Hard of Hearing *

Staff Contacts

Newborn Hearing Screening News

Oregon EHDI converts to OVERS Hearing Screening Module

Big changes are happening to Oregon’s Early Hearing Detection and Intervention (EHDI) program, all to ensure that as many Oregon babies as possible get their hearing screened within one month of their birth.

To obtain more accurate and complete demographic data on Oregon births, EHDI converted to the Oregon Vital Events Registration System (OVERS) hearing screening module this month, replacing HiTrack. This change eases the burden of reporting on hospital screening staff, who no longer need to spend extra time entering contact information for each baby born because it is already entered for them as part of the baby’s birth certificate. This transition will also allow EHDI to follow up on Oregon’s out-of-hospital births as parents file for their baby’s birth certificate. Tracking out-of-hospital births in a systematic way was impossible with HiTrack. This is a major step forward in ensuring that all Oregon families know the importance of getting their newborns’ hearing screened.



Screening Tips for Hospital Staff - What to Say to Parents (Part 1)



All screeners should introduce themselves to the parents and let them know why they are there when entering the room. If the screen is done in the nursery or in the NICU, the results and information should be put in the chart and marked so that the physician and/or nurse knows the parents need to be informed.

Some common questions that are asked by parents are listed below. If any other questions are asked, refer the parents onto a Pediatric Audiologist. (You may need to modify these answers slightly to fit your hospital’s procedures.)

When the parent asks, “Why are you testing my baby for hearing loss?” Your answer: “The State of Oregon started a mandatory newborn hearing screen in June of 2000. All newborns have their hearing tested.” If parent pursues with, “Why?” Your answer:

“It is best to find out if there is a hearing loss in your child as early as possible. For babies who have a hearing loss, it is important to start intervention as soon as possible to prevent delays with their speech and language development.”

If the baby PASSES in both ears, you say:

“Your baby has passed the hearing screen at this time. If there is a family history of hearing loss, or if you notice any signs of possible hearing complications, please call our Audiologist for further information.”

**** DO NOT say that the baby’s hearing is NORMAL - this is just a SCREEN.**

When the baby REFERS in one or both ears and the parent asks, “Does this mean that my baby has a hearing loss?” The BEST answer to alleviate any anxiety is:

“This test is just a screen. I am unable to interpret results from this test today. There are other reasons aside from hearing loss for why your baby referred today, such as fluid in the ears. If your baby refers on a second screen, I will refer you on to our Audiologist for further diagnostic testing. Of all the babies that refer from their hearing screen, only 5-20% will have any significant hearing loss. If you have any further questions, please contact our Audiologist and he/she will be happy to answer any questions you may have.”

**** NEVER SAY THAT THE BABY HAS A HEARING LOSS OR IS DEAF.**

To be continued -- More tips in the next newsletter.

New Features at the EHDI Web Page!



The [EHDI Web page](#) was recently overhauled to give both parents and health professionals a more user-friendly experience.

More resources and information were added, and the page was reorganized into two sections: “For Parents” and “For Providers.” The “For Parents” side provides information on screening, follow-up (diagnostics), and Early Intervention and family services, as well as downloadable PDF brochures. “For Providers” covers protocols, facilities, the loaner hearing aid program, downloadable forms, and information on the new OVERS hearing screening module.

Links to Google maps for outpatient facilities, diagnostic facilities and screening hospitals have also been posted, providing a great tool for locating nearby facilities and their contact information, even driving directions.

Please check out the changes and send any comments or suggestions to benjamin.spencer@state.or.us.

Free Infant and Toddler Hearing Screenings

Now available for babies and children up to 5 years old. Anyone can make an appointment to have their child’s hearing screened.

The screening is noninvasive and takes about ten to twenty minutes. Babies who are born in hospitals usually get their hearing screened before they are discharged. Many of those babies should be re-screened. Children born out of hospitals don’t get their hearing screened unless their parents take them somewhere to get it done.

