

Omaha Children's Museum



On November 15th, five families began a prehistoric tour of the DinO!saurs Traveling Expedition at the Omaha Children's Museum. Docents described the height, shape, color, habitat and history of 13 dinosaurs. The museum opened early and some barriers were moved to accommodate the group. Children climbed a ladder to explore a 22-foot long Tyrannosaurus Rex and strode along side a 22-foot string to physically see how tall a T-Rex really was in life. White drop cloths placed over the camouflaged environments increased the contrast making the dinosaurs easier to see. The sounds and movements of the robotic dinosaurs made us feel like we were roaming with dinosaurs millions of years ago! Thank you to the staff at the Omaha Children's Museum for the special accommodations for this event!

Beeping Easter Egg Hunt Returns!

Remember to have your Easter baskets in hand on Saturday, April 4, 2009 at 2 p.m. to join us for the third annual Beeping Easter Egg Hunt. Once again, the Lied Learning and Technology Center invites children with visual impairments and their families to enjoy an accessible egg hunt. Join us on the Boys Town campus for treats, photos and fun. If your family does not receive a personal invitation by mail, please contact Kristal Platt at 402-498-6365 for details.



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Nebraska Foundation for Visually Impaired Children

Pumpkin Patch

It was a chilly, blustery day on October 26th when we wove our way through the Corn Husker Maze at Vala's Pumpkin Patch. Five NFVIC families and 13 Omaha Council of the Blind Chapter members tried to keep warm while roasting hot dogs and marshmallows by campfire #5. Families wandered through the haunted houses and watched the dragon as he smashed pumpkins. Everyone cheered for his or her favorite pig, Hammah Montana and Brad Pig, among others, at the Pigtuckey Derby Races. Families and new friends networked around the blazing campfire. Thank you to the Omaha Council of the Blind for co-sponsoring this event!



Small Aids and Devices

Did you know that there are places that sell talking thermometers, talking scales, large print clocks and watches, raised-line coloring books and paper, beeping baseballs, large print and Braille UNO cards, low-vision kitchen utensils, talking pedometers, and so many more cool things for your home? Here are some of the more popular resources:

- Maxi Aids: Independent living aids for blind, low-vision, Deaf, physically challenged: www.maxiaids.com
- LS&S: Low-vision aids, such as magnifiers, assistive technology: www.lssproducts.com
- Independent Living Aids: Products for the blind and visually impaired: www.independentliving.com
- Braille Super Store: Future Aids: www.braillebookstore.com
- American Printing House for the Blind: Provider of accessible educational and daily living products: www.aph.org
- Lighthouse International: Hope When Vision Fails: www.lighthouse.org
- Speak To Me: Talking products: www.speaktome.com

Upcoming Weekend of Workshops for Students

The NFVIC and the Nebraska Association of Blind Students (NABS) are co-sponsoring a weekend of workshops for transition-age students at the Omaha Double Tree April 3-5th.

The NABS board is made up entirely of blind students.

Participants will use laptops equipped with screen reading and magnification software. Topics to be addressed will include hiring readers and interacting with offices working with students who have disabilities. Other topics to be addressed will include applying makeup, fixing hair, tying a tie, shining shoes, and learning to dance the YMCA and the Cupid Shuffle.

For more information call Karen Anderson at 402-319-7645.

N F V I C and L L T C

“It’s All About The Music!” Raises \$10,000 for NFVIC

On September 18-20th the three musical performances of “It’s All About the Music!” filled the Scottish Rite Theatre with singing and dancing. The audience excitedly shouted out famous show tunes as the singers and dancers twirled through the first act. The second act was a compilation of songs from Karen Sokolof Javitch’s musicals which engaged the audience to the very end. Karen Sokolof Javitch and Elaine Jabenis, writers of the show, were thrilled with the response. A hard-working cast of 23 plus guest appearances of three dance groups raised a total of \$20,000 which was split between Nebraska Foundation for Visually Impaired Children (NFVIC) and Little Sioux Scout Ranch. NFVIC children and their families were invited as guests. The closing patriotic section included color guard presentations by Boy Scouts.



