



www.idhandsandvoices.org

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We're looking forward to our first Family Camp, coming up September 13-15. If you're not coming to camp, you have another terrific opportunity that weekend, Deaf Awareness Day in Boise--see "Upcoming Events" for more details about this and other opportunities for parents and families.

A couple of our board members have had to step down due to plates that have become too full, leaving us even more short-handed than usual. If you've ever considered becoming more active in IDHV, now is the time! We welcome parents, professionals and deaf and hard of hearing adults, and you need not live in Boise. There's more information on our web page, under "About."

We were able to send two people to the national Hands & Voices Leadership Conference this summer. They've just completed their "homework"--here's some of the knowledge they brought home to share:

O. U. R. Children Safety Project

by Diana Collins

The 10th Annual Hands and Voices Leadership Conference was hosted in Madison, Wisconsin this year, and I was lucky enough to attend! Aside from the gorgeous city, and the amazing food and drink, this year's conference was just as informative and helpful as last year's. I learned so much, and wanted to share some information about an important topic for all of us.

Have you heard about the O.U.R. Children Safety Project? I had done a little research on it, previous to the conference, but attended a breakout session that expanded on the project. The O.U.R. project is a partnership between Hands and Voices and Harold Johnson, a researcher at Michigan State University. O.U.R. stands for Observing, Understanding and Responding in regards to child abuse, bullying and neglect. I was surprised and dismayed to learn that children with special needs are three times more likely to be a victim of child abuse or neglect; there are several reasons for this, but is commonly due to the fact that they are not able to communicate easily or fluently with parents, caregivers, neighbors, etc.

The following website has several resources and articles that are useful to parents and caregivers:

<http://www.handsandvoices.org/resources/OUR/>. Each link is full of information regarding the topic, but I especially found the PDF file titled "Silence is NOT an Option: A Parent Driven Plan to Keep Our Children Safe at Home and at School" interesting and helpful. It offers Parent Centered Solutions, Family Centered Solutions, School Centered Solutions, as well as suggestions and examples of how to include Safety Statements in your child's IFSP/IEP/504. At the end of the article, there are several questions, such as:

- What article can I share with family and friends to explain the maltreatment of children with disabilities?
- How can you know if a child is being maltreated?
- Why are children with disabilities at greater risk for maltreatment?
- What can schools do to keep children safe?
- Why does bullying occur and what can you do to stop it?
- Who are the parents and professionals working to keep our children safe?

After each question, there are links to more articles answering each of the questions fully. I am so grateful that Hands and Voices is pushing this project, and trying to bring this issue to the forefront for parents, families and professionals. To conclude, I'd like to pull directly from H&V's page: "If we can stop [the] cycle [of abuse]with even one child, one family...our efforts are more than worthwhile".

Attending the National Conference for Hands and Voices in Madison, Wisconsin was such a great experience for me, as the newest board member of the Idaho Chapter of Hands and Voices. I learned something new from each session I attended, but took the most away from the final presentation of the conference, given by Andrea Marwah of Illinois, titled “Advocacy 101”.

The purpose of the presentation was to give parents knowledge and understanding of how the special education system works, to learn strategies and techniques for advocating, and to gain confidence in advocating for our kids. The role of the parent in special education is to plan for their child’s educational future, to advocate for their educational future, to manage their current education and to maintain constant contact with their teachers and support educators.

Most of the presentation was geared towards the IEP meeting. What is the purpose of the IEP? Some of those purposes are:

- Accessing Free Appropriate Public Education (FAPE)
- Meeting unique needs of a child
- Preparing for employment
- Preparing for independent living
- Protecting the rights of children with disabilities.

So what are some rules of the game when it comes to advocacy and IEPs? Andrea suggested that parents be on time AND prepared for meetings, present concerns and problems in writing, and keep an open mind. She talked about how important it is to keep written records; not only making all requests in writing, but also documenting events when they occur. Create a paper trail by using a contact log, a journal, or a calendar. It is also a good idea to get copies of all forms that your school asks you to sign.

