

B U I L D I N G B L O C K S

Summer 2008

Omaha, Nebraska

Pottery Workshop



On February 23, 2008, families came ready to mold a clay masterpiece at the Lied Learning and Technology Center at Boys Town National Research Hospital. This was a joint project with the Nebraska Foundation for Visually Impaired Children (NFVIC), The Lied Center and Very Special Arts (VSA). Laura Givens, a local potter with VSA, discussed the different kinds of clay and tools that she uses. She demonstrated how to create a pinch pot by indenting the ball of clay with your thumbs. The children had fun rolling out the clay into snakes and then coiling it into pots of different shapes. Sam Winters created a football field out of his clay, while Christine Ratz molded a clay dolphin, and Alex Salgado assisted his mom in shaping clay squares for a box. Parents helped their children add colorful beads, feathers, wooden shapes, pipe cleaners and an assortment of other items to each modern masterpiece. If you have an art medium you would like to experience, please contact Teresa Gregg at (402) 218-7022.

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Nebraska Foundation for Visually Impaired Children

The American Council of the Blind of Nebraska (ACBN) State Convention

There are two national consumer groups for persons who are blind or have low vision – the American Council of the Blind (www.acb.org) and the National Federation of the Blind (www.nfb.org). Each national organization has a state affiliate in Nebraska and both host an annual state convention. The NFVIC is sponsoring families to attend one or both of these conventions.

The ACBN Convention was held in Columbus on April 18-20, 2008. One of our families attended this convention and had the opportunity to network with other blind persons. Friday evening was a time for food and fellowship. Saturday morning began with a panel presentation, from birth to retirement, discussing services and experiences relating to blindness. Harley motorcycle rides and a self-defense workshop revved up the activities for Saturday afternoon. Lucian Brown, a blind nine year old, sang “There Is Hope“ after the banquet. Teresa Gregg was the keynote speaker and spoke of her blindness growing up. She provided a history of the NFVIC and described her role as Executive Director. Saturday evening ended with a competitive auction of about 50 items. This auction produced lots of laughter and raised about \$900 for the ACBN. Sunday morning wrapped up the convention with the ACBN business meeting.

The National Federation of the Blind of Nebraska state convention will be held on October 10-12, 2008 in Grand Island. If your family wants to attend this convention, please contact Teresa Gregg at (402) 218-7022. Attending these state conventions and chapter meetings are a great way to network with other persons with visual impairments.

Janice Anderson Memorial Scholarship

Each year, the Nebraska Foundation for Visually Impaired Children (NFVIC) awards the Janice Anderson Memorial Scholarship to graduating high school seniors with visual impairments. A monetary gift of \$500 is given to applicants to be used for personal grooming and hygiene needs. This scholarship was established in honor of Janice Anderson, a past NFVIC President, who was passionate about teaching children with visual impairments the importance of good grooming and proper hygiene. It is rewarding for the NFVIC Board to review each scholarship application and discover the talent and ambition of these students. Due to the outstanding applications received, the Board elected to award four scholarships! The four selected scholarship recipients are Adelaide Marie Bryan, attending Indiana University in Bloomington; Mara Winter, attending Grinnell College in Grinnell; Monica Olson, attending Nebraska Wesleyan University in Lincoln; and Rachna Keshwani, attending The University of Nebraska-Lincoln. Best wishes to these young women! Janice Anderson would be so proud!



O'Neill Family Wins Mount Batten Essay Contest

The NFVIC is pleased to announce that the O'Neill family won a Mount Batten Braille Learning System through a Braille literacy essay contest sponsored by Human Ware, a national manufacturer of products for the blind and low vision. This system will enhance Braille learning for their daughter Camille, who is three and a half and has Retinopathy of Prematurity.



The Mount Batten Braille Learning System is a Braille tutorial with speech output to reinforce Braille literacy. It is essentially an electronic Braille writer/embosser that has easy touch keys with a friendly Australian voice that repeats each character Brailled.

This system makes Braille learning fun and inclusive for all involved. A printer can be hooked up to the Mount Batten to produce a print and Braille document at the same time. For those students with limited dexterity or strength in their fingers, this is a great learning system to begin Braille instruction.

Its features include:

- Develops awareness of Braille symbols and characters by utilizing audio response to reinforce which commands are being entered
- Simple editing functions for correcting and erasing
- Variety of paper types can be used, ergonomically designed keyboard, page formatting, produces graphics and charts
- Can be set in one-handed mode if required
- It can store up to 32 pages of Braille, enabling review of Braille in progress or to check back over previous work
- MIMic visual display - an LCD display allows easy supervision by sighted teachers
- Can be hooked up to PC computer to transfer files

The NFVIC has four of these Mount Batten Braille Learning Devices for schools or families to check out for three months to encourage and foster Braille literacy. Please call Teresa Gregg at (402) 218-7022 for more information.

NFVIC Services

The NFVIC provides funds state-wide for students to receive Braille, large print or talking technology for home use. Supported technologies have included: notetakers, CCTVs, Braille writers, talking dictionaries, computer systems with JAWS, OpenBook and Zoomtext and much more. Funding is also available to vision teachers for educational training.

