

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

January 2008

Omaha, Nebraska

Annual Ruth Sokolof Christmas Party



Despite the tragedy at Westroads Mall on December 5th, the NFVIC hosted its annual Ruth Sokolof Christmas Party on the 9th in the Tilt Area. One hundred twenty-nine children with visual impairments, K-12, who live in the Omaha Metro area, signed up for an exciting day of shopping and pizza. Each child was given \$100 and matched with a high school volunteer to shop for friends and family. Last year was a record-breaking year for the number of volunteers; this year was no different. A couple of the children took their money and shopped for the homeless instead of their families. Other children purchased gifts for their teachers of the visually impaired. The spirit of giving and genuine gratitude of these children can bring tears

flowing! This event demonstrated how the community can unite and celebrate the spirit of giving even under the haze of sadness and loss of life at Von Maur.

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Princess Diana Event



On August 19th at the Ironwood Country Club, the community remembered Princess Diana at a fundraiser for the NFVIC and the Omaha Children's Hospital. Princess Diana once said, "Nothing brings me more happiness than trying to help the most vulnerable people in society. It is a goal and an essential part of my life - a kind of destiny. Whoever is in distress can call on me." The community paid their respects by helping the two charities in her honor. Karen Javitch, a Board member of the NFVIC, sponsored this enchanting luncheon. Ms. Javitch wrote "Princess Diana, The Musical". It was produced twice in Omaha and began a tour of Germany and Austria in December 2007. Some of her songs from this musical were featured at this event

with Chuck Penington accompanying the talented singers. The atmosphere, food, entertainment and little dress-up princesses made the afternoon sparkle with joy and giving. Princess Diana would have been proud! Thank you all!

Fourth Annual Henry Doorly Zoo

Approximately 25 people wound their way bug-eyed through $\frac{3}{4}$ of an acre of the Kingdoms of the Night on September 30th. The families toured a dry bat cave, a wet 16 foot cave full of stalactites, and the world's largest underground swamp of 160,000 gallons. Many more creatures tantalized their imaginations in the sounds of the mysterious night. The docents did a magical performance of describing the environments so that the children could thoroughly be enthralled with the whole experience. A PB&J lunch with discussions of possible cultural events in 2008 made for a complete afternoon of exciting chatter and exploration.

Summer Reading Challenge



Each summer the NFVIC sponsors a Summer Reading Challenge for school-age children throughout Nebraska. This year the children were invited to "rock out" with new adventures in our "School of Rock Challenge". Each child records the title, author, and date of the books he or she reads in large print, Braille, or audio throughout the summer months. Different prizes are awarded each year. The winner of the "Base Players" Category 1 (K-6) was Maura Loberg who read 30 books and won a Talking GeoSafari Quiz Phone and the second prize winner was Samuel Winter who read 26 books and won a Speechmaster Talking Multi Function Clock Radio - AM/FM. There were no "Drummers" Category (7th-12th) winners. **Awesome job to all!**

Tech Tidbits: Victor Stream

Welcome to the world of portable listening with the Victor Stream. Similar to the Victor Vibe, it is a DAISY player/recorder with many more capabilities. You can download music, textbooks, novels, files and books from bookshare.org right in the palm of your hand. Convenience, portability, sleekness and fun listening all bundled into one small listening device! A student can even record quick notes to himself through its built-in microphone. Its features include:



- Removable SD card for storing books, e-text files, music, and voice recordings and audio bookmarks
- Ability to play National Library Service (NLS) download books and NLS book cartridges (for eligible members)
- Portable (4.6x2.6x0.9 inches) lightweight (6 ounces)
- Voice recording capability via built-in microphone or external microphone
- USB port to transfer books and music from your PC
- User replaceable rechargeable battery providing 15 hours playtime
- Four-arrow keys for navigation by chapter, section, page, and bookmarks
- Features to jump to a specific page, heading, book or bookmark
- Navigation of multiple books, MP3 folders, and voice notes
- Simple bookmark to mark a reading position
- Audio bookmark with recorded voice note



MARK YOUR CALENDAR!!

January

26 Commission for the Blind and Visually Impaired Omaha Group Teachings:
10:00 a.m.-2:00 p.m., topic TBA

February

9 Commission for the Blind and Visually Impaired Omaha Group Teachings:
10:00 a.m.-2:00 p.m., Cooking and Meet the Commissioners
12 PRISM: 6:30-8:30 p.m., Beveridge Magnet School
27 NCECBVI National Braille Challenge

March

11 PRISM: 6:30-8:30 p.m., Beveridge Magnet School
15 Commission for the Blind and Visually Impaired Omaha Group Teachings:
10:00 a.m.-2:00 p.m., Topic TBA
15 Boys Town National Research Hospital Beeping Easter Egg Hunt and TREE Program:
6:30-8:30 p.m.

