



July 2007

Omaha, Nebraska



On Friday, November 17, 2006 approximately fourteen families attended the “Disney on Ice 100 Years of Disney Show” at the Qwest Center. This event was sponsored by FELD Entertainment. Families watched the talented Disney ice skaters perform fancy footwork to well-loved Disney classic songs. Afterwards, the children participated in a ring-side clinic where they were able to explore the costumes, discuss emotions evoked from the Disney songs and challenge each other with fun Disney trivia. Everyone brought a sack lunch and was able to interact with the skaters. It was an enchanting morning for all!

### *Seussical: The Musical*

NFVIC sponsored families to attend the Millard West High School Musical, “Seussical: the Musical”, on March 17th. Each child was given a large print program autographed by leading cast members. This musical weaved the witty, wild and whimsical world of fourteen Dr. Seuss classics into a play that the entire family enjoyed. The children met the cast members and explored their costumes before the play began so that they could become familiar with their voices and costumes. The Mayor, Cat in the Hat, Horton the Elephant, Gertrude McFuzz and several other characters interacted with the families. The musical was a huge hit and many of the children were singing the songs from the play a week later! Thank you to Millard West for being so interactive with our families!



#### **What's Inside?**

- Page 2 . . . . . Tree Program
- Page 3 . . . . . Janice Anderson Memorial Scholarship  
Mark Your Calendar
- Page 4 . . . . . Beeping Easter Egg Hunt  
Pilot Study on Cochlear Implants for Combined  
Hearing and Vision Loss in Children
- Page 5 . . . . . The ABC's of Aniridia  
Educating Emergency Managers About Blindness
- Page 6 . . . . . Deaf-Blind Summer Institute
- Page 7 . . . . . PRISM



## Nebraska Foundation for Visually Impaired Children

### TREE Program

NFVIC and LLTC sponsored the “Teaching Resources Educational Exchange” (TREE) program, a quarterly meeting for parents of children with visual impairments. In March the parents discussed chores, discipline and a scan and read software program called “OpenBook.” Heather Magee, a psychologist from Munroe Meyer Institute, was the guest speaker. She stressed the importance of establishing good routines, time outs/rewards, and consistency in the method of discipline. She encouraged parents to set appropriate expectations based on their children’s abilities to complete chores as a member of the family. Heather emphasized that it is the responsibility of parents to give their children the tools they will need to be independent, self-sufficient adults.

In June, the parents met to discuss adaptive books, orientation & mobility (O&M) aids, and options for braille and speech notetakers. LeAnna MacDonald, a certified vision teacher, O & M instructor and low vision therapist, was the guest speaker. She discussed the different tools and techniques that individuals with visual impairments use while traveling in the community. She concentrates on helping students to develop concepts about the environment.

Adam Gottsch, a blind individual, and Patrick Fischer, the President of Accessibility dot Net, demonstrated OpenBook in March. Teresa Gregg demonstrated the braille and speech notetakers for the June program. OpenBook is a software program that converts scanned text into speech. It has some capabilities to configure the size, color, and spacing of the text. The voice selection and rate of speech can also be adjusted for more customized reading. Most schools in Nebraska use OpenBook; however, a few opt to use Kurzweil 1000. Teresa demonstrated a variety of notetakers. One can choose a notetaker with a computer style keyboard or a braille keyboard. These notetakers mimic a laptop without the screen. They have word processing, spreadsheets, email, calendars, calculators, internet capabilities and many more functions depending on the model.

On September 15, the TREE program will be treated to a presentation by Tami Lenhoff. Tami is a Certified Braille Transcriber who lives in Lincoln. Her certifications include: Literary Braille Transcriber, Transcriber of Mathematics Braille, and Braille Mathematics Proofreader. She is employed part-time with the Nebraska Center for the Education of Children Who Are Blind and Visually Impaired. Tami also independently contracts her braille services to several agencies throughout the country. She enjoys the challenge of producing raised line drawings so students can easily read and decipher the information. Tami has presented many workshops on tactile drawings to organizations including the National Braille Association. She is currently contracting with the National Federation of the Blind to review the lessons and tests for the Nemeth Braille Code (mathematics) on a national level. Tami is a strong advocate for properly trained transcribers to provide quality materials for students with visual impairments.