When it comes to your IEP, Andrea reminded us that neither teachers nor parents have the authority to make decisions alone. Decisions are made by the team which includes the parents, a regular education teacher, a special education teacher (Teacher of the Deaf/Hard of Hearing), an administrator and any other related service provider that your child needs such as a Speech and Language Pathologist, Occupational Therapist and/or Physical Therapist. She also reminded us that school districts have a chain of command, so instantaneous decisions cannot always be made regarding a commitment to resources. Remember to control your emotions, ask questions, and remember that you’re there to work TOGETHER. Chances are, your school district wants what is best for your child as well, and showing appreciation and keeping a positive attitude goes a long way.

Finally, Andrea stressed the importance of always, always, always asking questions if you don’t understand something. Remember the “5 W’s + H + E”: Who? What? Why? Where? When? How? Explain. Asking questions, plus the advice given above will help put you on the path to successful advocacy for your child.

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Idaho Educational Services for the Deaf and the Blind Welcomes a New School Year by Paula Mason

The IESDB Outreach Team is excited to start a new school year. We would like to share some changes. We have hired a new Education Specialist who will be supporting students, families, and districts in Region 7, Whitney Halling. Mallory Henry will provide supports to families, students, and districts in Region 2, the Moscow/Lewiston area. Arden Schmitt and Tammy Wilhoite have swapped Regions. Arden is now in Region 3, Caldwell/Nampa and Tammy is supporting families in Region 5, Twin Falls/Magic Valley. For the past three years Idaho Division of Vocational Rehabilitation has partnered with us to fund our Post-Secondary Transition Specialist positions. This spring IESDB and IDVR decided we would continue to provide great services through a partnership, but IDVR is no longer funding our positions. As a result, Ann Flannery will provide post-secondary transition supports to students statewide. She continues to be based at the College of Southern Idaho in Twin Falls. Steven Birkby will be taking on a regular caseload and will serve students, families, and districts in Region 3.

We have created a partnership with the Idaho Virtual Academy and we are in the process of creating Transition and Work Readiness classes that will be shared and made available to students online. We are researching the possibility of

making these classes a dual credit class through the College of Southern Idaho. We will be sharing more information as soon as we have those plans solidified.

Our IESDB staff will be supporting the Hands & Voices Family Camp September 14 in McCall, as well as the Idaho Deaf Awareness Day in Boise this same date. A language goal writing workshop is on the drawing board to be held in Region 5 at the College of Southern Idaho October 5. We will be mailing out flyers soon with more detailed information. A literacy workshop for teachers, support staff, and parents is in the works for Regions 1 and 2. Barbara Luetke will be our presenter and we are tentatively looking for dates toward the end of October. The literacy workshop will be funded by the Bright Family Trust, a grant awarded to IESDB to support education for students in North Idaho. Your Education Specialists are also planning family sign language classes; watch for flyers in the mail. Dates, times, and locations are being set up at this writing for each region.

We are looking forward to the great school year ahead. Please visit our website to gain information for upcoming events, www.iesdb.org. Speaking of our website, a recent expansion of the information we share might surprise you. Make a point of surfing into *Outreach Services* and find our soon-to-be-launched *new face*.

Opportunity for Treasure Valley Families to acquire an FM system:

The Idaho Educational Services for the Deaf and the Blind Foundation was recently awarded \$6,000 by the Laura Moore Cunningham Foundation to provide up to 10 FM systems in Ada and Canyon Counties. These FM systems will be for children ages 3-24 with priority preference going to preschool age children. The criteria for receiving the FM systems are:

- Deaf or Hard of Hearing Child ages 3-24 years
- Must provide proof of residence in Ada or Canyon Counties
- Must have an income of less than 150% of the federal poverty guidelines (\$35,325 for a family of four) OR have no insurance coverage for FM Systems
- Request for applications should be sent to director@iesdb.org by between August 28, 2013 and September 12, 2013. The IESDB Foundation Board will meet on September 18, 2013 to prioritize applicants.
 - Applicants should complete 1 page request
 - Provide a check stub for each person in the household
 - Provide verification that the insurance does not cover FM Systems
- The project is dependent on grant funding for future services. Services will be provided for this project until funds are fully expended.

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Upcoming Events

(Be sure to check our webpage or "like" our Facebook page to receive up-to-date information. If you'd like to have an interpreter present for an Idaho Hands & Voices activity, please let us know by email as far in advance as possible.)

Idaho Deaf Awareness Day Saturday, September 14, 9:00 am to 4:00 pm, at the Best Western Plus Vista Inn's Rocky Mountain conference Center, 2645 Airport Way, Boise. Free Admission, family and children's activities, entertainment, mini-workshops, exhibit and information booths. For more information, contact Steven Snow at (208)334-0879 (voice), (208) 473-2122 (videophone/voice) or steven.snow@vr.idaho.gov.

