



# Oregon Deafblind Project



## Building Effective Programs

Lyn Ayer, Project Director • Winter-Spring 2010

Hello everyone:



It can be deceptive, but it looks like spring is here! I saw a couple of trees in bloom, and some flowers, And many migrating birds have returned too. Hope everyone had a good winter. I am glad it was mild — although I can hear all those winter sports persons shouting me down!

The project continues to provide team trainings to district teams, personnel at the Providence Child Center, and to present to a variety of audiences who come in touch with children who are deafblind — and their families.

Our ever-improving (although slow!) website now has a home page and some introductory information about the project. We will soon be adding a module that provides an overview on deafblindness, and one on the art of observation. Although ALL modules target our families, and we hope they will find them useful, we are also planning to set up a family specific segment on our website. Of course, we are hoping that some parents will contribute to this section. If any of you have any ideas for the family section — send them our way!

In this issue we have several pages that are related to school-to-post-school transition, and some REALLY positive ideas to us from Amelia — who used to be on our project register — several years ago.

Enjoy this end-of-winter/spring newsletter!

Lyn



### CONTENTS

Director's note	1
Project Information	2
OrPTI <b>RISE</b> Conference Announcement and Info	2
Did you know...? Becoming an Advocate	3
Perkins' Webcasts	3
Have you heard...? (Miscellaneous News)	4
WESD Vision Program Training Announcement (Linda Burkhart)	4
Film info: Temple Grandin	4
Unique books website	4
One Deafblind Woman's Approach To Life: by Amelia Westerfield	5-7
Transition: A personal and Professional Perspective (Dorothy Walt—HKNC)	7-8
HKNC 2-week summer program Announcement	8
The Deafblind Working Group	9
Project Contact Information	9





Child Registration — Remember that we search for and register children who are deafblind on a CONTINUOUS basis, and not just once a year. SO, if any of you (families and professionals) have a child who has significant combined vision + hearing issues, be sure to let us know!

This will ensure that that families and teams can access our training and services. REMEMBER:

- You can register a child at ANY TIME during the year. Every year each deafblind project in each state counts how many children there are as of December 1 of that year. The numbers are then submitted to the National Consortium on Deafblindness (NCDB), who in turn submit the numbers to the Federal Government. We are required to do this to ensure continued funding — and continued services in Oregon.
- 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!
- Sometimes the term “deafblind” can be misleading. Most children who are considered “deafblind” have some vision and/or hearing — and very few are totally blind and profoundly deaf.
- Within this group, there are children who may have cochlear implants. Having cochlear implants changes what educational teams do and how they need to approach these children.



If you want to register a child, or ask questions, please feel free to call Lyn Ayer at (503) 838-8328 or e-mail her at [ayerl@wou.edu](mailto:ayerl@wou.edu)

The Oregon Department of Education continues to be a major partner in our grant efforts, and continues to assist us with family events and family-related project plans. Updated information is at <http://www.ode.state.or.us/search/results/?id=185>

**IMPORTANT CONFERENCE ANNOUNCEMENT**  
**Hold the dates!!**  
**April 30 and May 1, 2010**



OrPTI is bringing back their annual Conference. For those of you who attended in the past, it used to be called “Wagon Wheel”.

It is now called **RISE**, an acronym for:

- ✿ Respect
- ✿ Inspire
- ✿ Support
- ✿ Educate



The really great part is that you can apply for and receive a stipend to attend — but you must do so as EARLY as possible. Here is the website:

[www.OrPTI.org/rise2010](http://www.OrPTI.org/rise2010)

Because we REALLY want you to attend, we are attaching an application form and the stipend form to this newsletter (English and Spanish). Hurry, hurry!

LOCATION: Salem Conference Center  
 200 Commercial Street  
 Salem, OR

AGENDA:

There is a tentative agenda on the website. Among the many great topics, there are three sessions that will target children who are deafblind/multi-disabled — one on movement; and two on literacy. Tom Udell of NCDB and Lyn Ayer of the Oregon DB Project will facilitate these three interactive sessions. It'll be FUN and educative too.

COME — and enjoy meeting other families and professionals!



