

July 2009

Omaha, Nebraska



## Dot Detective: Breaking the Braille Code

Sign up to learn the fundamentals of braille for everyday use. Intended for parents, this lively series of workshops will intersperse games and riddles between lectures and drills to make learning fun. Practical ways to incorporate braille literacy at home will be emphasized.

Join us for six Saturdays: September 12, 19 and 26, October 3, 10 and 17, from 3:00 to 5:00 PM at the Lied Learning and Technology Center at 425 North 30th Street in Omaha. All materials, childcare and refreshments will be provided.

For more information or to register, contact Teresa Gregg at (402) 452-5096.

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## Nebraska Foundation for Visually Impaired Children

### TREE: Guide Dogs and GPS for the Blind

On June 6th, the Teaching Resource Educational Exchange (TREE) program began with a demonstration of talking Global Positioning System (GPS) products for the blind. These devices use the standard GPS maps with added points of interest. Unlike a standard GPS with a touch screen that is not accessible to a blind person, they allow a blind person to manipulate the options and keys with audible feedback. Blind people can record routes, customize by adding points of interest, browse with no satellite connection, and choose a pedestrian or driving route. Press a button and they will announce landmarks and locations with precision.



Thatcher could only be petted when his harness was off.

There are three choices for talking GPS devices:

- 1) Trekker has more options for recording points of interest for routes, has a better voice quality and has the capability to purchase additional hardware and software to turn it into a PDA (Personal Data Assistant).
- 2) Trekker Breeze is more affordable with fewer buttons.
- 3) BrailleNote or Braille Sense notetakers can be turned into a talking GPS device with the purchase of additional GPS software.

Trekker Breeze is discussed in more detail in the accompanying technology article. Visit [www.accessibility.net](http://www.accessibility.net) or [www.humanware.com](http://www.humanware.com) for additional information.

After the technology presentation, Kathy Brown-Hollins, a counselor at the Commission for the Blind and Visually Impaired, showed off her guide dog, Thatcher. Thatcher is a Laborador who likes his belly rubbed, but only when his working harness is off. The harness means he is in working mode. Ms. Brown-Hollins discussed the 28 day training she had with her guide dog. She said it was a little difficult trusting a dog while walking, but it did not take long for her bond with the dog to blossom. Ms. Brown-Hollins still uses her white cane in situations when she does not want to take her guide dog. Persons who have guide dogs must also be good cane users. Thank you Ms. Brown-Hollins and Thatcher for coming and sharing your story with us.

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### Janice Anderson Memorial Scholarship

NFVIC was excited to award four scholarships this year. The Janice Anderson Memorial Scholarship is awarded to graduating high school students with visual impairments. These funds are available to enhance students' physical appearance through the purchase of new clothes, make-up, hair cuts and personal grooming products. The four recipients include: Andrew Olney who will be attending college to pursue a hunting dog training career; Sean Lentz who will be attending a Nebraska university; Kelly Coleman who will be attending the Colorado Center for the Blind and Visually Impaired and the University of Kearney; and Kelsey Saltzman who will be attending the Nebraska Commission for the Blind and Visually Impaired's Orientation Center. We are proud of their achievements and determination. We wish them all the best!



# N F V I C continued...

## Trekker Breeze: Talking GPS

Trekker Breeze is a hardware product for the blind. It is a seven ounce talking Global Positioning System (GPS) device that allows people with visual impairments to receive audible directions to destinations. It has an eight hour battery life and is 5x2x1 inches, smaller than a TV remote. Trekker Breeze has a built-in speaker with an easy to reach volume control. Its features include the ability to:



- Hear audible information on foot or in a vehicle
- Receive audible information on surroundings including public services and businesses while in route
- Record landmarks along the route, such as to a favorite restaurant or a friend's house
- Manipulate easy to touch keys for menu navigation
- Get the step-by-step instructions from start to end

Trekker Breeze is half the cost of the Trekker and provides independent travel for blind people anywhere without asking a sighted friend, family member or stranger for directions! This powerful portable talking device allowed eight blind people to climb Kilimanjaro this past spring. For more information, visit [www.accessibility.net](http://www.accessibility.net) or [www.humanware.com](http://www.humanware.com).

