



# Oregon Deafblind Project



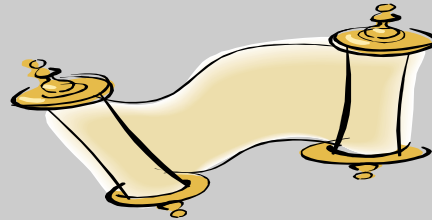
## Building Effective Programs

Lyn Ayer, Project Director • Winter/Spring 2009

### Grant News

We are happy to let you know that from October 1, 2008, we began a new 5-year grant cycle. Thank you to all of you who helped us through letters of collaboration and support. Our goals for the next five years include:

- Finding children and youth in Oregon who are deafblind, but who are not currently registered with us — especially birth-3 yrs.
- Helping families determine whether their child who is Deaf or Hard of Hearing has Usher Syndrome. Children who have Usher Syndrome are likely to lose some or all of their vision during their lifetime — some earlier, some later. It is important for us to get to know these families so that we can find out how we may be able to assist them — and their children.
- Continuing to offer “technical assistance” to families and service-providers. This is offered via phone, e-mail or face-to-face — depending on what is needed.
- Continuing to offer TEAM TRAININGS to those who request it — on a first-come-first-served basis.
- Sending out this newsletter at least three times each year — and expanding the mailing list. So if you know of other families or service providers who are NOT on our mailing list and would like to be, have them send an e-mail to [ayerl@wou.edu](mailto:ayerl@wou.edu)
- Family Leadership Training (See pg. 3) for this and other Family-related information.



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Below is the definition of "Deafblindness" that we use to determine whether a child or youth is deafblind. Many of our children who are deafblind (estimated 90%) have additional challenging conditions, including orthopedic or cognitive impairments, autism, traumatic brain injury etc. So we are looking at a population of children with complex and multiple needs!

"Children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities"

Within this group are also children who may have cochlear implants. Having cochlear implants changes what educational teams need to do and how they need to approach these children. Having a cochlear implant creates a set of needs very different than wearing hearing aids.

The Oregon Department of Education continues to be a major partner, collaborating with the Oregon Deafblind Project on many aspects of the grant. You can find updated information about the project on ODE's website at:

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

All newsletters and project brochures will continue to be posted at ODE's site.

For planning our Family services, our main project partners are the National Consortium on Deaf-Blindness (NCDB), and the Oregon Parent Training and Information Center (OrPTI), and the Oregon Department of Education will be the main funding agency for this aspect of our work. Read more on page 3 of this newsletter.



## COCHLEAR IMPLANT NEWS

Children are being implanted when they are really young — infants.

When Kelli and Michael's 10-month-old daughter, Landry, was born deaf, the couple faced a difficult decision: let her grow up deaf, or allow her to undergo a controversial surgery to have a cochlear implant placed in her ear." Read more about this, and see a video-clip of the surgery at

[http://www.thedoctorstv.com/main/procedure\\_list/47](http://www.thedoctorstv.com/main/procedure_list/47)

*(Thank you, Kathy Z from the DBCI listserv for this information)*

PARENTS and families — take a look at this website for the JOHN TRACY CLINIC:

<http://www.jtc.org/corres/submit/ccfaq.php>

It contains Distance Learning for Parents of children who are Deaf/hard of hearing, five years or under. You can enroll from anywhere in the world — and it is FREE OF CHARGE to parents.

In answer to the question: "Is there a special course for children with a cochlear implant or hearing aids?" the site says, "No. Parents can begin immediately using a course to help children learn communication skills. All children (hearing and deaf) develop listening and spoken languages in the same manner. The courses provide developmentally appropriate information no matter what devices a child uses.

Connected to this is [pals@jtc.org](mailto:pals@jtc.org) — a team of parent educators and hearing loss specialists.

You can get a Spanish version of information on the website, and also meet families and watch videos from them.

## FAMILY FOCUS

### FAMILY LEADERSHIP TRAINING

A group of around 10 parents from the state will receive training during 2009-2010. The training is offered to all states by the National Consortium on Deaf-Blindness (NCDB), via an application process. We are fortunate that our proposal was accepted by them! This training aims at strengthening parents in their efforts in advocating for their children, finding creative solutions, and gradually building a support system within this state. Of course, we also plan on having fun too! We are hoping that this group will help the project plan for "events" that will truly have a family focus. We would really like to see families in Oregon get together because we believe this is very important.

