



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Project Director • Winter-Spring 2011



February 2011

Hello everyone!

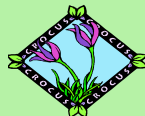
Brrr! Cold snap over??

I actually saw some crocuses peeking through and a few daffodils too — So I guess it's time for another newsletter!

Did you know that the project is now on **facebook**? An easy way to link to it is to go to our website: [www.oregondb.org](http://www.oregondb.org), scroll to the end of the home page and click on the facebook link there.

Take a closer look at:

- The "Wall" — where we are posting all kinds of interesting information — most of the posts include the necessary links so you can get more details. PLEASE ADD YOUR COMMENTS too.
- The "Info" section tells you about the project, in brief, with links to our website where you can get more information. If you have questions, you are welcome to e-mail me [ayerl@wou.edu](mailto:ayerl@wou.edu).
- Under the "Photos" section we have two albums of many of our wonderful children and their families at a couple of family events.
- HELP! Under the "Discussions" buttons I have been attempting to post something that may lead to a discussion — but have not succeeded yet! SO — professionals and parents out there.... e-mail me your suggestions.
- We have no "Events" posted yet since we have not had any project-specific events. But we will use this when we do!
- Don't forget to check out other websites on "favorites" — and send in more that you may find too!



Lyn



### CONTENTS

Director's note	1
Oregon Deafblind Project	2
Wrightslaw humor	2
Usher Syndrome updates	3
Guide dogs for persons who are deafblind	4
Guide dogs: personal story	5
The Toolbox: Let's Make That Functional — Brain facts	6-7
Upcoming events and news:	
CHARGE conference	8
R.i.s.e. conference	8
Tech flash—Read2Go	8
Professional Development	9
Technology	9
Attention Parents: NFADB and Other family organizations	10
The Deafblind Working Group	11
Project Contact Information	11

In the words of Helen Keller:  
 "Everything has its wonders, even darkness and silence, and I learn whatever state I am in, therein to be content"

## Oregon Deafblind Project

facebook

LIKE?

The Project is now on Facebook — and we hope you will visit us there. One way to get there is to go to [www.oregondb.org](http://www.oregondb.org), scroll down to the bottom of the home page, and click on the link there.

The project depends on YOU to make the facebook page a successful networking site. We would really like it to be more interactive. SO — go on there, write your comments, "like" us — or write to me with ideas for:

- More favorite sites to link to
- Ideas for Discussions
- Topics you would like more information about
- Send us photographs of your children (We will send you a permission form to sign before we put anything on any of our sites — webpage or facebook).

Facebook is a really efficient way to connect to all the other deafblind projects in the country — or even elsewhere. This includes not just state deafblind projects, but also national ones like the National Consortium on Deaf-Blindness (NCDB), or the National Family Association for Deaf-Blind (NFADB). Each project in the country has information to contribute — and we can certainly all learn from one another much more easily than we did in the past. I will attempt to post information as it comes out — or search for information which you may find interesting and/or useful. However, it will be really wonderful if I had help with WHAT people want to see posted. So — parents, professionals — please feel free to add to the interest-value of this facebook page. In advance — thanks!

## Learning Special Education Law

Do any of you get the Wrightslaw newsletter, "The Special Education Advocate"? It is an excellent source of information about law, regulations, and case law. There is a lot of emphasis on the IEP and how parents can advocate for themselves and their children. Wrightslaw has several excellent publications as well. Their website is at: <http://www.wrightslaw.com/>

One of the things that caught my attention was that one of the mothers, attorney Aimee Gilman, is able to see the funny side of things and to realize that humor is good for the soul — and for the IEP process! One such collection is at: <http://www.fetaweb.com/humor.htm>

Here are some samples from her pages.....

**IEP:** "Your school district, in an ongoing effort to remind you of the incredibly small role moms and dads play in this process, will start by sending you an "Invitation" to attend your child's IEP meeting. Of course, the parents are the only ones on the team who receive such an invitation, as though the district expects that you may politely decline and simply send a gift instead."

