

North Dakota  
Deaf-Blind Services Project

**D - B I N F O R M E R**

**MAY 2007**

WWW.ND.GOV/DEAFBLIND/ 1-877-630-6214

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**KAYLYN'S TRANSITION STAGE BY KARA MACIVER**

The road we have traveled over the past three years has had many bumps. We continue to be thankful to all the care-givers, doctors, and professionals we have come into contact with through this journey. There are many moments of Kaylyn's life that I remember vaguely; changing Kaylyn's first diaper, reading to her in the open bed in the NICU, cutting her thumb the first time I tried to clip her fingernails, her first scraped knee... However, there are three specific events that I remember vividly. The first event, holding Kaylyn for the first time (she was 30 days old.) Kaylyn was still hooked up to a ventilator and very, very fragile. There were few babies in the NICU at that time so the



nurses decided it was worth a try. At that moment, both Cory and I knew that we would do whatever we could to make sure this little girl was safe and loved every moment of her life. She had fought so hard to stay with us and was such a special gift!

The second event was being told there was evidence

of retinal detachment in both of Kaylyn's eyes. I remember the exact area of the Trinity NICU where Kaylyn was located, the nurses on duty, and the time of day when we were told that Kaylyn may never see. The ROP in both eyes had drastically worsened since her first laser surgery. I was absolutely devastated! I think that was the first moment, after Kaylyn was taken of the ventilator that I sat and cried and cried and cried. The emotional roller coaster had finally hit a point where we could take no more. Once we had a plan of action and we visited with another parent, whose daughter had been through the same surgery, I was fine. From the explanation we were



A division of the North Dakota  
Department of Public Instruction  
Dr. Wayne G. Sanstead  
State Superintendent

## KAYLYN'S TRANSITION STAGE CONTINUED. . BY KARA MACIVER

given, we knew that she was blessed to at least have light perception sight. Beyond that only time would tell.

Three weeks later the third event occurred. We were preparing for discharge and were informed that Kaylyn failed her hearing screening. We knew that she had already overcome so much. This would be another bump we could conquer. We were given all the information we could digest while still in the NICU. Dr. Klein came to the hospital and explained the results of Kaylyn's ABR. She told us the steps we needed to take to have Kaylyn fitted for hearing aids ASAP. At that point we just wanted to get Kaylyn home and away from everything!

The next month we began the early intervention process with our first visit from Infant Development, ND Vision Services/School for the Blind, and the ND School for the Deaf. We have had the opportunity to work with outstanding professionals over the past three years. Kaylyn has made progress in all areas of her development. She is seeing much more than we ever expected. She is beginning to talk..... and talk and talk. She walks, excuse me, runs towards new adventures constantly. What a miracle!

Kaylyn is one month shy of her third birthday. That means we are into the heart of the transition process. Our emotional roller coaster ride is beginning all over again. As a parent, how do you know what is best for you child?

We participated in Kaylyn's first transition meeting in early February. It was a nightmare! Cory and I are both employed in the education field and thought we knew about the IEP process and were prepared for the meeting. We couldn't have been more wrong! We were disappointed in the fact that key members of the team were not in attendance on this important day for Kaylyn. We were informed of the available services in the area and that was basically the extent of the meeting. Another meeting date was set and everyone went on their way.

Luckily one of the team members stayed around after the meeting and informed me of an option that I had not thought of, involving protection and advocacy. That was the best move we could have made. The purpose of P & A is to look out for the best interests of the child. Sometimes meetings become so intense and emotional that it is hard to control thoughts and actions. Our advocate gathered all the information on file pertaining to Kaylyn and came out to Plaza to meet with us. She also helped me prepare for the meeting by organizing my thoughts and sorting through the pros and cons of all possible placement options.

We met again the first part of May with a team quite larger than the previous meeting. We had invited our advocate, the director of our local special education unit, and our daycare provider to offer their expertise at the meeting. This meeting was much more positive and I left feeling that all team members truly had Kaylyn's best interests at heart. We had a productive discussion and idea share time. Many team members expressed concerns and suggestions. We did not make a final decision on Kaylyn's placement or write IEP goals. We decided to try to get together as a team again August 2<sup>nd</sup>. We realize many things may change during that time, but we hope to come to a consensus and finalize the decisions on Kaylyn's educational developmental plans at this meeting.

The transition process from early intervention services to the school system is an extremely stressful time. The best advice we can give is to educate yourself as much as possible. Feel confident that you have the right people at the meeting and invite those you want in attendance. Know that if you are not happy with the decisions made you can meet again.

We hope that our story has given you confidence in yourself. You are your child's best advocate. Believe in yourself and fight for what you believe is best for your child.



## COCHLEAR IMPLANTS FROM NIDCD

A cochlear implant is a small, complex electronic device that can help to provide a sense of sound to a person who is profoundly deaf or severely hard-of-hearing. The implant consists of an external portion that sits behind the ear and a second portion that is surgically placed under the skin (see figure). An implant has the following parts:



- A microphone, which picks up sound from the environment.
- A speech processor, which selects and arranges sounds picked up by the microphone.
- A transmitter and receiver/stimulator, which receive signals from the speech processor and convert them into electric impulses.
- An electrode array, which is a group of electrodes that collects the impulses from the stimulator and sends them to different regions of the auditory nerve.

An implant does not restore normal hearing. Instead, it can give a deaf person a useful representation of sounds in the environment and help him or her to understand speech.

### How does a cochlear implant work?

A cochlear implant is very different from a hearing aid. Hearing aids amplify sounds so they may be detected by damaged ears. Cochlear implants bypass damaged portions of the ear and directly stimulate the auditory nerve. Signals generated by the implant are sent by way of the auditory nerve to the brain, which recognizes the signals as sound. Hearing through a cochlear implant is different from normal hearing and takes time to learn or relearn. However, it allows many people to recognize warning signals, understand other sounds in the environment, and enjoy a conversation in person or by telephone.

