



# Information Update

Winter Newsletter 2006

## Hand in Hand: A Partnership Serving Families, Educators, and Service Providers of Children and Youth Who Are Deafblind



*Pennsylvania Training and Technical Assistance Network  
Pennsylvania Department of Education  
Bureau of Special Education*



### Deafblind Advisory Council

The Deafblind Project's Advisory Council is getting a "new look". The Advisory Council has developed a mission statement as well as roles and responsibilities for the Council Members. By doing this, the Council can better assist the project in identifying and addressing the needs of children and youth who are Deafblind. Currently, Council Members consist of family members, consumers, professionals working with children and adults with sensory impairments, and staff from the Deafblind Project. We would like to identify additional representatives to include higher education, medical professionals, the Department of Health, and family members. If you are interested in participating on the Council or would like to recommend someone for the Council, please contact Jackie Brennan at [jbrennan@pattan.net](mailto:jbrennan@pattan.net) or call (215) 877-0313, ext 215. Council Members must be able to meet the roles and responsibilities listed below. See the *Spotlight on our Advisory Council* article on page 3 to learn more about one of our members.

#### Mission Statement of the Deafblind Advisory Council

The Mission of the Deafblind Advisory Council is to provide direction and support to the PA Deafblind Project, Hand-In-Hand, in its efforts to ensure high quality services and technical assistance to all individuals, ages birth to 22, who are deafblind and their families. This will occur through the dissemination of information, identification of needs and resources, interagency collaboration, and advocacy for the rights of all individuals with deafblindness.

#### Roles and responsibilities of the Deafblind Project Advisory Council Members

- | <u>Roles</u>   | <u>Responsibilities</u>  |
|--|--|
| 1. Advise DB Project on the priorities, standards, goals and activities                  | 1. Maintain involvement with Advisory Council through face-to-face and remote meetings |
| 2. Suggest additional or alternate activities to support DB Project goals                | 2. Participate in a work group(s)  |
| 3. Review current DB Project goals/activities and timelines                              | 3. Stay informed of DB Project goals and activities                                    |
| 4. Advise on future DB Project activities or initiatives                                 |  |
| 5. Advocate for services for children and youth with deafblindness                       |  |
| 6. Advocate for and support DB Project activities  |  |
| 7. Facilitate partnerships between the DB Project and other agencies, programs, etc.     |  |
| 8. Share DB Project goals and activities with relevant agencies and organizations        |  |
| 9. Refer individuals to the DB Project, when appropriate                                 |  |
| 10. Share information with the DB Project that is relevant to the field of deafblindness |  |



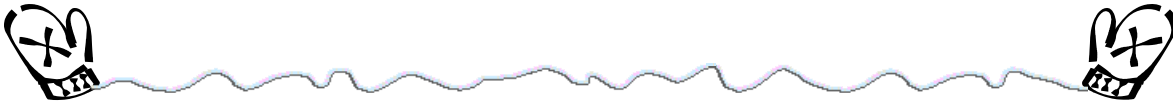
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## Deafblind Census

We are currently in the process of receiving updates from families, schools, intermediate units, and early intervention agencies for children who are Deafblind or at-risk for Deafblindness.

This yearly event is a federal requirement that allows us to maintain records about children and youth who are Deafblind in Pennsylvania. This activity provides us with valuable information on our families, educators and service providers serving our children and youth. Please contact your child's teacher about the census to ensure your child's information is updated. Your help with this process is greatly appreciated. The deadline for updates is Friday, March 10, 2006.

Please feel free to contact Kim Fino at [kfino@pattan.net](mailto:kfino@pattan.net) or 1-800-360-7282, ext. 3115 with any questions about this process.



## Family Learning Conference Survey Results

In October 2005, a survey was mailed to all families on our Deafblind census. The survey's questions pertained to our annual Family Learning Conference. Twenty-three surveys were returned. Some of the results are as follows:

When asked were you aware that the Project sponsors an annual Family Learning Conference, 17 responded "Yes", and five "No" and one gave no response to this questionnaire, but made comments.