Submit requests to NFVIC: E-mail: teresa@nebraskafoundation.org, or mail to:

Teresa Gregg, The Nebraska Foundation for Visually Impaired Children

Lied Learning and Technology Center, 425 North 30th Street

Omaha, NE 68131

Boys Town National Research Hospital's



Lied Learning and Technology Center

Second Annual Beeping Easter Egg Hunt



The Lied Learning and Technology Center hosted the second annual beeping Easter Egg Hunt on Saturday, March 15. A stiff wind blew outside the Hall of History on the Boys Town campus while twenty families hunted eggs, posed for photos, and snacked on Easter sugar cookies. Again, the Omaha chapter of the Telecom Pioneers loaned brightly colored beeping eggs and donated a bunny costume for precious photos.

At sixteen stations around the museum, children listened for the pulsating noises from the eggs. Once the egg was in hand, it was traded with a volunteer for a prize or treat. Several youth with visual impairments volunteered. Children received a plastic egg containing a Braille number; the number was traded for a favorite prize, an Easter stuffed animal donated by REJERCE, a women's group from New York that provides items to hospitals. Many community partners including Costco, Baker's, Nobbies and Wal-Mart donated items to fill tummies and Easter baskets.

Mark your 2009 calendars for Saturday, April 4 at 2 PM to join us for next year's fun!



Visitors To The Preschool

The children sat in a circle with their noses almost touching the book. It wasn't because they could not see well, but rather so they could get as close as possible to the Braille book. It was a special day at the Boys Town National Research Hospital (BTRNH) Preschool Program for Children who are Deaf or Hard of Hearing. Two visitors, Teresa Gregg and Kristal Platt, came to demonstrate Braille and go to art class with the children. Kristal read pages from *The Dot* by Peter H. Reynolds to the children and they in-turn described the drawings to Kristal and Teresa. This children's story tells of a young girl's journey from doubt to joy through art.

Teresa asked if the children could show her their sign names because she couldn't see their hands. One-by-one the children showed his or her name to Teresa through tactile signing. Then the class moved downstairs to the art room where the group finger-painted a circle outlined in sand. All the artwork was on display at the Preschool's art museum.

The ABCs of LCA

Leber Congenital Amaurosis (LCA) recently made headlines when clinicians from Children's Hospital of Philadelphia described in the April 27, 2008 issue of the *New England Journal of Medicine* that three patients with LCA had regained usable vision through gene therapy. These young adults ranging in age from 19 to 26 years participated in an international clinical trial (www.newswise.com/articles/view/540141/). Although these results offer promise for LCA and many other eye conditions, it is important to note that the current research applies to a relatively small percentage of individuals with LCA (individuals with alterations in the RPE65 form of LCA).

LCA is characterized by eye poking (oculo-digital sign) and presentation before age one year with nystagmus, severely impaired vision, and a nearly unrecordable or absent electroretinogram (ERG). Usually individuals with LCA only have visual problems; however, infrequently the eye problems can be seen as part of a syndromic condition.

Typically LCA is seen among brothers and sisters (autosomal recessive), although rare families will pass one non-working gene from parent to child causing the condition. Currently fourteen genes are known to cause LCA when both members of the gene pair are not working properly; this accounts for 75% of individuals with LCA. According to Gene Reviews (genetests.org), different alterations within each of the LCA-associated genes are known to cause other retinal dystrophies, such as retinitis pigmentosa (RP) and cone-rod dystrophy.

There are many organizations that collaborate in research and provide information on LCA. One such non-profit group is called Project 3000 (www.project3000.org). Its mission is to reach the estimated 3,000 individuals across the U.S. with LCA to offer them genetic testing even if they are uninsured. Additional resources include:

The Foundation for Retinal Research
www.tfrr.org

Foundation Fighting Blindness
(888) 394-3937
(800) 683-5555 (tty)
Email: info@blindness.org

Retina International
Email: info@rpinternational.org
www.retina-international.org

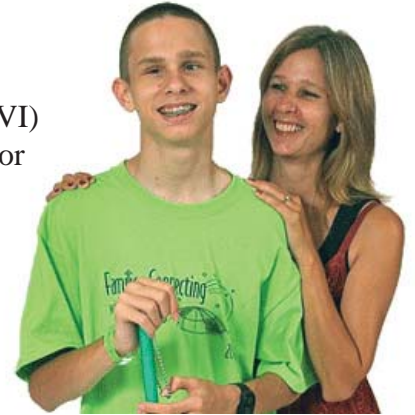
COMMUNITY

Family Connect Website

Submitted by Sally Giittinger

The National Association for Parents of Children with Visual Impairments (NAPVI) and the American Foundation for the Blind (AFB) have unveiled a new website for parents of visually impaired children and their families.

Family Connect is designed to provide a social network for families of children with visual impairments with interactive features such as message boards, blog posts, and personal stories written by parents about their own experiences. The website gives you the option to create a personal profile to receive information, events, and news based on your child's age, eye condition, and geographic location. This website also includes videos of families sharing their stories which are both insightful and hopeful.



