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Hands & Voices of Oregon

# Hands & Voices of Oregon

June 2011

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## Quick Updates

### **H&V Annual Picnic!**

August 21st; 11:30-3:30

Town Center Park

29250 SW Parkway Court

Wilsonville, 97070

Splash in the fountains, play on the jungle gym, dig in the sandbox, meet other parents.

Fun for the entire family!

Drinks, hamburgers, hot dogs, veggie options provided.

Please let us know if you plan to bring a dish to share.

RSVP by August 14th:

503-750-1097 or

[info@handsandvoicesor.org](mailto:info@handsandvoicesor.org)

See you there!!

We wish Don Plapinger a fun retirement in Arizona and Kimberli Davenport an incredible new chapter in her

## Letter from the Executive Director Helen Cotton Leiser

Dear Hands & Voices Family,

Last week we did take the plunge and wrapped our daughter's cochlear implants so they could hear with one ear each while swimming. I was as excited as I was nervous (for the safety of the \$20,000 worth of equipment we were allowing to be put at risk!).

While watching my girls in the pool with their friends my heart stopped each time my oldest dove under water but I was also watching to see if there was a difference in their experience. Both girls have always done very well and their friends know they have to face the girls so they can lip read. It has always been a challenge with new kids and the lifeguards. But they always managed to have a great time.

At one point while watching them I realized this wasn't just our experience, but also that of their friends. That day at the pool had a whole new meaning as I realized this was a new experience for their friends too. I immediately started forming interview style questions in my head as I wanted to know more about how they felt. I quickly learned that starting the "interview" while pulling/pushing them on the inner tube was not the best timing on my part! One of the girls looked at me like I was crazy!

On the walk home my eagerness was better timed as I again asked their friends how it was having Ashlin and Mikaylin able to hear while in the pool. I was thinking they would exclaim with great excitement that it was awesome and the best thing on earth, instead I got a shrug of the shoulders and a comment that yes it good. But when my oldest asked if she could wear her "ear" the next time we went swimming her friends chimed in with games that they would be able to play if Ashlin could hear and the one friend who spent most of the time playing with 3 year old

life in Los Angeles. Both Audiologists have been incredible friends of H&V and have worked with almost all of our kids in Oregon. They have both been some of the most important people in my family's life and they will both be missed tremendously by all of our families!

Thank you, Don and Kimberli for your commitment over the years to all of our kiddos.

Thank you for your compassion and dedication.

### Quick Links

[www.handsandvoicesor.org](http://www.handsandvoicesor.org)  
[www.ndep.org](http://www.ndep.org)  
<http://www.ushersyndrome.nih.gov/>  
<http://groups.yahoo.com/group/AtresiaMicrotia/>  
<http://deafed-childabuse-neglect-col.wiki.educ.msu.edu/>

**1-800-4-A-CHILD:** when you suspect a child is experiencing maltreatment.

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Mikaylin stated that it was definitely easier that she could hear her. I for one have to admit that I am excited my girls will be able to play "Marco Polo". To me that is a quintessential pool game that all youngsters should learn. (ok, so I am excited to play it with them, too!!)

I am definitely not recommending parents attempt to wrap their child's equipment so they can hear in the pool. As soon as my girls were done swimming I ripped open the wrapping to ensure the CI's were dry. They were and we will do it again, knowing full well that one time it may not work. Thankfully Advanced Bionics is working on a water-proof CI which means Cochlear America likely is too.

On a separate note, while at the H&V National Conference last month we all went out dancing one night. One of the highlights of that night was watching four deaf adult women dancing the night away while the ASL interpreters translated the songs for them. The best was watching one of the interpreters interpret an M&M song!

Hearing makes things easier, but it isn't necessary to have an incredible life experience!

FYI.. there will not be a newsletter in August so I hope to see you at the annual picnic on August 21. Have a great rest of your summer!

Regards,  
Helen

## Welcome to My World By Sara DesGeorges, H.S. Student

I walk and sit down at my desk. I look up, thinking the same thoughts I always have on the first day of school, and see my interpreter. Comfort surrounds me knowing that one person in the room knows how I feel. I scan the room. There's that boy who is the funny one, the class clown. There's the pretty girl all the guys love. I continue to scan to hope to find another comfort. I continue hoping to find a friend in that class. My eyes land on the last person. No luck. I have no friends in that class. An overwhelming fear comes in my mind. I think, I hate this class, and I hate having to declare to everyone that I'm hard of hearing. Once again, I have to go through the experience of seeing the wandering eyes of people trying to find out who the girl is that needs an interpreter. Throughout class everyone is looking for that one girl. The whole class time I'm thinking to myself: Ugh why me? What did I do to deserve this? I would go through the same thing for seven periods. Over and over again I would freak out. By the end of the day I just wanted to go home. I didn't want to have anything to do with my first day of high school. I hated high school.