Ruth Sokolof Christmas Party

The 48th Annual Ruth Sokolof Christmas Party was a huge success on December 14th. With Christmas music, Santa ringing his bell, and 129 blind and visually-impaired children scouting out gifts for families and friends, the Westroads Mall came alive with holiday spirit! Each child was given \$100 and paired with one of the 230 sighted high school volunteers. Lucian asked to shop with a tall blond volunteer, while Amy asked to be paired with two cute male volunteers. High school volunteers often ask to shop with the same visually impaired child as in the past.



Anticipating the event, checking shopping lists and shopping without family, makes for a monumental day for these children. It truly is a humbling experience to witness! Thank you to Karen Sokolof Javitch and Norma Johnson for their time, talents and funding.



Ian Webster with buddy Hana Kendric and friends



Zachary Anderson with shopper Sarah Fulton

Boys Town National Research Hospital's

L L T C NEWS

Conference Overview

Nearly 55 educators, therapists and administrators attended the conference, "Where Medicine and Education Merge: Implications of Genetic Vision and Hearing Conditions". Sponsored by Boys Town National Research Hospital's Lied Learning and Technology Center and Nebraska Foundation for Visually Impaired Children, the conference delved into the medical and genetic issues of five conditions. Dr. Brad Schaefer provided the key note address. He has the gift of entertaining the audience while educating. Dr. Schaefer practiced clinical genetics for nearly 20 years in Omaha and surrounding satellite clinics. Attendees were fortunate to have Dr. Schaefer return to Nebraska from Little Rock where he has recently moved to become the Founding Director of the genetics program. He spoke on the topic, "Modern Diagnostic Techniques at the Fingertips of Clinical Geneticists".

The conference covered two conditions that cause deaf-blindness, Usher and CHARGE syndromes. With Dr. William Kimberling at Boys Town, a world-renowned expert on Usher syndrome, this was an easy choice. Usher Syndrome causes combined hearing loss and retinitis pigmentosa, a degenerative retinal disease. CHARGE syndrome has multi-facets and a relatively new identification of a gene alteration causing approximately 60% of the cases.



To make sure the conference was not too esoteric some conditions that may not be thought of as causing deaf-blindness but can have both components were included.

Oculo-Auriculo-Vertebral Spectrum offers some unique characteristics with unilateral hearing loss and sometimes vision issues. Stickler and Down syndromes, although not typically thought of as conditions causing deaf-blindness, are relatively common and can both impact hearing and vision; therefore students should be followed with respect to the problems that can occur.

The feedback from the conference was positive. It is hoped that similar educational opportunities will be available in the future.

Preparing The Children's Museum

Kristal Platt, of the Lied Learning and Technology Center and Teresa Gregg, of the Nebraska Foundation for Visually Impaired Children, conducted staff and docent training in preparation for the tour of the dinosaur exhibit at the Omaha Children's Museum. The audience watched "The Encounter" which is a locally produced video by the Nebraska Commission for the Blind and Visually Impaired. The video states there are no rules for dealing with a blind person. It says to "use your head" when meeting a blind person and stresses that "people are people". Kristal and Teresa described how blind and visually impaired people are able to function independently with appropriate training. For instance, they demonstrated the use of a white cane and discussed street crossings.

Kristal and Teresa had previously toured the Children's Museum offering some suggestions to make the facilities more accessible. Verbal cues that are descriptive help more than simply saying "this" or "that". Contrast is important since most people who are blind or visually impaired have some usable vision. It is necessary to place padding in areas that a white cane could go under to keep someone's body from striking a hard surface. Whenever displays can have actual materials, concepts can be reinforced. For example, where there is a tractor tire representation, tread can be attached so the model has the feel of a tractor tire.

The staff asked questions about audible traffic signals, transportation and practical questions about how the museum would be modified for the upcoming tour. The staff is excited to provide good service and is looking forward to future offerings with new exhibits.

L L T C continued...

