

# Oregon EHDI Newsletter

April 2012



## In this issue:

EHDI Newborn Hearing Screening Workshop

\*

Free Infant & Toddler Hearing Screenings

\*

Need to Contact Oregon EHDI?

\*

OSD to Host Annual Middle School Conference

\*

More Than We Know: a Grandparent's Journey

\*

Study Reveals Sign Language Users Pick up Body Language Faster

\*

"Love Language" Video Raises Awareness of Deaf Children

\*

Survey Assesses Dx Peds Hearing Assessment Practices

\*

So...How is Oregon's Dx Loss to Follow-up?

\*

Genetics Home Reference Information

\*

Language Outcomes for Deaf and Head of Hearing Children

## Annual EHDI Newborn Hearing Screening Workshop Brings Hospital Staff Together

Newborn hearing screening coordinators, birth clerks, and hearing screeners from hospitals all over Oregon gathered at the Portland State Office Building on November 3, 2011 to celebrate their success in providing 95% of Oregon's babies with a newborn hearing screening. Everyone is doing such great work in this area - thank you for your diligence! It was difficult to single out superstars in a galaxy of so many fantastic workers, so certificates were distributed to those hospitals who achieved *extreme* excellence by screening 99 to 100% or more of their births in the first half of 2011.

**Congratulations** to the following SUPERSTARS:

Bay Area Hospital \* Harney District Hospital  
 Kaiser Sunnyside \* Providence Hood River  
 Providence Milwaukie \* Providence Seaside  
 Silverton \* Willamette Valley Medical Center

In addition to getting a refresher from EHDI staff on screening and reporting protocols, attendees discussed the challenges of closing the gap so that all of Oregon's babies are screened by one month of age.

Attendees felt positively about the workshop. Thirty-one of the 36 participants (84%) completed an evaluation survey. All respondents reported overall training satisfaction and agreed that the material was relevant and would be useful in their work. Many participants felt the best part of the day was the opportunity to learn from each other and problem-solve within small groups. Attendees also appreciated when two parents shared their experience and feelings about their child being diagnosed with a hearing loss due to a failed hospital hearing screening. Suggestions for improving the workshop included allowing more time for questions and providing hospitals with more outcome data on babies who fail hearing screenings at their facilities.

**MANY THANKS TO ALL WHO PARTICIPATED - WATCH YOUR E-MAIL FOR NEWS ABOUT A WEBINAR VERSION OF THE WORKSHOP!**



# Free Infant and Toddler Hearing Screenings

## Always Available at PSU Audiology Clinic

Free hearing screenings are now available for babies and children up to five 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, and 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, which may be unaffordable for some. This 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. Three out of every 1,000 babies born will have some degree of permanent hearing loss. Another 3/1000 will acquire a hearing loss between birth and kindergarten.
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 for a free screening. To make an appointment, call Melinda at 503-725-3070 or e-mail Anne Heassler at [anh@pdx.edu](mailto:anh@pdx.edu).**

**Note: If you are pressed for time, calling is the fastest way to get an appointment.**



## Need to Contact Oregon EHDI?

**EHDI Program questions: 1-888-917-HEAR (4327)**

**EHDI Website: Type [healthoregon.org/ehdi](http://healthoregon.org/ehdi) in your browser's address bar.**

**Submit newsletter contributions to [julie.a.hass@state.or.us](mailto:julie.a.hass@state.or.us)**

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 EHDI at 1-888-917-HEAR (4327) to arrange for the alternative format that will work best for you.

# Oregon School for the Deaf (OSD) to Host its Annual Middle School Leadership Conference, April 17-20, 2012

This April, OSD will host its annual Middle School Leadership Conference called “LIFE”. All Deaf or Hard of Hearing students from Oregon, ages 11 – 15, are invited to participate in this free event. There are evening activities, educational workshops and fun social events for students. Please contact Sharla Jones at [sharla.jones@state.or.us](mailto:sharla.jones@state.or.us) for more information.



## More Than We Know: a Grandparent's Journey

“We will teach all that we know. You will teach us more than we know”. I reread these lines from a welcoming prayer I had written to my first granddaughter for her birth, as I tucked in both of my precious little girls on New Year’s Eve. We were tending that night, so their mom and dad could go out for a date. As the year turned the final corner and a new one loomed ahead, I was given pause to think about the true depth of what these words had come to mean for me.