The cost is usually \$100, maybe beyond the reach of the uninsured, which is why these free screening clinics are so important.

THE FACTS:

1. Hearing loss is hard to identify without testing - it can be subtle, yet serious.
2. Six out of every 1,000 babies born will have some degree of hearing loss.
3. Hearing loss may result in delays in speech and language development.
4. Early identification and intervention enhances your child's potential for speech and language development.

You must make an appointment. To make an appointment, call Carol Gray at 503-236-2999 or e-mail Carol Gray at carol@carolgray.com.

*Free infant Craniosacral therapy is available at all of the hearing screening clinics listed below. Please let us know if you would like an appointment for both. Craniosacral Therapy (CST) is a gentle, noninvasive, yet effective type of bodywork. Seldom does the therapist use more than five grams of pressure (the weight of a nickel). In infants, it is used to treat colic, sleep disorders, feeding problems, breathing or digestive difficulties, various congenital, neurological and genetic problems, plus the effects of forceps, vacuum extractor or cesarean delivery. For more information about craniosacral therapy, visit http://www.carolgray.com/carolgray/Craniosacral_Therapy.html

SCREENING DATES AND LOCATIONS:

Friday October 22, 2010

[Alma Midwifery](#)

1608 Southeast Ankeny Street
Portland, OR 97214

Friday December 3, 2010

[Alma Midwifery](#)

1608 Southeast Ankeny Street
Portland, OR 97214



First Hands & Voices Parent Conference a Great Success



Hands & Voices of Oregon

On May 15, 2010, Hands & Voices of Oregon and its Executive Director, Helen Cotton-Leiser, hosted the first Hands and Voices Statewide Conference in Portland. Presenters covered topics related to deaf and hard-of-hearing children and their families, including Advocating for Children using the Individuals with Disabilities Act, Audiology 101, Qualifying for Special Education, and Communication and its Importance. Plans for future parent events are in the works.

Guide By Your Side: An Invaluable Resource for Families

Guide-By-Your-Side is a Hands & Voices parent-support program in which trained parent guides provide non-biased emotional support to families with children who have been newly diagnosed with a hearing loss. GBYS guides also have children with hearing loss and are familiar with the emotions and processes a family has to go through to get a child needed services. Through direct peer communications, guides promote self-efficacy and reduce isolation by exploring their common bond, shared experiences, wisdom and insight. If you are interested in hearing about



future Hands & Voices or Guide By Your Side events, or you are a parent of a child who is deaf or hard of hearing and would like to connect with a GBYS guide, please contact Helen at 971-673-2302 or helen.cotton-leiser@state.or.us.

The National and Oregon Trail to Early Hearing Detection and Intervention



Please note: The following time line documents but does not adequately reflect the incredible individual and collective contributions of children, parents, families, scientists, audiologists, speech pathologists, physicians, hospital personnel, nurses, public health officials, educators, community members and legislators in the process of achieving early hearing detection and intervention for Oregon children.

- 1977 David Kemp, PhD, discovers otoacoustic emission (OAE).
- 1981 Portland area hospitals conduct risk factor screening through volunteer-administered questionnaire and volunteer-administered follow up.
- 1986 The Early Intervention Council creates two new member positions for newborn hearing screening advocates.
- 1988 Technology becomes available for clinical screening:
* Otoacoustic emissions (OAE) *Automated Auditory Brainstem Response (AABR)
- 1988-93 Oregon participates in a study with Rhode Island and Hawaii to study the feasibility of universal newborn hearing screening.

Oregon uses electronic birth certificate screening of risk factors for statewide notification of parents and physician. Rhode Island and Hawaii use electronic technology. The use of electronic technology results in better outcomes for children.
- 1993 Joint Committee on Infant Hearing endorses two goals:
* Detection by 3 months * Intervention by 6 months
- 1994 The National Institute of Health (NIH) study reports “the silent epidemic of infants born with hearing loss.”
- 1995 Yoshinaga-Itano publishes study demonstrating improved outcome in children with early detection and intervention.