## DID YOU KNOW....?



If you are interested in training as an advocate (for children with special needs), you could get information from:

- OrPTI at <http://www.orpti.org/>. Their network of personnel across Oregon offer frequent trainings — one day; and conferences that are topic specific too. They also host an annual conference which provides insights into advocacy — see RISE conference info on pg.2. **Upcoming presentations:**

Moving to and through high school transition and into adulthood. 3.1.10, 6:00-8:00 p.m. at McMinnville High School Library

IFSP, EI, ECSE...what do they mean? 3.2.10, 6:30-8:30 p.m. at Willamette ESD, Salem

- The Wrightslaw organization: <http://www.wrightslaw.com> . Their latest newsletter talks about:
  - What training do you need?
  - What you need to know?
  - Start an advocacy flyer campaign.
  - Featured advocacy training.

This group also has publications that are great reference books, and you can subscribe to their FREE newsletter. They also host face-to-face trainings and conferences at a variety of sites across the country.

- Take a look at resources by state: <http://www.yellowpagesforkids.com/>
- Circle of Friends believes "Parents are the crucial player in the success of a student's educational journey". Their philosophy page states, "The intention of this website is to assist you in attaining basic skills that will empower you to become an equal member of the special education team": <http://www.circleoffriendsadvocacy.com>

Take a look at Perkins' WEBCASTS:

<http://support.perkins.org/resources/webcasts>

There are currently two on CHARGE syndrome.:

- CHARGE Syndrome: An Overview: "In this webcast, Pamela Ryan, Perkins School Psychologist, offers an overview of the characteristic features of CHARGE syndrome and discusses the very diverse ways these features manifest themselves in children. She talks about some of the early medical complications that many children face and how these issues affect development and learning"
- CHARGE Syndrome: The impact of Communication and learning: (by Martha Majors). This webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors offers guidance for educators in developing an effective educational program that will improve the emotional wellbeing and success in learning for students with this syndrome.

There is an excellent one on early literacy:

- Early Literacy for Students with Multiple Disabilities or Deafblindness. Deidre Leech explores a "new" definition, the challenges, what early literacy means to these children, and ideas for adapting books.

This one contains good ideas for students transitioning out of school:

- Creating Vocational Portfolios for Adolescents with Significant Disabilities. Contents include:
  - Why Create Portfolios for Transition
  - What is a Vocational Portfolio?
  - How to Create a Portfolio
  - Effective Portfolio Development Process
  - The Components of a Portfolio
  - The Individual's Perspective Component
  - The Personal Information Component
  - The Vocational Experience Component

**SIGN UP TO RECEIVE INFORMATION ABOUT WEBCASTS DIRECTLY FROM PERKINS — FREE!!**

## HAVE YOU HEARD....?

[http://](http://www.ohiostatealumni.org/media/Pages/LarrySanger.aspx) • Larry Sanger, co-founder of Wikipedia says that we need to be aware of the effect the internet has on learning. Take a look at: <http://www.ohiostatealumni.org/media/Pages/LarrySanger.aspx>

He acknowledges the great wealth of information "out there", but he is now looking at other aspects that he had not anticipated. It is notable that he says, "Keep reading books. Keep doing the sorts of things we've always done to become well-educated." He believes that the internet creates "passive consumers of information". Good to think about with our children who are deafblind..... too much technology is possibly as harmful as too little!



FIELD TRIPS can be challenging to organize and there are not really many guidelines on how to keep things moving — except experience. A home-schooling group (Homeschool Rewards) decided that they would do something about this. They have an e-book on sale that you might like:

<http://www.homeschool-rewards.com/school-field-trip-ideas.html>

## Ph.D. anyone?

- The National Leadership Consortium in Sensory Disabilities (NLCSD), funded by the U.S. Department of Education, Office of Special Education programs, is accepting applications to doctoral programs in the areas of blind/visually impaired, deaf/hard of hearing, and deafblindness. **Full tuition and a minimum of \$20,000 annual living stipend will be provided to NLCSD Fellows for up to four years of full-time on-campus study.** Applications due **MARCH 26, 2010.** Check for information at: <http://www.salus.edu/nlcsd/index.html>

## TRAINING ANNOUNCEMENT

**Willamette ESD's Vision Program is organizing a training!**

**TOPIC:** Multi-Modal Communication Strategies for Children Who Face Severe Physical and Multiple Challenges. SIMPLIFIED TECHNOLOGY