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## Film Streams and NFVIC Present “The Miracle Worker”

NFVIC is honored to be selected for a community collaboration with Film Streams at the Ruth Sokolof Theater, Omaha's nonprofit cinema. On August 25th at 6:30 p.m., Film Streams will feature “The Miracle Worker”, the 1962 movie about Helen Keller starring Patty Duke and Anne Bancroft. A discussion of services for people with deaf-blindness will follow the film with audience participation.

### Film Streams' Ruth Sokolof Theater

1340 Webster Street

Omaha, NE 68102.

See [www.filmstreams.org](http://www.filmstreams.org) to view daily film listings.

This is an exciting collaboration to raise awareness of Nebraska services for students who are deaf-blind. This year marks the 200th anniversary of Louis Braille's birth, the inventor of braille. Whether your child or student is blind, visually impaired, or deaf-blind, the determination of Louis Braille and Helen Keller as self-advocates may inspire your family. Please come join us for an informative evening.

The 1979 version of “The Miracle Worker” with Melissa Gilbert can be purchased with audio description at [www.barnesandnoble.com](http://www.barnesandnoble.com). Audio description inserts commentary between the dialogue of a movie allowing a blind person to hear the description of scenes, actions and fashions. These relevant details help blind movie-goers understand what can be seen and not heard.

# Boys Town National Research Hospital's

## L L T C NEWS

### The A B C's of SOD

Septo-Optic Dysplasia (SOD) is a disruption of certain structures in the middle of the brain which form four to six weeks after conception. The diagnosis of SOD is made when at least two of the three features are present: optic nerve hypoplasia (underdevelopment of the nerve from the eye to the brain); absence of the septum pellucidum (midline structure of the brain); and hypopituitarism (decrease or absence of the hormones produced by the pituitary gland). One third of individuals with SOD experience symptoms in all three areas. Individuals with SOD have varying degrees of each associated problem including learning difficulties. SOD can be seen by itself or as part of a broader issue such as a syndrome or chromosome alteration.

An ophthalmologic exam in conjunction with a CT (X-ray) or MRI (Magnetic Resonance Imaging) scan can visualize the affected structures; however, the scan cannot be used to predict function. There is no cure for SOD although vision may improve slightly as the brain matures.

The pituitary gland orchestrates the production of many hormones directly or indirectly. One such hormone is growth hormone. Tests can identify which hormones are decreased or absent. Treatment for this aspect of SOD can be managed by a pediatric endocrinologist with the replacement of missing hormones.

The vision of people with SOD can vary from near normal to low vision to total blindness. More commonly seen problems include loss of visual field, decreased acuity (clarity), nystagmus (rapid movement of the eyes) and photophobia (sensitivity to light). As for children with other conditions, teachers need to pay particular attention to print size, contrast and lighting. Field vision loss can interfere with the placement of teaching materials. Orientation and mobility instruction is helpful for the above mentioned reasons as well as because difficulty with depth perception is frequently observed. Many aspects of a child's health and education can be affected, including diminished or absent taste and smell. Therefore, each child should be monitored carefully for his or her medical and educational needs.

In most cases of SOD, the cause cannot be attributed to one specific factor. SOD is thought to be due to a combination of poorly-understood genetic and environmental factors. Some researchers have reported a higher number of babies with SOD born to teen mothers or in first pregnancies. Cases of more than one person in the family with SOD are rare. Researchers have discovered less than 1% of individuals with SOD have an alteration of the gene known as HESX1. Scientists believe there is much more to the story of Septo-Optic Dysplasia.

For more details on SOD, sometimes known as DeMorsier Syndrome, see the resources below or contact Kristal Platt at (402) 498-6365.

MAGIC Foundation  
1327 N. Harlem Avenue  
Oak Park, IL 60302  
Tel: (708) 383-0808 Fax: (708) 383-0899  
[www.magicfoundation.org](http://www.magicfoundation.org)

[www.blindbabies.org/factsheet\\_onh.htm](http://www.blindbabies.org/factsheet_onh.htm)



## Beeping Easter Egg Hunt

Once again the day of the Beeping Easter Egg Hunt was rainy, but it did not dampen the fun. The third annual Egg Hunt sponsored by Boys Town National Research Hospital’s Lied Learning and Technology Center was held on April 4 at the Hall of History on the Boys Town campus. As in the past, the Center’s community partners contributed great prizes and treats. The Nebraska Qwest Pioneers provided a braille book for each child with a visual impairment and funded the costumed bunny. The Qwest Pioneers also provided Silly Putty, bouncing balls and jelly beans for all the children. Re:JERSE, a women’s philanthropic group from New York, supplied stuffed animals. Baker’s, Costco and Target helped fill the Easter baskets and refreshment table.