Routine screening of all NICU infants begins in a Portland hospital.
- 1996 Center for Disease Control (CDC) establishes EHDI program.

2007 Following 70% of hospitals voluntarily transitioning to the electronic reporting, EHDI mandates the use of HiTrack by fall of 2007.

2008 Audiologist Anne Heassler works on behalf of EHDI to establish Oregon's first free hearing screening clinic, located at Portland State University.

Infants and older children can go to the PSU Audiology Clinic or other selected sites for a free hearing screening. Anne sees patients who need a repeat screening as well as babies born out-of-hospital needing an initial screening. EHDI hopes the free clinic will be especially helpful to families without health insurance to cover the usual cost of the screening. The PSU clinic sees about 100 babies during its first year. Plans are made to open more free clinics at universities across Oregon as resources allow.

In October, the Oregon Family Resource Guide, first published in 2004, is updated with current resource information and distributed to Oregon diagnostic facilities. The Family Resource Guides are given to parents with children newly diagnosed with hearing loss.

2009 Helen Cotton-Leiser is hired as EHDI's new part-time parent coordinator to work with Hands & Voices of Oregon, a non-profit organization, to establish a "Guide by Your Side (GBYS) parent-support program in Oregon. GBYS guides are parents of deaf or hard-of-hearing children trained to provide compassionate support and unbiased information on treatment options to parents of children newly diagnosed with hearing loss. Helen hires nine guides for Oregon, including a Spanish-speaking guide, and assigns them to families of children diagnosed with a hearing loss.

2010 In May, Helen and Hands & Voices of Oregon conducts the first Hands and Voices Statewide Annual Conference in Portland. Presenters cover topics related to deaf and hard-of-hearing children, including Advocating for Children using the Individuals with Disabilities Act, Audiology 101, Qualifying for Special Education and Communication and its Importance.

In July, to obtain more complete demographic data on Oregon births, including out-of-hospital births, and ease the burden of reporting for hospitals, EHDI converts to the OVERS hearing screening module, replacing HiTrack in July. Hospital staff no longer needs to enter contact information for each baby born because it is already entered for them as part of the baby's birth certificate.

To streamline the reporting process for diagnostic centers, EHDI begins constructing a web-based diagnostic reporting tool using Filemaker Pro software. This system will replace the time-consuming and sometimes unreliable fax-back system.

SCIENTISTS CREATE FUNCTIONAL INNER-EAR CELL AIMING TO TREAT DEAFNESS

After many years of lab work, researchers in Heller's lab reported in the May 14 issue of *Cell* that they have found a way to develop mouse cells in a petri dish that look and act just like the animal's inner ear hair cells - the linchpin to our sense of hearing and balance. Researchers believe, if they can further perfect the method to generate hair cells by the millions, it could lead to significant scientific and clinical advances to treating deafness in the future. Experts explain that humans are born with 30,000 cochlear and vestibular hair cells per ear. Hearing loss occurs when a significant number of these cells are lost or damaged. The major reason for hearing loss and certain balance disorders is that humans and other mammals are unable to spontaneously regenerate these hearing cells, unlike other species such as birds. David Corey, PhD, professor of neurobiology at Harvard University who was not a part of the study believes, "this gives us real hope that there might be some kind of therapy for regenerating hair cells. It could take a decade or more, but it's a possibility." To read more, go to <http://www.medicalnewstoday.com/articles/188782.php>.



The Oregon Deafblind Project (ODP)

ODP is the state's federally funded project that provides technical assistance, training, and information to enhance services for children in Oregon who are deafblind, birth through 21 years. The office is located at the Teaching Research Institute in Western Oregon University (Monmouth). It functions year-round.

