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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



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THANK YOU!! This goes out to all who took the time to fill out and return the survey that NFADB sent out this February. The survey went to members and various service providers, including state deaf-blind projects. All were asked to comment on the image, role, and status of NFADB. We asked and you told us. Your Executive Committee and advisors spent two days in March going over the survey and determining what those results meant for the future of NFADB and determining a plan of action.

Website

Within the next month our website will sport a new look and over time more changes and updates will be in place.

Newsletter

A newsletter will be published twice a year containing articles and information that help convey and promote the issues families are most concerned about or need to have a more in depth level of awareness and knowledge.

Conference

It was clear from the comments that all missed the conferences we had in the past. We are investigating some options for parents and professionals to be brought together to learn and share experiences.

Confusion over identity

There is confusion as to who are **American Association for Deaf-Blind (AADB)**, **DB-LINK**, **Helen Keller National Center (HKNC)**, **National Consortium on Deaf-Blindness (NCDB)**, **National Coalition on Deaf-Blindness (NCDB)**, etc. Within the next few newsletters we will have an article on each of these groups so that our members will know who they are and what they do.

Advocacy

As a national organization we need to be more proactive on issues that affect our children and families. Advocacy will become one of our priority areas. We need to educate our families on various issues so that they can advocate on the state and national level. This must be a partnership so we can have the greatest impact.

Over the next two years we plan to address many of your concerns. The National Family Association for Deaf-Blind wants to be an organization that represents its members and their needs. We want you to be proud to be a member of NFADB. ♥

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."

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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

ADVOCACY



This is Marcus at the prom with his friends. Marcus is in the bow tie.

Looking Good! He is the son of NFADB board member Erma Hill.





ALLIANCE NATIONAL PARENT TECHNICAL ASSISTANCE CENTER INSTITUTE ON CHILDREN'S MENTAL HEALTH AND EMOTIONAL BEHAVIOR DISORDERS

JANUARY 26-28, 2010 ARLINGTON, VA

Submitted by Janette Peracchio, NFADB Secretary

The Institute on Children's Mental Health and Emotional Behaviors opened with Roberto Rivera as the speaker who spoke about developing hope and leadership skills in students. He was so inspirational to the audience, sharing his poetry and profound insight into helping youth to have a happy, balanced life. Here are a few of the statements from Roberto that gave me pause:

- **For youth to find their voice in the world they must "get their ships together:** citizenship, leadership and relationships."
- **Students need a vision to move forward in their life** - Answer: Who am I? Why am I here? What are my options?
- **Happy people have healthy relationships,** have meaning in their lives from church or temple, and often have goals to make a difference in the world, to make lives better.
- **"Unless we stand for something,** we will fall for anything."
- **Students may show they have courage to do the correct things.** "Courage is not the absence of fear but is taking action while facing fear."

Susan Jenkins, M.D., was an excellent speaker about "The Many Faces of Anxiety in Children and Teens" that can show up at home or in the classroom. Information was shared on how common anxiety is (snakes, spiders, heights) and what treatment methods are available. Anxiety is felt by everyone. You may have your emotions under control and look poised on the outside or you could have a physiological response to a perceived threat and get physically sick or lash out. Dr Jenkins described four faces of anxiety by dressing up in costumes and acting like each "face," which was very cleverly done and easy to understand the differences of each one. The four faces:

- **Phobia** - is a focused anxiety. You become anxious when you are faced with something that triggers physical symptoms - spiders, clowns, speaking to large audiences, flying in an airplane, etc. You may react with a headache, rapid breathing, dry mouth, gag sensation, sweating, or increased heart rate .

