



# News From Advocates for Deaf-Blind

A Publication of the National Family Association for Deaf-Blind

Volume 11 Issue 2

FALL 2007

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## President's Report A BUSY TIME FOR NFADB

by Linda Syler, President, NFADB

This has been a busy time for NFADB. In July the NFADB Board met at Overbrook School for the Blind for their board meeting. As you may know



we have under gone some changes in the committee structure. The **National Issues Committee** reported out on their survey regarding adult transition. The committee is very excited

about the response from the surveys and how it can help our family members with deaf-blindness. Check out this newsletter for more information on this survey.

The **Legislative Committee** will be working closely with Betsy McGinnity of the National Coalition on Deafblindness ([www.dbcoalition.org](http://www.dbcoalition.org)). Janette Peracchio is our liaison to the Coalition. Our Communication Committee is working on giving the newsletter a new look and bringing information to you that will be helpful and meaningful. Please let us know what you would like to see in your newsletter. It is planned to give you an option to either receive your issue through the mail or electronically. Our website will soon have a new look - easier to use and more informative. We need to get information to you in as many ways as possible.

The meeting at Overbrook was our final meeting for the 2006-07 planning year and I would like to recognize

some individuals for all the extra time they gave to me and NFADB this past year. Do to the sudden death of my husband last year, past president Sheri Stanger and vice president Pear Veasart had to step in and take over some of my duties just as our new year began. I cannot thank them enough for their help and support throughout the year. Our special advisors have always been there to help this organization in any and all ways. Thanks to Joe and Kathy McNulty, Steve Perreault, Nancy O'Donnell, and Clara Berg for always being just a phone call away. And last, but by no means least, thanks to our grantors, Hilton-Perkins and HKNC. We will also continue to work with Charity Rowland at Oregon Health and Science University on her research project on assessment strategies. Next year it is hoped that training on assessment strategies will be made available to interested parents.

Elections for vice president and secretary were held. Debbie Ethridge, previously our secretary, was elected vice president and Janette Peracchio, former board member in region 1, was elected secretary. They will join myself and Cynthia Jackson-Glenn (treasurer) on the Executive Committee.

Our 2007-2008 funding cycle started September 1, 2007. Each committee spent time planning for the coming year, listing outcomes, timelines, strategies, and responsibilities. The Board realizes its responsibility to you, our members. We are a resource for you. You will find various com-

(Continued on page 10)

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

**Linda Syler**  
President

**Pearl Veesart**  
Vice President

**Cynthia Jackson-Glenn**  
Treasurer

**Debbie Ethridge**  
Secretary

### EXECUTIVE BOARD MEMBERS

#### Region 1

**CT MA ME NH RI VT**

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(open)

**4B - KY NC SC TN**

(open)

#### Region 5

**IL IN OH MI MN WI**

(open)

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**Newsletter Editor** - Lisa Rohr, Jamie Coonts

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

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

## NFADB Board Elections

**Congratulations** to all our board members elected at the 2006 Annual Meeting.



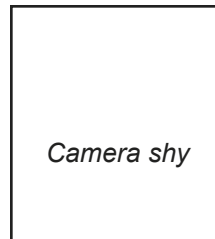
*President  
Linda  
Syler*



*Treasurer  
Cynthia  
Jackson-  
Glenn*



*Jamie Coonts*



*Camera shy*

*Cora Holloway*



*Nancy  
Cornelius*

**And a fond farewell to...**

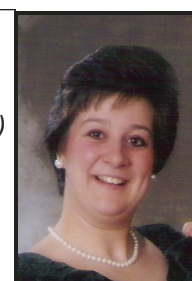


*Immediate Past President Sheri Stanger.  
Sheri will continue as a Special Advisor*



*(camera shy)*

*Tracy Jess*



*Susy  
Morales*

*Lisa Rohr*

*(camera shy)*

*Yolonda  
Scarlett*

**NFADB IS ACTIVELY SEEKING NEW BOARD MEMBERS.** Members in good standing may nominate him/herself or another member. Please contact: **Nancy Cornelius** ph: 858-513-9201; **E-mail:** nmcornelius@yahoo.com

## NFADB's Annual Membership Meeting

By Sheri Stanger – Past President

The National Family Association for Deaf-Blind held its Annual Membership Meeting on July 14, 2006, in Tampa, FL, in conjunction with the NFADB/NTAC National Parent Conference. Sheri Stanger welcomed the participants, who included parents, NTAC and DB-LINK staff, NFADB board members and special advisors and some deaf-blind project staff. A sit-down lunch was served while the presentations and business took place. Secretary Debbie Ethridge introduced the current board members and presented the minutes from the previous year's meeting in Salt Lake City, UT. The minutes were accepted. Nominations chairperson Cynthia Jackson-Glenn explained the election process and announced the new board members.

The highlight of the Annual Membership Meeting was honoring **Florida Congressman Bill Young**, who is also the Chairman of the House Appropriations Sub-Committee on Defense. He was honored for the advocacy work he has done on behalf of families that have children who are deaf-blind. Joe McNulty, director of the Helen Keller National Center and special advisor to NFADB, spoke about Congressman Young's work and presented the award – a beautiful, first day of issue Helen Keller/Anne Sullivan commemorative envelope and postage stamp encased in a 10x12 plaque. The 15 cents USA stamp and envelope were metered in Helen Keller's birthplace, Tuscumbia, AL, on her 100th birthday, June 27, 1980. Accepting the award on behalf of Congressman Young was Davide V. Macon. Mr Macon spoke about Congressman Young's respect for parents who advocate for their child. He told us that Congressman Young spent time with parents to ensure that federal funding was available to meet their needs. During his tenure as Chairman of the House Appropriations Committee, he supported funding for the Helen Keller National Center and programs that provide education and training opportunities for students with deaf-blindness. He has also been the Congress-

sional champion for the Recordings for the Blind program. Mr. Macon also spoke about the importance of advocacy so children have the best possible opportunities. This was a wonderful opportunity for conference participants to witness the impact that they can have at the federal level.

After the presentation, treasurer Linda Syler presented the financial report and it was accepted. Then, vice president Pearl Veasart presented the proposed changes to NFADB's by-laws. There was some discussion and all eligible voters (NFADB regular members in good standing) voted to make the stated changes. For a complete version of the current by-laws, visit [www.nfadb.org](http://www.nfadb.org).

NFADB's departing board members or those changing positions were honored and presented with a framed certificate in recognition of their service to NFADB. These included Sheri Stanger, president, now a special advisor; Linda Syler, treasurer, now president; Susy Morales, RD Region 4A; Lisa Rohr, RD Region 4B; Cynthia Jackson-Glenn, RD Region 5, and now treasurer; Yolonda Scarlett, RD Region 6; Tracy Jess, RD Region 10. In addition, Cynthia Jackson-Glenn presented a special award to Sheri Stanger in recognition of her four years as president of NFADB. It was a beautiful award that said "Bridge Builder" on one side and on the other side it stated "Without bridges, the best-built roads lead nowhere, the most impressive visions remain invisible, and the best-laid plans fail. In life and in work, connection is everything. You built the bridges. Made the connections. Brought us on to success. Thanks to you, we're going places."