Elks Hearing & Balance Center Parent Education Series (RSVP 489-4999; interpreters available on request.)

September 17: FM Systems and Assistive Listening Devices, 6:30-7:00 pm, Elks Hearing & Balance Center 510 N. 2nd St, Boise. Discover "What, When and How" to begin using assistive listening devices with hearing aids or cochlear implants in the classroom and at home. Hands-on equipment demonstrations will be available.

October 15: Are You Listening? 6:30-7:30 pm, St. Luke's Meridian Medical Center, Lemhi Room (Lower Level.) Learn about how to help your baby, child or young child develop listening skills, including ideas for activities to make it fun.

Third Annual Idaho Hands & Voices Golf Scramble, September 28 at the Boise Ranch Golf Club, 6501 S Cloverdale Rd, Boise. This is our big fund-raiser of the year, which allows us to offer scholarship memberships, buy food for events, and subsidize our family camp. If you know of any businesses or individuals that would like to support us, we offer lots of ways to do so, for every budget; if you golf, find three friends and sign up by September 16 to participate. Further details can be found at www.idhandsandvoices.org/golf.

Magic Valley Pumpkin Painting: Now in our 6th? 7th? year--don't miss the fun! We're combining forces with Magic Valley ESCAPADE for this one. Saturday, October 26, 2:00 pm at Lorna Irwin's house, 76 W 100 N in Jerome. A friend just gave us a whole box of plaster bobble-heads to paint, too. Watch for a flier, or contact Lorna at 324-7544 or niwri2@msn.com for more information.

North Idaho Hands & Voices Halloween party, in conjunction with North Idaho Deaf Club, October 26. Still in the planning stages, contact info@idhandsandvoices.org if you don't hear more as the date approaches.

North Idaho Deaf Club is planning a potluck picnic for September 21 and a pizza and games night September 28. Contact Darcy Sinsley at nidcplanner@gmail.com for more information.

Idaho Falls Hands & Voices informational meeting Tuesday, October 8, in the evening; time and place to be announced, watch for a flier or contact Lorna (niwri2@msn.com) or Ranie (ranie.mattingly@iesdb.org). Come learn more about Hands & Voices and help get a group started in Idaho Falls.

Idaho Parents Unlimited (IPUL) is holding "Success with the IEP" workshops around the state this fall. Check their webpage at www.ipulidaho.org for up-to-date and more complete information. September 17 in Pocatello, September 24 in Boise, October 8 in Sandpoint; October 16 in Hayden; October 17 in Moscow. There is also a special workshop in Twin Falls October 5, in conjunction with IESDB, focusing on writing language goals into the IEP.

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Genetic Testing: Our Story

by Andrea Amestoy

After my second child referred on his hearing screen and was diagnosed with a moderate-severe bilateral sensorineural hearing loss, I was devastated. I meticulously reviewed my pregnancy, dissecting every detail, convinced I had inadvertently done something to cause the hearing loss. Was it feeding my birds in an aviary that had a mouse infestation? Was it the brief dipping of my legs into a hot tub that caused it? Could it be the heat sensitive register tape, dusted in chemicals, that somehow robbed my child's hair cells? Did I garden and accidentally inhale cat feces which could harbor toxoplasmosis? Did I get CMV? All of these proved negative as I had tests run and nothing came back.

Still skeptical of the genetics and wanting a third child, our daughter Kylie was born. During that pregnancy I controlled for every absurd variable I thought caused the hearing loss. Like her brother, she referred on her hearing screen at birth and was identified with a similar hearing loss. Aha! So it was genetic. The weight of the world seemed to float off my shoulders when I realized I had done nothing; it was all up to chance and the toss of the genetic dice.

The type of mind I have never lets things go. In that vein, I doggedly pursued genetic testing as a means to an end to figure out my children's hearing loss. Being a nurse, my education is geared towards this type of thinking and problem solving. I was told about a study out of the University of Iowa that was recruiting those with hearing loss for a large genetic study. I immediately contacted them about my avid interest in participating and when Kylie was 10 weeks old, submitted blood from all family members.... *(to be continued in our November issue, along with more 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.