

Oregon EHDI Newsletter

October 2011



*****SAVE THE DATE*****

November 3, 2011

EHDI Newborn Hearing Screening Workshop

Greetings **Newborn Hearing Screening Coordinators,**

Birth Clerks and **Hearing Screeners,**

Oregon Early Hearing Detection and Intervention (EHDI) is pleased to announce the annual NHS Coordinator Workshop will be held on Thursday, November 3, 2011 at the Portland State Office Building from 9 a.m.-3:30 p.m. We look forward to celebrating your success in providing 94% of Oregon's babies with newborn hearing screenings, and will discuss the challenges and opportunities to close the gap so that all of Oregon's babies are screened by one month of age.

Detailed information, including a tentative agenda, is included in the [workshop brochure](#).

Click [here](#) to complete the online registration form. Lunch will be provided to all registered attendees.

Thank you for the important work you do for Oregon's babies and your participation in this workshop.



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Free Infant and Toddler Hearing Screenings

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. 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.



FREE HEARING SCREENING DATES AND LOCATIONS:

You must make an appointment for a free screening. To make an appointment, call or e-mail the contact person listed for each clinic. If none of the dates listed work for you, contact the person listed anyway as there are always future clinics being planned.

Monday, November 14, 2011

Portland, OR

Alma Midwifery Education & Movement Space
1233 SE Stark
Portland, OR 97214
Appointment times are available 9:30 - 2:00.

Wednesday, December 14, 2011

Portland, OR

Alma Midwifery Education & Movement Space
1233 SE Stark
Portland, OR 97214
Appointment times are available 9:30 - 2:00.

Monday, January 23, 2012

Portland, OR

Andaluz Waterbirth Center
3323 SW Naito Pkwy
Portland, OR 97239
Appointment times are available 9:30 - 2:00.

Wednesday, February 15, 2012

Portland, OR

Alma Midwifery Education & Movement Space
1233 SE Stark
Portland, OR 97214
Appointment times are available 9:30-2:00.

To make an appointment for any of the four clinics described here, contact Carol Gray at 503-830-8995 or e-mail carol@carolgray.com.

The Portland State University Audiology Clinic also offers free hearing screenings on various dates and times. To make an appointment at the PSU Audiology Clinic, call 503-725-3070 or e-mail Anne Heassler at anh@pdx.edu.

How is Your Hearing Loss Vocabulary?

1. *Large vestibular aqueduct, also known as enlarged vestibular aqueduct syndrome (EVAS), is a syndromic form of hearing loss caused by enlargement of the vestibular aqueduct in the inner ear. It is one of the most common inner ear deformities which results in hearing loss during childhood.*



2. *The vestibular system contributes to balance in most mammals and to the sense of spatial orientation. Together with the cochlea, a part of the auditory system, it constitutes the labyrinth of the inner ear in most mammals, situated in the vestibulum in the inner ear. - Wikipedia definitions*

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Progressive Hearing Loss: A Parent's Story

Enlarged Vestibular Aqueduct Syndrome and My Son Riley

by Tami Esmay, a Hands & Voices of Oregon Parent Guide

First, some background: Enlarged or Large Vestibular Aqueduct Syndrome (EVAS or LVAS) is a progressive, primarily sensorineural type of hearing loss. An aqueduct is a narrow canal that runs through the skull, connecting the inner ear to the cranial cavity. It can be detected through the use of a CT scan or MRI. Head trauma as well as barometric changes can cause a person's hearing to decrease.

To help reduce the potential of further hearing loss, children with LVAS are encouraged to avoid head impact sports and are encouraged to wear head protection when involved with any impact sports. Since a change in barometric pressure can also cause further change in hearing, activities such as scuba diving are discouraged. Due to the nature of this hearing loss, alternate means of communication are encouraged, which may include sign language or cued speech as well as using assistive devices such as hearing aids or cochlear implants.

Along with this being a progressive hearing loss, a person with LVAS can experience hearing fluctuations from day to day. One day a person can hear within their "normal" range, then the next day their hearing could decrease in decibels, with the third day their hearing going back up within "normal" range again.

Since the hearing loss affects the vestibular system, some people can experience episodes of vertigo. Episodes can be very minor with minimal side effects from minor nausea to vomiting and dizziness.

There has not been much research on LVAS, but there is an ongoing study with the [NIDCD](#) (National Institute on Deafness and other Communication Disorders). No proven treatments have been discovered thus far.

My 10-year-old son Riley was diagnosed with a possible hearing loss in his left ear through the EHDI-mandated newborn hearing screening. He was initially diagnosed with a slight mild conductive hearing loss in his left ear and no loss in his right ear. By 3 years of age, his hearing started to slope to moderate to moderately severe in his left ear and sloped to moderate for his right ear. At this time, he was fitted with his first hearing aids. He was very excited to pick out the color of his very first set of ear molds: red. At this time, the audiologist noticed that the sensitivity in each ear had started to decrease. By 4 ½ years old, his right ear displayed a mild sloping hearing loss while his left ear displayed a mild to severe loss. Riley's hearing remained stable until he was about 9 years of age with some fluctuation. At 10 years old, his right ear has stayed within the mild to moderate range, and his left ear has sloped from mild to profound loss.