The annual membership meeting concluded with a president's report by Sheri Stanger. That report can be read in its entirety in this issue of the newsletter. It was a well attended and successful annual meeting. ♥



## **Sheri Stanger - Past President's Report**

### **Presented at the 2006 Annual Membership Meeting, Tampa, FL**

As a parent of a child that's deaf-blind, I've wanted many things. I've wanted my child to be healthy, active and safe. But as you all know, we also want our kids to have the same opportunities as everyone else's kids. That's a constant struggle. Whether it's getting them included in our local schools or included in recreational activities or just included on the playground. And as they grow, we want them to have accessible housing, paying jobs and a social life. Like you, I struggle with these issues everyday. We all fight our battles one at a time; sometimes we fight multiple ongoing battles. Sometimes it seems unending. Who do we turn to for support? Where do we get our information? How do we affect change for our children?

As many of you know, I have been on the board of NFADB for the past 8 years. I've been a Regional Director for Region 2 and I have been your President for the past 4. I've had a reason for serving families on this board. I don't want families to be alone in their struggles and I want families to feel empowered. I want us to be able to speak up when something is not right - able to help change what is wrong. I have had a vision for NFADB that I believe is taking shape. I want to see a strong network of parents banding together to inform, support and take action when necessary. I see NFADB taking on a true national challenge as the group that families can go to when they want to learn about national issues, to help influence national policy and advocate for legislative change and to effectively communicate with each other.

NFADB has been working hard on becoming the type of group that can effectively take action. We have had training in advocacy and now we are hoping to pass that along to you and I applaud all of you for taking time out of your busy lives to learn and connect with each other. Our connections will make us effective. And NFADB has started making its connections with its Affiliations network. It is just beginning. I see NFADB's affi-

ates as the future of our organization. A wonderful network of families at the state level that we can call upon to help us affect change. I see our affiliates being called to action when there is an issue in their state or their senators or congress persons are influential in policy making that affects deaf-blindness. In addition, our affiliates can bring information from the national level to the state level and work more directly with the families. And they can provide NFADB with information from their states. I see us forming a beautiful network of families that rally around an issue when necessary. I also see the future leaders of NFADB coming out of our state affiliates.

We now have 2 affiliates - PA and WI.\* We are hoping to add more. I encourage all of you as parent leaders (and you really are parent leaders or else you would not be here) to encourage your state family groups to consider joining on as an affiliate of NFADB, or work towards developing a parent group in your state that will affiliate with us. It benefits all families that have children with deaf-blindness. We shouldn't be going at this alone.

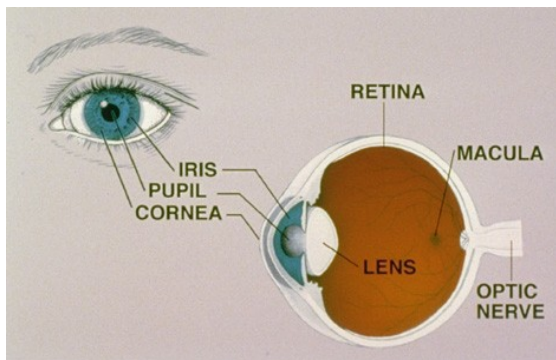
As I end my presidency this weekend, I feel positive about the changes taking place within NFADB and the direction the group is heading in. As I continue to serve as a special advisor to the group, I hope to see our affiliate network greatly expand. I hope to see us continuing our positive relationships with the professional groups, other family groups and consumer groups. Leaving this group is a bittersweet moment for me because this group has come so far. We've all worked so hard getting NFADB to be nationally recognized and respected. But I believe this group is in good hands and I look forward to being involved in a stronger NFADB. A stronger network of families. Thank you for allowing me to serve you for these past 8 years. ♥

(\*Ed. Note: two more affiliates have recently been added - New York and Puerto Rico.)

## The EYES Have It! RETINAL DETACHMENT

By Cynthia Jackson-Glenn, MS, Certified O&M Specialist  
Treasurer, NFADB

*Very often we, as parents, walk out of the optometrist or ophthalmologist's office not having a clear picture of our child's eye condition. Sometimes we are uncomfortable requesting more information from our doctor. So... here's another article to help NFADB families be more informed in this area.*



A retinal detachment occurs when the retina's sensory and pigment layers separate. Because it can cause devastating damage to the vision if left untreated, retinal detachment is considered an ocular emergency that requires immediate medical attention and surgery. It is a problem that occurs most frequently in the middle-aged and elderly; however, children with congenital rubella syndrome have been known to experience retinal detachment at puberty.

There are three types of retinal detachments. The most common type occurs when there is a break in the sensory layer of the retina, and fluid seeps underneath, causing the layers of the retina to separate. Those who are very nearsighted, have undergone eye surgery, or have experienced a serious eye injury are at greater risk for this type of detachment. Nearsighted people are more susceptible because their eyes are longer than average from front to back, causing the retina to be thinner and more fragile.

The second most common type occurs when strands of vitreous or scar tissue create traction on the retina, pulling it loose. Patients with diabetes are more likely to experience this type. The third type happens when fluid collects underneath the layers of the retina, causing it to separate from the back wall of the eye. This type usually occurs in conjunction with another disease affecting the eye that causes swelling or bleeding.

Signs and symptoms of retinal detachment are light flashes, "wavy" or "watery" vision, veil or curtain obstructing vision, shower of floaters that resemble spots, bugs, or spider webs, and a sudden decrease of vision. It is critical that these problems are reported early, because early treatment can greatly improve the chance of restoring vision.

The doctor makes the diagnosis of a retinal detachment after thoroughly examining the retina with ophthalmoscopy. The retinal surgeon's first concern is to determine whether the macula (the center of the retina) is attached. This is critical because the macula is responsible for central vision. Whether or not the macula is attached determines the type of corrective surgery required and the patient's chances of having functional vision after the operation. Ultrasound imaging of the eye is also very useful for the doctor to see additional detail of the condition of the retina from several angles.

There are a number of ways to treat retinal detachment. The appropriate treatment depends on the type, severity and location of the detachment. ♥

*Next time we'll talk about Retinitis Pigmentosa!*

If there is an eye condition that you would like to have more information about,  
please contact me at [cyn98onm@fuse.net](mailto:cyn98onm@fuse.net)

# What's Up?

## Research...brought to you by DB-LINK

### **ACCESS TO THE GENERAL CURRICULUM FOR STUDENTS WITH SIGNIFICANT COGNITIVE DISABILITIES**

by Cushing, Clark, Carter, Kennedy 2005. TEACHING EXCEPTIONAL CHILDREN, vol. 38, #2, Nov/Dec 2005, pp. 6-13.

Describes a process that educators can take to effectively meet statewide standards and at the same time meet individualized goals for students with significant cognitive disabilities. The process involves determining local and statewide standards, identifying classroom expectations, infusing individualized education program (IEP) goals, conducting classroom observations, developing and implementing appropriate adaptations, and assessing outcomes. This document at:

<http://journals.sped.org/TEC/Articles/Cushing.pdf>

**DB-LINK NUMBER: 2006-0122**

### **A FOUR-STEP PROCESS FOR ACCESSING THE GENERAL CURRICULUM FOR STUDENTS WITH SIGNIFICANT COGNITIVE DISABILITIES**

by Clayton, Burdge, Denham, Kleinert, Kearns; 2006, TEACHING EXCEPTIONAL CHILDREN, vol. 38, #5, May/Jun 2006, pp. 20-27.