April

TBA Tentative - PRISM: National Speaker, Beveridge Magnet School
10-11 NCECBVI Spring Fling
19 Commission for the Blind and Visually Impaired Omaha Group Teachings:
10:00 a.m.-12:00 p.m., topic TBA

June

21 TREE Program: 10:00 a.m.-12:00 p.m., Topic TBA

Boys Town National Research Hospital's

L L T C NEWS

THE A B C's OF ALBINISM

Albinism is a group of genetic conditions causing changes in pigment (coloring). One form only affects the eyes while several affect both skin pigmentation and the eyes. All forms of albinism have the following effects in the eyes:

- Nystagmus (quivering motion of the eyes)
- Decreased coloring in the iris and retina
- Underdevelopment of the fovea (structure of the retina responsible for fine discrimination)
- Decreased acuity
- Mis-routed optical pathways

These structural changes often result in poor depth perception, the need for glasses, light sensitivity, and strabismus (crossed eyes). Individuals with albinism should be seen annually by an ophthalmologist. People with albinism typically are near-sighted, far-sighted or have astigmatism and therefore should wear corrective lenses. Light sensitivity can be helped with sunglasses or special filter glasses; however there may be some reduction in vision due to the dark lenses. Rarely is strabismus surgery necessary unless for cosmetic purposes. A low vision assessment may prove helpful to evaluate devices.

Boys can have a type of albinism called ocular albinism affecting only the eyes due to changes in a gene called GPR143 (OA1). The majority of carrier mothers for this X-linked condition can be identified through an eye exam.

Both girls and boys can have oculocutaneous albinism (OCA) causing problems with the eyes and skin pigmentation. Several genes are known to cause OCA. All types of OCA result when a child inherits a non-working gene from both unaffected parents. In addition to vision care, individuals with OCA must be vigilant regarding protection from sun damage. Clinical testing is available to make a specific diagnosis of the type of albinism. Hermansky-Pudlak syndrome is much less common; it causes bleeding problems and may lead to lung disease.

For additional information on albinism, contact:

- The National Organization of Albinism and Hypopigmentation (NOAH): (800) 473-2310, noah@albinism.org; www.albinism.org
- The Albinism Database (HUGO): www.albinismdb.med.umn.edu/
- PanAmerican Society for Pigment Cell Research: www.paspcr.org
- Kristal Platt – Genetic Counselor: (402) 498-6365, plattk@boystown.org

COME JOIN US FOR THE BEEPING EASTER EGG HUNT



Saturday, March 15, marks the date for the 2008 beeping Easter egg hunt sponsored by the Boys Town National Research Hospital Vision Program. The beeping egg hunt is intended for children who find it difficult to participate in a public egg hunt because of vision problems. Their brothers and sisters are also welcome to attend. We invite older youth with visual impairments to interact as volunteers to pass out treats.

Children will hunt for each egg and trade their eggs for prizes. The egg hunt will be held at the Girls and Boys Town campus at Father Flanagan's Home. If the weather does not cooperate, we will hold the activity indoors at the Hall of History Museum. As was true for last year, the Omaha chapter of the Telecom Pioneers invites us to use the beeping eggs and will provide a bunny costume for delightful photos.

Kristal Platt Speaks At UNO

On October 29th, Kristal Platt lectured on visual impairments to a UNO senior level adapted physical education class, required for all exercise science and physical education majors. She provided introductory information on terms, causes and resources. Near the end, the class was divided into small groups to problem solve two specific scenarios.

- Imagine you are a student teacher for a cycling class in high school. You notice as the class is biking that one girl slips behind and you prompt her to keep up with the group. After class she tells you she is visually impaired and does not feel comfortable biking at the speed of the class because of safety concerns. What would you do?
- A student wants to play basketball in PE in a rural high school. The gym teacher is concerned that the student may be hit by the ball, so instead the student is assigned to weight training. Is this legal? What would you do?

Real-life stories can often make for the most interesting discussions. Some of the UNO students' suggestions included using a tandem cycle, or a peer as a guide, applying better markings on the course, modifying the game, slowing down the pace of the game, altering the general curriculum, and identifying a peer helper.

For more ideas and information, see these websites:

- National Center on Physical Activity and Disability (NCPAD)
www.ncpad.org (800) 900-8086
- Project Inspire
www.twu.edu/inspire/ (940) 898-2575
- PE Central
www.pecentral.org (540) 953-1043

C O M M U N I T Y

Mothers' Thoughts On The Families Connecting With Families Conference

Together The National Association for Parents of Children with Visual Impairments (NAPVI), The American Foundation for the Blind (AFB) and The Seeing Eye Inc. sponsored a National Family Conference in Omaha, July 13-15. Held at the downtown Hilton, the conference brought together more than 150 families from 30 states and 5 continents. The goal: "to gain support and to learn about all aspects of raising and educating a child with visual impairment." A grand total of 650 parents, teachers, volunteers, speakers, exhibitors and children attended or worked at the conference!

