



# HANDS

Winter/  
Spring  
2014

Hearts Advocating Needs for Deafblind Services: The Newsletter of the Illinois Advocates for the Deaf-Blind (IADB)

## 2014 Conference in Peoria Focuses on Sensory Issues

### Parent Weekend Planned for April 5-6

Join us for a parent training weekend put on by the Philip Rock Center, Project Reach and IADB in conjunction with the Illinois Family Leaders Collaboration Conference. IFLC will hold its 8th Annual Family Conference for adult family members and caregivers of children with disabilities at Peoria's Spalding Pastoral Center on Saturday, April 5th from 8:30 am to 3:00 pm.



Featured speaker, **Dr Jennifer Rosinia** will present *What's With All This Sensory Stuff?* Jennifer Rosinia, PhD, OTR/L, is a Registered Occupational Therapist with nearly 30 years experience in pediatrics. A master clinician and a gifted teacher, Dr. Rosinia has a special interest in sensory

Project Reach and IADB will pay for a Saturday night hotel stay at the Stonycreek Inn and mileage for attendees coming from outside the Peoria area. Contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or [ppausche@philiprockcenter.org](mailto:ppausche@philiprockcenter.org).

processing and neuroscience, the role of emotions and the impact of relationships on the developing child. With a growing national reputation as a powerful speaker and consultant, Dr. Rosinia brings a healthy balance of humor, passion, and expertise to all of her presentations. Join us for a light-hearted approach to learning about sensory processing (i.e. why do kids do the goofy things they do), includ-

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*Vicky Maag with daughter Kenna flanked by Doctors Rizzo and Braverman during clinic at the GFPD Conference in Lincoln, Nebraska*

### GFPD Conference and Study News

by *Vick Maag of Carrollton*



Our family attended the third annual 2013 GFPD (Global Foundation for Peroxisomal Disorders) Family & Scientific Conference in Lincoln, Nebraska in July. Twenty five families came from near and far to attend the conference, including parents, affected children, siblings as well as parents of "angel" children. We even had one family make the trip all the way from Australia.

Peroxisomal Biogenesis Disorder - Zellweger Spectrum Disorder (PBD-ZSD) is a genetic condition affecting all major systems of the body. It includes a wide range of phenotypes that were originally separately classified as Zellweger Syndrome (ZS), Neonatal Adrenoleukodystrophy (NALD), and Infantile Refsum Disease (IRD). As the understanding of this disorder has grown, there has been a movement away from the original classifications to simply PBD-ZSD to cover all phenotypes.

This conference was especially exciting  
**See GFPD, page 3**

### Experiencing the Wonder (and Heat) of the CHARGE Conference in AZ

by *Betty Metroz of Fairbury*

In July, our family attended the 2013 CHARGE Syndrome Conference whose theme was "Experience the Wonder". We stayed at the Fairmont Princess Resort in Scottsdale, which sits on 65 acres. While it's a beautiful place, we soon found out that it was not very handicapped accessible. Also, during our stay, Arizona hit their all time high temperature, and we were feeling it. Thank goodness for air conditioning!

Despite the heat and accessibility issues, we had an amazing time, meeting new families from all over the world. One



mom we met came all the way from Paris. She told us that her country is not very supportive of its citizens with special needs. In France, children who are 16 years old can no longer attend school and have few options once they age out. Her daughter is now in an "institution" where her behavior is sometimes out of control and there is no communication. This mom tried to keep her daughter at home as long as she could, but her

child's behavior issues made it impossible to care for her at home. Her tearful story made us appreciate the support and resources available to people with special

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## CHARGE *from page 1*

needs here in the United States.

Our son Adam enjoyed the conference as well. While my husband Jeff and I attended the meetings, Adam was at “camp” (which he saw as school). They had plenty of activities to keep Adam engaged and amused.

I think the most important thing about attending these conferences is not so much the information that we receive, but rather the connections that we make. It’s about getting to meet other families who are going through all the same feelings and emotions everyday and sharing our experiences with each other.



*Adam Metroz hangs out with his camp counselor and buddy Robert at the CHARGE Conference.*

## Parent Weekend *from page 1*

ing an introduction to the major concepts and how sensory processing challenges influence development, learning, and most importantly, relationships. Childcare is not provided.