**VISION STATEMENT:** "The Department of Education recently designed an especially torturous device for IEPs called the Vision Statement. This Statement purports to allow the parents an opportunity to say where they see their child in the future. The Vision Statement is completely nonbinding on the District and serves no purpose other than to create an emotional outburst from parents who have no desire to speculate about their child's future in front of this unfriendly crowd, or anywhere else for that matter. I always advise my clients to tell the district they envision their child attending Harvard Medical School starting tomorrow. This usually sets an appropriate tone for the remainder for the meeting, and may help to avoid some of the pitfalls discussed above.

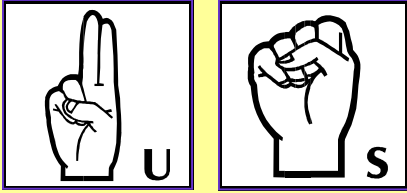
**RULES FOR MEDIATION:** This section starts this way: "Special ed mediations must always occur at the district board of education office so that parents and their advocates are the only ones inconvenienced (and intimidated) by the location. Initially, the parties convene in one room, then separate into two rooms because by the time mediation is necessary, they can no longer stand the sight of each other. ..."

**ABOUT PARENTS,** she says: "There are 2 kinds of parents of disabled children: moms and dads. There is a very important distinction between these types and one could never be confused with the other."

About herself: "I am always amused when people describe my son as being "perseverative." At least he lets go after a while, while I can go on and on long after anyone has demonstrated any ongoing interest in my subject matter". Tongue-in-cheek about her husband (Dads): "Dad is pretty happy to let this child do as he pleases. Dad does not mind when Johnny is brushing the turtle's teeth because Johnny is GENERALIZING the skills he has learned in school, and besides, its football season. Of course, Dad is in serious trouble with Mom because he has failed to notice the trail of toothpaste plastered in every upstairs room, all of which will now be used to decorate Dad's pillow. "



## USHER SYNDROME UPDATES



Remember to take the time to check on what's new in the world of Usher Syndrome research: <http://ushersyndromeblog.blogspot.com/>

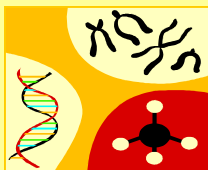
Blog

At the beginning of February, Jennifer Phillips reported on a study published in the journal of Investigative Ophthalmology and Visual Science (<http://www.iovs.org/>). The study uses gene therapy via a "viral delivery" mechanism to help retinal cells produce an Usher's protein needed by the body to counteract the deafblindness of Usher Syndrome. The researchers used mice for whom the Usher2d gene had been deleted — and so the mice were blind from birth and lost vision later. The results showed that

- The viral delivery system was successful in delivering its "cargo" and that the protein was still being made at 6 months — indicating the results were long-lasting;
- The protein was being delivered to the right location after it was being made — i.e. , it was behaving as it would in a normal eye; and
- That the molecular functions that the protein was predicted to perform happened as predicted.

As in most research, this is all just a step in the process — but a step in the right direction, and one that was deemed "safe".

(Jennifer Phillips, Ph.D., is a research biologist specializing in the molecular cell biology of Usher syndrome).



On January 24, 2011, Mark Dunning wrote an article "**Follow up On The Need for an Usher Registry**". He answers several questions that he received:

- Who would administer the registry?
- Why not use an existing registry from a larger institution with more resources?
- Who would "own" the data and what entities would have access to this data?
- Great idea. How can I help?

Read his responses on the blog! If you want to volunteer to help with the registry, contact him at [m.dunning@lek.com](mailto:m.dunning@lek.com)

(Mark Dunning is co-founder of the Decibels Foundation and a founding member of the Coalition for Usher Syndrome Research)

Other Usher Syndrome sites:

- [www.usher-syndrome.org](http://www.usher-syndrome.org) — The website for the Coalition for Usher Syndrome Research. The site's section for families begins with the headline, "There is Hope". The following page on this site provides a long (and current) list of therapies and research: <http://www.usher-syndrome.org/index.cfm?pid=10257>
- Google groups hosts:
  - Usher Life
  - Usher Science
- <http://ghr.nlm.nih.gov/condition/usher-syndrome> — The Genetics Home Reference site, with an overview of Usher Syndrome
- <http://www.ushersyndrome.nih.gov/> — Usher Syndrome (National Institutes of Health) website. On this website, you can find out more about Usher Syndrome, join an NIH clinical study, or find out what resources/funding there is for scientific research.