**PRESENTER:** Linda J. Burkhart

**WHEN:** April 22-23  
9 a.m. to 4 p.m.

**WHERE:** Kroc Center  
1865 Bill Frey Drive NE  
Salem, OR 97301

**COST:** \$15.00 for two days  
\$7.50 for one day  
(Make checks payable to Willamette ESD)

FOR REGISTRATION INFORMATION,  
call/e-mail: Colleen Johnson  
(503) 385-4645  
[Colleen.Johnson@wesd.org](mailto:Colleen.Johnson@wesd.org)

**IMPORTANT: You need to pre-register by April 9, 2010.**



Have you watched the following HBO full-length film?

**Temple Grandin: Autism Gave Her a Vision, She Gave it a Voice**

Unique Books is a new website that promotes books by deaf-blind authors:

[www.uniquebooks.webs.com](http://www.uniquebooks.webs.com)

FREE promotion for authors who are DB  
(Thanks, Scott Stoffel! CI listserv)



## Thoughts on "TRANSITIONING"

By Amelia Westerfield




**USHER SYNDROME** is a genetic disorder that is characterized by congenital hearing loss and progressive vision loss caused by retinitis pigmentosa (RP).

There are three subtypes of Usher syndrome: I, II, III. Usher syndrome type I patients have profound congenital sensorineural hearing loss, vestibular dysfunction, and progressive retinal degeneration, with impaired night vision and decreased visual fields. Usher type I is typically diagnosed within the first few years of life by early onset retinitis pigmentosa. Usher syndrome type II, the most common form of Usher syndrome, is characterized by moderate to severe sensorineural hearing loss that is stable in most cases, normal vestibular function, and later onset retinitis pigmentosa during the second decade of life. Usher syndrome type III is the least common type, characterized by moderate sensorineural hearing loss with progression to acquired deafness, progressive and variable vestibular dysfunction, and later onset retinitis pigmentosa.

### ONE DEAFBLIND WOMAN'S APPROACH TO LIFE

Three months before the end of my senior year of high school in Oregon, I was diagnosed with Usher syndrome II. On that particular Saturday afternoon, my parents called my brother and me into the living room and broke the news. I do not remember what was said, but I do remember lying in bed that night believing that my life was over and that all of my plans and dreams were unattainable. Little did I know that 11 years later I would be where I am today—living out my dreams in Seattle, creating more plans for the future, and knowing that despite my vision and hearing loss, anything is possible.



As I sit here at my computer and reflect on the impact that Usher syndrome has had, I realize that I am living the life that I always wanted to live. I am surrounded by my loving family and friends; I am married to my best friend; I recently got my graduate degree as a Master in social work and have begun my professional career as a MSW. I am training for my first marathon and am planning a trip to Russia next summer. At the same time, this does not mean that living with Usher syndrome is always a piece of cake. I still have moments when I want to curl up into a ball of self-pity or times when I am overcome by negative thoughts about what the future might bring. Despite these feelings, however, I accept who I am—deafblindness and all. We all have challenges in life that must be faced, and mine just happens to be Usher syndrome. Here are  things that I have found helpful in my approach to life with Usher syndrome.



### DEAFBLINDNESS IS NOT AN EXCUSE

I have never used my deafblindness as an excuse to stop working toward my goals or as a reason to lower my expectations. After I was diagnosed with Usher syndrome, my parents never once changed their expectations of me. It was never a question whether I was going to attend college, develop friendships, travel the world, start a career, fall in love, and continue to seek out new adventures while doing the things I love to do. It was my parents' confident, consistent, overarching belief in me that taught me that despite my disability anything is possible. Over time, I have learned that I really don't know what I'm capable of until I try, and that if I don't try, I'll never know. Once I truly began to adopt this philosophy, I found that things always have a way of working out for the best.



## **ADAPT, ADAPT, ADAPT, AND THEN, CONTINUE TO ADAPT SOME MORE**

The hardest thing for me about living with Usher syndrome is that my vision loss is progressive. Although the deterioration has been slow, it seems like as soon as I become comfortable with the way things are, my vision decreases some more, forcing me to start all over again. I feel like I constantly have to adapt and adjust the way I do things.