The IFLC Conference is designed for parents, caregivers and educators of children with any kind of disability. Parents of children with deafblindness are invited to attend additional events just for them organized by Project Reach and IADB. On Saturday evening, families will meet for a group dinner at a local restaurant. Later at the Stoney Creek Inn, we’ll have a deafblind experience activity, sign survival presentation, followed by brief IADB Board Meeting. We’ll end the weekend on Sunday morning, with a fun “Make and Take” session led by Rose Slaght.

For information and registration, contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or [ppausche@philprockcenter.org](mailto:ppausche@philprockcenter.org).

## *Reading Resources that are Just a Click Away*

### Literacy Online

#### National Braille Press - [www.nbp.org](http://www.nbp.org)

A non-profit braille publisher, NBP promotes literacy for blind children through outreach programs and provides access to information by producing information in braille for blind children and adults.



Check out their Children’s Braille Book Club, ReadBooks! national children’s braille literacy program, and rub ‘n smell scented Braille Valentine’s Day cards.

#### Bookshare - [www.bookshare.org](http://www.bookshare.org)

Funded by the Department of Education, Bookshare provides accessible books and periodicals for readers with print disabilities. Free memberships are available to qualified students and schools.



#### Seedlings Braille Books for Children - [www.seedlings.org](http://www.seedlings.org)

Seedlings is a not for profit organization that provides high-quality, low-cost braille books for children. It has over 1,200 braille books available. Check out the Book Angel Program for V-I Readers and the Rose Project: World Book Encyclopedia Articles in braille.



## Candy Sale Kicks Off in April

IADB’s annual World’s Finest chocolate bar sale is back by popular demand. We’ll be launching the fundraiser at our annual Parent Weekend in Peoria in April (see story page 1). A variety of World’s Finest chocolate bars are available for \$1 each: milk, almond, crisp, caramel, and dark almond. Almost everyone on IADB’s board of directors (listed below) will have a box or two (or five) to sell, so you know who to call to get your chocolate fix. Or

if you’re ever at the Philip Rock Center in Glen Ellyn, see Michelle Clyne, she’ll hook you up.

If you’ll be at the Parent Weekend and would like to help with the fundraiser, organizers plan to order a few extra boxes for anyone who wants to start selling (or eating) at home.

For more information, contact Jayne Wright at (309) 726-1036 or [jm.wright@mediacombb.net](mailto:jm.wright@mediacombb.net).

### Illinois Advocates for the DeafBlind

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Membership in IADB allows you to connect to families throughout the entire state of Illinois who have members who are deafblind. IADB works to ensure that anyone who is deafblind is able to live a full and productive life. Membership entitles you to receive the IADB newsletter and attend events that provide opportunities to network with other families and educators, and service providers.

IADB offers one-year memberships for only \$12, or lifetime memberships for \$100. To join or renew your membership, please make checks payable to IADB and mail to: IADB Membership, 818 DuPage Blvd., Glen Ellyn, IL 60137.



*Some of the many children who attended the GFPD Conference in Lincoln, Nebraska*

## Transitions

### PASSING

**Nicholas Wright**, 18, son of IADB members Mark and Jayne Wright of Hudson, died on November 4th. Nicholas was one of the oldest people living with Trisomy 13 in the United States.



Our readers might remember Nick, as his photo has appeared on these pages as a frequent attendee of the SOFT Conference. Our condolences go out to the Wright family.

### RETIREMENT

**Peggy Whitlow**, Chief Administrator of Philip J. Rock Center and School in Glen Ellyn retired in December after many years of faithful service to the school. Her job title is not an accurate reflection of all that she did for the staff and students at Philip Rock. Thank you Peggy, you will be missed!

for our families because of the first ever open study happening right in the world of PBDs. Our hard-working scientists have found a drug, that in the labs, has shown an increase in Peroxisome function. This drug is called Betaine and it is FDA-approved for treating homocystinuria. Our daughter Kenna is participating in the study and has started taking the drug. There is no placebo given because of the limited number of kids in the world with this disorder. She began with a dose of 6 g and increased quickly to 12 g given three times a day. Dr. William Rizzo, from the Nebraska Medical Center in Omaha, is our monitoring physician. Kenna had labs drawn at the conference. As the study

progresses we will do more labs closer to home at St. Louis Children's Hospital that we will send to Omaha. After six months, we will travel back to Omaha for the final blood draw and to meet with Dr. Rizzo again. Our hope is that there will be enough improvements to continue the study for a longer period of time.

