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# News From Advocates for Deaf-Blind

A Publication of the National Family Association for Deaf-Blind

## NFADB UPDATES

Linda Syler, President, NFADB



That buzzing sound you heard this winter was not being made by honey bees but by your NFADB Board. **At the end of the summer of 2010 we received notice that we had been awarded a TERP grant** (Training & Educational Resources Program at Perkins). The board met at HKNC (Helen Keller National Center) in November and spent 3 days discussing issues and dividing up their work assignments. If you have not checked out our website, please do so and notice the calendar of events, the link to Family Connect, the parent survey, and many more exciting additions. **We also welcomed 6 new board members:** Sheri Stanger, Veronica Castillo, Monica Quesada, Patti McGowan, Paddi Davies, and Edgenie Bellah. With the change in our by-laws, Paddi and Edgenie are the first 2 board members who are not parents of children with deaf-blindness but have experience in the field. We are happy to have all these additions to our board. To find out more about these new board members click on to our website and read over their bios.

In January NFADB **took part in a webinar that was sponsored by NCDB** (National Consortium on Deaf-Blindness). The webinar was for service providers including PTIs (Parent Training and Information Centers) and other agencies that work with individuals who are deaf-blind. NFADB now has a PowerPoint presentation on who we are and what we do. We will be sharing this PowerPoint at various conferences and trainings throughout the year.

**A survey with linkage to our website was made available to our parents in December 2010.** So far we have had response from 25 states and Puerto Rico. The responses are telling us those areas of concern that families are struggling with. They include communication with the individual with deaf-blindness, maintaining a sense of balance and well-being within the family, the impact on siblings, and many others. Your board will be looking at ways to address these needs using various social media. There is little doubt that many issues deal with the quality of life not only for the individual with deaf-blindness but also for their family. We greatly appreciate those of you who took the time to fill out this survey.

**During 2011-12 NFADB will sponsor a symposium for families of individuals with deaf-blindness!** We will be using the results of the survey in selecting a topic or topics for this activity. More information will become available in the coming months. Please check out our website and Listserv for further information. A committee is already hard at work planning for this exciting event. We hope that this activity will become a regular occurrence for NFADB.

**The National Family Association for Deaf-Blind sits on the Executive Committee for the National Coalition for Deaf-Blind.** We have been active in the discussions and support of the Coalition's comments on that portion of the 21<sup>st</sup> Century Communication and Video Accessibility Act that provides up to \$10 million to assist individuals who are deaf-blind. We thank those parents who signed on to support the Coalition's comments.

**Read over our newsletter and find out how to join us on Facebook and be an active member of your organization.** Our website and listserv will help keep you up to date on what is happening with NFADB and the world of deaf-blindness. Don't forget to look for further information on our symposium. ♥

## THE NATIONAL FAMILY ASSOCIATION FOR DEAF-BLIND (NFADB)

SUPPORTING PERSONS WHO ARE DEAF-BLIND AND THEIR FAMILIES. A non-profit national family organization established in 1994. The philosophy of the Association is that "Individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of the community."

### NFADB EXECUTIVE COMMITTEE

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Vice President

**Cynthia Jackson-Glenn**  
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**Susan Green**  
Secretary

### BOARD OF DIRECTORS

**Edgenie Bellah - Texas**  
512-563-3676  
Bellahbunch@yahoo.com

**Patti McGowan - Pennsylvania**  
724-989-4640  
pmcgowan@pattan.net

**Veronica Castillo - Arizona**  
602-454-7692  
Bunnycast@aol.com

**Monica Quesada - Puerto Rico**  
787-315-3411  
itziamonique@gmail.com

**Paddi Davies - Oregon**  
503-838-6408  
daviesp@wou.edu

**Sheri Stanger - New York**  
914-478-7248  
SheriME@aol.com

**Erma Hill -Virginia**  
804-282-0239  
Hill2C@aol.com

**Blanche Stetler - New Jersey**  
732-721-5448  
JTMommy@aol.com

**Pearl Veesart - California**  
805-528-5673  
pearlve@sbcglobal.net

**International Liaison**  
**Clara Berg - New York**  
718-428-1591  
Clara.Berg@qc.cuny.edu

**Lori Bookstaver**  
**Administrative Assistant**  
800-255-0411  
mfnfadb@aol.com

**Special Advisors** - Betsy McGinnity, Kathy McNulty, Nancy O'Donnell

**Newsletter Editor** - Lori Bookstaver

**Editorial/Technical Support** - Allison Burrows, Nancy O'Donnell

Please address all correspondence to: **NFADB Newsletter Editor, 141 Middle Neck Road, Sands Point, NY 11050-1299. Voice/TTY: (8:00 a.m. - 3:45 p.m., EST) 800-255-0411; Fax: 516-883-9060; E-mail: NFADB@aol.com**

This newsletter supports "person first" language. All submitted articles will be edited accordingly. This publication is supported in part by the Helen Keller National Center, Sands Point, NY, and the Hilton/Perkins Program of Perkins School for the Blind, Watertown, MA. The Hilton/Perkins Program is funded by a grant from the Conrad N. Hilton Foundation of Reno, Nevada. Opinions expressed in the newsletter do not necessarily reflect the opinions of NFADB, HKNC or Hilton/Perkins. Newsletter is available in braille, large print or electronically upon request. NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. ♥

## A Webinar? What's a Webinar?



*By Sheri Stanger*

So if you asked me last year about the definition of a webinar, I'm not sure I could give a coherent answer. Fast forward to this year and I had the experience of presenting on a webinar through the National Consortium on Deaf-Blindness (NCDB). For those of you who have not experienced a webinar, it is an economical way to convey a message to many people at once. Webinar is short for **Web**-based seminar. It is an interactive presentation, lecture, workshop or seminar that is transmitted via the Web. The interactive nature of a webinar distinguishes itself from a Webcast where data only flows one way. More and more, organizations and universities are hosting webinars to reach a broader audience without spending money on travel. A webinar can reach people in their homes and offices and is a great "distance learning" tool.