## GUIDE DOGS FOR PERSONS WHO ARE DEAFBLIND



There are several places in the US where persons who are deafblind can find a guide-dog and the training that is needed. It is a little more challenging if a person has additional disabilities — but not an impossibility — as you can hear from Debbie Cole (page 5).

**Leader Dogs for the Blind** graduate between 4 to 6 persons who are deafblind each year. The instructors use ASL to communicate with their students.

<http://www.leaderdog.org/programs/deafblind/index.php>

The dogs who are trained to work with persons who are deafblind also recognize and respond to ASL. The site states, "It is important to note that these dogs are trained solely to guide — not to be hearing dogs".

Their web-page stipulates their prerequisites and requirements. If they accept your application, the program is offered free of charge at their residential campus (Rochester Hills, MI). They also pay the expenses for public transportation for students traveling within the country, and for room and board.

Take a virtual tour of their residence center, read about the center and how to get there. You can apply online, via snail mail, or just find out more:

<http://www.leaderdog.org/programs/apply/index.php>

Leader Dogs for the Blind also conducts Seminars and trainings for O&M professionals — and students get a chance to receive hands-on experience working with persons who are visually impaired and who have chosen to get guide dogs.

xxxxxxxxxxxxxxxxxx

See Debbie's story on the next page. Debbie got her dog — and her training — at Guide Dogs of the Desert

<http://www.guidedogsofthedesert.org>

**Guide Dogs of the Desert** was founded in 1972, with a mission to improve the lives of the blind by creating opportunities for life-changing independence, and by conducting community outreach and education programs. It is a small school where family environment, small class size and individualized attention is a priority.

<https://www.guidingeyes.org/>

**Guiding Eyes for the Blind**, founded in 1956, is an "internationally accredited guide dog school providing greater independence, dignity, and new horizons of opportunity".

<http://www.seeingeye.org/default.aspx>

**The Seeing Eye, Inc.**, at Morristown, NJ, is the oldest existing dog guide school in the world.

<http://www.dogsfortheblind.org/>

**Dogs for the Deaf** is unusual in that they work with and train rescued and homeless dogs, often adopting them from shelters. Among other trainings, they train the dogs as:

- Hearing dogs — to alert people to household sounds — door bell, phone etc.
- Autism Assistance dogs — to enhance the safety of children with autism

The organization finds placements for dogs who cannot complete their training because they themselves are "special" (e.g., have emotional needs) - "Harmony's Hounds"; or dogs who are "Career Change Dogs" who just make great pets!

Their mission statement is: "Rescuing and professionally training dogs to assist people and enhance their lives, maintaining a lifelong commitment to all dogs we rescue and all teams we serve".

<http://www.cci.org/>

**Canine Companions for Independence** was founded in 1975—started in Santa Rosa, CA. They train Hearing Dogs, Service Dogs, Skilled Companions, and Facility Dogs.

Get their Newsletter, "[The Companion](#)".

## I'm Never Giving Up!!!



I'm Debbie Cole of Oregon City, Oregon. I am 54 and had a very good year in 2010. I've been legally blind and hearing impaired since age 6 as a result of Rubella/German measles. Slowly, over the years, my hearing and vision got worse. I can still see but not well at all.

I was neglected as a child and put in schools with resource classes for the blind and partially sighted, but not taught ASL or sign language. It was at age 18 I set out on my own to learn to communicate. At that time the given sign language was SEE. We had to sign each English word. I liked SEE. ASL confuses me.