The preference for type of venue for a conference elicited the response that 16 would attend a conference in a campground setting, five would not attend in a campground setting, and two made attendance at a campground setting conditional upon oxygen availability and public transportation.

All (22) responded that they would attend at a hotel setting. Two responded that public transportation is imperative and one noted that although they would attend at a campground, a hotel would be preferable.

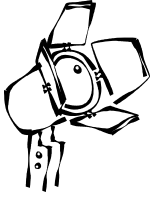
The majority (20) prefer a two nights, three day conference. Fourteen participants also stated that they would attend a one night, two day conference if offered. Only four responded positively to a one day only conference, if offered.

Families were informed of the National Conference being sponsored by American Association of Deafblind in Baltimore, MD, in 2006. Seventeen responded that they would be interested in attending.

Five families responded that they would not attend a conference without their child/children, even if financial aid were offered to offset their costs. However, 13 agreed they would attend without their children, but one clarified that only one parent could be present, and one commented "not sure."

One family returned their survey not complete because they felt that their child was functioning fairly well, and that the Project's activities may not be a good fit for their family. Please see the article on page 4 written by Allison Jenkins, who, until recently, was not sure her family was a good fit with the Project. We encourage ALL families who have a child with deafblindness (regardless of how they function or their degrees of hearing/vision losses) to seek out the services and activities of the Project. You may be surprised that you might find another family just like your own!

We thank those of you who took the time to complete the survey and return it. The information is invaluable to the Project. This is one of the ways we learn how to better serve and meet the needs of families. If you wish to assist in the planning of 2006 Family Learning Conference, please contact Kim Fino at [kfino@pattan.net](mailto:kfino@pattan.net) or 1-800-360-7282, ext. 3115 .



## Spotlight on our Advisory Council:

As an added feature of this newsletter, the Project takes this opportunity to inform our readers about a member of our Advisory Council, Betty Hane. Betty is a long time family member of the Deafblind Project, as well as a committed participant in an advisory capacity.

Betty's family experienced the sadness of a lifetime, this past year with the loss of their beloved Beth, who was 18 years old. Beth was a fixture at our Family Learning Conferences, and Betty was a tireless advocate on Beth's behalf, especially as she was entering her adult transition years.

Despite this terrible loss, Betty's smile and determination have not lessened her resolve to ensure opportunities for individuals with disabilities. To continue her advocacy and interests in this area, Betty is now a full-time student at Carlow College in Pittsburgh, PA. In fact, Betty was featured on the cover of the most recent issue of Legacy, the Carlow University Annual Donor Report. Betty is the recipient of the F. E. McGillick Scholarship. Betty is quoted in the article, "Beth is the driving force behind my achieving a teaching degree. My dream is to help other children with disabilities achieve their dreams and goals in life and to help their parents see the potential in their children and not give up."

We congratulate Betty and wish her continued success in her college career!

## Update on Juli Baumgarner

As some of you know, Juli Baumgarner, one of our Deafblind Education Consultants, has been battling breast cancer. Juli has undergone chemotherapy, surgery and radiation. As her treatments are nearing their completion, Juli is slowly rebuilding her strength. Throughout this ordeal, her spirit and faith have never faltered. She credits the well wishes, thoughts, prayers, and cards from deafblind families and staff for uplifting and supporting her. Juli reports that she plans to use this experience to help support others. If you wish to send along your continued well wishes for her full recovery, she may be reached at:

343 Glass Road  
Newcastle, PA 16101

## Project Sparkle Supporting Parent Access to Resources, Knowledge, Linkages and Education

The PA Deafblind Project has sponsored over 20 families to participate in Project Sparkle. We would like to recognize and congratulate the following participants who have completed Project Sparkle, as of December 1, 2005, on their efforts, hard work and perseverance. We look forward in congratulating Group III in our next newsletter as they are near completion as well.