To access the services of the project, a child needs to be first registered with the project so we can "connect" with the family and service team. There is a special form for this – and it is usually filled out by the child's Parents/Family with the IFSP or IEP teams – or through a designated "DB" regional consultant. This means that a child needs to be identified as "deafblind" before services can be accessed. However, the identification process is not always simple!

The term "deafblind" can be misleading, even though it indicates a dual sensory disability affecting the two major distance-senses.

FIRST, most children who are deafblind have some vision and/or hearing, one more dominant than the other – and very few are totally blind and profoundly deaf.

SECOND, the majority of children who are deafblind have additional challenges, some severe (nationally, 90%). So there may be children identified with cognitive and orthopedic impairments, autism, traumatic brain injury, etc, but who are also deafblind. There are a small number of children who have this dual sensory loss and no other major challenges – mainly those who have Usher Syndrome – a (recessive) genetic condition where a child is born with deafness or is hard of hearing, and loses vision later on.

THIRD, there may be little or no documentation of functional vision or hearing loss.

FOURTH, children who are considered "deafblind" may also have cochlear implants and/or other devices to help them see or hear, and there is an assumption that vision and/or hearing are "corrected" to normal levels.

The Project serves children birth through 21 years. Services include:

- Technical assistance to IDENTIFY children as early as possible
- OBSERVATIONAL ASSESSMENT and CONSULTATION to determine the child, family, and service-provider needs; and observation of the environment. Training topics are dictated by these needs.
- Scheduling TRAINING. The Workshop Series training consists of several 1 ½ to 2 hour sessions over the course of several months. Each session is tailored to the specific child, although others may benefit from the techniques. Each session builds upon the information and skills developed in previous sessions – and an on-going feedback/evaluation system helps determine if the training is on track and is actually benefitting the child. If a child has a one-on-one (IA) person working with them, this person must participate in the trainings.
- SELECTED TOPICS trainings. Sometimes a family or team may need some ideas for a specific reason, or to achieve a specific goal.
- Consultation and information sharing. This can be done via e-mail, on the phone, or (if needed) in person.

Contact information:

Project Director: Lyn Ayer

E-mail: ayerl@wou.edu

Phone: (503) 838-8328

Web information: www.oregondb.org or <http://www.ode.state.or.us/search/results/?id=185>

Educators of the Deaf & Hard of Hearing

SUMMIT

Making Connections!

Salem, Oregon

August 19 & 20, 2010

Come join us for a two-day,
exciting, up-to-date-best-practices,
low-cost conference!

Date: August 19 & 20, 2010

Location: Oregon School for the Deaf, Salem, OR

Lodging: Included (stay in the dorms of OSD ~ bring your own linens/sleeping bag)

Meals: Continental breakfast included both days. Lunches & dinner on your own

Cost: \$ 120

Registration: <http://events.nwresd.org> (Select "Special Student Services"
then select "Deaf/Hard of Hearing")

Target Audience: Educators of Deaf/Hard of Hearing,
(e.g. Itinerant teachers, classroom teachers, SLPs, etc.)

Tentative topics include:

- *Literacy *Using Technology in the Classroom *New Graduation Requirements
- *Vocabulary Instruction *Cochlear Implants
- *Creative Smart Board Use *Transition Plans *Working with Hispanic Families

Sponsored By: Northwest Regional ESD, Oregon School for the Deaf, Columbia
Regional Program and Willamette Regional Program

Website: <http://www.nwresd.k12.or.us/DHHSummit.html>

Email: summit@nwresd.k12.or.us

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Staff contacts

EHDI Program questions: 1-800-917-HEAR (4327)

Web site: <http://www.oregon.gov/DHS/ph/ch/hearing/index.shtml>

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Guide By Your Side Coordinator
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This document can be provided upon request in alternative formats for individuals with disabilities. Other formats may include (but are not limited to) large print, Braille, audio recordings, Web-based communications and other electronic formats. Call the EHDI program coordinator at 1-888-917-HEAR (4327) to arrange for the alternative format that will work best for you.