Riley was diagnosed with LVAS when he was five years old. We also had him evaluated by an occupational therapist to see what she could do to help him increase his balance and gross motor skills. After receiving Occupational Therapy services for a couple of years, his balance and his coordination improved tremendously and put him within his age group developmentally.

Although Riley has LVAS, we have chosen to only limit him from participating in a few extracurricular activities. Now that he is older, he is more aware of the risks and chooses his own activities cautiously with some guidance. Riley has always used the proper safety equipment when needed. He has played baseball since he was 5 years old as well as tried soccer and basketball. Due to the high concussion rates in soccer and football he has decided not to play those sports.



Riley experiences episodes of vertigo which started off minor when he was younger but as he has grown and gotten older the frequency and the intensity has increased. The last couple of years he has experienced nausea with vomiting, not being able to walk very well as well as being very sensitive to light. When his episodes occur, they usually last a couple of days with the first day being the most severe and the second with minor dizziness and no other related symptoms. Our ENT has informed us that a low percentage of people with LVAS have these vertigo episodes.

Riley's hearing tends to fluctuate on a weekly basis with it being as frequent as daily. He does not have the maturity yet to identify this, but it is obvious due to the nature of him saying "what" more often, and not responding when he normally would.

Now that he is older he is starting to share more openly about his hearing loss and recently shared with me that he is scared to lose his hearing and feels left out at times being the only one with hearing aids/hearing loss. He does have a younger brother with a unilateral loss, but it just is not comparable. To try to ease his anxiety level about the unknown future, we have learned some ASL with plans of more classes in the future. We also participate in all Hands & Voices family events. I have shown and discussed with him information about cochlear implants. He has firmly stated that he does not want a cochlear implant because he thinks that it will interfere with him learning more ASL.

One of the biggest frustrations that my husband and I have encountered is being able to get professionals within the educational setting to understand the nature of his hearing loss. Some of these frustrations include: making sure that Riley's technology (Hearing Aids and Personal FM) are working properly in the classroom and the level of social awareness/maturity as well as Riley's processing/understanding of materials presented to him.

Although Riley has had many challenges, he has been very successful in his academics. He has also increased his willingness to try new things as he has gotten older. Many people comment on how well natured he is amongst others.

A lot of Riley's successes can be attributed to him helping guide us to what he feels most comfortable with along this lifelong journey.

Two chat groups that contain a lot of information from other parents and professionals are Facebook and a Yahoo group; The Yahoo e-mail is LVAS@yahoogroups.com. The information I have shared here was derived from various articles I have read.

EHDI Advisory Committee Member Travels to Vietnam

To Teach Audiology and Help Children

This summer, Oregon Pediatric Audiologist and longtime EHDI Advisory Committee Member Christi Sperry went to Vietnam for a month on a Global Foundation for Children with Hearing Loss (GFCHL) project. There, she and other Audiologists taught Audiology students and provided free audiological evaluations to children in need. Below, Christi shares some of her experiences....

I worked at a school for kids with hearing loss. The first half of my stay was focused on teaching a group of Audiology students on the basics of Audiology and how to manage children and their families with hearing loss. The students

in our class consisted of about 18 individuals - clinicians, otolaryngologists, hearing aid dispensers, teachers, and teacher aids. There is no formal education for Audiologists in Vietnam, so there is no place for anyone to learn how to best evaluate and manage the hearing loss population.

For two weeks, we spent most of the day lecturing to the students. The lectures were put together by a five-person team of Audiologists months ahead of time and were translated into Vietnamese for class. We lectured on diagnostics, newborn hearing screening, hearing aid evaluations and fittings and overall best practice. The rest of the day was spent in hands-on labs teaching the students how to perform basic evaluations, troubleshoot hearing aids and counsel patients.

An audiology clinic took up the last two weeks. Children

came with their parents from all over southern Vietnam to be seen for proper audiology evaluations and, when necessary, hearing aid evaluations and fittings. Our students worked with us as we evaluated, diagnosed and managed over 60 families. Fifteen families received brand new hearing aids from various donors in the U.S.

During this trip, I learned that there are vast differences in what we are able to provide for our families, and that we really can help families here if we work to counsel and empower them to be their families' best advocates. I also learned that there are many similarities among families globally. This is helpful when working with and relating to the families I see here in Oregon's Providence hospitals.

For example, I saw one single mom with her 3-year-old son with profound bilateral hearing loss. She was unable to handle his behavior and had no help or resources to manage her child. Unfortunately, she was unwilling to follow any management strategies we laid out for her (with the help of our Vietnamese counterparts) as she said it was "too difficult".