I had a dream. It was to get a Guide Dog to help me get around. I applied at many Guide Dog Schools in the U.S.. Because of both hearing and vision impairment, I was denied every time.

In 2009 I learned there were a couple of Guide Dog Schools offering one-on-one classes to the Deaf/Blind and I applied at both. The reason I was given was they said I could not communicate. At that point, I set out to research and got a Cochlear Implant in my right ear.

I see myself as a "go-getter" type of person. I don't let things get me down. Before my Cochlear Implant surgery I had zero speech comprehension in both ears. I could hear sounds but not understand spoken words. In December, at my last audiologist appointment at OHSU in Portland, I was thrilled to learn that with beeps and tones I could hear 100%. My speech comprehension was 80%. I was thrilled.

Last July, at a Guide Dog Users of Oregon Convention at Portland State University I met Bob Wendler. He is the Executive Director of Guide Dogs of the Desert in Palm Springs, CA. I told him my story. Bob is a very compassionate man. I look at him today as a Saint and Miracle Worker! He told me, "Debbie, we'll get you your dog." I applied as soon as I got home — this time, with hope on my shoulder.



I am on America's first ever blind/visually impaired Dragon Boat team. We race in large canoes with one paddle. The sport originated in China. We race in Oregon, Washington, Arizona, and British Columbia. It so happened that two other women from my Dragon Boat Team were awaiting their guide dogs.

I got the call from Bob Wendler late in October, just before Halloween, and it was the happiest day of my life. He said, "We have a match for you and you are accepted at GDD". I had tears of joy rolling down my cheeks.

Three weeks later I boarded an Alaskan Airlines plane with my friend Ayla who was also getting her dog. She got a lovely Labradoodle named Victory and I received my precious female yellow Lab, Leone. There was one more team member, Patricia, who graduated with us — with her German Shepherd.

In class, I pretty much got most of the information I needed. My hearing is not perfect. What I didn't understand Ayla signed to me.

Graduation Day with my Leone was a very emotional day for me. I was crying before and after Graduation. Bob cried too when he listened to my speech.

Now, that I have my guide dog, we are searching for a three bedroom house with a large backyard for her to burn off some of her energy. I'll also be looking into classes to take at PSU and major in something that interests me.

In closing — If you have a dream, NEVER GIVE UP. I didn't and I will continue to grow and be strong.

## *Debbie Cole and Lovable Leone*

Read the experiences of other persons in the "process" of getting a Guide Dog at:

<http://usherchic2.blogspot.com/>

Blog

Or

<http://www.deafblind.com/wilma.html>

## THE TOOLBOX



### Let's make that **FUNCTIONAL**

Recently, I was reading some of Eric Jensen's books on teaching and the brain. I came across many pieces of information that made me say, "YES!" Each piece of information not only applied to me, but to any child we may teach. Here are a random assortment of these — and some possible applications to children who are deafblind (and other special needs populations):

#### **Brain fact:**

Of the frontal lobe where short-term visual memory is located: "Researchers say that we can take in only 3 to 7 chunks of information before we simply overload and begin to miss

So remember to (a) "chunk" the information you want to share with the child, (b) restrict the amount of information shared at any one time, and, (c) notice when there are indications of overload and STOP. This applies equally to materials from the general education curriculum, or to a new concrete communication system (such as an object calendar); simple or sophisticated alike.

#### **Brain fact:**

We require "rest time" to process — organize, integrate and store — new information. More is not necessarily better. "We can teach more and faster, but students will simply forget more and faster." The hippocampus is like a "surge protector" and may actually slow down the

Sound familiar? In past newsletters we have discussed the importance of pausing—to allow a child to absorb information or even to "rest". So we teach something, and then PAUSE. During the pause, even if a child has his/her eyes closed, the brain may still be busy — processing the information and fitting it into the brain's existing scheme — of "things remembered". Don't we all "mull things over" and fit pieces together in our brains? We do not allow ourselves to be overcome by a vast amount of unconnected information.

Take that a step further. We all know how important sleep is to each of us. If we don't get enough sleep, we do not function well.