A webinar is similar to a conference call because people dial in to a webinar with their phone. However, with a webinar you also log onto a website where you can see the presenter in real time along with the documents they are discussing. You can also ask questions via voice or by typing your message in a message box on your screen. Webinars can be a collaborative experience with just a few participants or many. And webinars can be recorded and archived for future viewing. If you have the opportunity to experience a webinar, I highly recommend it. Please visit NCDB's website at [www.nationaldb.org](http://www.nationaldb.org) to see a listing of upcoming and archived webinars for parents and professionals. You can also see a listing of upcoming webinars posted in this newsletter. ♥

## COMMIT TO NFADB



NFADB has several areas of activities that help keep the organization viable. We welcome your participation in any of these following areas. Please contact our main office at 800-255-0411, if you would like more information about these activities and/or are interested in lending a helping hand. Thank you.

**MEMBERSHIP**

**AFFILIATION**

**NEWSLETTER**

**FUNDRAISING**

**WEBSITE**

**LISTSERV**



## What is NFADB?

The National Family Association for Deaf-Blind is an organization that has been supporting individuals who are deaf-blind and their families for over sixteen years. We would like to invite all families, consumers and professionals to become a member of this incredible organization.

## Our Mission Statement

NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs.

## Our Fundamental Beliefs

NFADB believes that individuals who are deaf-blind are valued members of society and are entitled to the same opportunities and choices as other members of their community.

## We offer support in a variety of ways:

- A toll-free number (answered by a real person) that connects families and others to resources and one-to-one support
- Current information and national updates delivered through a bi-annual newsletter
- Online resources and support through our website and Facebook page
- A member listserv that connects you by email to hundreds of other members

In addition, NFADB connects you to a much larger network of support. We represent families on the *National Coalition on Deaf-Blindness* by providing a unified voice on national issues related to deaf-blindness. We continue to expand and support a national NFADB Affiliate Network that supports state parent groups as they develop and grow. We can also help families access the services of the state deaf-blind projects, the *National Consortium on Deaf-Blindness*, the *Helen Keller National Center* and the *American Association of the Deaf-Blind*.

## How Can You Become a Member of NFADB?

We offer three membership options for families and professionals. Each membership is a household membership and includes all family members living at one address.

One year: \$15

Three years: \$35

Lifetime: \$100

Please take the time to join NFADB today. Together we can work to make a difference in the lives of individuals who are deaf-blind.

***For questions, please call Lori at 1-800-255-0411 or NFADB@aol.com ♥***





# NFADB Membership Application

Information about you		
Name(s):		
Address:		
City:	State:	Zip:
Phone:	Email:	
Information about the individual who is deaf-blind		
Name:		Birthdate:
Relationship to you:		
Cause of deaf-blindness:		
Information about your membership		
<i>(Click on the boxes to select)</i>		
Please select your choice of membership.		
1-year - \$15	3-year - \$35	Lifetime - \$100
I give permission to use my email address to sign me up for the NFADB listserv.		
Yes	No	
I give permission to share my name with other families who have a family member with similar etiologies, disabilities or challenges.		
Yes	No	
How would you like to receive your NFADB newsletter?		
Email	Regular mail	
Would you like materials in:		
Large print	Braille	Spanish

Please make checks payable to NFADB and  
return your membership application and payment to:

NFADB Membership  
141 Middle Neck Road  
Sands Point, NY 11050-1129

*For questions, please call Lori at 1-800-255-0411 or NFADB@aol.com*





## TRAINING & EDUCATIONAL RESOURCES PROGRAM (TERP)

SUBMITTED BY BETSY MCGINNITY

The Training & Educational Resources Program at the Perkins School for the Blind has developed a series of webcasts that may be of interest to families and professionals. We currently have 18 webcasts on a variety of topics including three on CHARGE Syndrome; two with Barbara Miles on Conversations and Hands and Touch; early literacy, mealtime skills and more. Perkins posts a new webcast every month. <http://www.perkins.org/resources/webcasts/> We have also introduced two new publications, Making Science Accessible and Communication and Congenital Deafblindness Booklet Series from the Netherlands. <http://www.perkins.org/resources/educational-publications/>

In the coming months, we will post webcasts on Good Sleep Strategies and Tangible Symbols. We have also filmed two webcasts with Jan van Dijk. Also coming soon is a new series of booklets developed with the New Jersey Statewide Parent Advocacy Network on Deafblindness: Educational Service Guidelines Companion Materials for Families. This collection of resources is designed to help parents advocate for effective services to meet the needs of their child who is deaf-blind. Topics include early intervention services, the evaluation process for children who are deaf-blind, checklists for Individualized Education Program (IEP) meetings, appropriate public education options, the transition to adult life and more. Contacts for additional information and support are also included. ♥

*Join the  
Conversation!!*



### Buenas Noticias!!!

Un cordial saludo a todos nuestros amigos de habla hispana en los Estados Unidos. Mi nombre es Mónica Quesada, y formo parte de la directiva de la N.F.A.D.B., y para mí, y mis compañeras, será más que un placer ayudarte y servirte siempre. Y es por esa razón que nos llena de júbilo informarte que ahora en la N.F.A.D.B., hablamos español. Si... en la N.F.A.D.B., seguimos creciendo y por eso que te invitamos a que te unas y hagamos la diferencia, no solo para nuestros niños sino también para los que vienen.