### Group I

Molly Black  
Gordon Boe  
Mary Boe  
Jennifer Davidson  
Betty Hane  
Deb Kantor (Family  
moved to Florida)  
Patti McGowan  
Kim Resh

### Group II

Jim Abel  
Ruth Braga (transfer  
from Utah)  
Linda Radzik  
Dorothy Williams

Anyone interested in this unique training program designed specifically for families of children and youth who are deafblind to be used in their own homes. Please contact:

Jeanne Gardier [jgardier@earthlink.net](mailto:jgardier@earthlink.net)  
Molly Black [mblack@pattan.net](mailto:mblack@pattan.net)  
Patti McGowan [pmcgowan@pattan.net](mailto:pmcgowan@pattan.net)

## Introducing Kim Fino, Customer Service Representative

In November 2005, Kim Fino was hired to replace Nancy Lehr, who retired. Kim will be working closely with the Deafblind Project in her role as Customer Service Representative for Lancaster-Lebanon Intermediate Unit 13 at PaTTAN in Harrisburg, Pennsylvania.

Having graduated from Shippensburg University with her Elementary Education degree, she has worked with children of various ages and abilities. Kim also has some office experience. She is excited to be able to use her skills to be part of an organization that serves both children and teachers.

Kim can be reached at the Harrisburg PaTTAN office at 1-800-360-7282 or 717-541-4960, ext 3115 or [kfino@pattan.net](mailto:kfino@pattan.net). Please feel free to contact her with any questions you have about Hand in Hand.

## Leadership Network Opportunities

The Leadership Network is up and running having held our first training in November. Nine parents are participating, and will continue their training in January and May to become our first official Parent/Family Leaders. Please read why Mary Beth and Jim Abel decided to become involved.

*We wanted to get involved with the Leadership Network because we wanted to be more involved with the Deafblind Project.*

*Over the past several years, we have been involved with a phone study, planning of Family Learning Conference Weekends, a specific project for the family weekend and Sparkle.*

*We have dealt with State Legislation in advocating our daughter's law known as "Elizabeth's Amendment", which prevents parking in front of warning signs pertaining to vision and/or hearing issues. We realized that thousands benefited with this law.*

*After the 2004 family weekend, Jim said to me "why don't you do Sparkle?" I suggested to him "why don't you?" He did. He enjoyed the DVD and the phone conference calls. The participants told him that they were glad to have a father's point of view.*

*We both want to be able to connect with other parents and share information. We feel that we can assist in mentoring and advocating needs not only for our daughter, but for others.*

*We believe the Leadership Network gives us the opportunity to do so.*

*Mary Beth & Jim Abel*

Mary Beth and Jim Abel live in Eastern, PA. Their daughter, Elizabeth recently turned five years old, and is a preschool student. They have attended several Family Learning Conferences and have recently completed the second of three training sessions of our Leadership Network.



## Why the Jenkins got Involved

The following Article was written by Allison Jenkins in response to the question: Why did you decide to explore the services of the Deafblind Project, when you expressed that you were not so sure that your family was a good "fit".

We had big troubles at home with our six year old son, Joey. He had a seizure disorder, low muscle tone, worsening scoliosis, global developmental delay, hearing aids, and cortical vision impairment. The last thing we needed to hear was more bad news. At least Joey was hearing with his bright blue little hearing aids connected to the FM system, and no one could say for sure that he was not seeing something even with CVI!!!

Hearing first from the Deafblind Project by browsing through periodic mailers that came to my house, the group sounded big and smart, but my concerns for Joey had little to do with those two senses; he was having a feeding tube put into his stomach, we were discussing back surgery, and the neurologist was trying to manage worsening seizures. Joey has arrested the seizures successfully, gained weight, and straightened his spine with vertical rib placements.

Looking back, I see how his therapists at Easter Seals always saw him as a learner, even if I could not, because of my worries with physical problems. I do see the light at the end of the tunnel because Joey has convinced me that he indeed wants to communicate. There must be more ways to get into his head. Teaching Joey is one of those beliefs not always shared by family and friends who are convinced my optimism is not realistic, or maybe not worthwhile.

Meeting others at the Deafblind Project supports my belief that what I want for Joey is valuable for this world, and possible. This Project wants the most for Joey; like its parent members want the most for their own children. It was unexpected to find that we would share so much in common, even though each of our children with disabilities seems so different.