### FAMILY DIRECTORY

NCDB and Area One states have a paper directory that is distributed a couple of times each year. If you would like to "connect" with another family in this or another western state — via phone, or face-to-face — this is the way to go. If you are a part of this directory, you can look through the information from parents in all the western states and see if you can "match" your family up with another family.

### FAMILY LISTSERV

The Area One Family listserv is administered by a parent of a child who is deafblind — and parents get to talk to each other whenever they need information and support.

If you are interested in any of these, please let Lyn Ayer know:  
(503) 838-8328  
[ayerl@wou.edu](mailto:ayerl@wou.edu)

## INFORMATION FOR FAMILIES:

**FREE!**

"Real time Convenience "

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

Wednesday, February 25, 2009, 4:00—6:30 p.m. Pacific time:

## SPECIAL NEEDS PLANNING:

An Interactive Online Seminar presented by EPLiveOnline and Merrill Lynch.



Join a Merrill Lynch Financial Advisor, a third-party special needs trust attorney and a representative from a third-party disability organization as they discuss the financial, legal and social challenges faced by families like yours. The panel experts will:

- Explore the team approach to special needs planning
- Discuss the financial challenges facing families of children with disabilities and review the key elements of an effective financial strategy
- Examine how a Special Needs Trust can be used to supplement income and protect quality of life for your child with special needs
- Explain how third-party disability organizations can play a role in the special needs planning process

**Note:** If you miss the conference, the content will be archived and made available 24/7 to registered participants after the event.

### NEW PUBLICATION

The Minnesota DeafBlind Project has a new publication :

THE PARENT ROAD MAP: Your Guide to Raising a Child with Combined Hearing and Vision Losses

[www.dbproject.mn.org](http://www.dbproject.mn.org)

## The elusive SENSE OF SMELL



Part  
ONE

In the field of Deafblindness, we emphasize the use of residual vision and hearing, and the other sensory modalities. We sometimes assume that a child's "other" modalities (touch & proprioception, taste & smell) are intact — and we have limited ways to measure how efficiently these are working.

Have you ever tried to imagine a world without smell? If your sense of smell was not functioning or functioning poorly, how would that change some things in your life?

To start with, **THINK ABOUT THESE:**

- Can you eat without associating smell with what you eat?
- How is our sense of smell affected when we (a) have a cold, or (b) our nose is "dry"?
- Do you realize how closely your sense of smell is tied to your emotions?
- Does a specific odor smell the same way to all of us?

Smell is a "chemical" and CONTACT sense — and there is yet a great deal for researchers to learn. Simplistically speaking, we know that the air around us has to carry the odor INTO the nose, otherwise we cannot "smell" the odor. There it is put in contact with the mucus layer of the nose. Located in the mucus layer is an area the size of a dime that contains the sensory receptors. Information is carried to the brain, where it not only compares the smell in an "odor bank", but associates the smell with past experiences. This will create a repertoire of reactions — usually associated with our LIKES and DISLIKES.



**WORKING WITH CHILDREN** who are deafblind, we need to:

- ♦ BE AWARE OF THE SMELL OF A FOOD AS WELL AS THE TASTE.

We actually smell in three different ways - (a) from outside -- when the smell wafts to our noses through the air, (b) from inside - through food going through our mouths, and (c) sometimes when something is injected and gets to our nose via the bloodstream. SO when we chew our food, air goes upwards into the nasal cavity and we smell what we are eating. Be aware of the fact that food smells that go through the mouth (and are mixed with saliva) are different than those that go through the air - even of the same food. Try eating a boiled egg with your nose closed, and then open - and notice the difference.

- ♦ NOTICE WHETHER THE CHILD HAS A COLD - OR A VERY DRY NOSE.

It is truly not surprising that we often feel less like eating, and that nothing tastes "normal" when our noses are affected. To get the full impact of what we eat, we NEED the sense of smell. For example, research has shown that - if the nose is blocked - coffee loses its "flavor" and is often not even recognized as coffee. Surprisingly, this is also true of garlic, pineapple, cranberry juice, chocolate and sugared water as well!!! Test this out for yourself.



**Note:** odors seem to be stronger and clearer when the mucus of the nose is normal and moist. The moisture appears to be an important factor in having a "sharp" sense of smell. SO if the nose is "stuffed up" as in a cold (and the mucus layer is swollen), or dry (e.g., this can occur in dry winters), the sense of smell is diminished.