- **Panic** - an attack happens when your mind generates ideas about what might be happening and you have a breakdown of your ordinary coping skills. You could have fast breathing, talk at a rapid rate, blush and overheat, and you may engage in substituted behaviors like excess eating, bathing, picking skin.
- **Obsessive Compulsive Disorder (OCD)** - your coping strategies are turned on to high intensity and you cannot control your actions. You may be experiencing unwanted thoughts and doubts and the intensity may cause feelings of dread and negative thinking. You carry out rituals that you hope will decrease your anxiety but the distress causes interference with having a normal life.
- **Post-Traumatic Stress Disorder** - results in social anxiety which interferes with participation in normal daily activities. There are a wide range of characteristics which Susan described using a five point color scale: **blue** describes a cool, calm patient person; **green** describes an awake and fresh person; **yellow** describes someone who is ready for action; **orange** describes someone in their battle station - ready to fight; and **red** describes someone who is lashing out, losing control. Music can sometimes help lower stress to a calmer color, isolation can help, and inquiring what the person needs to calm down can be helpful.

The main thing Dr. Jenkins stressed was to treat anxiety of all kinds with gentleness and respect.

The third speaker, who was outstanding, was Read Sulik, M.D., Child Adolescent Psychiatrist. He spoke about "Depression - What Every Parent Needs to Know." Depression affects your mood, sleep, energy level and your thinking. It will impact your interpersonal relationships, performance at school and work, and in adolescents it can affect the development of the brain.

- **Mood:** Students who are depressed can be described as having *anhedonia*. They have an incredibly flat mood. They can't react properly or feel joy or sadness. There is no variation of mood, making it difficult to take things forward in their lives. They want to be alone, have no motivation and severe cases can lead to self injurious behaviors.

....continued on page 4

AFFILIATE UPDATE....

Pennsylvania Partnership for the Deafblind (PPDB) Update

submitted by Gordon Boe, President, PPDB



In January 2010, the Pennsylvania Partnership for the Deafblind published a guide on transition for parents of youth who are deaf-blind. The guide is the end product of a two-year grant from the Pennsylvania Developmental Disabilities Council.

Hopscotching Your Way Through Transition: Questions Parents Need to Ask as Their Child with Deafblindness Moves from School to the Adult World was written by parents for parents. It is intended to answer questions, provide resources and give insight to parents faced with planning the future of their child with deaf-blindness. The guide differs from so many transition publications because it includes information specific to deaf-blind issues and resources.

Hopscotching is available in print or CD form, as well as online at the PPDB website: www.papdb.org. To obtain a copy, or learn more about PPDB, you can contact Molly Black at 1-800-446-5607 x 6866, or at mblack@pattan.net.

In other news, the PPDB Board is preparing for its participation in the Pennsylvania Deafblind Initiative's Family Learning Conference, to be held in June. At that time, we will hold our annual membership meeting, hold Board elections, begin our 2010-11 membership drive, and decide on our key priorities for the coming year. Finally, with the completion of the Developmental Disabilities Council grant, we are actively exploring opportunities for future grants.



Alliance National Parent Technical Assistance Center Institute (continued from page 3)

- **Physical Symptoms:** There can be sleep difficulty - too much or too little; having fatigue and feeling like you did not sleep at all; appetite changes can occur - loss of appetite and/or increased cravings for carbohydrates.
- **Cognitive Symptoms:** In infants and toddlers, depression can lead to extra whining, too much crying, not wanting to cuddle, lack of interest in surroundings, sleep disturbance, having a sad expression, a low tolerance for frustration and distractibility. In older students, the symptoms are similar and may also include difficulty concentrating, decreased ability to focus, feeling worried, having guilt of not being able to "snap out of it," low self-esteem, misperceptions of the world around them, and **suicidal thoughts** which **MUST** be talked about and not ignored. They will often have a drop in their school grades and have the feeling of being rejected by family and peers. They do not recognize their change in thinking and will not understand what to do.

The **treatments for depression** are: education of child, family, school and community; psychotherapy in the form of play therapy or art therapy; finding the correct medication which can help the transmitters in the brain to function properly. Children often metabolize medications quicker than adults so they must be closely monitored. Families and schools can help promote good mental health by addressing self-awareness, tolerance of differences, self-esteem building, being resilient, finding purpose and meaning of life, teaching good communication skills, fostering interpersonal relationships, teaching about self-soothing, encouraging recreation and having fun.