This article describes a model developed to assist teachers to align instruction for students with cognitive disabilities to content standards that have been developed for all students and ensure that student learning is matched to IEP objectives. It details the four steps of the process. Step 1 - identify or link to the appropriate standard. Step 2 - define the outcome of instruction for all students. Step 3 - identify the instructional activities. Step 4 - target specific objectives from the individualized education program (IEP).

**DB-LINK NUMBER: 2006-0121**

### **TEACHING LANGUAGE ARTS, MATH, & SCIENCE TO STUDENTS WITH SIGNIFICANT COGNITIVE DISABILITIES**

by Diane M Browder, Ph.D. (Ed.), Fred, Spooner, Ph.D. (Ed.) -- Paul H. Brookes Publishing Co. 2006, 324; [www.brookespublishing.com](http://www.brookespublishing.com)

The purpose of this book is to show meaningful ways to help students with significant cognitive disabilities meet the expectations of the No Child Left Behind Act in reading, math, and science. It includes chapters on promoting access to the general curriculum; building literacy at the pre-symbolic and early symbolic levels (by June Downing); learning to read; balanced literacy classrooms and embedded instruction; enhancing numeracy; math standards and functional math; science standards and functional skills; math and science skills; how students demonstrate academic performance and portfolio assessment; and promoting alignment of curriculum, assessment, and instruction. Cost: \$49.95.

**DB-LINK NUMBER 2006-0082**

### **BUILDING LITERACY FOR STUDENTS AT THE PRE-SYMBOLIC AND EARLY SYMBOLIC LEVELS/**

Downing, June E. -- Paul H. Brookes Publishing Co. 2006, 39-61. This book chapter looks at literacy from a broad perspective as "ways of learning about and sharing information with others." It addresses recommended approaches for introducing literacy activities to students with significant disabilities who may just be beginning to learn about the use of symbols. Topics addressed include life experiences as a basis for literacy, the link between communication and literacy, augmentative communication systems, the importance of high expectations for literacy, making literacy accessible (adapting materials, following a student's interests, offering choices, identifying preferences), making use of natural opportunities for literacy instruction, creating meaningful literacy opportunities, the use of specific instructional strategies, prompt fading procedures, measuring effectiveness, data collection, and the use of a team approach.

**DB-LINK NUMBER: 2006-0120**

### **USING IMITATION WITH CONGENITALLY DEAF-BLIND ADULTS:**

Establishing Meaningful Communication Partnerships by Paul Hart, 2006, INFANT AND CHILD DEVELOPMENT, vol. 15, pp. 263-274

The author describes how imitation can be used to establish communication with individuals who are congenitally deaf-blind. The article begins with an overview of the history of deaf-blind education over the past 150 years and a description of the communication challenges faced by people who are congenitally deaf-blind, particularly difficulties that involve the attitudes and actions of communication partners. Examples of intervention approaches for individuals who are deaf-blind are linked to theories of infant communication which includes attracting attention, stimulating turn-taking, allowing partners to recognize each other, and crafting morality (based on the idea that "the moral mind, which asks you to treat your neighbor as yourself, could not develop without imitation").

**DB-LINK NUMBER 2006-0123**

**CVI PERSPECTIVES** (video/DVD) by Christine Roman, Alan Lantzy. -- American Printing House for the Blind, Inc., 2005.

In this multi-part video, Dr. Christine Roman, APH project leader for cortical visual impairment, guides the viewer through three perspectives of CVI. The first segment offers an in-depth look at the characteristics of CVI and recommended approaches for educators to apply

*(Continued on page 10)*

## The National Coalition on Deafblindness

The National Coalition on Deafblindness was formed in 1987 in response to a need to provide feedback to legislators and policy makers regarding the ongoing needs of children who are deaf-blind and the reauthorization of Individuals with Disabilities Education Act (IDEA). Founding members of the Coalition include:

- American Association of the Deaf-Blind [www.aadb.org/](http://www.aadb.org/)
- American Foundation for the Blind [www.afb.org/](http://www.afb.org/)
- Association for the Education and Rehabilitation of the Blind and visually Impaired [www.aerbvi.org/](http://www.aerbvi.org/)
- Council of Schools for the Blind: [www.cosb1.org/](http://www.cosb1.org/)
- Helen Keller National Center [www.hknc.org/](http://www.hknc.org/)
- National Association for Parents of the Visually Impaired [www.spedex.com/napvi/](http://www.spedex.com/napvi/)
- National Family Association for Deaf-Blind [www.nfadb.org/](http://www.nfadb.org/)
- Perkins School for the Blind [www.perkins.org/](http://www.perkins.org/)
- The Teaching Research Institute [www.tr.wou.edu/](http://www.tr.wou.edu/)

Since that time, the National Coalition has maintained an active role on the Consortium for Citizens with Disabilities Education Task Force:

[http://www.c-c-d.org/task\\_forces/education/tf-education.htm](http://www.c-c-d.org/task_forces/education/tf-education.htm)

Advocacy efforts on the part of the coalition have focused on legislation in education and rehabilitation, helping legislators to understand deaf-blindness as a unique and complex disability, and to appreciate the important role the federal government plays through its discretionary programs with regard to this low incidence disability.

### The Braille Rap Song

The Braille Rap Song was written by Lynn Horton and Tammy Whitten as a fun way to teach braille to their students at the Helen Keller School located in Talladega, AL. Lynn played the song during her session at the 2001 CEC Conference in Kansas.

It met with such great interest that APH volunteered to produce a high-quality, professional recording and make it available to the world! Listen at:  
[http://www.aph.org/edresearch/braille\\_rap/index.html](http://www.aph.org/edresearch/braille_rap/index.html)



Today, the National Coalition on Deafblindness is a 2,000 member organization of parents, professionals, people who are deaf-blind and agencies serving the population who are deaf-blind. There have been many successes since the coalition began but in 2005 we find ourselves with a growing population and diminishing resources. Since the mid 1980s the number of children who are deaf-blind needing services has nearly tripled - increasing from roughly 4,000 to more than 10,000 today. At the same time the amount of federal funding for this group has remained level funded at \$12.8 million (see graph below)

In response to this crisis the National Coalition on Deafblindness has decided to launch the **Children First Campaign (CFC)**. CFC is embarking on an authorization strategy beginning with FY2007 to strengthen support for children who are deafblind and their families. If the appropriation strategies is successful, appropriators may be able to help fill the gap between the needs of the growing population of children who are deafblind and the federal funding available to assist them.