Our first granddaughter, Ashlin, was born 7 1/2 years ago in a very successful water birth. We had the honor of being present for that miracle. Both mama and baby were just fine, healthy, and robust. We even photographed the truly exceptional moment when Ashlin actually reached up toward her father’s face, as he leaned in to say, “Hello”, to his new daughter! Our son, Walker, and his beautiful wife, Helen, had made us grandparents, at long last! We were ecstatic!

Ashlin was such a sweet little baby, so happy, responsive, so loved. I remember bowing over her and talking to her and hearing her laugh and smile up at me. As she grew, her sweet demeanor remained. Time went by and yet she hadn’t yet spoken any words. She was nearly two and not talking yet. My son and I were convinced that she would speak up when she was good and ready to do it, on her own time frame. I guess we were in denial, looking back. However, my husband and Helen had some concerns. One day at her doctor’s appointment it was suggested that hearing tests should be done.

The result of the test told us that Ashlin was profoundly deaf. It was the most shocking and devastating news I had ever heard. There was no family history of deafness that we knew of, nothing to help us understand how this could be. We reeled with the news, passing through the stages of grief, loss, and confusion like moving through heavy water. How would my beautiful granddaughter ever hear the rich beauty of music, so dear to my heart? How would she know the sounds of nature and life? How would she communicate with us? How could she ever hear the words, “I love you”?

Then the family had to move into action to find out what we could do. This was a fact of life for us and we simply had to move ahead. Helen and Walker began a search into all of the options which might be pursued. We all

learned so much. They told us about an incredible procedure called cochlear implanting. I had never been aware of this miraculous answer to deafness. It took me some time to come to acceptance of it, as I was concerned about the potential dangers to Ashlin. Through the help of a friend, I even found a family whose young son had been implanted. That family was gracious enough to meet with me and let me ask questions of the father and the boy. It really helped me to become willing to go down the path of cochlear implantation.

I fully understood that I was just the NaNa and it was not my decision to make, but I desperately wanted to believe it was the right thing to do.

So, the day came when Ashlin was just over two years old that she had her first implant. It was so hard to see that little baby girl being carried off into the operating room. The family waited in agonizing tension for her return from the surgery. I filled the air with my quiet prayers for her, asking that she come back to us, asking for her protection. At last she came out; the poor thing looked like she had been hit by a truck. But, after awhile her little spirit awakened and she was with us again.

When our second beautiful Granddaughter, Mikaylin, was born 3 1/2 years ago in another successful water birth, we all held our breath, wondering if she too would be deaf. This time the testing was done early on. We awaited the results with stilled hearts. The answer came back that she was, indeed, deaf. How could this be? Again, we were thrown into sadness. And yet, this time we had more hope. We knew now of the miracle of cochlear implants. We knew that there was a way for her to hear; there was an answer.

Mikaylin had her first implant surgery when she was less than a year old. I'll tell you, it doesn't get any easier to see a second baby girl carried off to the operating room. The prayers were every bit as strong for her. Even though we had been through this before, it was still so hard. But, Mikaylin bounced back from her surgery very quickly and she was in her full force very soon.

I think, honestly, that it is a blessing that both of the girls are deaf, and both have now had bilateral cochlear implants. They share a bond between themselves that none of us can ever fully fathom, as hearing adults. They will always have this bond. Their relationship will always be strong and magical.

Both of our beautiful granddaughters are strong, healthy and smart. They love to dance and sing. Their speech is clear and their diction as good as or better than hearing kids of the same ages. They have been going to school since age three and had lots of special training from a wonderful school called Tucker-Maxon. They are now even learning some sign language, which pleases me immensely. I hope that they will master several languages in their lives. The girls have bright futures with unlimited possibilities.

My husband and I have tried to help in any way we could, from financially to child care, when needed. We will always put those girls at the top of our priority list, no matter what. We have made special arrangements for their education, for their futures. We love them so deeply. We thank them so much for being in our lives. They have and will continue to, "teach us more than we know".

Bonnie Leiser (NaNa)  
January 2012

# Study Reveals Deaf Sign Language Users

## Pick Up Faster on Body Language

Deaf people who use sign language are quicker at recognizing and interpreting body language than hearing non-signers, according to new research from investigators at UC Davis and UC Irvine. The work suggests that deaf people may be especially adept at picking up on subtle visual traits in the actions of others, an ability that could be useful for some sensitive jobs, such as airport screening.