It was a wonderful conference with outstanding speakers and topics. I learned a lot. ♥



NATIONAL COALITION ON DEAF-BLINDNESS

Article submitted by Betsy McGinnity, NFADB Special Advisor

The National Coalition on Deaf-blindness is a 2,000+ member organization of parents, professionals, consumers and agencies serving the population who are deaf-blind. We have been collectively advocating for the needs of children who are deaf-blind since 1987. The Coalition has established an Executive Committee to help guide and direct advocacy activities. The committee has representation from the following groups: American Association of the Deaf-Blind (AADB), National Family Association for Deaf-Blind (NFADB), Helen Keller National Center (HKNC), The Teaching Research Institute - Western Oregon University, Perkins School for the Blind, Sowell Center for Research and Education in Sensory Impairments, and several individual leaders in the deaf-blind community.

The Coalition is seeking a \$5 million increase above the President's FY11 budget request to address the resource needs of children who are deaf-blind and their families. The state and national projects that support children who are deaf-blind, their families and educators have not had a budget increase in over 20 years, despite a doubling of the population of children who are deaf-blind over that same time period. The modest \$5 million increase we are requesting for deaf-blind programs for FY11 is urgently needed to help states improve their services for families, to support the activities of the national technical assistance and dissemination center on deaf-blindness, and to strengthen personnel preparation programs.

This year, the coalition worked with Rep. Edward Markey (MA) and Rep. Mike McCaul (TX) to lead an effort in the House to send a group letter to the Chair and Ranking Member of the House Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies (Labor, HHS), urging them to support the \$5 million increase. The Coalition also worked with Senator John Kerry (MA) to lead a similar effort in the Senate.

The following signed these letters:

Representatives

Ed Markey (D-MA)
Mike McCaul (R-TX)
Jim McGovern (D-MA)
William Delahunt (D-MA)
John Tierney (D-MA)
Barney Frank (D-MA)
Mike Capuano (D-MA)
Steve Lynch (D-MA)
Edolphus Towns (D-NY)
Niki Tsongas (D-MA)
Steve Israel (D-NY)
John Conyers (D-MI)

Senators

John Kerry (D-MA)
Chris Dodd (D-CT)
Ben Cardin (D-MD)
Sherrod Brown (D-OH)
John Cornyn (R-TX)
Chuck Schumer (D-NY)
Kirsten Gillibrand (D-NY)
Dick Durbin (D-IL)
Russ Feingold (D-WI)
Bob Casey (D-PA)
Scott Brown (R-MA)*



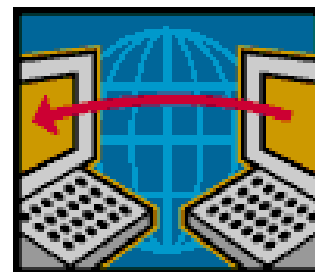
*Sent individual letter

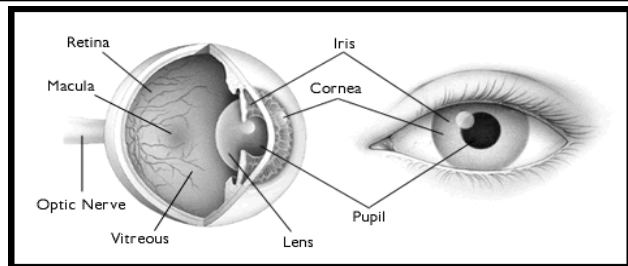
Both letters have now been sent. The Coalition will soon be asking members to contact the key members of the Labor HHS Subcommittees. We will continue to monitor the budget process and inform members about next steps.

We need your help. Please join us. Visit our website <http://dbcoalition.org/>, sign up for our discussion group <http://groups.yahoo.com/group/national-db/> or join us on Facebook <http://www.facebook.com/#!/group.php?gid=108602429165679>

The Helen Keller National Center (HKNC) has a new electronic newsletter called *CONNECT*!

Visit us at www.hknc.org to read and/or subscribe.





The Eyes Have It

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

Cortical visual impairment (CVI) is caused by nerves that are hurt in the brain, not in the eye. Sometimes it is called “neurological visual impairment.” Neurological means that it is a problem in the nerves or in the brain. People who have CVI often have other disabilities as well. Doctors and teachers are learning more about this kind of visual impairment all the time.