La Asociación Nacional de Familias para Sordo-Ciegos (N.F.A.D.B.) ha estado ayudando y apoyando a individuos sordociegos y a sus familias, por más de dieciséis años. Si tienes preguntas o dudas, solo debes comunicarte con nosotros a nuestra página "web" o a través de "Facebook" y sin duda te contestaremos a la mayor brevedad posible. Si aun no eres miembro de nuestra asociación... ¿Que esperas? Se parte de nosotros y ayúdanos a seguir caminando en pro de nuestros niños, adolescentes y adultos con sordoceguera. Si deseas obtener más información sobre como unirse a nuestra asociación solo comunícate con nosotros y te haremos llegar la información, en español, al instante. Recuerda la N.F.A.D.B. está aquí para ti y tu familia... ¡juntos haremos la diferencia. ♥

Mónica I. Quesada  
N.F.A.D.B. Board Member

The screenshot shows the Facebook mobile app interface. At the top, there's a blue header with the Facebook logo. Below it, there are input fields for Email and Password, a 'Login' button, and links for 'Keep me logged in' and 'Forgot your password?'. On the left, there's a section titled 'Heading out? Stay connected' with a subtext 'Visit facebook.com on your mobile phone.' and a 'Get Facebook Mobile' button. On the right, there's a 'Sign Up' section with the text 'It's free and always will be.' followed by input fields for First Name, Last Name, Your Email, Re-enter Email, and New Password. Below these are dropdown menus for 'I am:' and 'Select Sex:', and a 'Birthday:' section with dropdowns for Month, Day, and Year. A link 'Why do I need to provide this?' is below the birthday section. At the bottom of the sign-up section is a green 'Sign Up' button and a link 'Create a Page for a celebrity, band or business.'

English (US) Español Português (Brasil) Français (France) Deutsch Italiano العربية 中文(简体) 日本語

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## AFFILIATE UPDATE

### Pennsylvania Partnership for the Deafblind (PPDB)

*submitted by Gordon Boe, President, PPDB*



The Pennsylvania Partnership for the Deafblind (PPDB) will be awarding the Noah Blake Radzik Memorial Scholarship this spring. The scholarship, which will be up to \$500, represents our effort to highlight and recognize the contributions made by the brothers and sisters of our children with deaf-blindness.

To be eligible for consideration, an applicant must be: 1) a sibling of a person who is deaf-blind; 2) a resident of Pennsylvania; 3) a member of PPDB (or if under 18, the family must be members); and 4) either registered or accepted as a full-time student at an institution of higher education/trade/business school for the fall of 2011.

The scholarship recipient must agree to give a presentation to a group within his/her home community. A one-page essay giving the highlights of the intended presentation shall accompany the application. The presentation can be on one of two topics: 1) how having a sibling who is deaf-blind has affected the applicant; or 2) the effects that deaf-blindness has had on the applicant's sibling and family. The recipient will work with a PPDB Board member on developing the presentation.

The award is established in memory of Noah Radzik, who was deaf-blind. Noah's mother, Linda, has written the following: "Noah Blake Radzik was a child with wavy brown hair and brown eyes. Although he was born with many challenges, including deaf-blindness, Noah did have some hearing and vision, and seemed to prefer the color green. This led to Noah's large collection of frogs, and eventually to be called our 'little green frog.' Then one night, at only 7 years old, our frog was kissed by an angel and became a prince, living in the home of the King. However, he left many family and friends behind, and so we have created this scholarship to keep his memory alive."

PPDB will feature the winner on its website and in its updates to members. ♥



### New York Parent Network

*By Barbara Loughran*

New York Parent Network welcomes a new board for 2011. Our Board Members include Barbara Loughran (President), Clara Berg (Family Specialist), William Grimes (Treasurer), Mary Conlon (Advisor), Evelyn Popper (Newsletter Editor), Brent Bailer (Outreach), Suzanne Chen (CHARGE Facilitator), and Antionette Salierno (Usher Facilitator). We will be meeting with Kathy McNulty, our Professional Consultant, to review our goals and priorities for the upcoming year.

NYPN publishes our printed newsletter twice a year, and sends *NYPN e-news* twice a month to inform families of events, webinars, articles, and things of interest in New York.

New York Parent Network sponsors monthly conference calls for our support groups: Usher Syndrome, Cornelia de Lange Syndrome, and Spanish speaking families. Our newest support group is for families of children with CHARGE Syndrome. One of the participants, Sheri Stanger, will be familiar to NFADB and CHARGE Foundation members.

NYPN and New York Deaf-Blind Collaborative (NYDBC) co-sponsored a Communication Conference at Queens College last fall. The presentation by Samuel Morgan, NYDBC Director, focused on the Communication Matrix by Char-ity Rowland.

NYPN will be participating in Lord & Taylor's "SHOP SMART - do good!" Fundraiser at the Garden City, NY store on April 12. We encourage all New Yorkers to come!

NYPN will sponsor an *Orientation & Mobility Workshop for Families* at the Helen Keller National Center on Sunday, June 12, 2011 with a presentation by Dr. Eugene A Bourquin, DHA, COMS, CI & CT, CLVT. NYPN is very grateful for our support from HKNC.