# N F V I C and L L T C

## Janice Anderson Memorial Scholarship



Each year the NFVIC grants a \$500 scholarship to one female and one male high school graduating senior who is blind or visually impaired. The graduating seniors must write a letter of request explaining their disability, accomplishments in school, plans for the future and how they would like to use this scholarship. This money is to be used for personal care such as clothing, hair cuts, manicures, or personal care products. The scholarship was created in the memory and honor of Janice Anderson, the past President of the NFVIC. Janice Anderson, a blind mother of a blind daughter, had a passion for teaching proper grooming and hygiene to children with visual impairments. This year the scholarship was granted to two females as there were no male applicants. Congratulations to Chelsea Ross and Maida Avdic. Ms. Ross graduated from Bellevue East High School. She will be attending Creighton University with the aspiration of becoming a public defender. Ms. Avdic graduated from Millard South High School. She aspires to get a doctorate degree in physical therapy. Both of these young women are strong leaders and will make us proud of their achievements.



## ***MARK YOUR CALENDAR!!***

- July 22 - 26** NCBVI Transition Program-Project Independence in Lincoln
- August 7** NCBVI College Workshop in Lincoln
- August 8** NCBVI Employment Workshop “Round Tuit” in Lincoln
- August 11** NCBVI -Board of Commissioner’s Meeting in Norfolk
- August 18** Princess Diana Party
- September 8** NFVIC Annual Henry Doorly Zoo Trip
- September 19** NCECBVI Sensory Safari Zoo in Lincoln
- December 9** NFVIC Annual Ruth Sokolof Christmas Party at West Roads Mall

# Boys Town National Research Hospital's



## **VISION PROGRAM HOSTS BEEPING EASTER EGG HUNT**

Twenty children with visual impairments and their families gathered at Girls & Boys Town's Hall of History Museum for a beeping Easter egg hunt on March 31. The goal of the Boys Town Hospital Vision Program is to identify and address the unmet needs of children and youth who are blind and visually impaired. We recognize that families who have children with visual loss do not always have an opportunity to participate in activities that other families take for granted. Making an Easter egg hunt accessible is one way the Boys Town Hospital Vision Program can help families enjoy time together and interact with other families.

The beeping egg hunt was a sensory experience, not a race to see who could get the most eggs. Baskets in-hand, the children wound their way through the museum localizing the eggs by listening for the pulsating beep. Youths with visual impairments and siblings were invited to hunt eggs or act as volunteers. Each volunteer hid a beeping egg and carried a bag of goodies. All of the children had an opportunity to find every egg regardless of whether their vision was relatively good or poor. The children gave their newly-discovered beeping eggs to the volunteers in exchange for prizes or candies. Thanks to the generous donations of our community partners: Hy-Vee; Baker's; Oriental Trading Company; Target; Wal-Mart; and Avon representative, Carol Carney; the children received fun prizes.

One set of plastic eggs had a slip of paper with a braille number. The braille number corresponded to an Easter stuffed animal. Each child left the egg hunt cradling a beautiful stuffed animal complements of Re:JERCE, a women's group from New Jersey that purchases toys to donate to hospitals. In addition to loaning the beeping eggs, the Omaha chapter of the Telecom Pioneers rented a bunny costume for adorable photo opportunities. As one mother wrote, "My son enjoyed it so much. It was a great success. We are looking forward to it again next year!!!"

---

## **PILOT STUDY ON COCHLEAR IMPLANTS FOR COMBINED HEARING AND VISION LOSS IN CHILDREN**

The Lied Learning & Technology Center (LLTC) is collaborating with the Nebraska Project for Children and Youth with deaf-blindness to recruit children for a research study. Nebraska is one of seventeen states participating in a pilot study called, "Cochlear Implants for Children: Outcomes for children who are deaf/hard of hearing and have vision impairments". Research on selection criteria, outcomes and habilitation is limited for this population. The study hopes to gain a better understanding of the impact of cochlear implants on the development of auditory skills, as well as communication, language, speech and social skills. For more information regarding this pilot study or to reach the Nebraska Project for Children and Youth with Deaf-Blindness, contact Teresa Coonts at (402) 595-1810 or email: [teresa.coonts@nde.ne.gov](mailto:teresa.coonts@nde.ne.gov).

LLTC's cochlear implant program began in 1991. Since that time approximately 320 children and adults have received implants through the center. Roughly 350 individuals receive on-going services. The vast majority of these individuals do not have combined hearing and vision loss. The Lied Learning & Technology Center program is unique in its offering of a multidisciplinary approach including audiology, speech and language therapy, early intervention, counseling, deaf education and educational consultation. For additional information regarding LLTC's cochlear implant program, contact Jeff Simmons at 402-452-5040 or email [simmonsj@boystown.org](mailto:simmonsj@boystown.org).

