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This issue marks the tenth anniversary of "Wavelengths." Idaho Hands & Voices came into being in early 2003, and by November we had started to send out a newsletter. Our first issue was two pages long and had no name. Someday soon we hope to get all the back issues onto our webpage. Meanwhile, it's been a busy fall--here's what we've been up to:

Our first Family Camp was a great experience for us, and we hope, for all the families who came. We want to thank everyone who volunteered their time and talents: IESDB, for helping with publicity, insurance, and loaning us some incredible staff members. Emily Donaldson, Janna Dunagan, Mikkel and April Nelson, Kim Cunningham, Joy Kane and Becca Seaman led the younger campers on journeys of exploration; Emily, April, Jayne Womack and Kyle Irwin provided interpreter services; and parents learned a lot about telecommunications equipment and education in the mainstream from Emilie Pennie (thanks to her employer, Hamilton Relay Services) and Darcy Sinsley. Jim Athinson ("Opa") was our man-about-camp, lending a hand or set of eyes wherever needed. Our hosts at Paradise Point Camp generously covered half the insurance costs for us and provided plenty of exciting activities. We sure hope to do this next year, and are working on fundraising ideas.

Our third annual golf scramble raised most of what we'll need for a second annual family camp. A great big Thank You to all our sponsors, including major donors Ada Vision Center and Dr. Michael and Gloria Myher, hole sponsors IESDB, IESDB Foundation, Idaho Council for the Deaf and Hard of Hearing, Dr. Rad and Injury Care EMS, M. J. Hawkins, Maynard Davis and Sandy Pichette, Erin Davison and Patti Campbell. A big thanks also goes to those who donated items for the raffle, and the 48 golfers!

We continued our quest for funds with a table at the Idaho Association of the Deaf/Boise Valley Association of the Deaf Holiday Bazaar on November 2. We earned enough to send at least half a family to camp next year (or at least buy the T-shirts) and Diana makes magic pot scrubbers that sell like hot cakes! Thank you, Kyle Irwin for once more doing face painting.

New Board Members

Jessica Stich-Hennen, Au.D., F-AAA is a pediatric audiologist for Elks Hearing & Balance Center-Boise and St Luke's Childrens Otolaryngology. She specializes in pediatric diagnostics and intervention. Dr. Stich-Hennen manages the St. Luke's Boise newborn hearing screening program and is the primary audiologist for Idaho Craniofacial Deformities team. In April 2011, Dr. Stich-Hennen became one of seven audiologists in the country to obtain Specialty Certification in Pediatric Audiology.

Valorie Ruth is the mother of six children; two of them are adopted and have a hearing loss. Her 15 year old is visually impaired and hard of hearing, and her 2 year old is profoundly deaf and has recently received a cochlear implant on one side. Valorie brings additional new perspectives to our board as a foster parent and resident of a more rural area (Weiser.)

We still have room at the table for more board members. If you are the parent of a child who is deaf or hard of hearing, a professional (or student studying for a profession) who works with children with hearing loss, or an adult who has experience growing up with a hearing loss, we need you. The more people help out, the more we can do. The more varied the experiences and perspectives of our board, the better we do as Hands & Voices. There is an application form at our website, under "About Us."

Idaho Hands & Voices is coming to Idaho Falls! Idaho Falls parents Summer and Kevin Osmond and Natalie Clement will be organizing family activities for that area. Thank you for stepping forward! If there are no activities happening in your area of the state, it's because no one in your area has volunteered... it could be you! It's easier than you think.

IAD Logo Contest: The Idaho Association of the Deaf is sponsoring a contest to design a new logo for the group, open to deaf and hard of hearing Idaho residents who are in 8th grade or older. We've shared the complete rules of the contest on our Face Book page, or you can email wildingbiz@gmail.com for more details.

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Upcoming Events

(There are no Idaho Hands & Voices events planned at this time for the next couple of months, but be sure to check our webpage or "like" our Face Book page to receive up-to-date information.)

North Idaho Deaf Club is in the planning stage for several events, including a November 20 presentation by Steven Snow at the Post Falls library, a possible ice-skating event in partnership with IESDB, a December 7 Christmas party, and a December 31 New Year's party. If you live in N Idaho, you'll want to be on Darcy Sinsley's mailing list to get up-to-date information; contact her at nidcplanner@gmail.com.