### Who gets cochlear implants?

Children and adults who are deaf or severely hard-of-hearing can be fitted for cochlear implants. According to the Food and Drug Administration's (FDA's) 2005 data, nearly 100,000 people worldwide have received implants. In the United States, roughly 22,000 adults and nearly 15,000 children have received them.

Adults who have lost all or most of their hearing later in life often can benefit from cochlear implants. They learn to associate the signal provided by an implant with sounds they remember. This often provides recipients with the ability to understand speech solely by listening through the implant, without requiring any visual cues such as those provided by lip-reading or sign language.

Cochlear implants, coupled with intensive post-implantation therapy, can help young children to acquire speech, language, and social skills. Most children who receive implants are between two and six years old. Early implantation provides exposure to sounds that can be helpful during the critical period when children learn speech and language skills. In 2000, the FDA lowered the age of eligibility to 12 months for one type of cochlear implant.

### How does someone receive a cochlear implant?

Use of a cochlear implant requires both a surgical procedure and significant therapy to learn or relearn the sense of hearing. Not everyone performs at the same level with this device. The decision to receive an implant

**COCHLEAR IMPLANTS CONTINUED . . . FROM NIDCD**

should involve discussions with medical specialists, including an experienced cochlear-implant surgeon. The process can be expensive. For example, a person’s health insurance may cover the expense, but not always. Some individuals may choose not to have a cochlear implant for a variety of personal reasons. Surgical implantations are almost always safe, although complications are a risk factor, just as with any kind of surgery. An additional consideration is learning to interpret the sounds created by an implant. This process takes time and practice. Speech-language pathologists and audiologists are frequently involved in this learning process. Prior to implantation, all of these factors need to be considered.

**What does the future hold for cochlear implants?**

With advancements in technology and continued follow-up studies with people who already have received implants, researchers are evaluating how cochlear implants might be used for other types of hearing loss.

NIDCD is supporting research to improve upon the benefits provided by cochlear implants. It may be possible to use a shortened electrode array, inserted into a portion of the cochlea, for individuals whose hearing loss is limited to the higher frequencies. Other studies are exploring ways to make a cochlear implant convey the sounds of speech more clearly. Researchers also are looking at the potential benefits of pairing a cochlear implant in one ear with either another cochlear implant or a hearing aid in the other ear.

**For more information on cochlear implants, please visit the National Institute on Deafness and Other Communication Disorders (NIDCD) website @ <http://www.nidcd.nih.gov>**

**DID YOU KNOW . . .**

- Helen Keller was the first deaf and blind person to earn a college degree. She graduated from Radcliffe College, with honors, in 1904.
- “The best and most beautiful things in the world cannot be seen nor even touched, but just felt in the heart.” -Helen Keller, 1891
- “If I, deaf, blind, find life rich and interesting, how much more can you gain by the use of your five senses!” -Helen Keller, 1928

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 ☆ OUR TEAM ☆  
 ☆ Our team is here to serve families ☆  
 ☆ and professionals of individuals who ☆  
 ☆ are deaf-blind, birth through age 21. ☆  
 ☆ Please get in touch with us if you ☆  
 ☆ have questions, or feel we could be ☆  
 ☆ of assistance! ☆  
 ☆ How to access our services: ☆  
 ☆ **ND Deaf-Blind Services Project** ☆  
 ☆ Sherri Nelson, Project Coordinator ☆  
 ☆ 701-665-4401 or 877-630-6214 ☆  
 ☆ **North Dakota School for the Deaf** ☆  
 ☆ Outreach teachers 701-665-4400 or ☆  
 ☆ 800-887-2980 ☆  
 ☆ **ND Vision Services/** ☆  
 ☆ **School for the Blind** ☆  
 ☆ Outreach teachers 701-795-2700 or ☆  
 ☆ 800-421-1181 ☆  
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## Syndromes Which Often Result in Combined Vision and Hearing Loss

by Kate Moss, Family Training Specialist, TSBVI Outreach

Usher Syndrome is one disorder that comes to mind readily for professionals in both the field of vision and hearing when they think of syndromes which result in dual sensory impairment or deaf-blindness. However, there are many syndromes that have both vision and hearing impairment as part of the conditions that define the syndrome. It is important to be aware of these conditions, since one of the sensory disabilities is often times more evident than the other. This situation makes it easy to overlook the impact of the combined vision and hearing loss.

Below some of the more common syndromes, which can manifest with both vision and hearing loss, are described. If you are interested in obtaining more detailed information about any of these conditions, you may contact:

National Organization for Rare Disorders  
P.O. Box 8923  
New Fairfield, CT 06812-1783  
(203) 746-6518



Most of the information about these syndromes comes from reports provided by NORD. The exception is the information on Congenital Rubella Syndrome which comes from a booklet, "Congenital Rubella Syndrome: Health Care Challenges" written by Dr. Steven Parker from Boston University School of Medicine in collaboration with Perkins School for the Blind, Helen Keller National Center and St. Luke's-Roosevelt Hospital. This publication is available through Perkins School for the Blind.

### Alport Syndrome

Alport Syndrome is a group of hereditary kidney disorders. They are characterized by progressive deterioration of the glomerular basement membranes which are microscopic parts of the kidney. This deterioration may lead to chronic renal (kidney) failure causing excess waste products in the blood (uremia). Eventually severe renal failure may develop. Uremia and kidney failure may cause heart and bone problems.



Abnormalities of the eye may occur in the juvenile forms of Alport Syndrome. The surface of the eye's lens may be cone-shaped (lenticonus) or spherical (spherophakia). The lens of the eye may be opaque or cloudy (cataracts). White dots may appear on the retina (retinal macular flecks or fundus alpinunctatis). Children with Alport syndrome may be nearsighted (myopic).

Type I, Type II and Type VI Alport Syndrome includes kidney disease with nerve deafness and eye abnormalities. The difference between these two types is that Type I is a dominantly inherited juvenile form and Type II is an X-linked dominant juvenile form. Type VI is the autosomal dominant juvenile form.