“There are a lot of anecdotes about deaf people being better able to pick up on body language, but this is the first evidence of that,” said David Corina, professor in the UC Davis Department of Linguistics and Center for Mind and Brain.

Corina and graduate student Michael Grosvald, now a postdoctoral researcher at UC Irvine, measured the response times of both deaf and hearing people to a series of video clips showing people making American Sign Language signs or “non-language” gestures, such as stroking the chin. Their work was published online Dec. 6 in the journal *Cognition*.

“We expected that deaf people would recognize sign language faster than hearing people, as the deaf people know and use sign language daily, but the real surprise was that deaf people also were about 100 milliseconds faster at recognizing non-language gestures than were hearing people,” Corina said. This work is important because it suggests that the human ability for communication is modifiable and is not limited to speech, Corina said. Deaf people show us that language can be expressed by the hands and be perceived through the visual system. When this happens, deaf signers get the added benefit of being able to recognize non-language actions better than hearing people who do not know a sign language, Corina said.

The study supports the idea that sign language is based on a modification of the system that all humans use to recognize gestures and body language, rather than working through a completely different system, Corina said.

The research was supported by grants from the National Institutes of Health and National Science Foundation.

Story from *Science Daily*: <http://www.sciencedaily.com/releases/2012/01/120112142243.htm>. Thank you to the American Academy of Pediatrics’ *EHDI E-mail Express* newsletter for providing this article.

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## “Love Language” Video Created to Raise Awareness of The American Society For Deaf Children

The American Society for Deaf Children is a non-profit organization started in 1967 that supports and educates families of deaf and hard of hearing children and advocates for high quality programs and services. The video was created by The Jubilee Project, which makes films for good causes.

Check out the video when you have a few minutes. It is well-done and a sweet reminder that love transcends all languages and all barriers.

[http://www.youtube.com/watch?v=QyB\\_U9vn6Wk&feature=related](http://www.youtube.com/watch?v=QyB_U9vn6Wk&feature=related)

## Survey Gauges Pediatric Diagnostic Hearing Assessment Practices

A recent issue of MCH Alert featured highlights of a survey conducted of families to determine the ease of finding audiology services for children under the age of 6 months. The following results were yielded:

“The responses we received in this study suggest that it might be difficult for some families to identify pediatric audiology facilities that provide services for children less than 6 months of age,” state the authors of an article published in the December 2011 issue of the American Journal of Audiology. Newborn hearing screening has become a standard of care over the past decade, yet there remain barriers to effectively connecting parents to appropriate assessment services in a timely manner. The Joint Committee on Infant Hearing (JCIH) recommends the completion of a comprehensive diagnostic hearing test no later than age 3 months when an infant fails a newborn hearing screening. The article explores current practice patterns nationally for infant diagnostic hearing-assessment services offered by facilities identified as providers of pediatric diagnostic testing.

The study used a cross-sectional survey design. State Early Hearing Detection and Intervention (EHDI) coordinators from all states were invited by e-mail to participate in survey distribution. Twenty-nine EHDI coordinators agreed to participate by mailing the surveys to all the facilities in their states that self-reported the ability to provide infant-hearing-testing services. In August 2009 surveys were mailed to 1,091 facilities in 28 states and the District of Columbia. Surveys were collected through November 2009.

The authors found that:

- Of the 1,091 surveys mailed, 356 were returned (33% response rate). Of those returned, 18 facilities reported not providing any type of infant testing, and 34 reported providing only screening services for infants.
- Responses to the survey revealed that audiology facilities have different test batteries in place to provide infant diagnostic testing; 146 facilities (48%) offered a partial or incomplete test battery, 94 facilities offered all tests indicated in the JCIH (2007) guidelines except one or more, and 25 facilities offered all recommended tests.
- Additional areas of variability included appointment length; wait time for an appointment (ranging from 3 days to 5 months); the condition under which testing was available (natural sleep, sedation, or operating room); and the need for repeat testing.
- Respondents reported that the most common challenges to testing infants by age 3 months were related to scheduling and medical issues. Other challenges reported included staffing problems, reimbursement, and people not showing up for appointments.

“As shown by the results of this study, even though there are guidelines for infant hearing assessment (ASHA, 2004; JCIH, 2007), there exists variability in reported test protocols among clinics,” conclude the authors. They add that, “physicians and professionals in audiology, speech-language pathology, deaf education, and early intervention are challenged to work together to support families and help all children reach their full potential through timely and appropriate diagnosis and intervention.”