Visit our website: [www.nypn.net](http://www.nypn.net) for more information about NYPN Activities. We hope to offer more activities and welcome new members in the year ahead. ♥



## NYPN e-news

*Supporting Families of People who are Deaf-Blind  
Or Visually & Hearing Impaired*

### Professional Trainings in Deaf-Blindness Spring 2011

[www.nypn.net](http://www.nypn.net)

#### DEAF-BLIND TRAINING, INTERPRETING & PROFESSIONAL DEVELOPMENT ONLINE WEBINAR SERIES

Website: <http://www.deafblindtip.com>

Contact: [DeafBlindTIP@gmail.com](mailto:DeafBlindTIP@gmail.com)

Level 2: "Deaf-Blind Interpreting Strategies: Modifications". Five individual 90-minute sessions will be held from 11:00AM - 12:30PM EST. The dates and topics are below:

- 1/22/11: Deaf-Blind Interpreting:  
General Modifications
- 1/29/11: Interpreting Modifications:  
Close Vision
- 2/5/11: Interpreting Modifications:  
Reduced Peripheral Fields
- 2/19/11: Interpreting Modifications: Tactile
- 3/5/11: Describing Visual Information

You can choose to join the live sessions above or register to view the sessions at your convenience. The Deaf-Blind Interpreting Strategies Online Webinar Series is an online learning platform geared towards the professional development of **interpreters, interveners, teachers, related service providers & families.**

#### NYDBC Webinars:

- ☐ *New York Deaf-Blind Collaborative - Intervenors: Appropriate Intervention for Learners who are Deaf-Blind in New York State* 02/08/2011 03:00 PM
- ☐ *The Use of Systematic Instruction to Achieve Sensory Skill Acquisition for Learners who are Deafblind* 02/17/2011 03:00 PM
- ☐ *New York Deaf-Blind Collaborative - Transition Planning for Young Adults who are Deaf-Blind in New York State* 03/08/2011 03:00 PM Go to Public Sessions Page:

[https://tadnet.ilinc.com/perl/ilinc/lms/event.pl?div\\_view=reg&event\\_user\\_id=](https://tadnet.ilinc.com/perl/ilinc/lms/event.pl?div_view=reg&event_user_id=)

Check the Webinar(s) you are interested in to Register.

#### On-Line Graduate Certificate in Deafblindness and On-Line Deafblind Intervener Certificate Program

East Carolina University (ECU) offers 2 Certificate Programs in Deafblindness.

Both Certificate programs are taught online and are accessible to anyone across the state and the country. Both include practica with support via e-supervision.

[www.ecu.edu/cs-educ/ci/sped/dbproject/DB-Intervener-Certificate.cfm](http://www.ecu.edu/cs-educ/ci/sped/dbproject/DB-Intervener-Certificate.cfm)

Contact: Mary W. Schmidt, PhD, Coordinator, Deafblind Certificate Programs [schmidtma@ecu.edu](mailto:schmidtma@ecu.edu)

#### National Consortium on Deaf-Blindness Webinars

<http://nationaldb.org/ISFutureWebinars.php>

**NCDB Webinar: Network Supports & Resources for Families** Archived Recording: <http://nationaldb.org/NCDBProducts.php?prodID=124>

#### *The Use of Cochlear Implants and their Impact on Children who are Deaf-Blind: Research Findings and Implications*

Presented by Kat Stremel and Mark Schalock, Influencing Outcomes for Children Who Are Deaf-Blind with Cochlear Implants Project Wednesday, March 16, 2011, 10:00 AM - 11:30 AM Pacific

This webinar described the presenters' current studies on the use of cochlear implants with children who are deaf-blind and provided information to help service providers gain an understanding of appropriate and realistic outcomes when working with a child who has

*(Continued on page 8)*

a cochlear implant.

***NCDB Web Tour: Focus on Families***

Presented by Gail Leslie and Peggy Malloy, NCDB Wednesday, March 30, 2011, 10:00 AM - 11:30 AM Pacific

This webinar will provide an overview and virtual walk-through of the extensive array of resources available on NCDB's website, as well as those available through NCDB's DB-LINK Information Services.

***Customized Employment Strategies for Students who are Deaf-Blind***

Presented by Mike Fagbemi and Jon Harding, NCDB, and invited colleagues Wednesday, April 13, 2011, 10:00 AM - 11:30 AM Pacific

This webinar will highlight findings and strategies resulting from NCDB's Transition Focus Group specifically as they relate to customized employment for young adults with deaf-blindness. In addition, customized employment activities conducted by several state deaf-blind projects will also be shared.

***Increasing Highly Qualified Educators to Serve Children who Are Deaf-Blind***

Presented by Ms. Linda Alsop, Director, Project STRIPES; Dr. Christina Reagle, Helen Keller Fellows Project; Dr. Kathleen Huebner and Dr. Brooke Smith, National Leadership Consortium in Sensory Disabilities

Wednesday, May 18, 2011, 10:00 AM - 11:30 AM Pacific

This webinar is intended to increase awareness of educational opportunities for para-professionals and teachers of children who are deaf-blind and inform state deaf-blind project personnel about new leadership training opportunities in the field of deaf-blindness. Three OSEP funded personnel preparation and leadership training pro-

grams will be highlighted—the Helen Keller Fellows Project, the National Leadership Consortium in Sensory Disabilities, and Project Stripes.