- ◆ **MAKE A NOTE OF A CHILD'S REACTIONS TO FOOD - WHICH WILL INDICATE LIKES AND DISLIKES. THESE MAY NOT MATCH UP WITH WHAT WE THINK OF THE SPECIFIC FOODS THAT WE FEED THEM. "ASSOCIATIONS" OF SOMETHING PLEASANT OR UNPLEASANT MAY AFFECT THEIR REACTIONS TOO.**

It is likely that the child is both smelling AND tasting the food if there is a lot of pleasure in a specific item. Children who have suffered brain trauma may smell things very differently. Adults with traumatic brain injury have described how their sense of smell changed - a rose no longer had a sweet and pleasant perfume, but was rancid and unpleasant. They have even described having "smell experiences" that were internal, not external. For example, one person report smelling something "burning" when no one else could detect this smell in the immediate environment. It is thought that this phenomenon may just be occurring at the level of the brain (and memory) - with no connection to the environment around the person.

We will continue to explore the sense of smell in our next issue of this newsletter. But — while you are thinking about the sense of smell, here is some "smell trivia" for you!

It is thought that possibly, like different areas of the cochlear in the ear detect different tones, the sensory cells of the nose are not all alike. Dr. John E. Amoore, a British biochemist from Oxford University first proposed the "stereochemical theory" for olfaction. His theory, "simply stated, proposes that the shape of a molecule determines its smell. In other words, a rose molecule smells like a rose molecule because its shape is coded precisely for the nose to interpret this way. It does this by a lock and key method within the olfactory nervous system: the shape of an airborne molecule (the key) fits into complementary odorant receptor proteins on the outside of the nasal cell (the lock)." Amoore also classified odors into seven primary categories. More recently, Luca Turin suggests that smell is connected with vibration!

<http://www.firstscience.com/home/articles/humans/decoding-odors>

For some anatomical images of the nose and its functioning, here is one website you can take a look at:

<http://www.contmediausa.com/shop/app/products/Human3D/human3dhumannose.html>

And two sites for the kids!

<http://kidshealth.org/kid/htbw/nose.html>

(Also in Spanish)

<http://faculty.washington.edu/chudler/nosek.html>

## LITERACY CHANGES LIVES



<http://www.perkins.org/literacy/louisbraille/>

Read about Braille literacy. January 4, 2009 marked the 200th anniversary of Louis Braille's birthday. You can also ask to receive "Perkins Insight", their e-mail newsletter. Their current issue also highlights literacy.

There will also be a new book available soon: "DRAWING WITH YOUR PERKINS BRAILLER". This book has been written by Perkins Braille & Talking Book Library Director, Kim Charlson. It contains step-by-step directions for creating 36 different drawings including basic shapes, various animals, and pictures with holiday and transportation themes.



An Post issued a new 55 cent stamp in Braille in January 2009. It commemorates the bicentenary of Louis Braille's birthday. The stamp, designed by Red Dog Design Consultants, features an eye in black ink on a white background with the 55 cent denomination in Braille.

Visit some sites that are both fun and informative:

To be introduced to Braille, and play some Braille games:

<http://www.afb.org/braillebug/>

At the National Federation of the Blind site, look under the section titled "What Can You Do? Learn more about Braille" for the **VIDEO** "Braille, Unlocking the Code" — and learn why "Braille is beautiful":

[http://www.nfb.org/nfb/Braille\\_Initiative.asp](http://www.nfb.org/nfb/Braille_Initiative.asp)

## TEK TALK

offers webinars and conferences.

To learn more about this, go to <http://www.accessibleworld.org>

On February 2, 2009, the topic is the **DEAFBLIND COMMUNICATOR**. Even if you miss the session, you can access the archived information.

The DeafBlind Communicator (DBC) offers the deaf-blind population a truly portable multi-functioning communication device. Consisting of a standard Humanware Braille Note with specific software installed, and a cell phone for a face to face companion, the communicator provides several ways for a deaf-blind user to communicate. Using the DB companion, the user can easily communicate in virtually any face to face environment with a sighted peer.

The built in modem enables the DBC to operate as a standard Braille TTY, and by using the DB companion's cell phone capability with a SIM card, the deaf-blind population can now utilize Short Message Service (SMS) technology.