Muñoz K, Nelson L, Goldgewicht N, et al. 2011. Early hearing detection and intervention: Diagnostic hearing assessment practices. American Journal of Audiology 20(2):123-131. Abstract available at <http://aja.asha.org/cgi/content/abstract/20/2/123>.

## So...How is Oregon's Diagnostic Loss to Follow-up?

As most of our readers know, EHDI's program goal is that all infants who need screening follow-up receive a diagnostic evaluation by three months of age. However, as is true in most States, achieving this goal in Oregon is an ongoing challenge. Consider the data from 2010, when 941 (or 2.2 %) of the 42,822 screened infants failed or "referred" on their hearing screen. As seen in the table below, only 31.7% of these infants received a diagnostic evaluation by three months of age. The biggest differences in this milestone were regional: infants who live in the Portland metro area were much more likely to receive a diagnostic evaluation.



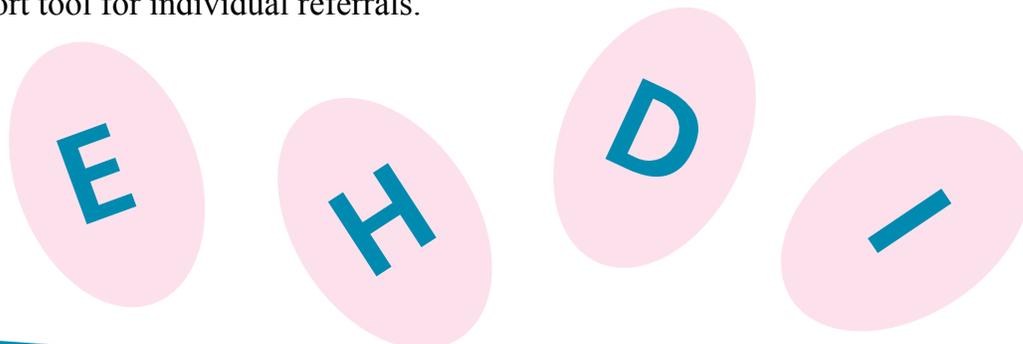
Region	% (n) of referred infants evaluated by three months	% (n) of referred infants evaluated at any age
Portland Metro area	50.4% (192)	66.1% (252)
Willamette Valley	36.1% (70)	46.4% (90)
Coastal/NW Oregon	27.6% (8)	27.6% (8)
Eastern Oregon	24.0% (25)	38.5% (40)
Southern Oregon	9.6% (22)	20.4% (47)
Central Oregon	5.4% (4)	13.5% (10)
<b>Statewide</b>	<b>31.7% (321)</b>	<b>44.2% (447)</b>

### What are we doing to reduce our diagnostic loss to follow-up (LFU)?

Oregon EHDI staff are currently taking the following action steps to improve diagnostic follow-up:

- Full implementation of a web-based audiology reporting system, the EHDI Information System (EHDI-IS)
- Hiring an EHDI audiology consultant to work with diagnostic sites
- Working with specific regions (Central and Southern OR) to place additional diagnostic equipment
- On-going mailings and partnerships with Hands & Voices/Guide-By-Your-Side and local Public Health Nurses to contact families and encourage follow-up
- Monitor screening results, and contact families at risk for LFU by letter, guide, or public health nurse
- On-going support to audiologists through trainings and technical assistance
- Monitor audiology reporting with the EHDI-IS

Future efforts will include: strengthening the linkage to a child's pediatric medical home, and developing a decision-support tool for individual referrals.

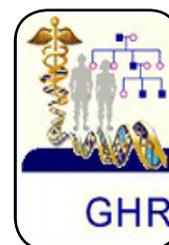


## GENETICS HOME REFERENCE INFORMATION “RX” FOR PARENTS ON NEWBORN HEARING SCREENING AND OTHER GENETIC DISORDERS

Physicians can help patients and families access up-to-date, reliable, consumer-friendly information about a genetic condition and the basics of genetic science by referring them to Genetics Home Reference, a free, patient-friendly Web site of the National Institutes of Health (NIH), at <http://ghr.nlm.nih.gov>. A free and convenient Information Rx prescription pad makes it easy to refer patients directly to Genetics Home Reference.