Idaho Parents Unlimited (IPUL) has a few "Advocacy 101" webinars scheduled. Go to their website, www.ipulidaho.org, and check the calendar for the contact information you'll need to register for one of these. You attend the webinar from home via the internet, or even at your public library if it provides this service. Webinars are scheduled for November 14, 10:30 am -12:00; November 21, 3:00 - 4:30 pm; and December 5, 9:00 - 10:30 pm.

Thunder Mountain North Pole Express: Special group rates and a sign language interpreter have been arranged for this train journey from Horseshoe Bend to Montour and a meeting with Santa and Mrs. Claus. You'll need to buy your tickets on or before November 22, and be at the train by 9:00 am December 7. The organizers are Sherry Matthews and April Nelson (april.nelson@iesdb.org) and they are collecting the money; checks or money orders should be made out to Thunder Mountain Line. The discount prices are Adults (age 13-59) \$31; Children (age 3-12) \$21; Seniors (age 60+) \$28; Infants/Toddlers (age 0-2) \$11. Wear layers of warm clothes, and bring your camera.

Signing Santa is coming to the River Valley Elementary Preschool December 19 at 1:00. A flyer will be going out, but in case it misses you, please contact Jill Muir (jill.muir@iesdb.org or 914-3728) for more information and to RSVP by December 15.

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Genetic Testing: Our Story (Part Two)

by Andrea Amestoy

When Andrea's daughter Kylie was born with a hearing loss similar to that of her older brother, it was immediately clear to Andrea, a nurse, that the cause was genetic, and she wanted to know more. She found resources for genetic testing, and sent in blood samples, and waited.... Here is the second part of the story we started in our September issue:

When reading about the genetic causes of hearing loss, I could with a high degree of certainty rule out Usher's I and III. However, Usher's II seemed to ignite a sixth sense within my body. Perhaps it was because my cousin played Helen Keller in the high school play when I was young or I ran by the Idaho Commission of the Blind on a daily basis for cross country practice. In another psychic meltdown about two weeks before receiving the results, I had Ryder go to the pediatric ophthalmologist. I voiced my concerns about Usher's but was told that it is extremely rare and that this particular doctor had never had an Usher's patient before. Walking out with a new sense of relief, I patiently awaited the definitive results.

On July 17th, my birthday, I received a message on my phone from my children's pediatrician. I immediately called him back and was told that the children had Usher Type IIc. I collapsed in grief but bucked up and took my kids to their swim lessons. The remainder of the night and summer was pure hell.

One of my favorite country crooners, Willie Nelson sung in a song "and I know just what I'd change if went back in time somehow But there's nothing I can do about it now." This quote keeps reverberating around my head because I would never choose to have children with Usher's Syndrome. However, there is nothing I can do about it now...but be proactive.

So what you may be wondering is the point of finding out about something that you can't do anything about? Trust that I have questioned at times, my decision to doggedly pursue genetic testing. However, I truly believe the pros outweigh the cons. I have my children wear sunglasses and hats while outside. I feed them foods rich in vitamin A. Think pumpkin, sweet potatoes and liver. Not combined together however. Lest you think my children toss back orange food that isn't candy on a regular basis, let me clarify. I hide pureed sweet potatoes, pumpkin and shredded liver into food like waffles, muffins and hamburgers. I look for food with high sources of Omega 3's. I also give them a multivitamin and fish oil caplets. None of this will prevent the inevitable but who knows, it may slow down the progression.

In addition, I joined a fabulous community called the Usher Syndrome Registry and network. This delightful group is comprised of parents of children with Usher's and those with Usher syndrome themselves. My family went to the Usher Family Conference in Portland this summer and met other families in similar situations and listened to amazing guest speakers who provided hope for the future in terms of medical treatment, clinical trials and gene therapies. My kids were around those who utilized a cane, guide dog and who communicated beautifully through tactile sign language. What a wonderful foundation to commence the crucial conversations with my kids about what they have when the time comes.

In addition to being a part of a vibrant and accomplished Usher community, knowing the genetic cause of the hearing loss provides a connection to a medical world that may solve the vision part of Usher's. Keeping abreast of clinical trials assures that a boat with the solution doesn't sail past us in the night. Much like cochlear implants have the best outcome during a certain time frame, the same may be true for future therapies targeted to vision loss. I also have connected with IESDB to begin Braille training and other teachings of visual services for my children. Not that this will necessarily be a reality but I firmly believe that the more exposed my children are to this world, the less scary it will be for them. In addition, they may find a passion in working with those who are blind or visually impaired.