***Helen Keller National Center for Deaf-Blind Youths and Adults National Training Team Professional Development for Employment Training Specialists***

Helen Keller National Center for Deaf-Blind Youths and Adults National Training Team, 141 Middle Neck Road, Sands Point NY 11050

***Orientation & Mobility***

***Expanding the Curriculum for Travelers Who Are Deaf-Blind***

Helen Keller National Center, 141 Middle Neck Road, Sands Point NY 11050

Website: [www.hknc.org/FieldServicesNTT.htm](http://www.hknc.org/FieldServicesNTT.htm)

Contact; Doris Markham, Administrative Assistant, NTT, (516) 944-8900 ext. 233/239, TTY: (516) 944-8637, Fax: (516) 944-7302, [doris.markham@hknc.org](mailto:doris.markham@hknc.org)

This is a 2-part hybrid course

Online portion: April 27-May 6, 2011

Onsite at HKNC Headquarters, NY:

May 16 - 19, 2011

Registration Deadline - Friday, April 22, 2011, 4-day Seminar Cost - \$500

The standard techniques of orientation and mobility were designed for persons who were blind and hearing. The modifications and adaptations of these techniques are the challenge of the O&M Specialist working with consumers who are deaf-blind. This seminar includes strategies for curriculum modifications, communicating with the public, effectively working with interpreters, and street crossing techniques for travelers who are deaf-blind. An overview of the deaf-blind population and insight into deaf-blind culture will be explored. The participants will acquire the tools, strategies, and resources needed to teach a comprehensive O&M program to deaf-blind adults. CEU credits and Certificate of Completion are available.

(Continued on page 9)



## **Perkins Training Center Schedule in NEW YORK STATE**

### **Weekend Assistive Technology Workshops for Personnel who Work with Students who are Blind or Visually Impaired**

Weekend workshops at Dominican College will continue this spring and offer professional development opportunities for Teachers of the Visually Impaired and other vision educators. Located in Rockland County, NY, the workshop sessions will be scheduled on Saturday from 9:00-3:30 and Sunday from 9:00-2:30. Accommodations are available at a Holiday Inn, within walking distance of campus. All dates are to be determined. This spring's schedule will include:

**Functional Vision Assessment:** April 2-3, 2011 The Functional Vision Assessment workshops will address: the components of visual functioning, how to prepare for the assessment, conducting the assessment – materials and approaches appropriate for different populations and different ages, creating your own FVA kit, documenting findings, and making recommendations. This workshop will be lead by Dr. Rona Shaw, Dominican College & Darick Wright, M.A., COMS, CLVT, Coordinator of the New England Eye Clinic at Perkins School for the Blind, Adjunct Faculty at UMass-Boston, and Adjunct Assistant Professor of Vision Rehabilitation at the New England College of Optometry, and other experts in low vision assessment.

**EBooks:** April 16-17, 2011 The Ebook workshop will address: legislation and technology enabling use of ebooks for students who are visually impaired; comparing available software and hardware- how to determine which device will meet your student's needs; application to IEP- how to incorporate ebooks into the curriculum for students who are visually impaired. This workshop will be lead by Dr. Richard Jackson, Boston College and Dr. Rona Shaw, Dominican College.

**JAWS - Intermediate Level:** May 7-8, 2011 Ryan Jones, Freedom Scientific and Tina Perretti, NY Institute for Special Education, Bronx, NY, will conduct this 2-day workshop on JAWS. The training will provide an intensive immersion experience that enables participants to enhance their teaching of JAWS.

[www.perkins.org/resources/training-conferences/trainingcenter/schedule.html#parent/professional-series](http://www.perkins.org/resources/training-conferences/trainingcenter/schedule.html#parent/professional-series)

### **New Professional Training Opportunity: Watch Perkins Webcasts and Earn ACVREP Credits**

ACVREP certified professionals are required to renew their certification every five years. Now you can earn ACVREP credits simply by viewing Perkins webcasts and completing a short questionnaire confirming your participation. All you need to do is watch three educational webcasts at your own convenience, complete the test, and print your certificate.

[https://secure2.convio.net/psb/site/Ecommerce?store\\_id=1641](https://secure2.convio.net/psb/site/Ecommerce?store_id=1641)

This information is also posted on New York Parent Network's Website [www.nypn.net](http://www.nypn.net) Newsletters & e-news page, "Professional Trainings in Deaf-Blindness Spring 2011" ♥



## Research on Cochlear Implantation for Children Who Are Deaf-Blind

**Kathleen Stremel Thomas**

***Director, Children Who Are Deaf-Blind with Cochlear Implants Project***



As cochlear implantation has become more common for children who are deaf-blind, research to learn about the effectiveness of implants for this population of children is essential. The Children Who Are Deaf-Blind with Cochlear Implants Project was created to begin to address this need by conducting research that will advance knowledge of cochlear implantation for children with deaf-blindness and help families make informed choices about cochlear implants for their children. The project, funded by the U.S. Department of Education, brings together the expertise of three agencies: the Teaching Research Institute at Western Oregon University, Cincinnati Children's Hospital Medical Center, and East Carolina University. The researchers have been assisted by numerous state deaf-blind projects that have helped locate families who are interested in participating.

Currently, there are approximately 105 children from 22 states involved in the study. All have severe to profound sensorineural hearing loss, vision loss, and often other disabilities. The children are evaluated for speech and listening skills as well as overall communication ability and language development. The research project is in its third year and so far we have found that the progress made by children after implantation varies greatly from very little progress at all, to an ability to detect environmental sounds, to clear speech with complex sentences. For many, we have seen cochlear implant technology have a tremendous impact on their development and quality of life.