*Allison Jenkins lives in the Eastern part of PA. Allison and her children attended their first Family Learning Conference in 2005. She is also a member of our Leadership Network.*

## AADB 2006 National Conference News

“AADB On The Move:  
No Deaf-Blind Left Behind”

American Association of the Deaf-Blind  
2006 National Conference  
Baltimore, MD  
June 17-23, 2006

The American Association of the Deaf-Blind (AADB) is a national consumer organization of, by, and for deaf-blind Americans. AADB has deaf-blind members from all walks of life with diverse educational, vocational, social, and ethnic/racial backgrounds. The membership also includes many people who are not deaf-blind themselves but who support AADB's mission and activities.

AADB's mission is to endeavor to enable deaf-blind persons to achieve their maximum potential through increased independence, productivity and integration into the community. AADB is governed by a board of directors of whom the majority are deaf-blind themselves.

Conference full week packages are available. It includes room for six nights, 3 meals a day, banquet, selected tours, workshops, recreation, socials, and more!

Registration is available online at AADB's website: [www.aadb.org](http://www.aadb.org). They are designing it so that it will be accessible to everyone, including screen readers and Braille. You can contact them at 301-495-4403 or 301-495-4402 (TTY) to request a packet be mailed to you.



### HELP!! New Name Needed



We are looking for a new name for our newsletter. Email or call in your suggestions for the new title to Kim Fino at [kfino@pattan.net](mailto:kfino@pattan.net) or 1-800-360-7282, ext. 3115. You might just be surprised to see your ideas in print!

## SAVE THE DATE for our next Family Learning Conference June 16–18, 2006 Harrisburg, PA

Plans are being made for the next Family Learning Conference in Harrisburg, PA. Mark your calendars now for the weekend of June 16 – 18, 2006, Father's Day Weekend. Exciting activities and learning opportunities are being planned for parents, children with Deafblindness and their siblings. We are also looking into trips to local events in the Harrisburg area. This is a funded event through a Federal grant administered by Hand in Hand to families in Pennsylvania who have a child who is eligible for the Deafblind Census. Please keep watching for further information. We are looking forward to seeing both familiar faces and new ones.

See you in June!

### Trainings

Would you like to receive electronic notification of upcoming Bureau of Special Education/PaTTAN training opportunities in the areas of Deafblind, vision, or deaf or hard of hearing? If so, e-mail Kim Fino at [kfino@pattan.net](mailto:kfino@pattan.net).

### Resources

Listed below are resources with wonderful materials you might be interested in. Please check their websites for information on ordering from their catalogs.

AbleNet: [www.ablenetinc.com](http://www.ablenetinc.com)  
[www.enablemart.com](http://www.enablemart.com)

Adaptivation, Inc.: [www.adaptivation.com](http://www.adaptivation.com)

American Printing House: [www.aph.org](http://www.aph.org)

Ann Morris Enterprises, Inc.: [www.annmorris.com](http://www.annmorris.com)

Attainment Company:

[www.AttainmentCompany.com](http://www.AttainmentCompany.com)

Crestwood Communication Aides, Inc.:

[www.communicationaids.com](http://www.communicationaids.com)

Don Johnston: [www.donjohnston.com](http://www.donjohnston.com)

Enabling Devices: [www.enablingdevices.com](http://www.enablingdevices.com)

Harris Communications: [www.harriscomm.com](http://www.harriscomm.com)

Independent Living Aids, Inc.:

[www.independentliving.com](http://www.independentliving.com)

IntelliTools: [www.intellitools.com](http://www.intellitools.com)

Maxi Aids, Inc.: [www.maxiaids.com](http://www.maxiaids.com)

SoftTouch, Inc.: [www.softtouch.com](http://www.softtouch.com)



# Announcing.....

## New Research Project

### Outcomes for Children Who Are Deafblind After Cochlear Implantation

Teaching Research Institute at Western Oregon University was recently awarded a grant from the U.S. Department of Education to study the outcomes of cochlear implantation for children who are deaf-blind. The grant is funded under the Department's Steppingstones of Technology Innovation for Students with Disabilities program. The three-year research project will be carried out in collaboration with the University of Kansas, the Midwest Ear Institute/St. Luke's Hospital, and approximately ten state Deafblind projects including CA, KS, NE, NJ, NY, OR, PA, TX. The objectives include the following:

1. Compile demographic information on children who are deaf-blind who receive cochlear implants.
2. Identify a protocol of assessments to measure changes in auditory perception, language acquisition, communication, social interaction skills, and functional skills.
3. Develop a protocol to address four research questions:
  - a. Which children between the ages of 12 months to 12 years receive cochlear implants?
  - b. How does a cochlear implant impact auditory perception, social skills, communication, and language development?
  - c. How do age of implantation, severity of visual impairment, cognitive level, presence of additional disabilities, and length of time since implant impact outcomes of cochlear implantation?
  - d. To what degree do the intensity, duration, and quality of post-implantation rehabilitation services contribute to the positive or negative progress of a child who has received a cochlear implant?

For more information contact: Dr. Ella Taylor, Project Director, Teaching research Institute, 345 N. Monmouth Ave., Monmouth, OR 97361.  
Phone: 503-838-8589. E-mail: [taylor@wou.edu](mailto:taylor@wou.edu).

Reprinted from Deaf-Blind Perspectives, Fall 2005

## Gilles Estate Fund For Individuals Who Are Deafblind

The Gilles Estate Fund was established from a bequest given to the Associated Services for the Blind & Visually Impaired, ASB, located in Philadelphia, PA by the estate of Rosalie Gilles. The funds are used to provide adaptive devices for individuals who are Deafblind.

Through ASB, this program can provide limited funding to support individuals who are deaf-blind with their specific personal needs.

This funding can be used for such devices as mobility canes, amplifiers, hearing aids, vibrating watches, and recording devices. Other adaptive aids are also available to help assist an individual in day-to-day activities.

For more information or to apply for financial assistance call (215) 627-0600, ext 3297, or visit ASB's website at [www.asb.org](http://www.asb.org).

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## DB-Families-PA Listserv

Would you like to converse with other families of children with Deafblindness all over the state of PA? Now you can! Join our PA Deafblind listserv. This listserv is for families and guardians with children and youth who are deafblind in hopes to share information and support for one another.

If you are interested in joining the listserv as a member, please contact Patti McGowan at [pmcgowan@pattan.net](mailto:pmcgowan@pattan.net). Just send your name and e-mail address and you too will be a member.

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## Braille Print Books

BrailleInk is a new company that publishes existing popular children's books in a new format that makes the books easier to share between braille and print readers. Their first titles are "Guess How Much I Love You" with uncontracted braille and "The Dot" with contracted braille. Braille readers' hands don't cover the print and illustration, and it's easy for anyone to tell what the braille says. The books are board books, with the braille embossed directly on the pages, and include a braille glossary at the back.

Sample pages and other information about the books as well as information about how to place an order is available at [www.brailleink.org](http://www.brailleink.org).

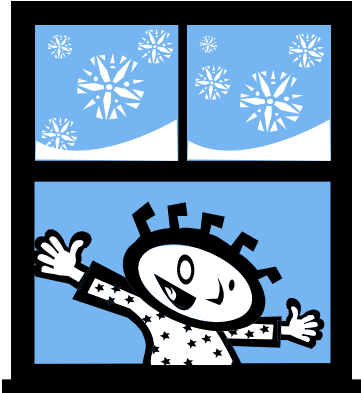
# CALLING ALL KIDS...

Do you have a short story, poem, joke, riddle or rhyme? How about an awesome drawing or fun photo to share? Submit them to KID'S CORNER, and your art work, writings, or pictures may be featured in the KID'S CORNER next newsletter. We would love to hear from you!