Causes

Nerve damage that causes cortical visual impairment can sometimes happen during birth. Sometimes a baby does not get air as soon as he or she is ready to breathe. The brain needs the air to stay alive. A car crash or a bad fall can also hurt the nerves in the brain. This is called traumatic brain injury (TBI). Vision after traumatic brain injury may be a lot like CVI.

Signs/Symptoms

People with CVI have vision that does not stay the same. The vision may change all day long. People with CVI may see something in the morning that they cannot see later in the day. Sometimes people think that people with CVI are playing games when they cannot see the same things they saw before. Vision may get better as a baby gets older and the injury to the nerves heals. After a car crash or a bad fall, the nerves may heal as well. Some people with CVI love to look at lights. Others may find it hard to see when there

is too much light (glare). People who have CVI have a hard time looking at more than one thing at the same time. They like to bring things close to their eyes so that they can just see one thing up close. When things are bunched up, it is hard for people with CVI to tell where one thing ends and another begins. It can be difficult to read. Letters may look like they are bunched up or crowded. People with CVI may see only the first and last letter in a word. Sometimes it is hard for them to read or see pictures when they are sitting still. People with CVI need more time to think about what they are doing than people who don't have CVI. They may need to rest their heads to use their eyes. Some people who have CVI like to look at colors. They see color best.

Care

If you have CVI, you may have to tell other people what helps you see. The teacher or doctor may not know what will help. Read about the kind of vision people who have CVI may have. Then think about the kind of vision you have. You can make a list of the things that help you see. Let your teacher or doctor know what helps you see best. Take your time, and tell other people that you need time to look and to think or to rest. If there is a color that you like, ask for things in that color. You can put that color on your table and chair at school and even on your backpack. Most of all don't be afraid to advocate for yourself.



HKNC
Deaf-Blind Awareness Week
June 27 - July 3, 2010

This year's theme:
Support Service Providers

Additional information
available at:

www.hknc.org

UPCOMING CONFERENCES

2nd Annual
Usher Syndrome
Family Conference

Seattle Children's Hospital
Seattle, WA
July 9 - 10, 2010

Registration information is
available at:

www.hearseehope.com

2nd Annual CHARGE Syndrome
Deaf-blind Weekend
July 16-18, 2010

Kingsport, TN

For Families and Professionals

TREDS (TN Deafblind Project)

Additional information available at
(or copy & paste to your browser):

**[http://www.nationaldb.org/
ppTraining.php?rID=1823](http://www.nationaldb.org/ppTraining.php?rID=1823)**

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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Newsletter Coordinator: *Vacant*

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

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International Coordinator: Clara Berg e-mail: ClaraB428@hotmail.com, ph: 718-428-1591; **EC:** Janette Peracchio e-mail: jbperacchio@gmail.com, ph: 860-558-7648.

Web Site Coordinator: Debbie Ethridge e-mail: debbieethridge@yahoo.com.

When sharing or copying information and articles from our newsletter, please credit

News From Advocates for Deaf-Blind
as the source. **Thanks!**

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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:

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State: _____ Zip: _____

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Send this form with your donation to:

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

Thank you!

SUPPORT THE NFADB! MEMBERSHIP CATEGORIES

(*U.S. FUNDS ONLY)

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

- ☐ **One Year:** \$15
☐ **Three Years:** \$35
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PROFESSIONAL/ASSOCIATE: individuals interested in supporting the mission and purpose of the Association.

- ☐ **One Year** \$15 ☐ **Three Years** \$35

ORGANIZATIONAL MEMBERSHIP: Organizations interested in supporting the mission and purpose of the Association.

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

Regular members are eligible to serve on the NFADB Board of Directors.

All members automatically receive our NFADB newsletter which is also available by request in BRAILLE, LARGE PRINT or electronically. Indicate preference on application.

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ALL MEMBERS AUTOMATICALLY RECEIVE OUR NFADB
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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

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

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