# THE ABC's OF ANIRIDIA

One of the most common descriptors of an individual is the color of his or her eyes. In a condition called Aniridia, the colored portion of the eye (iris) is absent or partially absent. Aniridia may make the pupils appear large. It is difficult to imagine how absence of the irises can cause vision problems; however, most individuals with aniridia experience problems with light sensitivity, glare and near-sightedness. Although aniridia is present from birth, glaucoma, cataracts and corneal disease can develop over time.

Aniridia is relatively rare, occurring in 1 in 40,000 to 1 in 100,000 people. Seventy percent of individuals with aniridia have a family member with the condition. Aniridia can be passed in a dominant fashion from parent to child. Most individuals have a recognizable alteration in a gene called PAX6. PAX6 directs the function of other genes in organ development. Some individuals are missing the entire PAX6 gene in addition to other nearby genes and have a condition known as WAGR; these individuals require medical surveillance of their kidneys. For more information on Aniridia, contact Kristal Platt at (402) 498-6365, or email [plattk@boystown.org](mailto:plattk@boystown.org).

## Additional resources:

USA Aniridia Network  
1138 N Germantown Parkway Suite 101  
PMB#109  
Cordova, TN 38018  
901-752-8835  
[info@aniridia.net](mailto:info@aniridia.net)

Aniridia Network International  
109 Gavin Way  
Colchester CO4 9FR  
United Kingdom  
[Hannah@aniridia.org](mailto:Hannah@aniridia.org)  
[www.aniridia.org](http://www.aniridia.org)

---

## EDUCATING EMERGENCY MANAGERS ABOUT BLINDNESS

Kristal Platt, Boys Town Vision Program Coordinator, was asked to provide information on Emergency Preparedness regarding persons with vision loss. Under a grant through the University of Nebraska Medical Center's Biopreparedness department, Kristal spoke to emergency managers in Kearney, Norfolk and Lincoln, reaching over 350 Nebraskans. Kristal described how blind and low vision people travel independently. She challenged the audience to interpret how travel needs might be different in a variety of emergency situations. For instance, a person might normally rely on a white cane; however, this mode of travel could be dangerous after an ice storm with downed power lines. Travel with a dog guide or sighted guide may not be feasible if the guide became ill or injured.

Kristal addressed concerns about access to information. Weather and civic warnings are sometimes scrolled at the bottom of TV screens without audio streams. Websites may have pages that do not meet universal design standards, and therefore, people with visual impairments cannot access them with their screen reading software. Kristal suggested that emergency providers make their materials available in alternative formats such as braille and large print.

Kristal recommended that emergency managers involve persons with visual impairments in their planning. She encouraged emergency managers to: identify persons who may need additional considerations; educate consumers so they have realistic expectations of emergency responders; and train volunteers so they have a better understanding of persons with visual impairments.

According to the National Organization on Disabilities, preparations to help a specific group can have far-reaching benefits. During the attack on the Pentagon, equipment previously installed to help employees and visitors with low or no vision to evacuate the facility made it possible for dozens of sighted individuals to flee the smoke-filled corridors as well.

# C O M M U N I T Y

## DEAF-BLIND SUMMER INSTITUTE

Each year for the past ten years, Teresa Coonts, coordinator of the Nebraska Project for Children and Youth with Deaf-Blindness, assembles experts from around the country to present at the Deaf-Blind Summer Institute. Participants include teachers, parents, related service providers, administrators and other key stakeholders serving children and youth with combined hearing and vision loss. The purpose of the annual Deaf-Blind Summer Institute is to increase the skills and knowledge of educators and families in the area of dual sensory impairments by providing training on current and promising best practices. The topics selected each year are based on needs assessment and input from the Advisory Committee specific to Deaf-Blindness. The Institute works in collaboration with the University of Nebraska at Lincoln vision endorsement program and offers the week-long course as an elective for vision teachers. In addition, other educators can take the class for credit. The Institute is fully supported by the U.S. and Nebraska Departments of Education. This year's agenda includes:

- July 23 "Students Having Deaf-Blindness and Other Severe Multiple Disabilities in Inclusive Settings" by Dr. June Downing, Professor, California State University, Northridge
- June 24 "Teaching Literacy Skills" Professor, California State University, Northridge
- July 25 "Self Determination and Deaf-Blind Culture by Jamie Pope, Executive Director, American Association of the Deaf-Blind and Randy Pope, Private Consultant for Support Service Providers (SSP)
- July 26 A.M. "Current Medical Research on Usher Syndrome and Other Forms of Combined Hearing and Vision Loss in Children" by Dr. William Kimberling, Professor, Boys Town National Research Hospital
- July 26 P.M. "Medical Impact on the Educational System" and "Update on Deaf-Blind Grant Activities" by Teresa Coonts
- July 27 "Building a Classroom for Children Who Are Deaf-Blind With the Help of Assistive Technology" by Jon Harding, National Consortium for Deaf-Blindness and Robert Taylor, Kansas School for the Blind

For more information on the Deaf-Blind Summer Institute, contact Teresa Coonts at (402) 595-1810 or email [teresa.coonts@nde.ne.gov](mailto:teresa.coonts@nde.ne.gov).