The ABC's of Anophthalmia

Anophthalmia (lack of development of the eye) and microphthalmia (small or underdeveloped eye) are medical terms often used together. The lack of development can occur on one side (unilateral) or involve both eyes (bilateral). Anophthalmia and microphthalmia (A/M) can occur alone (isolated) or as part of a generalized problem called a syndrome. One in three children born with A/M has other birth defects.

The diagnosis of A/M is made by examining the child and by using ultrasound combined with CT or MRI scans. Other testing is important to determine whether A/M is isolated or associated with other birth defects. These studies may include imaging studies of the brain, heart and kidneys, as well as blood studies such as chromosome testing and specific gene studies.

A/M can be due to environmental, chromosomal, single gene or unknown causes. Prenatal infections such as rubella are known to cause A/M. Prescription medications including thalidomide, retinoic acid and hydantoin have been implicated. Gene testing is available for several forms of A/M which are part of syndromes; however, testing for isolated A/M is only available through research labs. One gene called SOX2 causes 8-15% of bilateral severe A/M.

Typically, a child with A/M is referred to an ophthalmologist who makes prosthetic eyes. The ophthalmologist can reshape the orbit (eye socket) as the child grows. Ninety percent of orbital growth is done by age 5. Children and adults with A/M continue to visit the ophthalmologist for maintenance of prosthetics.

For more information on A/M, contact Kristal Platt, Genetic Counselor, at 402-498-6365, or refer to:

International Children's Anophthalmia Network (ICAN)
c/o Center for Developmental Medicine and Genetics
5501 Old York Road
Genetics Levy 2 West
Philadelphia, PA 19141
(800) 580-4226 or (215) 456-8722
Fax: (215) 456-2356
Email: ican@anophthalmia.org
www.anophthalmia.org

National Eye Institute
31 Center Drive MSC 2510
Bethesda, MD 20892-2510
(301) 496-5248
Email: 2020@nei.nih.gov
www.nei.nih.gov

Microphthalmia/Anophthalmia Parent Support
www.maparentsupport.com



MARK YOUR CALENDAR!!

- February 17 5:00-8:00: PRISM Resource Fair at OPS TAC Bldg., 5th Floor, Kristal Platt: 498-6365
- February 25 NCECBVI Nebraska Regional Braille Challenge: (800) 826-4355
- February 28 10:00-2:00: NCBVI Omaha office, Group meeting on cooking, eating and social skills: 595-2041
- March 17 3:30-5:00 & 6:45-8:30: PRISM "Special Needs Trusts", PVA, Kristal Platt: 498-6365
- March 19-20 NCECBVI Spring Fling Conference: (800) 826-4355
- March 19-21 NCBVI Winnerfest Program (ages 14-graduation): 595-2041
- March 21 10:00-12:00: TREE Program, TBA, 425 N 30th St., Teresa Gregg: 218-7022
- March 28 10:00-2:00: NCBVI Omaha office, Group meeting on "Being an Active Family Member": 595-2041
- April 4 2:00: LLTC Beeping Easter Egg Hunt, Boys Town Campus, Kristal Platt: 498-6365
- April 10 10:00-2:00: NCBVI Omaha office, Group meeting on Volunteering "Giving Back to Our Community": 595-2041
- April 17-19 ACBN State Convention In Hastings, Quality Inn Hotel & Convention Center: (888) 218-8061
- April 21 6:30-8:30: PRISM: "Self Determination", Beverage Magnet School, Kristal Platt: 498-6365
- May 16 10:00-2:00: NCBVI Omaha office, Group meeting on Clothing Care: 595-2041
- June 9 10:00-2:00: NCBVI Group meeting on Cane Travel, walking across the Bob Kerrey Bridge: 595-2041
- June 14 NCBVI Wages Program begins: 595-2041
- June 19-21 NCECBVI "Reach for the Stars" Family Weekend

COMMUNITY

Blind/VI Students Exploring the Globe

If you knew one trip could change your life, would you take it? Last summer 12 students, six blind and/or visually impaired, embarked on a truly life-changing adventure: Rafting the Grand Canyon.