In contrast, I saw another single mom with her 2 ½ year old son with profound bilateral hearing loss. She was also having difficulties with behavior, however she was willing to go over and above to do anything for her child. She had little to no financial resources, but she asked many questions and was able to advocate enough to get some aid from her school. The dichotomy of these two examples spoke to me on how there are similarities across such differing cultures.



One situation in particular helped me see my life and work from a fresh perspective. There was a family with a little girl with profound bilateral hearing loss. Her mother had acquired rubella during her first trimester of pregnancy, which is a common risk factor for hearing loss. (Vaccines are still not regularly provided in Vietnam.) This little girl had no residual hearing and could not benefit from hearing aids. The mother was told she would be “an excellent candidate for cochlear implants, however she was too poor”. After a little digging, I discovered the hospitals will offer financial aid to some families, however it greatly depends on their political standing, as well as their social and economic standing. I counseled this family to investigate places for their daughter to learn Vietnamese Sign Language. However, there were limited resources provided to them for this as well. The hopelessness of their situation and their reactions were unlike any I’ve experienced in my professional life. Among such great sadness and feelings of helplessness, I found myself feeling immense gratitude for what I have, not only in my personal life, but also in my professional and cultural life.

Public Health Pioneer Brings Sound to Generations of Babies

By Katie Kerwin McCrimmon for [Health Policy Solutions, Colorado*](#)

The Denver woman who has brought sound to life for generations of babies might have missed her groundbreaking career had the line to study audiology been longer.

Marion Downs, now 97, was headed back to school for a master’s degree at age 35 after raising her own children when she strolled in to the University of Denver.

“I went to register and found the shortest line. It was speech pathology and audiology. I became an audiologist by chance,” said Downs. “I just wanted to do something. You can be any age and make a difference.”



Downs has proved just that for decades. She famously jumped out of a plane to celebrate her 90th birthday and continued to play tennis well into her 90s, earning kudos as the top-ranked player in the U.S. over 90.

On August 24, 2011, public health experts from Colorado and the Centers for Disease Control and Prevention gathered in Denver to honor Downs and showcase her exceptional work that helps children with birth defects and developmental disabilities.

Marion Downs knew that early intervention would help the brain and speech development of children with hearing loss. Research later proved her correct and screening at birth is now standard in the U.S. and around the world.

Downs started the first infant hearing screening program in the country in Denver in 1963. Today, more than 95 percent of all babies in the U.S. are screened for hearing loss at birth, a direct result of Downs’ determination to find and help children with hearing deficits as early as she could.

After earning a masters in audiology from DU in 1951, Downs became convinced that children should be screened as babies. She was seen as a revolutionary for fitting babies who were just weeks old with hearing aides.

“If they have a problem, it’s best if they are identified early because the brain is only plastic in the early one or two years of life. Neurons that aren’t used will drop off. So it’s important for the brain to be stimulated,” Downs said.

There’s more to this trailblazer’s inspiring story. For the entire article, click [here](#).

*Thank you to Dolores Orfanakis for bringing this article to our attention.

Study: Benefits of Early Intervention for Deaf Children Far Outweigh Costs

Canberra, Australia — According to a new Australian study, every Australian dollar (A\$) invested in early intervention services for deaf children produces almost two dollars' worth of social, educational, vocational, and economic benefit.

The analysis, commissioned and launched by First Voice, a coalition of Australian hearing charities, showed that costs of early intervention programs, wages foregone by caregivers, costs of therapy, and costs of hearing devices were dwarfed by the long-term benefits, such as higher incomes, reduction in disability, avoidance of extra school costs, and the likelihood of those who underwent therapy being in longer term paid work.

Using a 50-year horizon, the cost of early intervention services was estimated at A\$203,307 in current dollar terms, while the lifelong benefit was conservatively estimated at A\$382,894 in current dollar terms, delivering an overall benefit-to-cost ratio of 1.9:1.

First Voice chairperson, Dr Dimity Dornan, said the report provided the economic rationale for government investment in early intervention services for Australia's deaf children.

He said, "We've known for some time that almost all of the hearing impaired children who participate in early programs that focus on listening and speaking go on to do well at mainstream schools. This report confirms the longer term economic and social benefits of that progress. These children end up in better jobs with higher salaries than they would have otherwise. It clearly shows they are avoiding the additional costs of special schools and the need for ongoing disability support," said Dornan in the press statement.

The report assumed a government contribution of 40% of the operational costs, or around \$6,000 per child per year, then goes on to conclude that "the [Australian] government is thus able to leverage private contributions to achieve an important social outcome with economic benefits that significantly exceed the government co-contribution."

For more information and copies of the report, visit [First Voice](#).

Many thanks to Tucker-Maxon Oral School for bringing this article to EHDI's attention.

Contact Oregon EHDI

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

EHDI Website: Type healthoregon.org/ehdi in your browser's address bar. (It's a shortcut that's much easier than using our actual looooong web address.)

Submit newsletter contributions to julie.a.hass@state.or.us

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