In 2014, there will be no scientific conference, instead GFPD is organizing a more informal gathering in Florida where families can vacation together, relax and reconnect. Other smaller, regional get-togethers are also in the works. For more information visit [www.thegfpd.org](http://www.thegfpd.org).

## Chicago-Area Girls Who Play a Sport (Any Sport) Can Get Help Paying for Hearing Aids



Do you know an elementary, junior high or high school girl who participates in sports whose family needs help paying for her hearing aids?

Thanks to a special fundraising effort, the Chicago Hearing Society (CHS) has a special fund to pay for hearing aids and related services for girls in the Chicago area. Girls who participate in any type of sport – through their school, park district, local Y or any youth sports – are eligible. If you

know a family who could benefit from this special fund, have them contact Jill Sahakian directly at [jsahakian@anixter.org](mailto:jsahakian@anixter.org) or 773-248-9121 ext. 307.

## Noisy Toys List

Every year the Sight & Hearing Association puts out a list of noisy toys. While the list is intended to serve as a warning, we understand some of our kids need a little more volume to enjoy their toys. Use it at your discretion.

Baby Einstein Take Along Tunes  
Twister Dance Rave  
B. Meowsic (Piano)  
Doc McStuffins Talkin' Check-up Set  
Road Rippers Road Rockin' Ricky  
Leap Frog Chat & Count Smart Phone  
Fisher Price Shake 'n Go Disney Planes -  
El Chupacabra



**Disney Baby Einstein Discovery Drums**  
Despicable Me 2 Fart Blaster  
Care Bears Wiggle Hugs Wonder Heart  
Bear  
123 Sesame Street - Steps to School -  
Ready for School Elmo  
Vtech Roll & Learn Turtle  
Nickelodeon Dora Rocks Singing Star  
Microphone  
Transformers Rescue Bots Electronic  
Bumblebee  
Laugh & Learn - Love to Play Puppy  
Marvel Iron Man 3 - Arc Strike Iron Man  
Disney Planes - Soar & Learn Plane  
**Star Wars - Darth Maul Electronic  
Helmet**



## September Mom's Retreat in Rockford

*by Rose Slaght of Rockford*

We gathered at Bishop Lane, near Rockford on Friday the 13th, but there was nothing unlucky about this night. Sandy Valentine, advocate and mentor, welcomed us with her wisdom and humor. Mothers of children with disabilities from all over Illinois and even from some from Iowa listened, laughed and networked. June Blunk, artist and inspirational speaker spoke to us about taking care of ourselves on Saturday. The next day we shared breakfast, reflections of our experiences, and then the ever-popular "white elephant" gift exchange before leaving for home and family. Wendy Partridge demonstrated a solution circle with Kara Sword as the focus, helping parents think about concerns in proactive and solution-oriented ways.

We enjoyed pampering, the outdoors, fellowship, meals, quiet time, shopping with vendors who brought their wares, information about various topics, reading, campfire, crafts, cooking demonstration by Chef Tom Sullivan, massages, manicures, reflexology, some laughter, tears and lots of resources.

We must make time to connect with other moms who walk on our same path in order to be better people, mothers, and friends. I encourage all of us to participate in upcoming retreats and other learning opportunities. The more we know, the better we can help our children and the people who love them.

Want to know more about upcoming Mom's Retreats? Contact me, Rose Slaght at (815) 389-1077 or rojo01@charter.net.

## Moms Night Inn - Central

**March 1 – March 2, 2014**

Hilton Hotel, 700 East Adams Street, Springfield, Illinois

Moms and female caretakers of children with hearing loss come together to bond and relax together. This event is for moms and female caretakers of children of ALL ages, no one is excluded from Moms Night Inn.

Brought to you by Illinois Families for Hands and Voices, a parent-driven, non-profit organization dedicated to supporting families that have children who are deaf and hard-of-hearing without a bias toward communication modes or methodologies.

For more information visit [ilhandsandvoices.wordpress.com](http://ilhandsandvoices.wordpress.com).