#### **Brain fact:**

The neurons "recycle" information in order to form long-term memories. SLEEP is a critical factor in this process because recycling

When we sleep, our brains do not stop their activities. This is more than evident because we continue to breathe, digest our food, turn in our sleep when our body needs readjusting, and our vital organs keep functioning! It becomes very important for a child with a disability to get sufficient sleep. Many children do not. Many others have sleep rhythms that do not allow sufficient or relaxing enough sleep to occur. Classroom teams usually know when a child has not had a good night's rest because the child is unable to function to the best of his/her ability. When we consider that sleep is a factor in efficient long-term memory, the significance of sleep for our children who are deafblind becomes so very critical. There is something to be said for those "cat naps" or classroom "quiet times"!

#### **Brain fact:**

Even though the brain is so FAST at what it does, it does take its time to actually set the learning in memory — takes up to six hours to complete the formation of synaptic connections. If the synapse is disturbed in this proc-

It takes our brains a relatively long time to establish a memory that will be easy to recall and connect to experiences. It makes sense then that it would not be good to teach several different ways to do something before the "base" is set. All too often, when a child doesn't "get it", we try to change the way we present the information. Possibly, we have totally confused him/her instead of helping to clarify. It is not too important to re-emphasize that, when carrying out a routine we are trying to establish with a child, we do it the same way each time, have the same cues, presented in the same way. Even having the same person(s) helps.

## THE TOOLBOX



Providing a *CONTEXT* for all learning makes it real — and, as we say, “not just semantics”. That is the whole point of making anything “functional”: to make it better to understand, useable, and likely to be remembered.

### Brain fact:

“Semantic learning” (e.g., words used in lectures) is held in the front part of the brain for only 5-30 seconds UNLESS meaning is attached to it. In a research study, college students who listened to a lecture knew only 8%

Five to 30 seconds is definitely not a lot of time. So when we plan on teaching anything, we need to plan ahead on how to fit it into a context **WHILE WE TEACH IT**. For example, don't teach washing hands just for the sake of learning the routine of how to turn on a faucet. Teach how to turn on a faucet when the child **NEEDS** to wash his/her hands. Don't teach a child how to “put **IN**” or “take **OUT**” just to go through the motions of “**IN**” and “**OUT**”. Concepts are very important, but without a context, they will not have meaning, and will be forgotten or disregarded.

### Brain fact:

Research has made quite clear that exercise enhances mood, increases brain mass and brain cells, improves circulation, and improves

*SO* — make sure that movement is included in your teaching. You could do a number of different things to help this happen. For example — **STOP** when you find a child's attention is wandering, and do something “physical”, even if it something as simple as stretching or going for a quick walk. For younger children you could make up a simple rhyme for something you just taught, and then teach some movements to go with it. The movement will help the child remember the information. And don't forget the child in the wheelchair. He needs the movement as much as anyone else does. Have the child move whatever part of himself that he can move; and then have him

partially participate, hand under hand, or being guided, in some additional movement. Teach him a new concept where he needs to use his head switch. And when he spent enough time doing this, take him for a run or a “spin” in his wheelchair. The following fact is hardly a surprise when we already know we need to attach importance to physical activities and movement.

### Brain fact:

Memory is not stored in one place in the brain. For the most part, memories appear to be stored in corresponding areas — e.g., visual memories in visual area. Some memories are even stored in molecules that circulate around the body via the bloodstream.

And don't forget how important motivation is in the learning process — and motivation is powered by emotion. So if we present cold, hard facts and not — in some way — connect to the child's emotions, we may find that it is not something that they **WANT** to recall and so that piece of learning falls by the wayside.