Factors that appear to impact how much progress children make include the severity of any cognitive delay, the age at which the child received the implant (with earlier being better), and the length of time a child has had the implant. Of these, cognitive delay seems to have the most influence. As children receive implants at younger ages and wear them for longer periods of time, we anticipate that we will see more positive outcomes.

Based on what we have learned so far, we feel that the majority of children who have received cochlear implants have the potential to make progress, but they need intensive individualized programs that focus on developing listening skills and that take a child's visual, motor, cognitive, and social skills into consideration. The following are some strategies that families can use to promote listening skills in children who are deaf-blind and have cochlear implants.

Make sure your child wears the implant as much as possible. Ideally this should be whenever the child is awake. For every hour that he or she does not wear the implant, potential progress is lost.

Talk directly and often to your child (watch less TV!).

When you talk to your child, do it at a close distance, not from across the room.

Give your child toys that make sounds, not just toys with vibration and light.

When communicating with your child, always lead with a spoken word. Follow this with touch cues, gestures, or signs if needed, and then end with the spoken word again. This is known as an "auditory sandwich."

Provide frequent opportunities for "listening" during routine activities.

Take the child to have the implant "mapped" frequently.

Please visit our website at [www.kidsdbci.org](http://www.kidsdbci.org) to access updates and resources.

Funded by the U.S. Department of Education, Office of Special Education-Technology and Media Services for Individuals with Disabilities (CFDA 84.327A). Grant H327A080045; Project Officer, Maryann McDermott. Opinions expressed within are those of the project/author and do not necessarily represent the position of the U.S. Department of Education. ♥

## LABELS AND PERSPECTIVE



Elisa Sanchez Wilkinson - [elisasw@salud.unm.edu](mailto:elisasw@salud.unm.edu)  
505-272-8195 (work) 5500203-8125 (cell)

The tendency to treat others differently, usually less kindly, is what is referred to as stigmatizing. A stigma is the labeling of a person with a descriptive name into which that person can be categorized. For example, a child who has trouble reading will be labeled “illiterate” or “learning disabled.”

Stigmas and disabilities are all a matter of perspective. A person’s self worth can be undermined if they are labeled as having a disability. The words *marked* and *markable* refer to whether a disability has outward signs that the disabled person can conceal in order to escape the effects of being stigmatized. This would be referred to as “passing.” A person with a disability is going to disclose little about their disability if it is possible to pass as normal.

In the cases of people whose disability cannot be hidden, norm ambiguity will be an issue that may have to be dealt with. Norm ambiguity is the reaction from others who do not know how to talk or associate with a disabled person. Their conversations may be stilted or monitored. Their behaviors may become very formal and very polite, reflecting a fictional acceptance, which is superficial. It is possible that people will ignore a person with a disabled DISABILITY simply because of these feelings of norm ambiguity and ambivalence. This tends to leave the person with the disability evaluating his/her relationships with others. It may lead people with disabilities to associate with others who share their disability. This, of course, is if the individual with the disability has the cognitive ability to understand they are being stigmatized.

There are three effects of stigmatizing. The first is objective consequences. This refers to the direct impact of the condition itself. It effects the education, employment, and activity restrictions for the person who is disabled. The second effect is the psychological asymmetry in relating to others, also known as interpersonal consequences. The person who is disabled may feel looked down upon by those around him/her. Then there are the psychological consequences. The feeling of being different is the third effect of stigmatizing.

*Stigmatizing and labeling can have lasting effects. Children who are labeled may have more difficulties developing and maintaining relationships when they become adults.*

It is all a matter of perspective. When viewing a fine piece of artwork, a person may notice the artist’s brushstrokes gives texture to the painting. Another onlooker may notice the gentle hues and tones giving the piece warmth. A third person may step back and take heed of the use of light and shadow. All three have seen the same masterpiece, yet each person sees something different.

I work with families who have a child or children with a disability. I am also a mother of two kids, one with disabilities. When talking with other moms, one of the common fears expressed is that our children will have to live with labels and preconceived ideas about their abilities. Stigmas can be damaging and difficult to overcome. I am aware of this because of the first hand experience with disabilities and stigmas my son and our family has had to face.

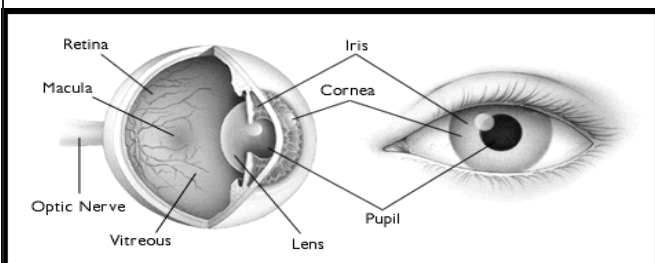
My son is dual sensory impaired. He is on the national census for individual’s birth through 21 with deaf-blindness. He also has a below the knee amputation due to a medical procedure done to save his life after he was born. People do not know about his amputation until he wears shorts in the summer. We have a picture of him at the beach. It is his favorite picture. Why? He says it is because in the water his prosthesis is unnoticeable.

Many people know he is hearing impaired because he wears hearing aids. He also has monocular vision. He sees out of one eye at a time. As one eye becomes fatigued, his brain switches to the other eye. No one knows how often this happens. He has adapted. It is a progressive loss. One day he will have no vision in one eye. He wears glasses, so many people are not aware of his vision issues, kind of an unconscious “passing.” He doesn’t move through his day telling everyone of his challenges. Yet, when people find out about his amputation, there is a tangible change in their reactions to him - norm ambiguity.