For the more advanced user, with the use of a high speed internet connection, the DBC software incorporates an XMPP messaging client, which allows anyone with a Google Mail (gmail), account, to engage in an instant messaging conversation with other gmail users. Gmail is quickly becoming one of the largest web based e-mail providers and with its Google Talk PC client that is available to everyone, DBC users can carry on conversations with both people using a PC for messaging, or with other users of the DBC.

For more information, contact: Greg Stilson, Humanware Product and Support Specialist  
Phone: 800.722.3393

[Greg.stilson@humanware.com](mailto:Greg.stilson@humanware.com)

*(Thank you to Angie O from the DBCI listserv for this information!)*

???Have you heard about....???

**William Gibson** who won the Tony Award for his play, "The Miracle Worker"? His play was meant to showcase Miss Sullivan, Helen Keller's "Teacher". Mr. Gibson said: "This stubborn girl of 20, who six years earlier could not write her name, and in one month salvaged Helen's soul, seemed to me to deserve a star bow." An interview with William Gibson, done a few years ago, can be found at:

<http://www.perkins.org/whatsnew/mircale-worker.html>

"What's fantastic about the story, these were two children. I mean Annie was a child, just turned twenty. Helen was seven, eight, and there these two kids are dealing with this problem. None of the adults knew what to do about the problem." Gibson said. "Well, this is an extraordinary event. The whole adult world doesn't know what to do and these two kids get together and in that first month, they solve this problem. Well, that's amazing!"

William Gibson passed away on Tuesday, November 25th, 2008, at the age of 94.

Here are some excellent sites with information about Anne Sullivan:

<http://www.afb.org/AnneSullivan/> (an "Online Museum")

[http://www.myhero.com/myhero/hero.asp?hero=a\\_sullivan](http://www.myhero.com/myhero/hero.asp?hero=a_sullivan) (Teacher heroes)

<http://www.lkwdpl.org/WIHOHIO/sull-ann.htm> (Women in History)

[http://www.brainyquote.com/quotes/authors/a/anne\\_sullivan.html](http://www.brainyquote.com/quotes/authors/a/anne_sullivan.html) (Anne Sullivan quotes).

"My heart is singing for joy this morning! A miracle has happened! The light of understanding has shone upon my little pupil's mind, and behold all things are changed!"

???Have you heard about....???

**John Lee Clark** who is a deafblind poet. The publisher of his collection, "SUDDENLY s l o w", says it "opens with a stumble:

*It was not there  
Until I tripped over it.*

...thanks to his sparkling language, and his capacity for wonder, together with his unique perception for life, his poems add a much-needed new wrinkle to the lexicon of imagination....". The site at HANDTYPE PRESS, <http://www.handtype.com/about/index.html> allows you to read a sample poem, "Something to Sleep On".

Unlike the work of some previous deaf-blind poets, Clark's poems hold genuine literary merit. Pia Taavila, who is professor of English at Gallaudet University and the author of "Moon on the Meadow" among other books, praises Clark's brilliant use of the English language.

She says "There are double layers and more of meaning in metaphors, in quick-minded word play and in the skill with which Clark describes the world as he 'sees' it." For these reasons, Taavila calls "Suddenly Slow" a "delicious" collection of poems that are "heartbreakingly beautiful."



## THE DEAFBLIND WORKING GROUP

Marria Knight— Region one, Eastern Oregon  
Colleen McLaughlin—Region two, Central Oregon  
Mark McKeirnan— Region three, Southern Oregon  
Terry Cadigan — Region four, Cascade Regional  
Anne Olson-Murphy — Region five, Willamette Regional  
Kim Puckett —Region six, Columbia  
Kit Staples—Region seven, Lane Regional  
Brenda Satter—Region eight, Northwest Regional  
Jennifer Orton—Oregon School for the Blind  
Donna Schuyler & Anne Harrington - 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  
Wendy White—Parent  
Sam Ko — Oregon Department of Education  
Lyn Ayer — Oregon Deafblind Project



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

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

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### Contact for the Oregon Deafblind Project!




Lyn Ayer, Director  
Oregon Deafblind Project  
(503) 838-8328  
[ayerl@wou.edu](mailto:ayerl@wou.edu)





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Lyn Ayer, Oregon Deafblind Project  
Western Oregon University  
Teaching Research Institute  
345 N. Monmouth Ave.  
Monmouth, OR 97361  
TRD 319