It's been seven months now since that first day of school. I'm a freshman at Fairview high school in Boulder CO, a mainstream public school. There are only two hard of hearing kids in my school, me and another boy I rarely see. It's hard to walk into a school when you're all alone and your mindset is that no one will understand what you're going through, but I must say that being in high school has made me more confident in who I am. I'm just learning to accept my hearing loss.

I've grown up in a hearing world. Every once in awhile I go to deaf events. I'm not afraid to be my silly self when I'm with deaf or hard of hearing people, and that to me is everything I need. For the past eight years I have gone to the Aspen Camp School for the Deaf. I loved every moment of it because there was always a group of kids who knew how I felt without even talking about it. I had the comfort of knowing that they understood me. Then I always had to come back to the hearing world.

I wouldn't say it's been easy. I think that some hearing people take things for granted, but same goes for deaf people. I've met many people who have so much confidence in being deaf, and they have shown me that it's ok to be hard of hearing, and I need to embrace it. In my mind, hearing people have normal, easy lives. (Feel free to prove me wrong.) Hearing people don't need to go to IEP meetings or audiologist appointments. One of my pet peeves is when I'm talking to some of my hearing friends and open up to them, tell them how hard it is to be a hard of hearing person in a hearing world, and the reply is, "I know how you feel." I think, sure, you might know how I feel, but in reality we're two completely different people with two different lives. You're going through a tough time, but it's not the same as mine. When I'm with my deaf friends they understand completely and I can have the comfort of knowing that they do.

It's so important if you're hard of hearing to be able to talk to other hard of hearing or deaf people to get their perspective on things. The past seven months of being a freshman have shown me that I don't need to worry about my hearing loss and what people think. You only get to live life once. So why waste your day pitying yourself and wishing when the door to the world is right there. Someone once told me that there was a girl who refused to wear her hair up and expose her hearing aid. She was deathly afraid to go in public because she worried too much about what people thought. Her friends started to drift away because she never wanted to hang out in public. When I first heard that it broke my heart. I promised myself that I would never stoop that low in my self-confidence. Insecurity can eat you up inside. Not knowing who you are and what you live for can leave you lost in this world.

This song, "The Way I Was Made," by Chris Tomlin describes how I wish everyone would live and accept themselves and the way I want to live. The chorus goes like this:

I want to be the way I was made.  
I want to live like there's no tomorrow  
I want to dance like no one's around  
I want to sing like nobody's listening  
Before I lay my body down  
I want to give like I have plenty  
I want to love like I'm not afraid  
I want to be the man I was meant to be

## A Note to the Coach

Dear Coach,

It's truly a thrill to sit in the stands and watch my child hit one out of the ball park, or wrestle an opponent to the mat, or tackle a running back. Even when it isn't a celebratory moment, the sounds of encouragement being yelled out by you, teammates, or fans during a critical moment create an aura of contagious excitement. They envelope the player with feelings of motivation and comradery. Every player on the team needs these enthusiastic signs of support, especially my child...even though he is deaf.

Although my child cannot hear you at the plate...on the mat... or from the field...please don't stop yelling for him! Yell for him and add some body language as well!! If you're silent, everyone (including the opposing team) will think 'no one cares about this guy.' Your behavior sends him an important message, and it presents a model for his teammates who will be wondering what's appropriate for their non-hearing teammate. If you're urging him on, they will, too. This creates an energy that's palpable, and a picture that tells a thousand words. My child will see this and he'll feel accepted and included as a valued member of the team... So don't let a player's deafness or hearing loss stop you from cheering him or her on. Show that you care, and know that you are making an impact that will affect this kid positively during the game, during the rest of the school day, and one that will even be felt and recalled positively all his or her life.

With high hopes,

A Parent in the bleachers,

Leeanne Seaver

## **It's Time to Do Something** By Julia Hecht, MD

Recently, the front page of The New York Times had a headline about the sexual abuse of deaf children by a priest at a residential school for the deaf many years ago. One of the most heartbreaking aspects of this story is the fact that these deaf children repeatedly spoke out about their abuse to no avail. As the Medical Director of a residential school for the deaf, my experience is that the sexual abuse of deaf children (girls and boys) by adults is grossly underreported. In my 11 years in this role, I saw that abuse of deaf children was actually more common outside of the school, more commonly caused by family or community members. Deaf children then came to their school where they could easily communicate and some, but not all, would report what was happening to them.

What happens when children disclose their abuse varies and ranges across a spectrum. Schools are required to contact the state's Child Protective Services. The ideal response would be that the child receives a "safe house" interview by an appropriate, trained professional who is fluent in the child's mode of communication and can accurately and directly document the child's story of abuse. Child Protective Services would then work with the family to create a safe situation for the child. In my professional practice, I have never seen this happen. Usually, what happens is an effort that is compromised by communication inaccessibility.