So when life hands you a Costco size load of lemons, make an equivalent amount of lemonade. Another quote I like from Robert Frost states "the best way out is always through" and good old Winston Churchill stating "if you're going through hell, keep going." These quotes reinforce my belief of taking pain head on and tackling the problems and challenges inherit with this earthly world and hopefully in the end, growing from it.

In the future, I would like parents of children with hearing loss to know that there is always the possibility for a co-morbidity of vision loss to be a part of the equation. The possibility of dual sensory losses can no longer be swept under the rug or ignored. It serves a gross injustice to those parents possibly facing it. Parents need to be given current, up to date genetic testing information so they can choose for themselves whether or not to pursue genetic testing. They need and deserve the correct knowledge in order to empower themselves to make decisions regarding the genetics of their child's hearing loss.

Without this knowledge, those who have Usher's Type II will start tripping over things in the dark, chalking it up to clumsiness. As their peripheral vision is slowly erased, they will accommodate and often it isn't until they go in for an eye exam in their twenties that the doctor notices something amiss. Often they are told "you're going blind and there's nothing you can do about it." These are not the words I want my kids to hear alone and blindsided. Just like I don't want my kids to learn about the birds and the bees on the school playground, I don't want them learning about their diagnosis in the cold seat of an eye doctor's chair. I want to teach, educate and empower them as best I can to deal and work with this challenge.

Lastly, I truly believe a cure is on the horizon in the not too distant future. However, you are the cure to the key. By knowing if a child has Usher's, you can get signed up on the registry, become passionately active in raising awareness, funds, Congressional money appropriation and the like for snuffing this recessive genetic condition. You are the key for all this to happen. It cannot happen without you. If the diagnosis is Usher's Syndrome, I truly think, with time, you will see the possibilities.

Resources:

<http://www.usher-syndrome.org/>

www.nsgc.org

<http://informeddna.com>

<http://www.acmg.net/GIS>

Labs that conduct Usher Syndrome testing:

OtoSCOPE, University of Iowa, <http://morl-otoscope.org>

OtoSeq, University of Cincinnati, <http://www.cincinnatichildrens.org/service/g/genetic-hearing-loss/default/>

OtoGenome, Harvard University, <http://pcpgm.partners.org/lmm/tests/hearing-loss/OtoGenome>

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Genetic Testing: Some Considerations

You may or may not wish to pursue genetic testing for the cause of your child's hearing loss. This is an entirely personal decision with no "right" answer. There are risks and expense involved, and not all the genes that cause hearing loss are known, so you may not get any answers in the end. If it involves many members of an extended family, it may reveal sensitive information about paternity or adoption.

We all carry mutated genes of some sort or another, and there is no "blame" attached to having a child who has a genetic condition. In fact, knowing that the cause of a child's hearing loss is genetic can serve to reassure you that it is not due to something you did or didn't do during pregnancy.

The results of genetic testing are private, and cannot be shared with anyone else unless you give permission. If the information does leak out, most states have laws prohibiting discrimination on the basis of genetic information.

Genetic testing and counseling should go hand-in-hand. A genetic counselor can explain the results of the test and what they mean for your family--will the hearing loss progress? Are there other medical problems associated with the genetic mutation causing the hearing loss? What is the chance of having another child with a hearing loss? It is important to note that genetic counseling should be non-directive. The counselor should not give you advice about treatment or having more children. Those decisions are yours to make.

Perhaps the biggest advantage of knowing more about the cause of your child's hearing loss is the one so well-defined in Andrea's article. Hearing loss can be associated with heart or kidney problems and other medical conditions, including the progressive vision loss of Usher's syndrome. Some of these can be treated if caught early; if not, knowing what the future may bring helps in making decisions about education and treatment options.

"A Parent's Guide to Genetics and Hearing Loss" is a publication from the Center for Disease Control, available on line at <http://www.cdc.gov/ncbddd/hearingloss/freematerials/parentsguide508.pdf>. It includes an explanation of the different kinds of heredity, along with information about genetic testing.

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We welcome submissions from our readers! Send in articles, stories, ideas for stories, book and product reviews, anything you have to share to niwri2@msn.com, or call (208)324-7544. "Wavelengths" is published every two months, give or take a bit.

Pardon our web page, our webmaster's computer died, and her iPhone isn't up to the job of updating! It should be back on track before long.

Your membership in Idaho Hands & Voices may need to be renewed! Check the label on your copy of "The Communicator" for a date--your membership expires at the end of the year shown. Renewals can be done on line, and you'll receive one special reminder in the mail sometime early next year.