### Cytomegalovirus (CMV)

Cytomegalovirus Infection is a virus infection occurring congenitally, postnatally or at any age. CMV ranges in severity from a silent infection without consequences, to a disease manifested by fever, hepatitis, and (in newborns) severe brain damage, and stillbirth or perinatal death.

Symptoms of CMV are also highly variable as well. The infection may be manifested only by CMV in the urine in an otherwise healthy infant. At the other end of the extreme, hemorrhaging, anemia, or extensive liver or central nervous system damage may occur. Infants born with a severe form of the disease typically have a low birth weight and develop fever, hepatitis with jaundice, and hemorrhages into the skin, mucous

**Syndromes Which Often Result in Combined Vision and Hearing Loss Continued . .**

by Kate Moss, Family Training Specialist, TSBVI Outreach

membranes, internal organs, and other tissues. Enlargement of the liver and spleen, decrease in number of blood platelets, inflammation of the choroid and retina, abnormal smallness of the head, and calcification around the veins of the cerebral portion of the brain may occur. Motor defects, spastic paralysis on both sides of the body, blindness, deafness or seizures may develop.

Vision loss in these children is related to scarring of the choroid (the dark brown vascular coat of the eye between the sclera and retina). Hearing loss in these children is sensorineural. Even though CMV infection may not be apparent in some infants, it may later cause hearing loss.

**CHARGE Association**

CHARGE Association is a very rare disorder characterized by a variety of symptoms. At least four of the following six characteristics must be present for the diagnosis of CHARGE Association: 1) Absence of some eye tissue, including the iris (Coloboma); 2) Hear disease; 3) Absence of the opening between the nasal cavity and the back of the throat (Atresia of the choanae); 4) Retarded growth and development and central nervous system abnormalities; 5) underdevelopment of the Genitals; 6) Ear abnormalities and hearing loss. The six letters of each of these conditions make up the name CHARGE.

**Down Syndrome**

Down syndrome is the most common and readily identifiable genetic condition associated with mental retardation. It is caused by a chromosomal abnormality. One additional chromosome is present in each cell. This extra gene material changes the development of body and brain. About half of these children have congenital heart disease. There is an increased incidence of respiratory problems. Recent studies have shown that there are more eye and ear problems in individuals with Down Syndrome. Eye problems associated with this syndrome are myopia and "Brushfield" spots (gray or pale yellow spots at the periphery of the iris). These individuals may have either sensorineural, conductive or mixed types of hearing loss.

**Marshall Syndrome**

Individuals with Marshall Syndrome have a distinct flat sunken midface with a flattened nasal bridge or "saddle nose". Their nostrils turn upward, there is a wide space between the eyes, and the upper portion of the skull is thicker than normal. Calcium deposits may also be found in the skull. Eye defects found in these individuals include nearsightedness, cataracts, and eyeballs that appear to be larger than normal because of the wide space between the eyes. Some people with this syndrome may also have crossed eyes, a condition in which the line of vision is higher in one eye than the other called hypertropia, retinal detachment, or glaucoma. Hearing loss may be slight or severe and is sensorineural.



**D-B Advisory Board Members**

- Sherri Nelson**  
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- Jody Neva**  
Parent
- Lisle Kauffman**  
Director of Education of the Deaf
- Jodi Appelt**  
Education of the Deaf
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Optometrist
- Linda Ehlers**  
Deaf Outreach

## Syndromes Which Often Result in Combined Vision and Hearing Loss Continued . .

by Kate Moss, Family Training Specialist, TSBVI Outreach

### Rubella Syndrome

If a pregnant woman contracts rubella, the virus can infect her fetus. Such an infection is especially dangerous in the first 4 months of pregnancy, causing damage to the developing organs. Although any part of the body can be affected, the eyes and ears seem to be especially susceptible to damage from a rubella infection.

Babies born with Congenital Rubella Syndrome vary greatly from one another. Some are only mildly affected while others have significant disabilities. Some of the problems associated with CRS include sensorineural hearing loss, visual problems such as cataract, inflammation of the retina (retinopathy), nystagmus, small eyes (microphthalmia), and occasionally optic atrophy, corneal haze, and glaucoma. These individuals may also experience hearing problems, neurological problems, growth problems, and other disabling conditions. In later life some individuals also experience glaucoma and detached retina.

### Stickler Syndrome

Stickler syndrome is a genetic disorder inherited as a dominant trait. Initial symptoms of Stickler Syndrome may include a broad, flat, sunken bridge of the nose which makes the face look flattened. A cleft palate and small jaw may also be present. In addition, sensorineural deafness may develop. Eye defects may include a high degree of nearsightedness (myopia), irregularities of the lens (astigmatism), and changes of the optic disk. Cataracts, detachment of the retina and blindness may develop during the first decade of life. A form of glaucoma called glaucoma simplex may also occur.

Bone abnormalities in joints such as the ankles, knees and wrists usually occur. During childhood, individuals may experience stiffness and soreness after strenuous exercise. Swelling, redness and a feeling of heat may occur occasionally, leading to cracking and temporary locking of the joints. Incomplete dislocation of the hips is another frequent occurrence.

### Other Syndromes

There are many other syndromes and conditions that are associated to some degree with combined vision and hearing loss. Some of these include:

- *Duane Syndrome*
- *KID Syndrome*
- *Leber's Syndrome*
- *Norrie's Disease*
- *Pierre-Robin Syndrome*
- *Trisomy 13*



Of course, vision and hearing loss may occur in children with any type of syndrome or condition in the same way that vision and hearing loss occur in the non-disabled population. However, in syndromes and conditions known to have related vision and hearing loss, we must be certain to provide ongoing, periodic assessment and monitoring of vision and hearing function.

For more information on syndromes please visit the TSBVI website @ <http://www.tsbvi.edu> and click on See/Hear Newsletter.