### Brain fact:

“Emotional responses triggered during or immediately after the learning will help embed the

### Want to learn more about brain-based teaching/learning, and the research base for this?

I learned the facts (in the green boxes) about learning/teaching from books by **Eric Jensen** — starting with his 1998 book, “*Teaching with the brain in mind*” now

Let me leave you with another thought from Jensen that caught my attention:

**There is no use studying how students learn if we do not also consider**

1. Nutrition
2. Racism
3. Poverty
4. Trauma and
5. Stress



## UPCOMING EVENTS and NEWS

Youngsters with **CHARGE Syndrome** — the fastest growing group of children who are deafblind. Unlike what one may think, sessions at a CHARGE conference are useful to parents and professionals for other children as well..... The conferences are known for their excellent presenters, well-chosen topics, and well-organized logistics — including taking care of children (sibling workshops). That said — here are some details:

**10th International CHARGE  
Syndrome Conference**  
<http://www.chargesyndrome.org/>

**WHEN:** July 28-31, 2011

**WHERE:** Orlando, FL

**REGISTRATION IS OPEN!** Go to:

<http://chargesyndrome.org/confreg2011.htm>

There are 60+ sessions and poster sessions. For example, here are some of them:

- So many ways to have a conversation
- Learning at any age— neuroplasticity
- CHARGE 101-103
- Toilet training
- ENT issues—A new understanding
- Problems with Self-regulation and behavior
- Creating Calm from CHARGE chaos
- Taking back the IEP
- Sensory Processing differences
- Technology for learning and fun

**PROFESSIONAL DAY** is on July 28.

The sessions on this day are more technical in nature, and presenters will address research and general studies about CHARGE. For example, several of the studies deal with genetics. Other examples:

- Identifying the "P" in CHARGE: Pain and the relationship of pain to challenging behavior
- National Cochlear Implantation Studies with children who experience Deaf-Blindness: Results for participants with CHARGE syndrome
- The potentials of diversity
- Principles of learning: Understanding and treating pediatric procedural pain



### FROM THE **r.i.s.e. Center:**

Get their "NEWSFLASH". Here is some of the information they shared:

- The Annual r.i.s.e. Parent Conference is on April 29th and 30th, 2011. The location this time is the Spirit Mountain Casino, 27100 S.W. Salmon River Highway, Grand Ronde, OR 97347. Visit their website for more information:

[http://www.oregonrisecenter.org/events/rise\\_conf\\_homepage.htm](http://www.oregonrisecenter.org/events/rise_conf_homepage.htm)

- You can keep track of what is happening in the Oregon Legislature at:  
<http://www.leg.state.or.us/index.html>
- Find out what is happening with state and federal funding for early childhood education and the effects it might have.
- There are links to state budget information for the Dept of Human Services, Oregon Health Authority, and the OR Dept of Education.

### TECH FLASH

- Benetech announces a new accessible e-Book Reader for Apple iOS devices—iPad, iPhone, and iPod touch users can read bookshare books with **Read2Go**

[http://www.bookshare.org/\\_/aboutUs/2011/01/read2go](http://www.bookshare.org/_/aboutUs/2011/01/read2go)

At the ATIA (tech) conference, Bookshare announced and gave demos of the new app. Cost \$19.95. A user must be a Bookshare member to use it, but can then download Bookshare books directly to the Apple portable hardware. Go to the link above to find out more about Bookshare membership.



## Professional Development



Announcement for a webinar series:

### Shifting Paradigms: Using Science Based Strategies to Teach Complex Children with Hearing Loss in the 21st Century

“Changes have occurred in the population of Deaf and Hard of Hearing children resulting in approximately 50% of the population now experiencing deafness complicated by other learning and emotional and behavioral disorders.”

(**Note:** all times indicated are CST)

- Surprising Truths About How Children Learn  
Tuesday 3/22, 7-8 p.m. \$89.00  
Saturday 3/26, 10-11 a.m. \$89.00
- Achieving Powerful Outcomes Using Learning Assessment Data to Individualize Instruction  
Monday 4/11, 7-8 p.m. \$89.00  
Saturday 4/16, 10-11 a.m. \$89.00
- If You Know Your Student You Can Develop Innovative Strategies to Modify the Core Curriculum  
Tuesday 4/26, 7-8 p.m. \$89.00  
Saturday 4/30, 10-11 a.m. \$89.00
- All senses on Deck: Reality Instruction  
Tuesday 5/17, 7-8 p.m. \$89.00  
Saturday 5/21, 10-11 a.m. \$89.00

Individual webcasts—\$89.00

Series of 4 webcasts — \$319.00 (save 10%)

Instructors: Patricia A. Scherer, Ph.D., and Tracy Meehan, BS, MS.