If you have questions, suggestions, and/or would like to become involved, please sign up for the National Coalition on Deafblindness discussion group at <http://groups.yahoo.com/group/national-db>

For more information about the Children First Campaign contact: Betsy McGinnity [betsy.mcginny@perkins.org](mailto:betsy.mcginny@perkins.org) To keep up-to-date on the Coalition activities or information on how to contact your legislators, go to [www.dbcoalition.org/index.htm](http://www.dbcoalition.org/index.htm)



### Adults with CRS Needed for Study

HKNC and the Centers for Disease Control and Prevention are collaborating on a study to determine if there are unique biomarkers in the blood of adults with congenital rubella syndrome. Fifty participants with CRS are needed for this study, which is taking place at HKNC headquarters in NY. For more information, please contact Nancy O'Donnell at 516-944-8900 ext 326 or [hkncnod@aol.com](mailto:hkncnod@aol.com)



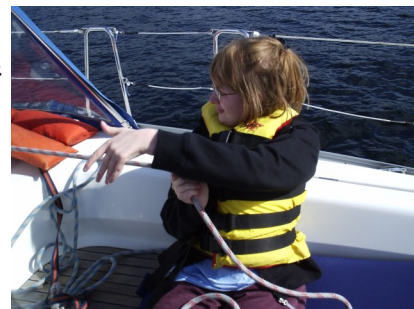


## Heart of Sailing

### By Tracy Jess, WA Family Specialist



My daughter, Ashley and I had a wonderful opportunity to experience something new. We went sailing. An organization called the Heart of Sailing offers free sailing excursions to children who have cognitive delays and other disabilities. George Saidah, who is the executive director as well as founder of the organization loved sailing and decided to share it with children with special needs. He began in Indiana and this year has expanded to: Houston, TX; Seattle, WA; Long Beach Island, NJ; Table Rock, MO; Bellingham, WA; Vancouver, BC; and Dana Point, CA.



The children get the opportunity to assist with sailing by steering, pulling the ropes for the sails, tying knots, etc. with whatever capabilities they are able to. When the trip is finished they are presented with a certificate, a medal, and a book that George has written on sailing.

Ashley had a terrific time and had to wear her medal for days afterwards, showing it to everyone she came in contact with. For more information on Heart of Sailing in your area go to: [www.heartofsailing.org](http://www.heartofsailing.org)

## Upcoming Conferences

### May 25-28, 2007

The 5th **Alström Syndrome** International Conference will be held in Fort Worth, TX, May 25-28, 2007. The theme is "Making a Difference: Parents and Patients in the Know: Medical and Emotional Strategies for Fighting Back! - Delaying, Moderating, Treating, and Managing Alström Syndrome." For more information go to <http://www.jax.org/alstrom/>



### July 27-29, 2007

The Eighth International **CHARGE Syndrome Conference** will be held in Costa Mesa, CA, July 27-29, 2007. For more information, go to [www.chargesyndrome.org](http://www.chargesyndrome.org)



### July 13-15, 2007



**Families Connecting with Families** will be meeting in Omaha, NE, July 13-15, 2007. Sponsored by Na-

tional Association for Parents of Children with Visual Impairments (NAPVI), American Foundation for the Blind and The Seeing Eye. For more information, please go to [www.napvi.org](http://www.napvi.org), [www.afb.org](http://www.afb.org) or [www.seeingeye.org](http://www.seeingeye.org).



**WORLD WIDE CONNECTIONS**  
*Breaking the Isolation*

### September 25- 30, 2007

The **Deafblind International** 14th World Conference will be held in Perth, Australia, September 25- 30, 2007. The Conference theme is '**Worldwide Connection : Breaking the Isolation**' and will feature exciting international and national speakers. For more information, go to:

[www.dbiconference2007.asn.au/](http://www.dbiconference2007.asn.au/)





## In Loving Memory

2006 was a tough year for NFADB. We lost several members of the NFADB family:



Mary Fox

MARY FOX, administrative assistant for NFADB, was the friendly voice at the other end of our 800 number for several years. She provided day-to-day support to the NFADB board in all aspects of the running of the organization. Mary passed with love and dignity in September, 2006, from cancer. Her ever-present smile and sunny disposition are sorely missed.



Kathy Michaels

KATHY MICHAELS, administrative assistant for the National Technical Assistance Consortium (NTAC), passed away in May, 2006. Kathy was a familiar face at the NTAC/NFADB parent meetings for many years. Although she never liked recognition, the work she did was invaluable. For those of us who knew her, you couldn't help but love her. Kathy rarely minced words, but had a heart of gold and would do anything for those close to her. She was a mother, co-worker, and friend. We are sad to see her go and miss her deeply.



Jamie and Jamison

JAMESON COONTS, son of NFADB board member Jamie and her husband, Bob, passed away unexpectedly on Saturday, August 5th, 2006, at Children's Hospital in Seattle. The week prior to his death, Jameson joyfully celebrated his 5th birthday with his family and friends. He was a remarkable child who touched all who had the honor of knowing him and his family. Jameson was loved and treasured by so many. Please keep Jamie, Bob and his sisters, Jamae and Jessa, in your thoughts and prayers.

JIM SYLER, husband of NFADB president Linda Syler, passed away suddenly on August 12, 2006. Jim was a veterinarian for almost 40 years, spending about 25 of those in Canton, OH. An active member of his community, Jim was involved in many civic organizations. His passing was quite unexpected and a shock to his friends and family. Jim and Linda have two children - Jennifer, 31, who is deaf-blind, and brother Jay, 32, in AZ.

And on an international level, we were sad to hear of the passing of NORMAN BROWN (UK) in January, 2007. NFADB international liaison Clara Berg notes: "What a privilege for those of us - parents and professionals - who had the honor of working with Norman! As the father of Stephen, a young man with CRS, Norman made his career as an international advocate and trainer, sharing his knowledge around the world. We are going to miss you, Norman, and your contagious sense of humor. Lucky are the angels who surround you now."



*("What's Up" continued from page 6)*

when working with children with CVI. The second segment is a clinical examination of the causes of CVI with neonatologist Dr. Alan Lantzy. In the third segment, parents and family members tell their stories of how CVI has impacted them-- their experiences from the difficulties of diagnosis, to how they learned about CVI, where they found help, and how they found hope for their children. Cost: \$25.00. Available from the American Printing House for the Blind, Inc., 1839 Frankfort Ave, Louisville, KY, 40206. Publisher's web site: [www.aph.org](http://www.aph.org)

**DB-LINK NUMBER 2006-0148**

**ON YOUR OWN TWO FEET: The Development of Orientation and Mobility In Blind Children from Birth to Six YearsofAge** (video/DVD) by Marjon Vink, Jan Ijzerman -- Bartimeus: 2002, 40 minutes.

Five blind children, from birth to six years of age, illustrate the development of movement and orientation. The video is produced in three parts: 1) Theory: the relationship between perception of the environment and what motivates movement is examined; 2) Characteristics: differences in the development of movement in blind children are explored; 3) Stimulation: addresses the role that parents and caregivers can play in encouraging movement. There is one short, but very clear, scene of an infant using a Little Room. Available from the Royal National Institute for the Blind in the UK; E-mail: [exports@rnib.org.uk](mailto:exports@rnib.org.uk).

Web: <http://onlineshop.rnib.org.uk>.

**DB-LINK NUMBER: 2006-0142**

**TACTILE LEARNING STRATEGIES : Interacting with Children Who Have Visual Impairments and Multiple Disabilities** (video/DVD) by Deborah Chen, June Downing -- AFB Press: 2006, 59 minutes.

Strategies and everyday activities for helping children who are visually impaired and have multiple disabilities to learn through touch are demonstrated using narration, interviews, and specific detailed examples of children and their families. Topics covered include: mutual tactile attention; tactile modeling; hand-under-hand guidance; hand-over-hand guidance; touch cues; object cues; adapted sign, coactive sign; and tactile sign. Available in video or DVD format. English and Spanish versions are on the same videotape. In the DVD format, English and Spanish versions are on separate DVDs that come in the same case. Cost: \$79.95 for the video; \$99.95 for the DVD. Available from AFB Press. Phone: 800-232-3044.