**UPCOMING EVENTS****Camp Abilities Tucson  
June 3–9, 2007  
Tucson, Arizona**

Sports camp experience available for elementary-, middle-, and high-school-aged children, who are blind, visually impaired, or deaf-blind. Provides an opportunity to participate in sports and recreational activities uniquely designed to meet the needs of participants. Contact: Megan O'Connell. Phone: 520-770-3188. E-mail: [campabilitiestucson@cox.net](mailto:campabilitiestucson@cox.net). <https://fp.auburn.edu/wertjea/tucsoncampabilities>.

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**HKNC Summer Seminar for High School Students who are Exploring Future Vocational and Educational Opportunities  
July 9–20, 2007  
Sands Point, New York**

A two-week seminar for junior or senior high school students who are deaf-blind and who are interested in learning about vocational rehabilitation services and meeting new friends. Participants will also have opportunities to learn ways to do some problem-solving and self-advocacy to promote a positive college experience. Contact: Dora Carney. Phone: 516-944-8900, extension 258. E-mail: [drchknc@aol.com](mailto:drchknc@aol.com).

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**Dr. Olaf R. McLetchie Training Institute  
July 9–20, 2007  
Watertown, Massachusetts**

The Dr. Olaf R. McLetchie Training Institute provides training to address the critical shortage of teachers who have the necessary skills and knowledge to work with learners who are deaf-blind. Contact: Marianne Riggio. Phone: 617-972-7264. E-mail: [marianne.riggio@perkins.org](mailto:marianne.riggio@perkins.org).

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**8th International CHARGE Syndrome Conference  
July 27-29, 2007  
Costa Mesa, California**

For more information contact the CHARGE Syndrome Foundation, Inc., 409 Vandiver Drive, Suite 5-104, Columbia, MO 65202. Phone: 800-442-7604. E-mail: [infor@chargesyndrome.org](mailto:infor@chargesyndrome.org). Web: <http://www.chargesyndrome.org/conference-2007.asp>.

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**14th Deaf-Blind International World Conference  
September 25-30, 2007  
Perth, Australia**

Exciting international and national speakers will form part of the conference program based around the theme, "Worldwide Connections: Breaking the Isolation." An estimated 1000 delegates will attend from throughout the world. Participants will include international, national, and local health and disability professionals and service providers; recognized experts in deaf-blindness; and representatives from the international blind and deaf-blind communities. For more information contact Senses Foundation, Inc., PO Box 14, Maylands WA 6931, Australia. Phone: 61 8 9473 5400. TTY: 61 8 9473 5488. E-mail: [conference@senses.asn.au](mailto:conference@senses.asn.au). Web: <http://www.dbiconference2007.asn.au>.

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## UPCOMING EVENTS

### Helen Keller National Center National Training Team Seminars Sands Point, New York

The Helen Keller National Center National Training Team (NTT) was established to increase knowledge and support the development of skills specific to deaf-blindness. The 2007 schedule includes:

- "Same but Different": Orientation and Mobility Techniques for Deaf-Blind Travelers – May 20–25, 2007.
- Interpreting Techniques for the Deaf-Blind Population: Touching Lives – August 6–10, 2007.
- Enhancing Services for Older Adults with Vision and Hearing Loss: "The Best is Yet to Come" – September 17–2, 2007.
- Transformation: Person Centered Approach to Habilitation – October 15–19, 2007.
- Technology Seminar: The Magic of Technology - December 3-7, 2007.

Contact:

Doris Plansker

Phone: 516-944-8900, extension 233

TTY: 516-944-8637

E-mail: [ntthknc@aol.com](mailto:ntthknc@aol.com)

Web: <http://hknc.org/FieldServicesNTT.htm>.



### A Collaborative Conference on Autism with Low Incidence Disabilities July 30–August 1, 2007 Columbus, Ohio

The Ohio Center for Deafblind Education, the Ohio School for the Deaf, the Ohio State School for the Blind, and the Ohio Center for Autism and Low Incidence are presenting this conference for parents and professionals. Contact: Sue Fraley. Phone: 866-886-2254 or 614-410-0321, extension 0739. E-mail: [sue\\_fraley@ocali.org](mailto:sue_fraley@ocali.org). Web: <http://www.ocali.org>.

### Overview of Deaf-Blindness with an Emphasis in Communication Online Course New Mexico

The Project for New Mexico Children and Youth who are Deaf-blind is offering a web-based distance education course for families, individuals, service providers, and educational teams. The class explores and defines the causes and learning consequences of deaf-blindness. Phone: 877-614-4051 or 505-272-0321 (V/TTY). E-mail: [nmdb@unm.edu](mailto:nmdb@unm.edu). Web: <http://cdd.unm.edu/deafblind>.

### Online Courses on Early Communication Oregon Health & Science University

Two new online courses are available from Oregon Health & Science University. Both are offered as self-paced noncredit learning opportunities. (1) **Pre-symbolic Communication** provides instruction on helping an individual to learn or expand pre-symbolic methods of communication and presents information on related research. (2) **Tangible Symbol Systems** provides instruction on all aspects of teaching an individual to use tangible symbols and also addresses the theoretical basis and research for this approach. Register online at any time. The cost for each course is \$165. For complete information and online registration visit: <http://www.designtolearn.com/pages/tsonline.html>.

**UPCOMING EVENTS**

**\*\* Is it sensory? –or- Is it behavior? June 4-5, 2007** Presenters Carolyn Murray-Slutsky, MS OTR and Betty Paris, PT, M. Ed. Contact: Dean Giedt, Outreach Specialist, Anne Carlsen Center for Children #1-800-568-5175 or dean.giedt@annecenter.org

The confusing and challenging behaviors children often demonstrate cause parents, teachers, and therapists to ask the questions: Is it sensory or is it behavior? This two day seminar will be discussed in depth.