## **Scenarios in the Real World**

The best outcome I've seen is when families are preserved by caring family members who step up and remove the child from the dangerous situation. The "best" (not optimal but better than the norm) safe house scenarios I've seen are when interpreters are called to facilitate communication with the interviewer and child during investigation. Sometimes another trusted adult, such as a teacher, will be present. This is often considered appropriate for "meeting the child's needs," but it does alter the genuine safe house protocol because there is no direct communication between the child and trained interviewer.

Another best-case scenario is arrest of the perpetrator(s). However, when the family is disrupted in this way, too often the deaf or hard of hearing child does not receive the therapeutic support to deal with the situation. There may be anger and denial within the family, and it may be directed at the child, who is further isolated. The most frustrating and ineffective outcomes are "lack of evidence" determinations of children with bruises who have described being beaten by adults. I have spoken with investigators who know something happened to the child but had no way to determine who the perpetrator was, and so no changes in the child's situation can be implemented. Unfortunately, I have seen reports disappear or fail to be investigated. I have also seen parents pull children from the school before an investigation can take place. In all situations where I have seen a meaningful measure of safety achieved for the child, it has been because of other family members who have intervened on his or her behalf.

## **What Keeps Us from Action?**

This subject is very emotionally difficult for adults for a number of reasons. Some of us have been traumatized ourselves as children, or attacked as adults. Others feel uncomfortable with the sexual aspect or helpless to make a difference through ignorance or lack of resources. These emotional obstacles are primary barriers to helping child victims. Therefore, unless a child is acting out and creating a disturbance, there is the lack of motivation to address what has happened. When a child continues to be victimized in an unsafe environment after making a disclosure, "learned helplessness" takes over and a child will silently cope.

Another barrier arises in situations when everyone involved is a hearing person except the child. Imagine how the situation is influenced when Social Services can communicate directly with adult perpetrator but not the abused child. Without the ability to represent the story from his or her own personal perspective in his/her mode of communication, the deck is stacked against the child's

credibility and s/he may never truly be "heard."

Finally, opportunities for therapy and healing are usually non-existent, scarce or inadequate. This is due to a combination of lack of funding, few deaf community members who are trained to deal with this subject, and even denial of the extent of the problem. The emotional wounds are buried. Later, these wounds can surface as emotional problems, addiction, and abusive relationships. Some victims will later become perpetrators, continuing the ripple effect of abuse, and the problem grows within the community.

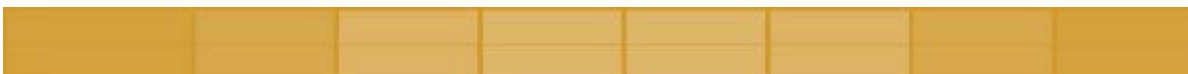
## Deaf Community Response

My experience within the deaf community (as an ASL-fluent hearing professional and as someone who socializes in this community) is that all of the above barriers and more exist. Some deaf communities have been "scandalized" by exposure of abuse in residential schools. Suddenly, the School for the Deaf is on the front page of the local paper, and the association is made in the minds of the hearing community who know nothing else about the school. Fear of exposure and harsh judgment can contribute to denial within the institution. This fear is not neutralized by the knowledge that the deaf school is usually the safe haven.

Awareness is only the first step...we must stay focused on the solution. Otherwise, it is easy to become overwhelmed with despair. The barriers that I've enumerated are not insurmountable. Whenever this difficult subject rises to public consciousness the soil is again fertile for change and inroads. I am so pleased to see that the Hands & Voices community is addressing this issue. What can we all do to help?

1. Coordinate with State Commissions for the Deaf to put this on the agenda. They are influential in needs assessments and funding allocation within the deaf community.
2. Collaborate with local rape crisis centers to identify, train and/or recruit "first responders" who can communicate in sign language with victims and are sensitized to the unique needs of a case involving a child with hearing loss.
3. Ask specifically about the protocol at your child's school for responding to abuse disclosures. What is done? Is the staff trained in this area and by whom? How are reports followed up?
4. Learn about treatment options like art therapy and play therapy that can be effective in healing child trauma. Create collaborations with art therapy and deaf education programs for specialized cross-disciplinary training. Set up scholarships for deaf college students who want to be art and play therapists.
5. Advocate for your schools to implement quality abuse prevention programs with students and families.
6. Promote early exposure to language and age appropriate language development, which are crucial in prevention. Children with language delay are at greater risk for abuse.
7. Finally, and most importantly, do not let your own discomfort be a barrier to your child's safety. Get help for your own trauma and break the cycle. Decide that you'll be part of the solution.

We can do this. ~



*"Faith is not about everything turning out okay; faith is about being okay no matter how things turn out."*

*- Van Barfoot*

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