The photos and videos featured on this website were taken during the National Family Conference which was held in Omaha last July. There are many Nebraska families featured throughout this site.

This is an awesome resource for families. For more information, contact Nebraska Center for the Education of Children Who Are Blind or Visually Impaired (NCECBVI) at (402) 873-5513.



Visit: www.familyconnect.org

Sibshops Are Coming To Omaha!

Submitted by Kristal Platt



Brothers and sisters of children with disabilities have unique needs which are often overlooked. The connection between siblings is typically the longest lifetime relationship yet little peer support is provided for the emotional well-being of siblings. Siblings may feel embarrassment, worry, envy, anger, guilt, joy, pride, and a host of other negative and positive feelings in their family role.

An internationally-recognized organization called Sibling Support Project developed Sibshops to make sibling support its primary goal. According to Sibling Support Project's literature, "Sibshops are opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context."

Beginning in the fall, the Ollie Webb Center will be coordinating Sibshops for brothers and sisters of individuals with special needs including visual impairments. A parent orientation meeting will be offered on August 6, 2008 at 7 PM at the Nebraska Children's Home at 4939 S. 118 St. Sibshops for siblings ages 6 to 9 will be held August 23 and October 25, 2008. September 27 and November 22, 2008 are reserved for siblings ages 10 to 13. Kristal Platt is a trained Sibshop facilitator. The Lied Learning and Technology Center may offer periodic Sibshops specific for children of siblings with visual impairments if this is a need. For more information, contact the Ollie Webb Center at (402) 346-5220.

Infant Massage: Enhancing Parent-Infant Bonding - Part I

Submitted by Stacy Groff

Infant massage has been used for centuries by parents around the world as a way to enhance the parent-infant bond, to improve and maintain physical well-being and to facilitate long-term positive emotional development. It is a skillful tool, taught by trained professionals to parents, combining Swedish massage strokes, principles of reflexology and yoga. The massage is given daily for the first six months, then 3-4 times per week thereafter. As the infant grows, the strokes can be adapted for the older child. The massage can be adapted for special situations such as infants born prematurely, addicted to alcohol/drugs, visually or hearing impaired and is especially beneficial for adopted babies.



Benefits to the infant are varied and may include:

- Interaction-bonding, secure attachment; verbal and nonverbal communication
- Stimulation of organ systems-sensory integration; mind and body awareness
- Relief of discomfort-colic, constipation; physical and psychological tension
- Relaxation-improve sleep patterns; increase environmental coping and self-regulation; and reduction of stress levels

Benefits for parents include better understanding of their infants; reading and respecting infants' cues; improved self-esteem and confidence; and improved parenting skills.

For more information regarding parent classes or infant massage, call Stacy Groff at (402) 871-5668. Stacy is a licensed massage therapist and licensed clinical social worker who is blind.

Deaf-Blind Institute

Submitted by Teresa Coonts

The annual Deaf-Blind Summer Institute is the week of July 14-18, 2008. Please contact Teresa Coonts at (402) 595-1810 or teresa.coonts@nde.ne.gov for additional information. Topics include: communication strategies; understanding the impact of Usher Syndrome and the use of a cochlear implant; using APH products in learning environments; services provided by the Helen Keller National office; and the future Nebraska Deaf-Blind grant specific to children birth to age 21.

Genetics Seminar For Educators

Submitted by Kristal Platt

On Monday, September 29, 2008 educators are invited to the Lied Learning and Technology Center for a seminar entitled "*Where Medicine and Education Merge: Implications Of Genetic Vision And Hearing Conditions*". Coordinated by Kristal Platt of Boys Town National Research Hospital's Lied Learning and Technology Center and sponsored in part by Nebraska Foundation for Visually Impaired Children, this one-day seminar will provide up-to-date information on numerous genetic conditions affecting vision. Experts including William J. Kimberling, Ph.D., G. Bradley Schaefer, MD, and other invited guests will speak on their areas of expertise. For more information, contact Kristal Platt at (402) 498-6365.

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

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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MARK YOUR CALENDAR!!

- July 14-18** Deaf-Blind Summer Institute -
Teresa Coonts (402) 595-1810
- July 20-24** NCECBVI Project Independence (ages 7-12) -
(877) 809-2419
- Sept. 17** NCECBVI Sensory Safari Lincoln Zoo trip -
(800) 826-4355
- Sept. 20** NFVIC-LLTC TREE Program, 10:00 AM-
12:00 PM Topic TBA - Teresa Gregg (402) 218-7022
- Sept. 29** LLTC-NFVIC "Implications of Genetic Eye
Conditions in the Classroom", 9:00 AM-3:00 PM -
Kristal Platt (402) 498-6365
- Oct. 23-24** NCECBVI Fall Foliage - (800) 826-4355
- Nov. 4-6** NCECBVI WINNERFEST Retreat (ages 14-18) -
(877) 809-2419
- Nov. 12-13** NCECBVI Low Vision Clinic - (800) 826-4355
- Dec. 6** NFVIC-LLTC TREE Program -
10:00 AM -12:00 PM -Topic TBA -Teresa Gregg
(402) 218-7022