**\*\*Emergent Literacy For Students: A Project-Based Approach June 11-12, 2007,** Rawlins, WY Caroline Ramsey Musselwhite, CCC-SLP For further information contact the WY Deaf-Blind Project at 307-324-5333 or [jwhits@educ.state.wy.us](mailto:jwhits@educ.state.wy.us)

This workshop is designed for Educators, Therapists, SLPs, and those interested in addressing the Literacy needs of their students. It will address the needs of upper elementary through high school students with significant cognitive impairments. A primary focus will be locating appropriate reading materials, helping students access them through a Project-Based Approach.

**\*\* 2007 Family Connections conference: When Children Have Special Needs** The Power of One: Hearts and Minds Together, **June 14, 15, & 16, 2007 Pre-conferences: June 13 & 14, 2007** Doublewood Inn, Fargo, ND

Keynote speakers: Michael Winer from Portland, OR, author of Collaboration handbook: Creating, Sustaining and Enjoying the Journey., and ResultScaping: Growing Resources You Hve into Results You Want., and Dr. Diane Hovey, founder of the Family Institute for Creative Well-Being. For further information go to [www.conted.und.edu/connections](http://www.conted.und.edu/connections) or call 866-579-2663

**\*\*007 Spy Camps for Deaf and Hard of Hearing Children,** North Dakota School for the Deaf, For more information contact Carol Lybeck @ #701-665-4400 or Linda Ehlers @ #701-239-7116

**Camp 1 June 11-15, 2007 (Ages 7-12), Camp 2 June 18-22, 2007 (Ages 13-18)**

**\*\*Families Connecting with Families July 13-15, 2007** Omaha, Nebraska

For more information go to: [www.napvi.org](http://www.napvi.org) or [www.afb.org](http://www.afb.org)

A national conference covering all aspects of raising and educating a child with a visual impairment.

**\*\*Midwest Conference on Deaf Education July 30-31, 2007** Augustana College, Sioux Falls, SD Cynthia Neese Bailes, Ph.D from the Department of Deaf Education at Gallaudet University in Washington D.C.

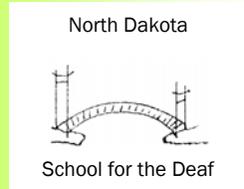
The MWCDE will address five major topical strand issues, as well as special topics associated with the education of students who are deaf and hard of hearing. The strand topics are: Literacy, Rural Education, Family Support, Educational Interpreting, Academic Achievement, and Special Topics. For more information go to: [www.MWCDE.com](http://www.MWCDE.com) or [Melissa Hawk@augie.edu](mailto:Melissa_Hawk@augie.edu) or [Monica Soukup@augie.edu](mailto:Monica_Soukup@augie.edu)

**\*\*Mind/Brain Myth-busters** An interactive seminar exploring the facts and fiction in popular “brain-based” media information **September 14-15, 2007** Minot State University Conference Center. For additional information call #701-858-3028 or 1-800-777-0750 ext. 3028

**ND Deaf-Blind Project Technical Assistance Team**

**ND School for the Deaf**

- Carol Lybeck => Devils Lake
- Linda Ehlers => Fargo
- Position Open => Grand Forks
- Tami Iszler => Bismarck
- Nicole Wittiko => Minot



**ND Vision Services**

**School for the Blind**

- Dianne Giessinger => Minot
- Linda Kraft => Jamestown
- Lanna Slaby => Jamestown
- Position Open => Fargo
- Mary Verlinde => Bismarck
- Katrina Wendel => Grand Forks
- Ken Dockter => Grand Forks
- Paul Olson => Grand Forks
- Pat Hill => Grand Forks
- Deb Johnsen => Grand Forks
- Candy Lien => Grand Forks
- Diane Mihulka => Grand Forks
- Tracy Wicken => Grand Forks



Technical assistance request forms are located at [www.nd.gov/deafblind/](http://www.nd.gov/deafblind/) or call 1-877-630-6214



## NEW BOOKS IN THE NDDBSP LENDING LIBRARY



### **A Parents' guide to Special Education for Children with Visual Impairments**

by Susan LaVenture, Editor, AFB PRESS –American Foundation for the Blind, 2007

This book is meant to be a guide for you. It is intended to help you understand the important information families need to know about education and their children who are blind or visually impaired. When a child has a visual impairment, learning and development may need to be helped along the way. Intervention, encouragement, and special educational planning therefore become an essential part of the school years. The authors of this book, experienced parents who have walked down the educational road successfully and specialists in the vision field, have provided the information they feel you should know as a parent to help you proceed down this road. Every child is an individual and has unique needs and strengths, and there is no one formula that fits for every child's successful education. But there is an educational process, and knowing what it is and what it can offer can lead to educational success. The process works, but it needs you. Parents play the most important and influential role in their child's education. This book is a means to help you in this role and through this process.

### **Silence with a Touch: Living with Usher Syndrome**

New York State Technical Assistance Project, National Technical Institute for the Deaf, New York, NY, 2006

Usher Syndrome is a genetic condition affecting thousands and thousands of people. This little known condition causes both hearing and progressive vision loss. In this DVD, you will meet people of all ages who share how their lives have been affected by Ushers, and how they've learned to adjust and overcome challenges along the way. Their stories will enlighten and inspire you.



### **Blind Rage: Letters to Helen Keller**

Georgina Kleege, Gallaudet University Press, 2006



As a young blind girl, Georgina Kleege, repeatedly heard the refrain, "Why can't you be more like Helen Keller?" Kleege's resentment culminated in her book, Blind Rage: Letters to Helen Keller, an ingenious examination of the life of this renowned international figure through 21<sup>st</sup>-century sensibilities. Kleege's absorption with Keller originated as an angry response to the idea of a secular saint, which no real blind or deaf person could ever emulate. However, her investigation into the genuine Helen Keller revealed that a much more complex set of characters and circumstances shaped Keller's life.

### **Successful Kindergarten Transition: Your Guide to Connecting Children, Families, & Schools**

By Robert C. Pianta, Ph.D. & Marcia Kraft-Syre, L.C.S.W.