From a parent's perspective, Cheryl Wichman shares, "This was my first-ever national conference. I couldn't believe the wealth of information offered to parents and teachers. In addition, meeting other parents and children with a similar diagnosis was invaluable during our round table discussion. After the discussion, the parents decided to share names, addresses and phone numbers so that we could meet again and/or share with each other throughout the year. For our family, that alone was priceless."

Cheryl Wichman, Mother to Joshua (7 years old, Retinopathy of Prematurity) and Nathan (twin to Joshua)

"It was really a privilege to have the Families Connecting with Families conference right here in Omaha. The speakers inspired our hearts to keep encouraging our daughter to the fullest degree. The education we received from the sessions has been invaluable in helping us find our way around obstacles. The opportunity to connect with other families and realize that they face many of the same challenges and joys that we do was truly the best gift of all. In a wonderful coincidence, I finally got to meet a mother who had read some of my posts on a Retinopathy of Prematurity listserv. Her family's story is eerily similar to ours and our connection was immediate. She will be a lifelong friend and source of support. That the conference could provide the atmosphere for these kinds of connections to take place is remarkable in my eyes."

Jennifer O'Neill, Mother to Camille (3 yrs old, Retinopathy of Prematurity) and Olivia (23 months)

Nebraska Commission for the Blind and Visually Impaired (NCBVI)

WINNERFEST is a three-day retreat giving blind teenagers the opportunity to focus on personal achievement, goal setting, communication and other life skills. In November, thirteen teenagers attended WINNERFEST at the Leadership Center in Aurora. It was a great time to meet other teens with visual impairments, as well as blind adults and other mentors. NCBVI Counselors and Consumer Volunteers were leaders of the activities.

Seminars were held on several topics such as non-verbal communication – why it is important, what messages we send, and why we need to pay attention to our own and other people's "body language". One workshop, entitled, "Time on My Hands and What To Do With It," addressed positive ways people use leisure time. Another seminar explored the subject of dating and blindness.

Some activities included assembling neck coolers for servicemen stationed in Iraq and bowling using sleepshades. The manager of Pin Setter Lanes gave a behind the lanes hands-on tour explaining the history and mechanics of automated pin setters. Team competition games and a chance to play Goal Ball with sleepshades were enjoyed by all the kids; several wished they could have played longer. The staff and volunteer consumers were constantly interacting with the teens, helping to make it a great time for everyone. WINNERFEST ended with an open seminar about personal interests and career goals.

Nebraska Deaf-Blind Project

The annual Nebraska Project for Children and Youth with Deaf-Blindness' Deaf Blind Summer Institute will be held the week of July 14 -18, 2008. Announcement information will be available in the spring of 2008. If you want to be placed on the mailing/email list or want additional details, you can access the website: <http://www.nedbp.org> or contact Teresa Coonts, Project Coordinator, at 402-595-1810.

COMMUNITY continued...

Nebraska Center for the Education of Children Who Are Blind or Visually Impaired (NCECBVI)

In the world of special education, educators rely on the great support of paraprofessionals (paras). At NCECBVI, we wouldn't survive without them! Many times in local school districts, a para is assigned to a student with disabilities and this practice is no different for those with visual impairments. As our state offers many resources for training of paras, we would like to add this to your tool kit which is specific for the VI field. *A Paraprofessional's Handbook for Working with Students Who Are Visually Impaired* is an excellent resource! This offers assistance for the paraprofessional's unique role in providing educational programming by giving:

- brief descriptions of social skills, daily living skills, and orientation and mobility skills and their importance
- specific points related to the paraprofessional's role
- suggestions and tips that may be helpful when working with students
- resources and references enhancing know-how
- information about technology and its applications
- information about adapting materials, equipment and environments
- special considerations for students who have visual and multiple impairments

To order this handbook, go to the Texas School for the Blind website (www.tsbvi.edu/publications/). Along with this book, they offer many resources which address professional development needs in our field.

PRISM for Parents of Visually Impaired Children

The Parent Resource Information and Support Meeting (PRISM), sponsored by the Ollie Webb Center, is held at Beveridge Magnet Center (1616 So. 120th Street) from 6:30 to 8:30 p.m. The meetings are held on the second Tuesday of September, October, November, February, and March with a kickoff in April. Everyone meets at 6:30 for an informational guest speaker followed by specific disability breakout sessions from 7:45 to 8:30. Dinner, childcare, transportation and interpreters are available. Teresa Gregg from NFVIC and Kristal Platt from BTNRH/LLTC co-facilitate the visually impaired group this year. Each month the group assembles after the main speaker and discusses the topic in more detail. The majority of the time, the families just have questions and stories to share with one another. It has become quite a networking group of dedicated moms and dads who are enthusiastically searching, sharing, laughing, and seeking the best for their child who is visually impaired. Some of the topics discussed were: adaptable toys, sibling interaction, employment, student inclusion, community resources, technology and much more.

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
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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>