### **COME VISIT BOYS TOWN NATIONAL RESEARCH HOSPITAL'S EXHIBIT!**

**Boys Town National Research Hospital is sponsoring an exhibit at the Families Connecting with Families Conference at the Omaha Hilton, July 13-15. Stop by the booth to:**

- gather information on the newly-created Vision Program
- learn about our beeping Easter egg hunt
- hunt for a beeping egg to win a prize
- register to win books from the Boys Town Press including "Common Sense Parenting"
- receive a catalog and coupon to order discounted books
- pick up pediatric health care tips

# C O M M U N I T Y continued...

## PRISM

Parent Resource Information and Support Meeting (PRISM) does not meet in the months of January and May. The February meeting was cancelled due to inclement weather. A nationally-recognized speaker was featured at the April meeting so no breakout sessions for specific disability groups met.

Sherry Dostal presented at the March 13th PRISM meeting on the topic of classroom adaptations for preschool children with visual impairments. Sherry is currently a preschool classroom teacher for children ages 3 to 5 in the Early Childhood Special Education Program at Omaha Public Schools, Mount View Elementary. She formerly worked as a home-based teacher.

Sherry showed a video and explained how she adapted a student's schedule, labeled his locker/classroom with Braille, and demonstrated special adapted materials. The video illustrated how the student used his mobility device devised by an orientation and mobility (O&M) specialist. The video also showed the student's interactions with the other students in the class. The PRISM meeting was informative and fun, as the student was someone familiar to the group, but the information could be applied to any student.

On June 2, seven PRISM families gathered for a picnic at Elmwood Park. This activity was not part of the regularly scheduled PRISM program, but an event specific to the parents of children with visual impairments. The families shared their summer plans informally over lunch and entertained their children at the playground.

Special PRISM meetings will not be held in the summer for parents of children with visual impairments; however, meetings focused on vision will resume in the fall. These meetings will be held on the second Tuesdays of September, October and November. For more information, contact Annie Anderson at (402) 346-5220 or Kristal Platt at (402) 498-6365.

**BUILDING BLOCKS** is sponsored by the Nebraska Foundation for Visually Impaired Children (NFVIC) and Boys Town National Research Hospital's Lied Learning and Technology Center for Childhood Deafness and Vision Disorders (LLTC). For programming ideas, suggestions for the newsletter, or questions, please contact:

Teresa Gregg, Executive Director  
NE Foundation for Visually Impaired Children  
PO Box 641905  
Omaha, NE 68164  
(402) 218-7022  
teresa@nebraskafoundation.org  
www.nebraskafoundation.org

Kristal Platt, Vision Program Coordinator  
Lied Learning and Technology Center  
425 North 30th Street  
Omaha, NE 68131  
(402) 498-6365  
plattk@boystown.org  
http://www.boystownhospital.org

**BUILDING BLOCKS**  
Lied Learning & Technology Center  
Attn: Kristal Platt  
425 North 30th Street  
Omaha, NE 68131



## Nebraska Foundation for Visually Impaired Children

The mission of the NFVIC is to enhance the lifestyle and education of children who are blind or visually impaired by providing funds and advocating for the following:

- Assistive technology, adaptive devices, and related services for the children's daily use;
- Cultural experiences for the children and their families;
- Training opportunities for educators and parents; and
- Mentoring/support programs for the children, their families, and their educators.
- [www.nebraskafoundation.org](http://www.nebraskafoundation.org)



## Lied Learning and Technology Center

The Lied Learning and Technology Center for Childhood Deafness and Vision Disorders serves children with hearing loss, visual impairments and other communication disorders with educational and rehabilitative services at Boys Town National Research Hospital.

The Mission of the Center is:

- To improve the lives of children with hearing loss, visual impairment and other communication disorders through early identification, education, state-of-the-art rehabilitation, rigorous research, and family support.
- To serve as a nationally and internationally recognized center of excellence for clinical services, applied research and information dissemination.
- <http://www.boystownhospital.org>