A smooth transition to kindergarten is an essential part of a child's early academic experience-and this guide has the field-tested methods you need to make this happen. Ideal for early childhood educators, administrators, and family support specialists, Successful Kindergarten Transition introduces a model that has been adopted in diverse schools and communities across the country. Step by step, this practical book helps you and the other members of the educational team develop a solid transition plan, implement the plan while keeping families involved and assessing effectiveness, and stay motivated and inspired with insights from real families, educators, and school personnel.

### **Achieving Learning Goals Through Play: Teaching Young Children with Special Needs, 2nd Edition**

By Anne H. Widerstrom, Ph.D.

Developed for use with children ages 2-5 years who have special needs-but equally effective for typically developing children-this practical, ready-to-use guide helps you address children's individual learning goals through play. You'll get age-specific strategies for creating learning opportunities in each of the classroom's play center, suggestions for supporting learning goals during familiar types of play, planning sheets on working play activities into the classroom schedule, and strategies that foster social skills during group activities and free play. Throughout the book, you'll find invaluable information on how play activities can help children develop cognitive, communication, motor, social, and pre-literacy skills.

**NEW BOOKS IN THE NDDBSP LENDING LIBRARY**

**Building Blocks for Teaching Preschoolers with Special Needs**

By Susan R. Sandall, Ph.D. & Ilene S. Schwartz, Ph.D. with invited contributors Foreward by Mary Louise Hemmeter, Ph.D.

In an inclusive early childhood classroom, the everyday challenges you face can seem overwhelming-especially if you have little experience working with children who have disabilities. This popular guidebook throws you a lifeline, offering strategies for teaching preschoolers with special needs, tailoring activities to individual needs, and working on a child's IEP goals. At the heart of this easy-to-use book are the authors' three practical methods for including young children with disabilities in the classroom: curriculum modifications that allow all children to participate, embedded learning opportunities that are used in typical classroom activities, and child-focused instructional strategies that help students achieve individual learning objectives.



**Pain in Children & Adults with Developmental Disabilities**

Edited by Tim F. Oberlander, M.D. & Frank J. Symons, Ph.D.



The first to synthesize research about pain in children and adults with a range of developmental disabilities, this landmark book will ensure that you're better prepared to assess and manage pain and deliver timely, appropriate health care. Expert researchers and clinicians cover a wide range of topics, including the impact of pain on quality of life, how pain might instigate or intensify challenging behavior, issues and challenges surrounding pharmacological treatment, neurobiological and neuropsychological processes, and assessment strategies and technologies. Essential reading for a wide range of professionals across disciplines, this research-based book will help you deliver the best possible pain management for both children and adults.

**Developmental & Therapeutic Interventions in the NICU**

By Elsie R. Vergara, Sc.D., OTR, FAOTA & Rosemarie Bigsby, Sc.D., OTR, FAOTA



The most comprehensive book available on neonatal intervention, this in-depth resource gives you the strong foundation of clinical knowledge you'll need to work with high-risk newborns in the NICU. Set apart by its developmental and therapeutic perspective, this book is filled with cutting-edge research and ready-to-use guidelines for promoting the well-being of infants and supporting their families. You'll find information on developmental models for intervention, medical conditions of newborns, functional abilities fo premature infants, proper use of equipment, teamwork in the NICU, positioning and feeding, family-centered care, assessments, the transition to home, and follow-up with high-risk infants.

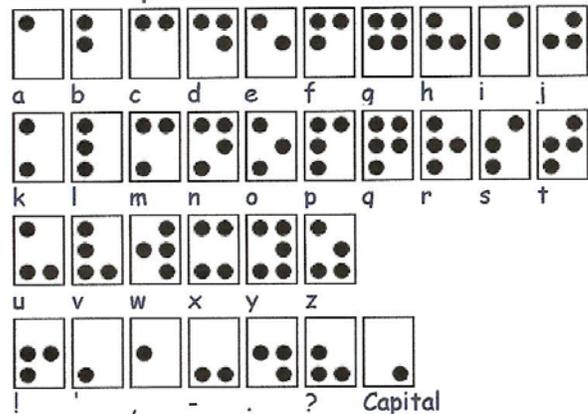
Braille is a system for reading by touch. Arranging one to six raised dots within a Braille cell can create letters, numbers, punctuation and capitalization. Braille books are larger than books in print, so the Braille code uses 189 different contractions and short-form words to reduce space and paper. Braille can be used to transcribe books of all kinds, including math, science, and music.

**American Foundation for the Blind (AFB)**

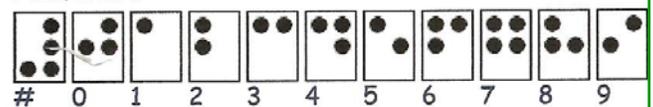
**[www.afb.org](http://www.afb.org) then click on Braille Bug**

**1-800-232-5463**

**Braille Alphabet:**



**Numbers:**



## USHER SYNDROME BY SHERRI NELSON, DEAF-BLIND COORDINATOR

I think it's only fitting that I share information about Usher Syndrome for this newsletter. My first exposure to Usher Syndrome occurred in the 1980s, with mention of this condition in my first audiology class at Minot State College. Following my graduate work, I began working at the ND School for the Deaf (NDS) in 1985 as the school audiologist.

In 1993, Dr. Sandra Davenport, a pediatric geneticist with a special interest in Deaf-Blindness, came to the NDS to screen all the students for Usher Syndrome. In addition, there was a regional representative from the Helen Keller National Center, Maureen McGowan, and a Fargo ophthalmologist, Max Johnson, that assisted with the screening. My son, who was three years old at that time, and his father were also seen by Dr. Davenport. We learned about the combination of the eye disorder, kerniticonus, the profound hearing loss, and the pie baldness that was detected in their genetic makeup. This screening raised suspicion for visual concerns with three students, who were later diagnosed with Usher Syndrome, and another nine students that had vision impairments that were recommended for further evaluation. What a successful screening this had been for the 50+ students from NDS!