Pediatricians can request free “Information Rx” pads, which will enable them to write “prescriptions,” pointing patients to the Genetics Home Reference site and to the wealth of information it contains. These free “Information Rx” pads can be ordered online by following these simple steps:

- 1) Go to <http://www.informationrx.org/> and select Genetics Home Reference
- 2) Choose the organization to which you belong (eg, AAP, AAFP, ACOG, ACMG)
- 3) Enter the quantity of free Rx pads that you would like and proceed to checkout
- 4) Complete the required information for mailing and submit



Genetics Home Reference includes over 500 topics on genetic conditions and related genes. The site features a richly illustrated tutorial that explains the basics of genetics, from the cellular level on up, and a glossary of genetics terms. The site is regularly updated by scientific staff and reviewed by external experts.

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## LANGUAGE OUTCOMES FOR DEAF AND HARD OF HEARING CHILDREN

### Oregon EHDI and Hands & Voices Participate in National Study

By Helen Cotton-Leiser, Executive Director of Hand & Voices of Oregon



Hands & Voices of Oregon

At this year’s Early Hearing Detection and Intervention (EHDI) Conference, Dr. Christine Yoshinaga-Itano presented research on the language outcomes of children with hearing loss. Here in Oregon, we are participating in the National Early Assessment Childhood Assessment Project (NECAP), one of Dr. Yoshinaga-Itano’s projects so that we can see how our children are doing but also so we can contribute to the research at large.

In 259 assessments the NECAP team has currently conducted in participating states, almost 80% of the children scored within an average range on the Minnesota Expressive Language subtest. On average, children scored more poorly on cognitive-linguistic items (Minnesota Language Comprehension) compared to more superficial language items (Minnesota Expressive Language). As Dr. Yoshinaga-Itano stated in her presentation, acquiring an age-appropriate lexicon is a challenge for many children, with 43% demonstrating significant delays.

One of the outcomes the NECAP team is studying is the delay in pragmatic language at 7 years of age for deaf/hard of hearing children. Pragmatic language refers to the verbal and non-verbal rules that dictate our social interactions. Pragmatic language is the social language we use everyday in many different settings, from knowing what to do when we enter a room full of people, to interacting in the classroom, to having the ability to perceive another person’s feeling based

on visual cues. If we don't understand how to interact socially, it can really hinder our ability to connect with others. (See also <http://www.speechlanguagefeeding.com/pragmatic-language-social-skills/>)

Dr. Yoshinaga-Itano breaks down pragmatic language into 7 characteristics:

1. Instrumental: the language we use to get what we want, satisfying our needs;
2. Regulatory Language: the language we use to maintain personal relationships, commands;
3. Interactional: the language we use as social rules, poise, politeness;
4. Personal Language: the language we use to express feelings or personality;
5. Informative: the language we use to convey information, cause/effect, compare/contrast, etc;
6. Imaginative: the language we use for pretend play;
7. Heuristic: the language we use for wondering, finding things out, questioning to gain information.

The NECAP team is examining when children with hearing loss, regardless of communication mode used, master specific pragmatic language skills as compared to their normal hearing peers. Some interesting points she made about pragmatic language are that “children who are deaf or hard of hearing use more directive and less informative communicative functions than their normally hearing age-matched peers” (Day, 1986; Nicholas, 2000; Nicholas & Geers, 1977). Another astonishing finding is that pragmatic language difficulties increase the risk for victimization (Conti-Ramsden & Botting, 2004).

#### **Percent (%) Mastery of 45 Specific Pragmatic Skills, by Age and Hearing Loss**

Age	Children with Normal Hearing	Children with Hearing Loss
3	44% (20 of 45 skills)	--
4	95.5% (43 of 45 skills)	--
5	98%	--
6	100%	6.6% (3 of 45 skills)
7	--	69% (31 of 45 skills)

Dr. Yoshinaga-Itano concluded that children who are deaf or hard of hearing begin to master pragmatic skills several years later than their normal hearing peers. This suggests the importance of supporting pragmatic skill development in children with hearing loss to reduce the risk for social-emotional deficits and victimization.

For a complete look at Dr. Yoshinaga-Itano's presentation please go to: [http://ehdimeeting.org/Users/Uploads/pdfs/sps\\_17ChristineYoshinaga-Itano.pdf](http://ehdimeeting.org/Users/Uploads/pdfs/sps_17ChristineYoshinaga-Itano.pdf)