Even with all the challenges, my son, Joe, is working at or above grade level in school. His ACT score is 31. Academically, he has yet another label. He is smart. He deals with his stigmas everyday. He is too hearing to hang out with the deaf kids, he is too deaf to hang out with the hearing kids, and he has a prosthesis, which sets him farther apart. Yet, he is a masterpiece! People who know him, are awed by him. He is such a charming, sweet young man.

Looking at the glass as half full or half empty is one of many adages that express the positive and negative perspectives of differences in people’s opinions. Appreciation of things is subjective. Perception of art, of family, of career, of right and wrong...not everyone sees the same thing. Thank goodness for this. Some people could see my son as a deaf-blind amputee with little hope for a successful future. We see him as a young man with inner strength, intelligence, and sensitivity who has limitless options and possibilities.

Society has strange ideas and practices. People are not comfortable until they can put a label on something or someone, for example - popular or lame, learning disabled or ‘sweet.’ A long time ago there was a commercial by Tony Danza. He said, “How do you treat a person with a disability...like a person!” I have never forgotten that. ♥



## The Eyes Have It

compiled by Cynthia Jackson-Glenn, M.S., COMS,  
NFADB Treasurer

**Keratitis** is an inflammation of the cornea—the domed, transparent circular portion of the front of the eyeball that lies over the pupil. There are several types, including *superficial punctate keratitis*, in which the cells on the surface of the cornea die; *interstitial keratitis*, a condition present at birth; and *traumatic keratitis*, which results when a corneal injury leaves scar tissue.

### Causes

A wide variety of conditions can lead to inflammation of the cornea. Among them are viral, bacterial, or fungal infections; exposure to ultraviolet light such as sunlight or sunlamps; exposure to other intense light sources such as welding arcs or snow or water reflections; irritation from excessive use of contact lenses; dry eyes caused by an eyelid disorder or insufficient tear formation; a foreign object in the eye; a vitamin A deficiency; or a reaction to eye drops, eye cosmetics, pollution, or airborne particles such as dust, pollen, mold, or yeast. The condition is also a side effect of certain medications.

### Signs/Symptoms

Keratitis usually makes the eyes very painful and watery, bloodshot, and sensitive to light. The condition is often accompanied by blurred or hazy vision.

### Care

Treatment depends largely on the source of the problem. If a virus is at fault, the condition is likely to clear up on its own, usually in about two to three weeks. Available medications for this form of keratitis include antiviral eye drops. In some cases, the doctor may gently swab or scrape the cornea to remove dead and damaged cells. Pain medications and an eye patch to prevent light from causing further irritation are often prescribed to speed recovery and provide relief from discomfort.

### Risks

Depending upon the cause and severity of the keratitis, the risks run the gamut from no lasting harm to total blindness. However, most people recover from keratitis fully, and the few who do experience some degree of visual impairment can have the condition corrected with surgery or a corneal transplant. The sooner medical attention is sought, the greater your chances of complete recovery.



## UPCOMING EVENTS....



**HKNC**  
**Helen's Walk**  
RAIN OR SHINE  
Sunday, May 1st

**Sands Point Preserve**  
**Check-in & Registration**  
**8:00 am-9:00 am**  
**Official Start 9:15 am**  
**[www.hknc.org](http://www.hknc.org)**



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**Rosen Shingle Creek Resort July 28–31, 2011**  
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## “Mom, I talked to my friend the other day.”

*By Danielle Poscival, mother of a teen who is deaf-blind*

“Mom, I talked to my friend the other day.”

Intrigued I ask, “Who?” Already knowing the answer would be one of three teenagers he called friends. I had a pretty good guess which of the three it would be.

“Elizabeth.” He answered. I was right. I guessed Elizabeth; she's the only one of his three self-proclaimed friends NOT on the Autism spectrum, therefore the one most likely to initiate a connection.

“Oh, how is Elizabeth?”

“I don't know.”

“Well, what did you talk about?”

“The new firmware update that's coming out for my Bookport.” My son, Justin, like his other two friends, is on the spectrum. That's not his only barrier to making long lasting, genuine friendships. He's also deaf-blind. Justin's deaf-blindness is characterized by total blindness and a progressive hearing loss. Phone conversations are difficult for him with hearing aids, a fluctuating loss and questionable sound quality, but his need for interaction has helped him find ways to use the phone. Yet I question his so-called friendships. He feels his social life is fulfilling. I do not, but I'm learning to accept his social life for what it is - *his social life, not mine.*



As a mother I wanted for so long for my boy to relate to me and others the way my other kids did. I saw moms of kids who were blind and deaf-blind whose children tried to connect personally. I didn't feel like I had that with Justin. I saw lots of kids that were special, some I even considered more involved than Justin, seek out human contact, communication and conversation. They yearned for it, and I yearned for that connection for my son. If he wasn't going to be like the sighted kids, I wanted him to at least be like the blind kids and other special kids I saw that craved interaction with people. Justin just doesn't connect that way. He prefers to be alone, to not be touched and doesn't have many reciprocal conversations. I get hugs at Christmas, my birthday and when someone dies because he knows I like hugs - but he does not. Shaking hands with others, making their acquaintance, asking how they are doing makes absolutely no sense to his sensibilities.