To register go to: [ICODAARTS.org](http://ICODAARTS.org)

For questions or further assistance, contact Kathy Herman: 847-509-8236 (x236) or [k.herman@ICODAARTS.org](mailto:k.herman@ICODAARTS.org)

## Technology



Read on..... <http://blog.easystand.com/2011/01/complete-guide-to-special-needseducational-apps/>

Thank you to Kathee Scoggin and parents from Washington's Sensory Disabilities program for sharing this information! There is a ton of info at this site — I picked a few examples to share with you.... The Capable Kids CLUBHOUSE connects to One Place for Special Needs — where special families can search for resources.

<http://www.oneplaceforspecialneeds.com/>

- Read how to pick great apps:  
[http://www.oneplaceforspecialneeds.com/main/library\\_special\\_needs\\_apps.html](http://www.oneplaceforspecialneeds.com/main/library_special_needs_apps.html)
- #### STANDERS
- Learn why it is important to STAND, and read about standers.
  - Read case-studies
  - Watch YouTube videos of children participating in various creative activities
  - Print activity or coloring sheets, an activity chart and certificates

#### COMMUNICATION APPS

- Read about 34 difference devices, with descriptions, and where to find them. These are also rated.

#### HOLIDAY SPECIALS

“Holiday Traditions with your Special Needs Child” has many do-able ideas.....

#### VISUAL PROCESSING APPS

- Get information about 362 resources

Search the site. There is a ton of information. For example, recent searches included information about employing someone with a disability, toileting social stories. One recent discussion is: “General ed teacher says, Special education students don’t need me”!

You can register to receive their e-newsletter, access twitter, face book, Flickr, or MySpace.

\*\*\*\*\*

Mac App Store:

<http://itunes.apple.com/us/genre/ios/id36?mt=8>

## ATTENTION PARENTS!



Are you a member of the National Association for Deaf-Blind? This organization was founded by parents and has been supporting individuals and state parents for over sixteen years.

“Raising a child with deaf-blindness can be overwhelming. It’s the family that is there when the child’s eyes first open for the day and then close again at the end of the day. FAMILY IS THE FIRST CIRCLE OF SUPPORT, the first circle of influence. WE WANT FAMILIES TO KNOW THAT THEY ARE NOT ALONE. We want to expand our network of support so no individual or family feels alone.”  
(From NFADB’s press release)

NFADB has a toll-free number and you will find a real person to talk with! As a member, you will receive two newsletters a year, have access to online resources and support (website and fb), a connection via a listserv to hundreds of other members — and become a part of a much wider network of support, including providing “a unified voice on national issues related to deafblindness”. It cannot be stressed enough that the last item is incredibly important in the present economic climate where everyone is “scrambling” for dollars!

- Each membership is a household membership
- There are three options:
  - Annual—\$15.00
  - Three years — \$35.00
  - Lifetime — \$100.00



Take the **online survey** to help NFADB focus on what you need — and to also learn more about the type of things that they are concerned with:

<http://www.surveygizmo.com/s/425189/1bepm>

If you have questions, visit their website at [www.nfadb.org](http://www.nfadb.org), or fb, or call/e-mail Lori : 1-800-255-0411 or [NFADB@aol.com](mailto:NFADB@aol.com). Get a registration form directly from them, or from us — write to Lyn at [ayerl@wou.edu](mailto:ayerl@wou.edu) (English or Spanish)

Here are a few other family organizations that might be of interest to you:

- **The National Association for Parents of Children with Visual Impairments (NAPVI):**

<http://www.spedex.com/napvi/>

Their mission statement says, “NAPVI is a national organization that enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities.