In September of 1995, a teacher from NDS and I attended a planning meeting in Pittsburgh, Pennsylvania, to develop an action plan for the state of North Dakota regarding the state-wide screening for Usher Syndrome. Over 15 states participated in this venture. I knew how valuable the screening had been at NDS and I was committed to the idea of a state-wide screening. A few months later, I moved and accepted a position with the Infant Development Program in Fargo, ND. The Ushers Task Force continued to meet at NDS, however, the state-wide screening idea dissolved.

When I began working for the Deaf-Blind Project in September, 2006, I began asking about the Usher task force and was anxious to contact our regional representative from the Helen Keller National Center, who continued to be Maureen McGowan. We talked about the idea of doing another screening at NDS in the spring.

We screened all the students at NDS for vision and balance concerns in April 2007. In-services were provided by Maureen McGowan for all teaching staff at both the School for the Deaf and ND Vision Services/School for the Blind. Following the testing, it was recommended that four students be referred to an area ophthalmologist due to concerns with their vision and balance test results.

I would like to share some information regarding Usher Syndrome (US). Usher Syndrome is the leading cause of Deaf-Blindness. It is one of several conditions that involve both the hearing and the vision. The major symptoms of US are a hearing impairment and retinitis pigmentosa (RP), an eye disorder that causes a person's vision to worsen over time. RP affects the sensory cells in the retina, which is the layer lining the inside of the eye. The retina itself is made up of several layers of interconnecting cells, two of which are called rods and cones. The 150 million rods in each eye control night vision so that people can see in dim light. About 7 million cones are present in each retina. By the time the cones deteriorate, doctors can see distinctive changes when they look at the retina. In RP, the rods deteriorate first, then the cones. This

## USHER SYNDROME CONTINUED. . . BY SHERRI NELSON, DEAF-BLIND COORDINATOR

means that night blindness occurs, followed by blind spots, then progressive tunnel vision during the day. Some people with US also have balance problems.

There are three general types of US at this time. The Syndrome was first described by Albrecht Von Graefe in 1858, but it was named after Charles Usher, a British eye doctor, who believed that it was inherited or passed from parents to their children.

Approximately 4% of all deaf children have US, so approximately 4 babies in 100,000 births have US. US is passed from the parents to their children through a recessive gene. Usually, parents are unaware that they have an Usher gene (they are a carrier). But when matched with another recessive gene, US becomes evident.

The three types of Usher Syndrome (US) are Type I, II, and III. People with Type I are born profoundly deaf and have severe balance problems. Most are very late walkers. Most use sign language as their main mode of communication and many are educated in schools for the Deaf. Many say they get little or no benefit from hearing aids. Many of these children are fit with a cochlear implant(s). Usually they begin to develop vision problems by the time they are teenagers. They experience visual problems first at night, with progression until the individual loses most of their visual field.

Individuals with Type II are born with a moderate-to-severe hearing loss and normal balance. They are able to detect low tones better than high tones. Most of these children are educated in their home schools and wear hearing aids. Most use speech as their primary method of communication. Their vision difficulties come on slowly and they often develop blind spots in their visual fields by their teenage years. As the individual's vision deteriorates, it becomes more and more difficult to speech-read. Later, they may learn sign language.

Children born with Type III have normal hearing and normal to near normal balance. This type is less common than the other two types. Hearing worsens over time. However, the rate at which their hearing and sight are lost varies. Often they become deaf by mid-to-late adulthood. Night blindness usually begins during puberty. By mid-adulthood, the individual often is blind. A fairly large group of people in central Finland are being studied for Type III US.

Usher Syndrome is diagnosed by completing special tests such as electroretinography (ERG) to diagnose the retinitis pigmentosa and the electronystagmography (ENG) to detect balance problems. Early diagnosis is important to help the individual and the family begin educational programming for the hearing and vision difficulties and accept the diagnosis. A number of conditions may be confused with Usher Syndrome. Therefore the diagnosis must be made by an eye specialist. Genetic testing is also recommended to confirm the diagnosis.

There is no cure for Usher Syndrome. According to the information from the National Institute on Deafness and Other Communication Disorders (NIDSD), there are currently 12 loci (small segments of chromosomes on which one or more genes are housed) that have been found to cause US. Further research continues to be done in this area. However, early identification is critical with Usher Syndrome.

## FAMILIES UNITING FAMILIES RETREAT By Linda Kraft, NDVS/NDSB

There are certain challenges and concerns unique to parenting a child with a visual impairment. No better support can be found than from other parents. To facilitate this communication, FOCVI (Families of Children with Visual Impairments) has been reorganized. FOCVI had been an active organization in the state as recently as 1999. The mission of FOCVI is to empower families so they may access information on topics relating to their child's visual impairment, develop an awareness of services available on a regional and national level and become more effective advocates for their child.

May 4-5 marked the first event coordinated by the newly reorganized FOCVI team. Families having a child with a visual impairment from across North Dakota gathered in Bismarck for a weekend of networking, information and fun!

Friday night began with a pool side social where families had the opportunity to swim and meet other conference participants. Saturday was a busy day, with a full schedule for everyone. Children participated in activities including Goal Ball, a "Super Saturday" mini carnival, and a visit to Gateway to Science, a hands on science center.