Publisher's web site: <http://www.afb.org/store>

**DB-LINK NUMBER 2005-0161**

For copies of complete articles or copies for loan (books and visual media), contact:

**DB-LINK, Teaching Research**

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**<http://www.dblink.org>**



*(President's Report continued from page 1)*

mittee reports throughout this newsletter.

Please take time and read these. See what NFADB is doing for you.

I am excited about NFADB and where we are heading. I see much work ahead for our organization if we are to make a difference in the lives of families with deaf-blind children and adults. We live in difficult times with many changes taking place in funding and availability of services. Our voices must be heard!

In July, a few days after our board meeting, I traveled to Washington, D.C., to attend the State Deaf-Blind Project Directors' Meeting (PDM). I attended one of the area meetings on Wednesday evening and the full day meeting on Thursday that was for all projects. Information was given to attendees concerning 3 research projects that would provide better outcomes for our children through functional hearing inventories, adaptive prelinguistic strategies, and evidence-based assessment strategies. We are proud to say that NFADB has been involved with the last research project. A number of state projects approached me about how to form a parent group and how they could become involved in our affiliation process. I left the meeting feeling energized and confident in our state deaf-blind projects. Your state project is a valuable resource for you and your child. They have expertise in deaf-blindness and offer training, printed information, consultations, and many other services that can be of help to your child and your family. They may be the first people you see that will look at your child and not just see their deaf-blindness. Please make use of this resource which is in your own state or region.



## 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.

**AFFILIATION** - Pearl Veasart. **ph:** 805-528-5673;  
**E-mail:** pearl@thegrid.net

**COMMUNICATION** - Jamie Coonts; **ph:** 360-668-3446; **E-mail:** 4JCOONTS@msn.com

**LEGISLATIVE:** Nancy Cornelius; **ph:** 858-513-9201; **E-mail:** nmcornelius@yahoo.com

**NATIONAL ISSUES:** Janette Peracchio; **ph:** 860-633-0042; **E-mail:** wperacchio@snet.net

**NOMINATIONS:** Nancy Cornelius; **ph:** 858-513-9201; **E-mail:** nmcornelius@yahoo.com

### Advertising Information

Are you interested in reaching families who have a member who is deaf-blind? Advertising available for the following cost (per newsletter):  
\$120 for entire page  
\$60 for 1/2 page of 1 column.  
Print ads only in black and white.

For more info or to place an advertisement, contact: Jamie Coonts - **ph:** 360-668-3446; **E-mail:** 4JCOONTS@msn.com

When sharing or copying information and articles from our newsletter, please credit **News From Advocates for Deaf-Blind** as the source.  
Thanks!

## LIVING HONOR GIFT, MEMORIAL OR CONTRIBUTION

to

### The National Family Association For Deaf-Blind

Enclosed is \$\_\_\_\_\_ given as a contribution or as a gift in honor or memory of:

☐ Living Honor - A tribute to someone you wish to honor while they are present to enjoy your thoughtfulness.

☐ Memorial - A gift in honor of someone who has passed on. The notice of this thoughtfulness will be sent to whomever you specify.

☐ Mary Margaret O'Donnell Memorial Fund - An ongoing fund established in memory of our former president.

☐ Contribution to NFADB - to be used as needed.

All honors, memorials and contributions are tax deductible and are used to further the goals and activities of NFADB.

**Please send a note about this gift to:**

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

Address: \_\_\_\_\_

City: \_\_\_\_\_

State: \_\_\_\_\_ Zip: \_\_\_\_\_

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Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

**Send this form with your donation to:**

**NFADB,  
141 Middle Neck Road  
Sands Point, NY 11050**

*Thank you!*



## Affiliate Round Up

### The Pennsylvania Partnership for the Deafblind, PPDB



**MISSION STATEMENT:**  
The Pennsylvania Partnership for the Deafblind exists to: Provide support for individuals with deafblindness & their families through a family-driven network

**INTRODUCTION:** In August of 2005, the Pennsylvania Partnership for the Deafblind (PPDB) had the honor of being selected as the first state affiliate of the National Family Association for Deaf-Blind (NFADB).

The Partnership's first year has been devoted to laying a strong foundation for the future. This report summarizes our progress and outlines our agenda for the coming year.

**THE CHALLENGE:** After selection by NFADB, the real work began. At that point, the Pennsylvania Partnership was more of an idea than reality. How could we turn this idea into a real organization? How could we develop a common understanding of why PPDB should exist and why people should join? How could we share ideas, discuss issues and reach consensus given the realities of living in a large state with long distances between members? How could we obtain the initial funding necessary to become a legally recognized non-profit organization?

**THE PROCESS:** Fortunately, we were able to work with the PA Deafblind Project, which was set to begin its first Leadership Training program in October 2005. The program involved three sessions (October, January, May). Eleven parents participated in the 1½-day sessions, which began on Friday afternoon and ended Saturday afternoon. We were extremely fortunate that Kathy McNulty from NTAC was able to act as facilitator for these discussions.

*October:* Determined the concerns that the Partnership should (and should not) take on

*January:* Finalized concerns to develop a draft mission statement

*May:* Finalized the mission statement and drafted five goals to implement the mission

The group (which had now morphed into the Partnership's Steering Committee) also decided to present our results to the annual **Family Learning Conference (FLC)**, sponsored by the deaf-blind project, in June.

Twenty-three families attended this year's FLC. After reviewing the mission and goals, we asked for the group's assistance in **identifying activities** that the Partnership could undertake in the next year to implement each goal. The participants were then asked to prioritize the activities. At its next meeting, the Steering Committee will use the results to finalize PPDB's action agenda for the coming year.

At the FLC, we also passed out an "Application of Intent" form, which asked participants if they would be interested in joining PPDB. Of 20 parents who are not already members, nine expressed strong interest, with four stating that they are willing to work on a committee.

Finally, we asked the parents to identify a talent that they could use to assist the Partnership. Fourteen responded, with talents ranging from fundraising to conference planning to web design.

**FIRST-YEAR RESULTS:** After a year, the Pennsylvania Partnership for the Deafblind has "turned the corner." A mission and goals have been finalized, members are being recruited, and an action agenda will soon be developed. All this without a formal organization!

Speaking of a formal organization, PPDB received some great news at our January meeting. The **Overbrook School for the Blind** has graciously offered to provide the Partnership with as much as \$2,000 to underwrite the cost of incorporating and applying for Federal non-profit status!

**NEXT STEPS:** In September, we finalized the action plan for 2006-2007, and developed ways to implement that plan. We need to address the issue of future Steering Committee meetings, now that the Leadership Training has ended. We will also begin the incorporation process, as well as applying for non-profit status.

