



Building Effective Programs



D. Jay Gense, Project Director • Sylvia Carnes, Coordinator • Spring 2006

Oregon "IN THE SPOTLIGHT" for Usher Syndrome Screening Project

By D. Jay Gense

We are pleased (*thrilled*, actually!) to announce that the Oregon Deafblind Project, working in collaboration with the Oregon School for the Deaf, Oregon's Regional Programs, Oregon Health Sciences University, will participate in a pilot study for screening for Usher Syndrome.

The study is spearheaded by Dr. Bill Kimberling of Boys Town National Research Hospital, Omaha, Nebraska. We are incredibly fortunate to be selected as the state for implementation of this pilot study, and know that the results of this study will help to advance appropriate treatments and/or interventions to address the impact of Usher Syndrome. Many states have had screening programs in the past, but such programs have been expensive, time intensive, arguably invasive, and have identified only a fraction of the children with Usher Syndrome. Exciting new medical technology may support identification of the Usher Syndrome gene through DNA analysis. The DNA is provided through a simple saliva sample, with no associated medical risks. The results of the study, however, significantly enhance abilities to appropriately identify children with Usher Syndrome, and ultimately, enhance abilities to provide appropriate services and/or treatments.

Usher Syndrome is one of the leading causes of deafblindness in the United States and worldwide. Usher Syndrome is an inherited condition that results in hearing loss and a progressive loss of vision from Retinitis

Pigmentosa (RP). The hearing loss is thought to be congenital, and ranges from moderate to profound. The vision loss is usually not noticeable until the child reaches his/her teens. It is estimated that between 5-10% of children with a hearing loss have Usher Syndrome. Often, it is Usher Syndrome for several reasons:

Safety: It is important for parents, friends and teachers to know that a child doesn't see well in the dark and cannot see off to the side very well.

Education: Teachers need to know so that the appropriate lighting can be provided in the classroom. People who communicate with someone with Usher Syndrome need to take the limited field of vision into account. Most students will benefit from specific educational services provided to address the impact of the vision impairment, including orientation and mobility instruction.

Treatment: Treatments that slow, or even stop, the vision loss are now being developed and will soon need to be tested in clinical trials. The key to effective treatment will be early identification.

NEW FEATURES!!

"Parent's Exchange" - Articles for Parents by Parents!

Causes of Deafblindness—We will explore different causes of deafblindness.

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The Blueprint

Former Student Named "Employee of the Year" by Oregon Commission for the Blind By Sylvia Carnes

Adrian Zarate, a graduate of David Douglas School District (SD) in Portland, Oregon was named "Employee of the Year" by Oregon Commission for the Blind. David Douglas SD was named "Employer of the Year". We are extremely proud that a former student has been given this honor and that his work place has been acknowledged for having the good judgment to hire him.

There are four criteria for being named "Employee of the Year". They are:

A person who is blind or visually impaired that presents a positive image of blindness.

A person who has made a meaningful impact on the public and has helped open doors to future success for other individuals who are blind or visually impaired.

A person who has made an obvious individual effort on his or her own behalf to overcome difficulties and has made significant gains in achieving personal independence.

A person who is involved in the community.

Adrian more than meets these criteria. Adrian is deafblind and bi-lingual. He is a wonderful example of someone who has overcome barriers with determination and perseverance. He has made an impact on others. It was Adrian's supervisor who inquired about the possibility of giving him an award. He attended the Summer Work Experience Program sponsored by the Commission for the Blind for two years. He then worked at David Douglas SD as a work experience while he was still attending school. Pictures were used to teach the job responsibilities and sequence. Soon the Commission paid Adrian's wages as on-the-job-training. When Adrian was out of school he was hired as a janitor substitute working 30 hours a week. He consistently

applied for full time positions as they became available. He waited patiently for four years before getting hired for a full time position earning \$14.00 an hour plus full benefits. Adrian has continued to learn and grow. He has taken classes in the community to improve his English, writing and math skills. He has spoken to a financial advisor. They have recommended that he continue his work for another year before applying for a loan to buy a home of his own.

To become an "Employer of the Year" the employer must:

Show the same objectivity in the selection of applicants that are blind as would be shown by any job applicant.

Respect the capabilities of workers who are blind and expect the same quality of production or services as would be expected of others.

Respond positively to identify employment opportunities for people who are blind/visually impaired and consider job modifications.

Show a positive attitude and objectivity.



The staff at David Douglas SD found effective ways to communicate with Adrian, then they let his work speak for itself. They do not treat Adrian differently than other employees. He is held to the same high standard. The modification that was important for Adrian's success was that they show him - not tell him - how to do the job. We thank Superintendent

Barbara Rommel and the staff at David Douglas SD for providing a place that Adrian is able to demonstrate the competent and reliable worker he is.

We cannot talk about Adrian's success without mentioning the love and support he receives from his family. This is vital to his success. The family has been able to find the correct balance in loving, believing and encouraging Adrian while also letting him grow and learn the sometimes difficult lessons of adulthood.

Dennis Crepeaux, the Commission for the Blind Transition Specialist, has also been a key player in this success story. We are extremely fortunate to have Dennis as part of our Project. He is on our Advisory Council and a part of our Working Group. Thank you for your good work.

Again, Congratulations Adrian! You make us all proud.

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This pilot project will involve a statewide effort, working in collaboration with parents of students age 14 and older with a diagnosed hearing loss. Those interested will be asked to participate in this study. The results will be used by Dr. Kimberling to persuade the National Institute of Health that this type of Usher Syndrome screening will be effective, and that national funding for screening is warranted. The objectives of the Oregon pilot are:

To demonstrate that families and children will participate in the screening;

To demonstrate that the technology exists to detect children who have Usher Syndrome;

To show that Usher Syndrome is common enough in deaf and hard-of-hearing children that screening will be cost-effective; and,

To determine parent and family attitudes about screening for Usher Syndrome.

Indeed, this is a *very* exciting opportunity for Oregon, and for Oregon's children and families with hearing impairment. We anticipate contacting appropriate parents across the state during the months of May and June. Contact will be facilitated by Teachers of Deaf/Hard of Hearing from the Regional Programs, from the Oregon School for the Deaf, and from our ten Deafblind Consulting Teachers. Parents and students will be provided information and materials that explain how to participate in the study. We strongly encourage families to join us in this study, knowing that the results will enhance future services and/or treatments. For more information, please contact Sylvia Carnes at 503-946-0589 or carness@wou.edu.

Resource Corner

Helen Keller National Center

Who do the "Feds" contact when they want to know how many people who are deafblind (DB), age 21 and older, live in Oregon? How many of those individuals have additional disabilities? Where can a state legislator find out the number of DB young adults who are in transition from school to adult services in eastern Oregon?

All of the above and much more can be learned from the Helen Keller National Center's (HKNC) database of information obtained from the registries.

You can register your child with the Helen Keller National Center's national census at any time. Not only will your child benefit by being counted,

he or she may receive resources and information related to issues that involve deafblindness.

To register you can do one of the following:

Go online to www.kknc.org and register online.

Contact Dorothy Walt, HKNC regional representative, to request a registry form.

206-324-9120 (V/TTY)

Email: nwhknc@juno.com

Contact the Oregon Deafblind Project and sign a release of information form giving them permission to give Dorothy the information from their census.

Thank you for considering the national DeafBlind registry of the Helen Keller National Center.