NAPVI provides leadership, support, and training to assist parents in helping children reach their potential. NAPVI is dedicated to giving emotional support, initiating outreach programs, networking, and advocating for the educational needs and welfare of children who are blind or visually impaired.”

Take a look at their “Useful links” page. It is excellent!

<http://www.spedex.com/napvi/links.html>

- **PEPNet**

<http://www.pepnet.org>

PEPNet’s mission is “to improve transition services and educational access for students who are deaf or hard of hearing including those with co-occurring disabilities, thus enhancing educational opportunities”.

Oregon would need to contact PEPNet-West. For our cluster of states (Alaska, Oregon and Washington), Heather Holmes is listed as the Outreach Specialist. You can contact her by calling 503-838-8642 or [heather.holmes@pepnet.org](mailto:heather.holmes@pepnet.org). She is located at the Regional Resource Center on Deafness on the campus of Western Oregon University.

- **Oregon Hands and Voices**

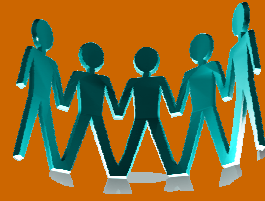
<http://www.handsandvoices.org/chapters/or.htm>

The contact person is Helen Cotton who is the program’s coordinator and Executive Director:

971-673-2302 or [Helen@handsandvoicesor.org](mailto:Helen@handsandvoicesor.org)

Their mission: “Hands and Voices is dedicated to supporting families with children who are Deaf or Hard of Hearing without a bias around communication modes or methodology. We’re a parent-driven, non-profit organization providing families with the resources, networks, and information they need to improve communication access and educational outcomes for their children. Our outreach activities, parent/professional collaboration, and advocacy efforts are focused on enabling Deaf and Hard-of-Hearing children to reach their highest potential.

## THE DEAFBLIND WORKING GROUP



**Marria Knight**— Region one, Eastern Oregon  
**Colleen McLaughlin**—Region two, Central Oregon  
**John Pierce**— Region three, Southern Oregon  
**Terry Cadigan** — Region four, Cascade Regional  
**Jan Hearing** — Region four, South Coast Regional  
**Anne Olson-Murphy** — Region five, Willamette Regional  
**Kim Puckett** — Region six, Columbia Regional  
**Timothy McCleod**—Region seven, Lane Regional  
**Brenda Satter**—Region eight, Northwest Regional  
**Donna Schuyler** - Oregon School for the Deaf  
**Dennis Crepeaux**— Oregon Commission for the Blind  
**Paddi Davies**— NCDB representative, WOU  
**Tom Udell** — NCDB representative, WOU  
**Sue Mathisen** — Regional Services, Management Team  
**Sam Ko & Colleen Stover** — Oregon Department of Education  
**John Killoran** — Director, The Teaching Research Institute, WOU  
**Lyn Ayer** — Oregon Deafblind Project, WOU

We have our newsletters and other information on our web-page with the Oregon Department of Education:

<http://www.ode.state.or.us/search/results/?id=185>

Also take a look at our project website at [www.oregondb.org](http://www.oregondb.org)

---

## Contact the Oregon Deafblind Project!



Lyn Ayer, Project Director  
Oregon Deafblind Project  
Western Oregon University (TRI)  
345 N. Monmouth Ave  
Monmouth, OR 97361

[ayerl@wou.edu](mailto:ayerl@wou.edu)

(503) 838-8328





The Oregon Deafblind Project is funded through grant award # H326C080036-09, OSEP CFDA 84.326C  
U.S. Department of Education  
Office of Special Education  
OSEP Project Officer: Glinda Hill

The opinions and policies expressed by this publication do not necessarily reflect those of The Teaching Research Institute, or the U.S. Department of Education.

Lyn Ayer, Oregon Deafblind Project  
Western Oregon University  
The Teaching Research Institute  
345 N. Monmouth Ave  
Monmouth, OR 97361  
TRD 383