Gordon Boe, President  
Pennsylvania Partnership for the Deafblind  
[g.boe@comcast.net](mailto:g.boe@comcast.net)

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**Our next newsletter will have reports from our new affiliates in WI, NY and PR. If your state has an established group that would like to become an affiliate of NFADB, please contact Affiliate Coordinator Pearl Veasart via e-mail: [pearlv@thegrid.net](mailto:pearlv@thegrid.net)** ♥

## Parents as Powerful Advocates

By Janette Peracchio, NFADB Board Member

At the 2006 Family Workshop in Tampa, sponsored by NTAC and NFADB, parents learned how to advocate at the local, state and federal levels. Parents received advice from experts and advocates before they had a chance to role play and practice advocating for their children with special learning styles. It was such a wonderful thing to watch parents formulate their talking points and bring them before "school boards, principals and superintendents" during the role playing sessions. Parents also practiced creating testimony to present at a public hearing and had the chance to email letters to their congressperson during a program on contacting elected officials. It was great to hear comments like "this isn't that hard," "it helped writing my talking points down before I testified," "I can't wait to get home to write more e-mails to my Congress person," "Is it okay to take my child with me when I visit my senator?" Let the grassroots efforts begin!

Here are some of the "Dos and Don'ts of Letter Writing" that was presented by Paddi Davies and Janette Peracchio during one of the parent workshops.

### Do . . . .

Spell the legislator's name correctly and know his/her appropriate title (Representative, Senator, Delegate, Commissioner, Director, etc.).

Write personally. Legislators pay the most attention to personal letters from their constituents explaining the direct impact that the legislation or policy has on your child, family and local community.

Keep it short. Limit to one page.

Cover only one subject and refer to the particular bill number addressed, including the person who introduced it and what it will do. This will speed up the routing of the letter in the office. Similarly, if you refer to the legislator's position, it will demonstrate your specific interest in his/her actions. Show as much knowledge as you can, but don't hesitate to write merely because you are not an "expert."

Make your letter timely. Legislators will appreciate having your views and information while the issue is before him/her.

Be specific about what you want the legislator to do. It is important to ask for a specific action such as, "Please vote for (or against) [number of the bill]" or "We recommend the following changes to the proposed priorities."

Be reasonable. A thoughtful, well-written letter will do more to win your legislator to your viewpoint than a threatening, negative one.

Send a copy of your letter/email to your local newspaper to build local support for an issue.

Include your name and how you can be contacted (return address, phone number, email) on the letter.

Use any form of letter (handwritten, typed, brailled) as long as it is legible. Write each legislator individually, avoiding photocopies. Braille letters are fine if accompanied by a print transcription of the letter.

Keep up the contact. Periodically write additional letters/emails to let your legislator know you've followed the votes on your issues, and thank him/her for the support or express your displeasure for the lack of support. Let your legislature know you are watching and interested. Maintain a file for each official including letters written.

### Don't . . . .

Don't write a letter demanding the legislator's cooperation.

Don't write a chain or form letter.

Don't threaten a legislator with defeat at the next election.

Don't adopt a politically partisan tone in your letter.

Don't become a chronic letter writer. Choose your issues wisely.

Don't use the legislator's first name in the salutation of your letter unless you know him/her personally.

Don't be discouraged!!!! You may not always receive a substantive response to your letters or communications, but following these suggestions will increase the chances that you will be heard effectively.

**Legislators really do listen to their constituents.**

**Let them know how you feel!**

*Adapted from: Excerpt from the Norwich Voices for Families Curriculum, Norwich Children First Initiative, Norwich Youth and Family Services – <http://www.democracyinaction.org/dia/organizations/ctparentpower/images/Writinglegs.PDF> and from "A Capital Idea" Paul W. Schroeder, Vice President, Programs and Policy, American Foundation for the Blind and from Barbara Jackson LeMoine, Legislative Assistant, American Foundation for the Blind, © 2005 American Foundation for the Blind.*



## Attention NFADB Membership

As of September 1, 2006, the renewal date for all memberships will follow NFADB's fiscal year of September 1 to August 31. If you have any questions or concerns, please call 1-800-255-0411. ♥

## The Paper Chase: Managing Your Child's Documents Under the IDEA

by Robert K. Crabtree, Esq.

Here's a list of the different documents that you'll see over the course of your child's special needs education. You should keep them all!

### 1. Individualized Educational Programs (IEPs) and other official service plans.

**2. Evaluations by the school system and by independent evaluators.** Depending on your child, these will include educational, psychological and/or neuropsychological, speech and language, occupational therapy, and physical therapy evaluations.

**3. Medical records.** You probably don't need to keep all medical records with your child's IDEA documents. Keep only those that relate to the disability or disabilities that affect his ability to learn or to access school programs and facilities.

**4. Progress reports and report cards.** These are the formal documents where the school system periodically describes how your child is doing.

**5. Standardized test results.** School systems often administer standardized tests (such as the California Achievement Tests) to all students. These tests can provide a helpful comparison to the progress reports written by your child's teachers.

**6. Notes on your child's behavior or progress.** These will include notes from you to the teacher, from the teacher to you, or journal entries between you and your child's service providers. Sometimes notes from a concerned teacher tell a different story than the formal report the teacher develops at the request of her supervisor when the TEAM convenes.

**7. Correspondence.** Save any correspondence between you and teachers, special education administrators, TEAM chairpersons, and

evaluators. Don't forget emails -- print them out and include them in your correspondence file. Also save correspondence from the school system that's addressed to you or to all special education parents describing issues that affect your child. This may include letters describing new programs, changes in programs or services, school system policies for children with special education needs, or budget issues.

**Note:** Do you use certified mail, return receipt requested, when you send letters or notices to the school system? Sometimes this is necessary, but more often, this just adds unnecessary delay to the delivery of the letter or notice.

It's better to hand-deliver the document and ask for a receipt. Remember that in most courts and administrative forums, a letter mailed in ordinary first-class mail is presumed to have been delivered within three days of its mailing.

**8. Notes from conversations and meetings** with school personnel, evaluators, the child's TEAM, or other interactions relating to your child's program or needs. Be certain to take excellent notes at key meetings or, better yet, bring someone with you whose only task is to take notes (especially at TEAM meetings). These notes can help enormously when, months later, you try to remember exactly what various people said or what agreements were reached.

**Note:** Should you tape TEAM meetings? Do you have the right to tape them? The answer to both questions is "probably not." Under the laws pertaining to discrimination on the basis of handicap, you may have the right to tape a meeting if it's necessary to accommodate a disability (for example, if one or both parents have a language processing disorder). You may also have the right to tape a meeting if it's conducted in a language other than the parents' first language. Generally, the right to tape a meeting

*(Continued on page 16)*



## **ACHIEVING THE VISION! A NATIONAL PARENT CONFERENCE ON ADVOCACY AND LEADERSHIP**

**By Carlen McCullers-Bitting**

As a parent of a ten-year old son with dual sensory impairments, I would like to thank the Virginia Deaf-Blind Project for inviting me to attend the National Convention held July 13-15, 2006 in Tampa, FL. But first, I'd like to give you a little background on how I met the new project director, Mark Campano. I gave him a call!

The state has said that my advocacy work was a model for others and that my school team could provide a beacon of hope for other families in Virginia. Well, I knew in my heart that our team needed much more training in deaf-blindness. After calling Mark, he took time out of his busy schedule and came to Newport News to work with the team. We got busy with a question and answer session from the team and I was able to explain how Charvell, my son, learns. Mark understood that like many other parents, I have lots of questions. The team built on this and was able to complete the VAAP (Virginia Alternate Assessment Program) with success. This was important because advocacy has been a huge part of my personal success with my son, Charvell.