Please Submit Articles/Items by email to: [pmcgowan@pattan.net](mailto:pmcgowan@pattan.net)

Submissions can also be mailed to:

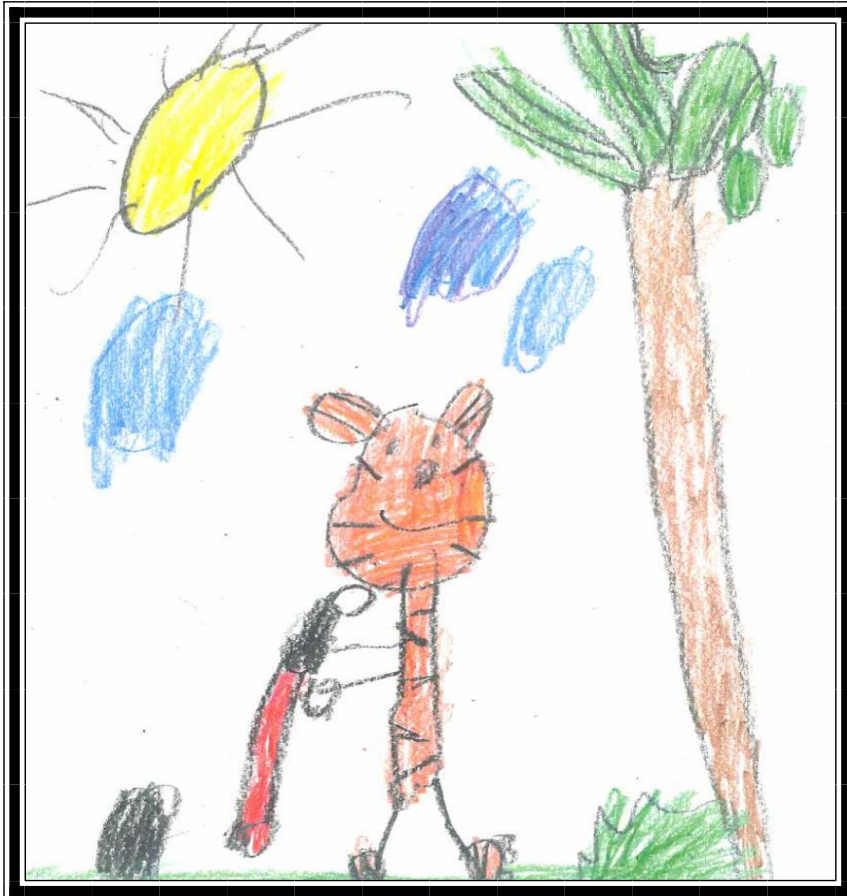
Patti McGowan  
12031 Blair Lane  
North Huntingdon, PA 15642



## Featured Author & Illustrator: Hunter McGowan

Hunter McGowan is a nine-year-old student attending the DePaul School for Hearing and Speech in Pittsburgh. He has been diagnosed with Ushers II Syndrome, which has left him both hearing impaired and legally blind. He wrote his story in both print and Braille so that all of his friends could enjoy it.

### The Case of the Missing Braillewriter By Hunter McGowan



There once was a tiger named Louie. He was very strong. He liked to type braille and use a cane to travel through the jungle. He had a secret place to practice his braille. The place was the library. The library had many books and he loved books. When Louie was sleeping, something happened. A black panther named Midnight stole Louie's braillewriter. When Louie woke up, he couldn't believe that his brailier was gone. He called the FBI. Louie was so sad. Soon the whole jungle knew that Louie's braillewriter was missing. Three of his friends, Hunter, Lauren, and Tiffany, decided to help him search for it. One day when they were on their way to the rainforest, they saw Midnight using the brailier. The kids shouted and Midnight ran off leaving the brailier behind. The three kids returned the brailier to Louie. He was so happy. Louie decided to have a party to thank them.

## The Staff of Hand in Hand

Kerri McCarthy  
Project Director

Juli Baumgarner  
Project Coordinator

Jackie Brennan  
Educational Consultant

Lauri Triulzi  
Educational Consultant

Molly Black  
Family Liaison

Patti McGowan  
Family Liaison

If we can be of assistance, please call Kim Fino at  
800-360-7282 (PA only) or 717-541-4960, ext. 3115, or email [kfino@pattan.net](mailto:kfino@pattan.net).



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HAND IN HAND  
PENNSYLVANIA TRAINING AND  
TECHNICAL ASSISTANCE NETWORK

6340 Flank Drive  
Harrisburg, PA 17112-2764