As a result, I have learned the importance of being open to change and developing new strategies to overcome the challenges brought on by my progressive vision and hearing loss. For example, during undergraduate school, I fell in love with running. After several blows to my forehead from low-hanging branches, I started wearing a hat with a visor when I was outside to help protect my head. Ten years later, I am still running and I am now training for my first marathon. In addition to wearing a hat, I now run in the evenings after work, using my husband's arm as a guide. I am also slowly learning to enjoy running on a treadmill. In spite of the inexorable progression of my vision loss, I know that running will always be an important part of my life. It may just require a few adaptations as time goes on.



## **TAKE ADVANTAGE OF SERVICES AND PROGRAMS AVAILABLE TO PEOPLE WITH DISABILITIES**

Another thing that I have found helpful in my approach to living with Usher syndrome is learning how to swallow my pride and accept help. Growing up with a moderate to severe hearing loss, my parents were constantly advocating for me at school and setting up special support in the classroom, which I found extremely embarrassing at the time. It was a constant fight in my house to get me to attend my IEP (Individualized Education Program) meetings. It was not until after I was diagnosed with Usher syndrome and began experiencing significant vision loss in addition to my hearing loss that I finally realized that to excel in school and life in general, I needed to accept help.

After graduating from high school, I headed off to Colorado to attend college just as I originally planned to do pre-Usher diagnosis. At the time, I remember wondering if moving halfway across the country away from my support system was the best idea, but it turned out to be exactly what I needed. Being in a new environment without my parents advocating and arranging support behind the scenes, I quickly realized that no one was going to help me, unless I took the initiative. I did not know what kind of help was available until I asked, so I decided to inform myself. I was amazed to learn about all the different levels of services that are available to students with disabilities. In addition to the services provided through my school, I also received an amazing amount of support from the Oregon Commission for the Blind.



## **STRIVE FOR INDEPENDENCE**

I believe that continuing to strive for independence is extremely important in maintaining my overall sense of wellbeing and self-confidence. As a deafblind individual, I have found that fitting into a society that revolves around being able to hear and see can be challenging. It would be extremely easy to sit back and rely on others to help navigate the world. I am married to a wonderful man who would not think twice about chauffeuring me to and from work and doing all the grocery shopping. I am not saying that I never ask for a ride or let my husband lend a hand; I am saying that for me, it is important to maintain my independence in certain areas of my life. For example, I have strategically picked where I live so that I am within easy walking distance of multiple bus routes, grocery stores, parks to walk our dog, and a gym. Being able to ride the bus to work and go shopping by myself provides me with daily reminders that, despite being deafblind, I am a capable, independent woman.



## HOPE

Another thing that I have found helpful in my approach to life with Usher syndrome, is maintaining a sense of hope about what the future in science might bring for individuals with deafblindness. Although Usher syndrome is incurable at this time, hoping for a cure helps me cope. With the help of my father, I stay current with the latest research on deafblindness. Researchers have succeeded in reversing one form of deafblindness in mice, and others have given sight back to blind dogs. Reading about new scientific advancements inspires me to be excited and hopeful about the future. Sure, it still may be relatively far off, but there are scientific advancements being made all the time, especially now since the Obama administration is once again supporting scientific and medical research. I definitely feel better when I think about the possibility that there will be some sort of biological or technological procedure by the time I am 40 or 50 (just a guess) that would at least prevent me from going completely blind, if not restore my vision to the normal (or even better than normal!) standard. Regardless of what happens in the future, it can't hurt to hope.



## ACCEPTANCE

Coming to terms with being born with Usher syndrome has been a long process for me. I realize that having Usher syndrome is something that I cannot change, so I try not to let myself worry about it or feel sorry for myself, because ultimately that will be unproductive and not change anything. Whenever I bump into someone or stumble off of a curb, I try to push away the negative thoughts and keep going because I know I could not have avoided it and that it is not my fault. Now that I have adopted this mindset, I spend less time dwelling on the negative aspects of my disability and more time being thankful for what I have and hopeful for the future. And, as my brother says, hearing and seeing are overrated anyway!