At the national convention, the speakers stressed the importance of families getting to know their state and Federal laws and which laws give the child greater protection. There is no doubt that parents left well educated on the facts. Attorney and child advocate, Matt Cohen, Esq., gave us a lot of new information about IDEA '04, the Individuals with Disabilities Education Improvement Act of 2004. It was very important to hear because we need to understand the new laws. I'll give you some examples of what I learned about.

The purpose of IDEA '04 is to increase emphasis on non-academics. Related services are any non-medical services necessary for the child to benefit from instruction, including speech, counseling, social work, "Parent Training," transportation, physical and occupational therapy, mobility and orientation training, interpreter services and any other service necessary to assist the child to benefit from education.

Under IDEA '04, there have been changes in IEP (individualized education plans) meeting attendance rules by mutual agreement between

the parent and school. This is dangerous because it means the school and parent can agree to modify the IEP without holding an IEP meeting, creating the potential for abuse and error. Parents may be misled to make changes that do not reflect the consensus of the school staff. Even when both parties are acting in good faith, there can be misunderstandings as to what agreements were reached.

We talked about FAPE (Free Appropriate Public Education) which provides the child with special education and related services necessary to benefit from education. It must be based on the child's unique needs and documented in the child's IEP.

Also, IEPs have to be developed following IDEA procedures and must be "reasonably calculated to allow the child to receive some educational benefit." Educational benefits are more than minimal benefits, but less than the most benefit possible. The meaning of a "benefit" varies by child and their individual needs—from learning to use the bathroom to learning algebra. They may include academic and/or non-academic benefits. Again, remember IDEA '04 increases emphasis on non-academics.

The last thing from IDEA '04 that I want to write about is that an IEP must include a statement of special education related services based on peer-reviewed research to the extent practicable (614(d)(1)(A)(i)(IV)). This puts the burden of proof squarely on school districts and puts methodology on the agenda. For peer-review research on deaf-blindness, go to DB-LINK at [www.dblink.org](http://www.dblink.org)

We were given a binder of priceless information that included advocacy websites, case studies and information on how to approach an issue with our state legislators. There is no doubt that parents left there well educated on the facts.

*-article excerpt from the Virginia Deaf-Blind Project newsletter,  
with permission. ♥*

(Continued from page 14)

hasn't been determined to exist under IDEA.

Ordinarily, if you ask in advance to tape a TEAM meeting, the school system should let you as a courtesy, and will usually tape the meeting also. You need to consider, however, that having a tape recorder may inhibit the participants and create a feeling of hostility at the meeting. Again, it's usually better if someone takes excellent notes.

**9. Documents relating to discipline and/or behavioral concerns.** These include notices of detention and suspension (both in and out of school), letters describing the concerns of service providers or school administrators about behavior, records of behavioral assessments, and records of behavioral plans for addressing behavioral issues.

**10. Formal notices of meetings scheduled to discuss your child.** When you get a notice like this, jot down the date you received it. Sometimes the question of whether a school system has met time requirements is important under IDEA. (It is sometimes a good idea to keep copies of the envelopes in which such notices arrive. Check the date of the notice or letter and the date of the postmark. It could be significant if the postmark is later than the date on the notice.) ♥

## Alphabet Soup!

Throughout this newsletter, you will see certain acronyms used over and over again. We have included a master list of the abbreviations and their meaning here, for your convenience:

**AADB** - American Association of the Deaf-Blind

**NCLB** - No Child Left Behind Legislation

**DB-LINK** - The National Information Clearinghouse for Children Who Are Deaf-Blind

**HKNC** - Helen Keller National Center

**IDEA** - Individuals with Disabilities Education Act

**IEP** - Individualized Education Program

**NFADB** - National Family Association for Deaf-Blind

**NCDB** - National Consortium on Deaf-Blindness

**PCP** - Person Centered Planning

**TA** - Technical Assistance

**SSP** - Support Service Provider

**11. Samples of schoolwork.** You don't need to keep every scrap of writing or drawing that your child produces, but it can be helpful to keep examples each year. You can compare these to show how much progress he's made in different academic areas.

**12. Invoices and cancelled checks.** Save the ones from services that you provide for your child's educational development. For example, if you hire a speech and language pathologist for an hour of therapy each week to supplement the school system's services, keep a record of any payment. Eventually, you can seek reimbursement for this expense. (You must be able to prove that it was necessary because the school's services weren't allowing your child to progress effectively.)

**13. Public documents.** These help explain how your school system works with children like yours. They include newspaper articles featuring special education administrators, school committee members, or superintendents talking about reorganizing special education programs, cutting expenses, or new teaching approaches.

Remember that except in rare cases, you don't need to keep drafts of any documents. The drafts may lead to confusion if you ever need to seek services for your child through the due process system. This is one area where you can and most often should lighten your document load.

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This article was originally published at [www.familyeducation.com](http://www.familyeducation.com) Reprinted with permission from author, Bob Crabtree is a partner at [Kotin, Crabtree, and Strong, LLP](http://Kotin, Crabtree, and Strong, LLP), a general practice law firm in Boston, MA. Among other areas of practice, Bob concentrates in special education and disability law.

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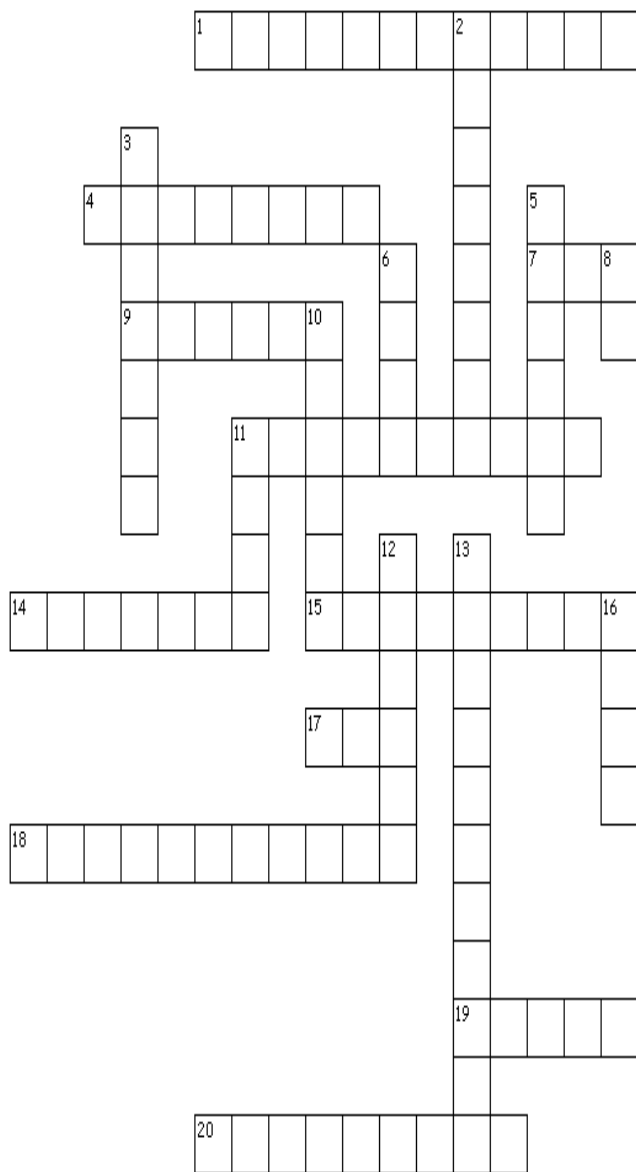
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# ADVOCACY CROSSWORD