*I get hugs at Christmas, my birthday and when someone dies because he knows I like hugs - but he does not.*

I brushed off the relationship he had with a kid from school. He'd known Kolton since fourth grade; they hardly ever spent time together outside of the school lunch room. Kolton was “quirky” and I was sure he was just being nice because he didn't notice Justin's differences as much as other kids did. Besides, when he and Justin did get together it was because his mom or I brought them together for a party or play date. Neither of them initiated the socialization. When they did get together, Justin talked incessantly about Furby's or computers and Kolton talked about his favorite subjects. They had parallel conversations. It didn't count as a friendship by my rules, so I negated the value of their relationship.

His second really good “friend” was born of a friendship I developed with the boy's mother, Anna. Anna's son, Joseph, is on the Autism spectrum and when I go to visit Anna I don't have to drag

*(Continued on page 14)*



Justin along. Anna's house is one of the few, *very few*, places Justin doesn't complain about going. For Justin that's a big deal, and I didn't pay attention to that fact for a while. See, Justin doesn't like to go anywhere really, unless food is involved. He is, in that sense, a very typical 14 year old boy. The boys will sit side by side on the couch, my son poised and working over his Braille Note, while Joseph is engrossed in his video game. They hardly talk to each other. Joseph has a special brother, too, and is more used to "guiding" and assisting Justin than most kids are. When they would go somewhere Joseph always guided Justin and Justin liked to 'go guide' (our name for sighted guide) with him. He usually opts for an adult to go guide with. I didn't 'count' the conversations they had during walks together...at first. They don't talk like I talk with friends and acquaintances. They talk about one, and only one, thing - computers. They never really call each other and they never really talk much together, and yet Justin claims Joseph as not just a friend, but a 'best friend.' It confused me. They weren't really friends, were they? That's not what friends do, is it? I talked to Joseph's mom and she said Joseph considered Justin a friend, too. If he thought Justin was his friend, and Justin thought they were friends, why was it so hard for me to accept?

Then there was Elizabeth. Sweet girl, comes from a big family and is one of the older kids in the group. She's been nice to Justin since pre-school when they first met. She's always been nice, talked to him, patiently and enthusiastically listened to him talk about his favorite subject. Sometimes he'd even tell me things about her, which meant she talked to him, as well as listened, and he paid attention. And yet, I tried to explain it away as anything but a genuine friendship. I'd think to myself that she was a nice girl and she was just being nice...but they couldn't be real friends. Other kids were nice to Justin, too, but they didn't call regularly to see what he was doing. Other kids had class with him but didn't walk to the car with him. If she said they were friends and he said they were friends, again, why was it so hard for me to accept?

And what about Kolton? Why couldn't they be friends? He did call last summer and invite Justin to the fair to see his goats. They walked around the fairgrounds together, talking about nothing but goats *and computers*. But Kolton wanted to be with Justin and they *were* socializing, even if it was a weird conversation. What about the teachers that remembered him and not only said 'hi' to him in the store, but stood there for several minutes listening to him talk about computers and asking him questions? What about his para-ed who has a swimming party for the VI kids in the district every summer, and who faithfully sends Justin cards on special occasions to keep in touch? Couldn't they be counted as friends and acquaintances? Why was it so hard for me to embrace the relationships Justin had as genuine and meaningful?

My answer....I was prejudiced. I had my own set of rules for "real" and valuable friendships. I wanted my deaf-blind son to have friends, and make friends like I did. I wanted him to follow the socially acceptable rules and "be the kind of friend a friend would like to have." To operate under the same set of social and cultural standards I did. But when I really stopped to think about his relationships, I had to come to terms with my own prejudices. It took me a long time to accept this. He's different than I am; he doesn't see, he doesn't hear well, he hardly talks about anything but computers. So why would I expect his social life to look like mine? And why *should it*? He treasures his friends and I do too, all of them. And I realize that there are many more than the three I used to question.

Deaf-Blind or not, Autism spectrum or not, Justin is a great kid and he has a rich social life. He's a pleasure to be around and he has lots of friends and acquaintances WHO know that. How many people feel like they have one truly genuine friend in life that they can share anything with...let alone three? He will have a full and meaningful life and part of what will make it so meaningful will be his social interactions. I know it will be a different sort of life than what I would consider a meaningful life. And I'm confident that just because it's different doesn't mean it's any less meaningful or fulfilling for him. More than all of that, Justin says he's satisfied with his social life. I know he's lucky on that part. ♥



## Commit to an NFADB Committee!



NFADB has several committees working behind the scenes all year. We welcome your participation on any of the following committees. Please contact the committee chairs, as indicated, or our main office at 800-255-0411, if you would like more information about the committees' activities and/or are interested in lending a helping hand.

### COMMITTEES & EXECUTIVE COMMITTEE (EC) LIAISONS:

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**Affiliate Coordinator:** Blanche Stetler e-mail: JTMommy@aol.com, ph: 732-822-3423; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

**Newsletter Coordinator:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.state.oh.us, ph: 513-504-8597.

**Fundraising Coordinator:** Vacant; **EC:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.state.oh.us, ph: 513-504-8597.

**Interpreter Coordinator:** Pearl Veasart e-mail: pearlve@sbcglobal.net, ph: 805-528-5673; **EC:** Cynthia Jackson-Glenn e-mail: Cynthia.jackson-glenn@rsc.state.oh.us, ph 513-504-8597.

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### Information about person who is deaf-blind

Name: \_\_\_\_\_

Birthdate: \_\_\_\_\_

Relationship to you: \_\_\_\_\_

Cause of deaf-blindness: \_\_\_\_\_

I give permission to share my name with other families whose children have similar etiologies or disabilities.

- ☐ Yes ☐ No

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