This unlikely team spent two weeks shattering expectations and using adversity to their advantage as they explored science, culture, leadership and service within the Canyon walls.

Nicole, 2008 Grand Canyon Student Participant said, “I hope to let other people know that they can step outside their comfort zones. This is a little hard for us, of course. But, I hope to inspire other people to just get out there and experience life for what it really is.”



Jamie Ann, another 2008 participant, echoed her courage, “I think the important thing is to challenge yourself. Let’s say I’m rafting down the Colorado River, then finding missing socks or whatever is not going to be that big of a challenge after this. This sort of minimizes other stuff in day-to-day life.”

Developed in partnership with world renowned blind athlete, Erik Weihenmayer, the “Leading the Way” program teams high school and college students who are blind, visually impaired and sighted for an unparalleled science, community service, leadership, and cultural adventure. In 2008, we traveled to the Grand Canyon, the Inca Trail and the Amazon. In 2009, we are returning to the Grand Canyon and piloting our first group that combines students who are hard of hearing, deaf and hearing and traveling to Costa Rica.

Not only is it an amazing experience for the participants themselves, each “Leading the Way” expedition is paired with a social awareness and media campaign which we use to educate a much broader constituency. These campaigns provide a message of hope and inspiration while helping to break down barriers, misconceptions and prejudices that the public has about people with disabilities.

To inquire about how you can be involved in the 2009 Leading the Way expedition, send an email to leadingtheway@globalexplorers.org or call 877-627-1425. Scholarship funds are available.

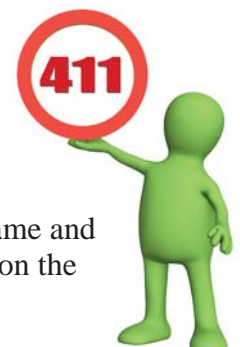
“Leading the Way” has been featured on CBS Sunday Morning, The Travel Channel, ABC Nightline, and World News Tonight.

National Federation of the Blind Teen Blog

Attention blind and visually impaired high school students! Blindness 411 was created by the National Federation of the Blind to give you a place to meet other teens with vision loss and to give you a chance to learn about resources that can help you in school, at home, and in your community.

The NFB is the largest blindness organization in the United States. We have over 50,000 members who work hard to make a difference in the lives of blind people. We are excited to provide this resource to you and hope that you will tell your friends about us!

If you are currently a Facebook member, go to groups, search for the group using our group name and request access to our group. If you are not signed up for Facebook, please consider joining in on the fun! Visit www.facebook.com to get connected with our NFB teen group.



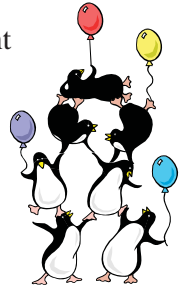
If you have any questions, call Rosy Carranza at (410) 659-9314, ext. 2283 or rcarranza@nfb.org.

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

NCECBVI... The Power of Team!

Sally Giittinger, Administrator

Each year, the NCECBVI staff members implement an inspirational theme which provides a focal point to keep us on track. "The Power of Team" is our theme which includes penguins representing the concept of huddling together and depending on each other for survival.



Each year in October, we have the opportunity to attend our national meetings in Louisville, Kentucky. This gives us the chance to share the Nebraska story as well as learn from other schools for the blind and other agencies.

At the national gathering, the highlight was when Nebraska students were recognized for their achievements. Jordan Merriman, NCECBVI student from Gretna, received a 3rd place honor in a national art contest for the American Printing House for the Blind (APH). And Chase Crispin, a student from Blair Public Schools, received a 3rd place honor in a national essay contest for APH. NCECBVI was proud to sponsor these two students and their parents to attend the awards banquets in Louisville.

The Power of Team is in action at NCECBVI! It happens every day, with every student, parent and teacher we serve. There is no better example of a profession where we see people huddling together, depending on each other, and learning from each other in order to be effective educators each day.



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:

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BUILDING BLOCKS
Lied Learning & Technology Center
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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



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>