## Across

1. Outgoing NFADB leader
4. Ongoing learning of best practices in education
7. Legal document of student plan of learning supports
9. Keep \_\_\_\_\_ of all correspondence
11. New NFADB president
14. Tactile words
15. US Dept of \_\_\_\_\_
17. Your child's best advocate
18. Collaboration for our cause
19. Communicate with officials by phone, fax, letter & \_\_\_\_\_
20. Individual who have both a visual and hearing impairment are individuals who are \_\_\_\_\_

## Down

2. Knowing and participating in the rights of your child
3. Direct educator
5. Snowman's season
6. Legal mandate for children with disabilities
8. NFADB Affiliate
10. US legislative body
11. We advocate because we \_\_\_\_\_
12. Season of many colors
13. Creative pumpkins
16. Co-sponsor of Summer conference in Tampa, FL

## NFADB SURVEY ON TRANSITION

NFADB is conducting a survey to increase our understanding of the most critical issues parents and families face during and after the transition process to adult life. This survey has been sent to families across the country who have young adults both in and out of school. NFADB will use the results of this survey to enhance its advocacy and training efforts at the national and state levels.

If you have not received the survey, please contact NFADB board members Janette Peracchio (860-633-0042 or email: [wperacchio@snet.net](mailto:wperacchio@snet.net)) or Blanche Stetler (732-721-5448 or email: [JTMommy@aol.com](mailto:JTMommy@aol.com)).





# International Report

By Clara Berg, NFADB International Liaison

## ARGENTINA

**Cordoba** - A symposium on congenital rubella syndrome took place in the city of Cordoba last November with the participation of 30 families and almost 100 professionals from Argentina and neighboring countries. One of the presenters was our own Nancy "Scoop" O'Donnell who reported on the latest international findings about CRS.

**La Pampa** - The School for the Blind and Visually Impaired from General Pico, under the direction of Professor Beatriz Zoppi, celebrated their 20<sup>th</sup> anniversary of providing services to a vast population in the area also including Patagonia. Mrs. Zoppi has been deeply involved in organizing professional training for teachers.

## BRAZIL

In 1999, following the example of NFADB, a group of parents from Brazil funded their own association (ABRAPASCEM - Asociación de Padres de Sordociegos y Múltiplos Deficientes Sensoriales del Brazil). Their main objective is to reach families throughout the entire country and to help disseminate information about deaf-blindness as well as providing support for the education of the children and adults in the community.

The Association is involved in creating awareness on issues regarding deaf-blindness. They planned a campaign of seminars including health service providers to obtain better health services for their children. They have a membership of 150 families mostly from the southern cities, and their goal is to reach areas in the north and northeast parts of the country where services are scattered. Every year they organize regional meetings with the participation of international guest speakers.

## URUGUAY

With permission from Teresita Onetti, this is the English translation of her introduction to the DB Spanish listserv, I think it is very inspiring and wanted to share it with you.

*"Dear listserv friends, I want to introduce myself to you and tell you a little bit about me. I am deaf and*

*totally blind with hypoacusia due to the fact that my mother had rubella when she was three months pregnant. Thanks to fervent dedication and excellent medical services, and most of all thank God, I had a very "healthy" development that allowed me to graduate from college and work for more than 30 years in a state agency. I have a very busy and rewarding life that includes one daughter and two grandchildren. I became totally blind at age 49 and started to wear hearing aids immediately after. From that moment on, I decided that if I wanted to have the same quality of life as before, I needed training and I enrolled at the Rehabilitation Center of Cachon. During this difficult, painful but successful process of my rehabilitation, I understood the imminent need of people who are blind or deaf-blind to receive disability specific and appropriate training to obtain a life with dignity.*

*It was then that I accepted the invitation to join ASCUY (Asociación de Sordo Ciegos del Uruguay), as they were starting, and today I am proud to say that I am the secretary and participate as a board member. I'm sure that our paths will bring us together to work for the same cause, Teresita"*

## VENEZUELA

With the initiative of FUNDAPAS (Parent Association for the Deafblind) and the financial support from local agencies and the Hilton Perkins Program, Massiel de Iriarte (president), Nelcida Salcedo de Suarez (vice president) and Orietta Leon de Goicoechea (director) visited the state of Nueva Esparta to work with about 50 people, including children, teenagers and adults who are deaf-blind due to Usher syndrome in different areas of the island.

One of their many objectives was to visit public and private organizations dealing with education, health and regional government. Information was shared about networks and resources to help this population. It was the first time that parents, relatives and children from Peninsula de Macanao and La Asuncion and Porlamar got together to address issues for their children.

*(International Report continued on next page)*

## International Report



**Massiel communicating to Loismar, Jeanette (teacher), Maria (mother) and Loismar's younger brother**



**Massiel, Nelcida, Orietta (parents) & Jeanette (teacher/interpreter)**

**Loismar, receiving O&M from Massiel in front of his home on the beach (Manglillo)**



### ICEVI

Representatives from Guatemala, El Salvador, Nicaragua, Panama, Dominican Republic and Costa Rica got together in Guatemala City last November, as a subregion from ICEVI, to create strategies to work in each of the countries:

Some of their common goals include:

- creating a database including professionals, parents and people who are deaf-blind
- sharing information from the O&M newsletter in each country
- developing a working plan for 2007 that will include:
  - strategies to improve information sharing
  - identifying each country's unique needs
  - establishing goals for each country.



## SUPPORT THE NFADB! MEMBERSHIP CATEGORIES

(\*U.S. funds only)

**REGULAR:** any person who is deaf-blind, their parent, guardian or family member.

- ☐ **One Year: Individual** \$15  
☐ **Additional family member(s) at same address** \$5 each  
☐ **Three Years: Individual** \$30  
☐ **Additional family member(s) at same address** \$10 each  
☐ **Lifetime (Individual only)** \$100

**PROFESSIONAL/ASSOCIATE:** individuals interested in supporting the mission and purpose of the Association.

- ☐ **One Year** \$15 ☐ **Three Years** \$30 ☐ **Lifetime** \$100

**ORGANIZATIONAL:** any established parent/family organization interested in supporting the mission and purpose of the Association.

- ☐ **One Year** \$100 ☐ **Three Years** \$250

☐ **SCHOLARSHIP:** I am an individual who fits the Regular membership category and am requesting a "scholarship" to receive the newsletter for a one-year period.

### ONLY REGULAR MEMBERS ARE ELIGIBLE FOR ELECTION TO OFFICE

ALL MEMBERS AUTOMATICALLY RECEIVE OUR NFADB  
MEMBERSHIP KIT AND OUR NEWSLETTER

**CONTRIBUTING SPONSORS:** those involved by reason of monetary or other gifts of value to the Association.

- ☐ **Contributing Sponsor** - \$ \_\_\_\_\_

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E-mail: \_\_\_\_\_

### 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

I give permission to include the above information in a "Members Only" directory. ☐ Yes ☐ No

NFADB Newsletter is also available by request in  
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