The whole family is encouraged to participate. As children “age out” of hunting eggs, they are invited to help younger children or pass out treats. Several families were interviewed and photographed for local media stories. KETV and WOWT returned to capture the smiles and excitement. Makenzie and her mother, Sara Gray, were interviewed by the Omaha World Herald for a story on local egg hunts. Maura Loberg was highlighted the next week in a feature story describing the egg hunt and explaining her family routine in Wayne, Nebraska.

Boys Town National Research Hospital would like to thank its community partners, volunteers and especially the participating families for making the third Beeping Easter Egg Hunt a hopping good time. Plan to join the fun next year on March 27, 2010.



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

- 7/13-17 Deaf-Blind Summer Institute: (402) 595-1810
- 8/7 10:00-2:00: NCBVI Teen Group - Riding Bus to Mall: 595-2041
- 8/11-13 NCECBVI Job Seeking Skills Workshop/Technology Expo: (877) 809-2419
- 9/12 10:00-2:00: Teen Group - SAC Museum: 595-2041
- 9/12, 19, 26 3:00-5:00: LLTC-NFVIC - Dot Detective: Breaking the Braille Code: 452-5096
- 9/16 10:00-12:00 & 1:00 - 3:00: NCECBVI Sensory Safari Lincoln Zoo: (800) 826-4355
- 10/3 10:00-1:00: Especially Artful Saturday, Joslyn Museum, Omaha: 661-3878
- 10/3, 10, 17 3:00-5:00: LLTC-NFVIC - Dot Detective: Breaking the Braille Code: 452-5096
- 10/17 10:00 - 2:00: NCBVI Teen Group - Hand ‘n Hand Fire Safety Skills: 595-2041
- 11/14 10:00 - 2:00: NCBVI Teen Group - Grooming Skills: 595-2041
- 11/5-7 NCBVI Winnerfest: (877) 809-2419
- 11/21 10:00-12:00: NFVIC-LLTC TREE - Adaptable board games, Ball, Computer games & DVDs: 218-7022
- 12/29 10:00 - 2:00: NCBVI Teen Group - Treats and Greetings: 595-2041

# C O M M U N I T Y



## Talking Books Without Green Boxes!

By Dave Oertli

Imagine talking book readers being able to download their favorite talking books through their computer instead of waiting for green boxes to arrive through the mail! The Library of Congress now offers a website with over 15,000 recorded books and 44 magazines. If your child is an active reader of the Nebraska Library Commission Talking Book and Braille Service, he or she can sign up for downloads if you have access to 1) a computer with email; 2) a high speed connection (sorry, dial-up is too slow); and 3) a digital player that is equipped for the talking book special format, plus a digital card. **Here is the download website:**<https://nlsbard.loc.gov>.

Eventually talking book readers will be loaned free digital players; however, probably for the next year, a reader will need to purchase a digital player and card in order to access the online books and magazines from Library of Congress. There are now three models of digital players which can be purchased:

- 1) The VictorReader Stream. [http://www.humanware.com/en-usa/products/dtb\\_players/compact\\_models/\\_details/id\\_81/victorreader\\_stream.html](http://www.humanware.com/en-usa/products/dtb_players/compact_models/_details/id_81/victorreader_stream.html)
- 2) The LevelStar Icon. [www.levelstar.com](http://www.levelstar.com)
- 3) Braille Plus Mobile Manager. [www.aph.org/tech/pda\\_info.htm](http://www.aph.org/tech/pda_info.htm)

For materials mailed directly to talking book readers and returned postage free, the change from audio cassette to flash memory cartridges will begin this fall. Veterans have priority for the first digital players. The Nebraska Library Commission will begin offering books on flash memory cartridges to be used with the new digital players this fall as well. At first, the selection of books on cartridges will be limited, and many magazines will be offered only on audio cassette for the foreseeable future. In the meantime, your child can continue to borrow cassette books, including new titles, and magazines from the Nebraska Library Commission just as you do now. **For more information, call toll-free (800) 742-7691 or local (402) 471-4038.**