[END]

### TRANSITION: A PERSONAL AND PROFESSIONAL PERSPECTIVE

Dorothy Walt

Q. What are the four most important things to focus on when helping a youth transition out of the school system?

For over 15 years, I have worked with a number of consumers who are deaf-blind and who have a variety of educational background and training experiences. There are MANY factors involved. Here I will consider four critical ones:

FIRST—I would hope a good Personal Future Plan or something similar had been developed to provide direction and goals when (or before) the child reached 14. I am a firm believer in planning and developing action steps for the future. Of course, these goals may change over the school years as

the youth matures, gains experiences, or his/her interests change. A top goal would be COMMUNICATION—both receptive and expressive; and being able to advocate for his/her communication needs.


SECOND — I would ask if the student had learned some life skills to be independent at home, in the community, and the workplace. This should include mobility training, how to use community services, knowing about safety issues, taking care of basic needs, making good choices and decisions, and staying healthy. Building a support system for this is critical.


THIRD — An employment goal should be designed. It should consider the student's interests, need for training and/or education, signing up for Vocational Rehabilitation services, and opportunities for work experience.


**FOURTH** — Social skills are very important for a student to be able to integrate into the mainstream, and make and keep friends.

**XXXXX**

The Helen Keller National Center (HKNC) can assist with the transition process. We offer several programs for youth to build upon existing skills or add new skills, to nurture self esteem and personal adjustment.

 In summer there is a two-week seminar that offers teens opportunities to broaden their experiences, awareness and knowledge.

 Also in summer is an eight-week evaluation program for students in high-school. HKNC provides a written report of recommendations. Comprehensive evaluation and training focuses on vocational goals and independent living — and using skills in the mainstream.

 Students can use our off-campus apartment to practice skills, or opt to live in a community of their choice.

The Oregon Commission for the Blind, and other support agencies in Oregon can facilitate a student's participation. As your HKNC representative, you can also contact me directly — for information, resources, participation in team meetings, consultation, and other services. The best way to reach me is by sending me an e-mail: [Dorothy.Walt@hknc.org](mailto:Dorothy.Walt@hknc.org) You can also go to our website for more information: [www.hknc.org](http://www.hknc.org)

**Helen Keller National Center (HKNC)**  
**14<sup>th</sup> Annual Summer Teen Program**  
**for Youth Who are Deaf-blind**

HOW FAR CAN YOU GO?  
IGNITE YOUR FUTURE!!

**READY?** to learn more about yourself and others

**SET?** to make plans for your career & life after High School

**GO AS FAR AS YOU CAN!!**

Come join teens from around the country for a fun-filled, action-packed two week program.

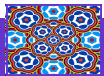
JOIN US **JULY 12-23, 2010** FOR:

**VOCATIONAL AND COLLEGE  
EXPLORATION,  
SHOPPING MALL SCAVENGER  
HUNT,  
NEW YORK CITY EXCURSION  
...AND MORE!**

Cost: \$800/week -includes tuition, room and board

*For registration materials or further information:*

Dora Carney  
Admissions Coordinator  
Helen Keller National Center  
141 Middle Neck Road  
Sands Point, NY 11050  
516-944-8900 ext 258  
[Dora.carney@hknc.org](mailto:Dora.carney@hknc.org)



Announcing:

**2010 Usher Syndrome  
Family Conference**

**DATES:** July 9-10  
**PLACE:** Seattle, WA  
**ORGANIZERS:** HearSeeHope  
**CONTACT:** Karmen Trzupekk  
[karmen@hearseehope.com](mailto:karmen@hearseehope.com)



## 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, Coastal Regional  
**Anne Olson-Murphy** — Region five, Willamette Regional  
**Kim Puckett & Stephanie Karpouzes**—Region six, Columbia Regional  
**Kit Staples**—Region seven, Lane Regional  
**Brenda Satter**—Region eight, Northwest Regional  
**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  
**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>

Our modules — in progress — can be seen at our website:

<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  
in part through grant # H326C030040,  
U.S. Department of Education,  
Office of Special Education.

Lyn Ayer, Oregon Deafblind Project  
Western Oregon University  
The Teaching Research Institute  
345 N. Monmouth Ave  
Monmouth, OR 97361  
TRD 360