Parent participants learned about the services offered by the North Dakota Protection and Advocacy agency. Janelle Olson of Williston offered information about when a parent might choose to utilize these services. Parents heard from successfully employed adults each having some degree of vision loss, regarding their experiences growing up and making their way in the world of work. Adults participating in this panel included Dr. Joe Miller/Grand Forks, Candy Lien/Fargo, Janelle Olson/Williston, Ken Dockter/Grand Forks, and Marie Gahner of Beulah. Doug Halverson, treasurer of the NAPVI (National Association of Parents of Children with Visual Impairments) provided information to parents about the upcoming national convention running from July 13-15, 2007 in Omaha, Nebraska. Doug also participated as one of a group of experienced parents who provided insightful information to the group regarding the joys and challenges of raising a child with a visual impairment. Other parents who were part of this panel included Lori Mattick of Minot, Ross and Michelle Engraf of Scranton, and Linda Johannes of Underwood. Dr. Joe Miller led an interactive discussion regarding the development of social skills in children with visual impairments. The group also received information regarding a number of agencies or businesses in the state that offer services to individuals with a disability. Agencies and businesses represented included The North Dakota State Library, Protection and Advocacy, The Store (ND Vision Services/School for the Blind), North Dakota Deaf-Blind Project, IPAT (Interagency Program for Assistive Technology), The Low Vision Store of Minnesota and NAPVI.

This conference was made possible through funding provided by The North Dakota Deaf-Blind Project, The North Dakota School for the Blind Foundation and Basin Electric Cooperative of Bismarck, North Dakota.

Future goals of the FOCVI team are to develop a family directory to enable easier communication between families, to hold future conferences around the state and to promote attendance at the National NAPVI convention in July by securing funding sources for partial scholarships. For further information about scholarship or if you would like to be part of FOCVI please call Linda Kraft at (701) 490-3878 or 1-800-421-1181 or email [lkraft@nd.gov](mailto:lkraft@nd.gov).



## BOXES FOR COMMUNICATION

By Linda Ehlers, NDSD & Lanna Slaby, NDVS/NDSB

Teachers are known for their creative uses of boxes. There is a box that some teacher hasn't adapted to fit some part of a lesson plan. They might use a shoe box for a diorama, a refrigerator box as a space ship, or an oatmeal box for a Valentine's box. The list is endless but did you know that boxes can be used as a way to communicate with students who are multi-sensory impaired?

The calendar box or calendar system is a unique way for educators and students to communicate about the past, present and future. Thanks to a very special educator by the name of Dr. Van Jan Dijk, the use of the calendar system was developed to help children who were deaf-blind to be a "conversation partner."

There are many benefits to a calendar system according to Robbie Blaha, a Deaf-Blind Outreach Consultant with the state of Texas. Blaha's book, "*Calendars*," divide the benefits of a calendar system into three areas: 1) the support and expansion of a student's communication, 2) the learning about time concepts, and 3) the emotional support and feeling of empowerment students receive from using a calendar system.

Linda Ehlers and Lanna Slaby, with the help of the North Dakota Deaf-Blind Project, traveled to Texas for their Deaf-Blind Symposium in February of 2007. During a tour of the Texas School for the Blind, various calendar systems were observed being utilized in the classrooms. Calendars used ranged in complexity from a beginner "anticipation level" to a more advanced detailed calendar system.

The simplest calendar box system is typically to build anticipation. This is done by having a real object representing the scheduled event. It is given to the student which s/he brings along to the activity. When the lesson is done, the student is assisted by an adult with placing the object into a "finish box" to indicate that experience is done. As the student becomes more advanced, the calendar communication system may include more "boxes." This can start by building on the anticipation box such as having two object cues and gradually increasing to a full day's schedule. Eventually the steps of each activity can be shared with the student in a calendar box system. Calendar systems begin in calendar boxes or boxes and then as the student becomes more sophisticated it can be displayed on a slanted reading stand, on a bulletin board and eventually in a communication book. It should be displayed left to right and be obviously separated from each other.



Robbie Blaha's book "*Calendars*" is an excellent resource and further explains how one can use "boxes" for the intent of a communication experience for children with multi-sensory impairments. It is available for check out from the library of the North Dakota Deaf-Blind Project in Devils Lake. It can be accessed by calling Sherri Nelson, Project Coordinator, at (701) 665-4401.

## About CHARGE

CHARGE syndrome is a recognizable (genetic) pattern of birth defects which occurs in about one in every 9-10,000 births worldwide. It is an extremely complex syndrome, involving extensive medical and physical difficulties that differ from child to child. The vast majority of the time, there is no history of CHARGE syndrome or any other similar conditions in the family. Babies with CHARGE syndrome are often born with life-threatening birth defects, including complex heart defects and breathing problems. They spend many months in the hospital and undergo many surgeries and other treatments.

Swallowing and breathing problems make life difficult even when they come home. Most have hearing loss, vision loss, and balance problems which delay their development and communication. All are likely to require medical and educational intervention for many years. Despite these seemingly insurmountable obstacles, children with CHARGE syndrome often far surpass their medical, physical, educational, and social expectations.

### CHILDREN ARE LIKE KITES

Author & Source Unknown



You spend years trying to get them off the ground.

You run with them until you are both breathless.

They crash . . . They hit the roof . . .

You patch, comfort, and assure them

That someday they will fly.

Finally they are airborne.

They need more string,

And you keep letting it out.



They tug, and with each twist of the twine,

There is sadness that goes with joy.

The kite becomes more distant,

And you know it won't be long

Before that beautiful creature will snap the lifeline

That binds you together

And will soar as meant to soar . . .

Free and alone.

Only then do you know that you have done your job.

### History of the name "CHARGE"

The name "CHARGE" was a clever way (in 1981) to refer to a newly recognized cluster of features seen in a number of children. Over the years, it has become clear that CHARGE is indeed a syndrome and at least one gene causing CHARGE syndrome has been discovered (see below). The letters in CHARGE stand for: Coloboma of the eye, Hear defects, Atresia of the choanae, Retardation of growth and/or development, Genital and/or urinary abnormalities, and Ear abnormalities and deafness. This information has been taken from the following website: [www.Chargesyndrome.org](http://www.Chargesyndrome.org)



We are on the web!  
[www.nd.gov/deafblind/](http://www.nd.gov/deafblind/)

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The D-B Informer is a free newsletter published by the North Dakota Deaf-Blind Services Project.

The newsletter is produced and distributed through Grant #H326C030031 from the US Department of Education. Points of view and opinions do not necessarily reflect the position of the US Department of Education or the ND Deaf-Blind Project

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