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## The O'Neill's Visit Hadley School for the Blind

By Jennifer O'Neill

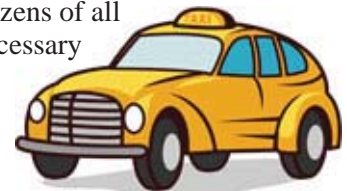
When my daughter, Camille, now age 4, was first diagnosed with a significant visual impairment shortly after birth, one of the first places I turned to for guidance was the Hadley School for the Blind, an educational outreach center based out of Winnetka, IL. In October of this last year, Camille and I were invited to Hadley during the biannual faculty meeting to meet the staff, tour the facility and attend a luncheon. We enjoyed a dinner where we met many people in the community and within Hadley who make it what it is. Getting to meet many of the teachers who have supported our family from afar through Camille's early development was an amazing experience. They helped me navigate the world of low vision, taught me braille and provided us with an endless amount of resources. I would highly recommend learning more about Hadley and the services it can provide by visiting [www.hadley.edu](http://www.hadley.edu).

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## What is Share A Fare?

By Jim Jirak

Share A Fare encourages independent travel for the visually impaired in the Omaha area by providing a timely curb to curb transportation option. The Share A Fare program allows qualified individuals to purchase a specified amount of cab coupons each month for half price, making cab service more affordable. This option permits participants to go to school, work, stores and appointments without relying on family, friends or taking lengthy bus trips. Since the launch of the pilot program, Share A Fare has provided a new level of independence for blind citizens of all ages. Blind and visually impaired youth are invited to learn the skills of independence necessary to use a cab while utilizing the Share A Fare program.



For more information about the program or to apply, please call (402) 827-9814 or visit Share A Fare online at <http://www.acb.org/nebraska/transportation/omaha/index.html>.

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

## Infant Massage Part II: Enhancing the Parent-Infant Bond

By Stacy Groff



One of the greatest benefits seen with infant massage is the enhancement of the parent-infant bond. In the realm of infant massage, bonding is referred to as the actions involved in the connection between two human beings and the quality of the connection. Early ties are crucial, however, it is never too late to bond. Bonds can consciously be created at any stage of life. This lifelong, reciprocal, interactive process begins during pregnancy.

Infant massage is an excellent way to continue strengthening the bond between an infant and his or her parents. If, for some reason, the bonding process has been disrupted, infant massage is a wonderful way to re-connect. It encompasses all of the elements of bonding which includes touch (the only sense without which humans cannot survive), eye contact, odor, hearing/speaking, smiling, nursing/feeding, imitation/entrainment/biorhythmicity, and crying.

All of the senses are involved in the bonding process. This is not to say that bonding cannot take place or that there will be difficulties in bonding with an infant who has a visual or hearing impairment. Maximizing the other senses and elements to compensate for the sensory loss and minor adaptations in the massage routine can achieve the same loving, secure bonds. **For more information on infant massage or parent-infant classes, call Stacy Groff, LMT, MSW at Life Therapy Massage, 402-871-5668.**

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## Jewish Guild for the Blind Phone Support Groups

Written by Kristal Platt from information provided by Dan Callahan

The Jewish Guild for the Blind sponsors weekly telephone support groups for parents of children who are blind or visually impaired. Any parent can participate at no cost. Each group is facilitated by a social worker or clinical psychologist. The groups are kept small with no more than 10 to 12 participants so that everyone has the opportunity to speak. The groups “meet” weekly for about 90 minutes by calling a toll-free number. Parents from 30 different states participate. Currently, support groups for parents of children with Retinopathy of Prematurity (ROP), Retinitis Pigmentosa (RP), Cortical Visual Impairment (CVI) and Leber Congenital Amaurosis (LCA), are offered. Recently a group for High School Seniors and College Students, as well as a generic group for Fathers have been started. With enough interest, a group for parents of children with Optic Nerve Hypoplasia (ONH) will get underway.



**For more information or to join a group, contact Dan Callahan, Director, Children’s Vision Health Initiative, Jewish Guild for the Blind, (800) 915-0306.**

**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  
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
- 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>