



HANDBS

Winter/
Spring
2012

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

IFLC 2012 Conference "Resources and Inspiration"

Family Leaders Conference to Return to Peoria

The Illinois Family Leaders Collaboration's 6th Annual Family Conference for adult family members and caregivers of children with disabilities returns to Peoria's Spalding Pastoral Center on April 28th.

Consultant, author, advocate and independent scholar **Dr. Paula Kluth** is the featured speaker. Her interactive, all-day presentation "Do You See Inclusion as a Place or a Process? And

Six Other Questions to Ask Your Child's School" will explore the philosophy of inclusion and how instruction can be designed for all learners. The conference is for parents, caregivers and educators of children with any kind of disability.



Parents of children with deafblindness are invited to participate in additional events just for them organized by Project Reach and IADB. We'll have a group dinner at

a local restaurant, and a parent chat and IADB board meeting. It's a wonderful opportunity to share information and resources and to network with other families who have children with deafblindness.

Watch for a mailing with further details and

registration information. Or visit www.starnet.org/training/workshops/APR28IF.php.

Questions? Contact Michelle Clyne at Project Reach, mclyne@philiprocenter.org or 630-790-2474.



The Kijowski family and a couple of friends at the CHARGE Syndrome Conference.

Recap of the 2011 CHARGE Conference

By Toni Kijowski



The Magic Happens Here was the theme of the 10th International CHARGE Syndrome Conference. It took place in late July in Orlando, Florida at beautiful Rosen Shingle Creek Resort. The three day conference held a total amount of 825 people including CHARGE families, professionals, and presenters from United States, Australia, Brazil,

Canada, Denmark, France, Germany, Italy, Netherlands, New Zealand, Norway, Spain, and the UK. There were about eight Illinois families with the children who have CHARGE present at this conference. The event was full of information, networking, support, and fun. We learned from the presentations and sessions about how to try to overcome the difficulties and challenges that we face every day. The presenters and professionals shared their information, research, and insights with us. The seminars had information for everybody including siblings, parents, grandparents, professionals, and people with CHARGE.

On Thursday, July 28th, the conference

1st GFPD Conference takes place in Omaha

By Maria M. McCarrick



My family and I were pleased to be able to attend the very first Global Foundation for Peroxisomal Disorders (GFPD) Family

and Scientific Conference in Omaha over the summer. This new foundation was formed in October of 2010 by a group of concerned parents looking to raise awareness and funds for Peroxisomal Biogenesis Disorders and to connect families affected

by PBDs (see box page 2).

Since this was the first conference of its kind, I wasn't sure what to expect when we rolled up to the Embassy Suites La Vista Hotel for the three-day event. We were met by GFPD's president Shannon Butalla and treasurer Melissa Gamble, both moms of children with PBDs (Sam and Ginny). Shannon and Melissa are forces of nature who willed this foundation and its first conference into existence.

See GFPD, page 2

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I was impressed by all they and their board accomplished in just a few short months.

The conference was well-organized and chock-full of valuable news, information, resources and advice from both professionals and parents. I can't emphasize enough how important it is for families to be able to come together, families that understand the unique challenges that we face caring for children suffering from Peroxisomal Biogenesis Disorders. Our daughter Katherine who has a PBD called Infantile Refsum Disease (IRD) had never even met another person with her condition. So it was great to be in Omaha where she was able to play in a room full of similarly-affected children. Katherine at 16 was among the oldest of the children at the conference, so the parents of the littlest kids were naturally curious about Katherine, how the disease has affected her, and how she copes. Just her presence there gave them a window into what the future might hold for their young children... that is, if they live that long. Sadly, many children affected by PBDs do not survive. Organizers planned a touching video tribute and candle-lighting ceremony for those children, many of them babies, who had passed away. There was also a special break-out session for grieving parents run by The Compassionate Friends of Omaha.

The conference featured an impressive slate of speakers: doctors, scientists and professionals (see list), leaders in their field, who came to present the latest research on and treatments for PBDs. Among the presenters was Dr. Gerald Raymond from the Kennedy Krieger Institute (KKI) at Johns Hopkins, who di-



Maria, Katherine, Thomas and Dan McCarrick enjoy dinner at Mahoney State Park near Omaha.

agnosed our daughter more than 13 years ago. At one of the sessions, Dr. Raymond presented the findings of his DHA/AA study, a double-blind study that toddler Katherine had participated in back in the late 1990s. There were presentations that covered almost everything: treatment and monitoring, screening and diagnosis (and pre-implantation diagnosis), diets and therapies, research and ongoing studies, hearing aids and cochlear implants, vision assessments, and deaf-blindness in general. To be honest, some of the scientific stuff was over my head, and I am no dummy, but the presenters were very patient with all of our questions. And I always appreciate having more information rather than less.

There was time to have fun and unwind as well. The kids had a toy-filled room staffed by enthusiastic volunteers. They got to play (and sometimes nap) while their parents attended the sessions. The last night featured a Mexican-themed dinner at the Riverview Lodge in beautiful Mahoney State Park. We enjoyed ourselves despite the oppressive August heat that greeted us whenever we left the comfort of the air-conditioned lodge to take in the spectacular view from the bluffs of the

What's a PBD?

Peroxisomal Biogenesis Disorder (PBD) refers to disorders in the Zellweger Spectrum, which include: Infantile Refsum Disease (IRD), Neonatal Adrenoleukodystrophy (NALD), and Zellweger Syndrome. PBDs are rare, genetic, metabolic, terminal conditions affecting all major systems of the body. Children with PBDs commonly experience sensorineural hearing loss, vision loss, hypotonia (low muscle tone), seizures, developmental delays, liver and kidney issues, problems with bone formation, feeding issues, and adrenal insufficiency.

Platte River.

The final morning we were fortunate to be able to participate in a clinic at Children's Hospital, where Drs. Rizzo, Raymond, Braverman and a host of attending physicians examined Katherine and answered all of our pressing medical questions and we answered some of theirs.

I think it is this give-and-take, this spirit of cooperation, and sharing of information that made the whole event worth the trip to Omaha. We left Nebraska with so much more than we came with, including a wheel chair provided to Katherine from GFPD's equipment exchange program. Now she is riding in style in her new (to her) raspberry Convoid transport chair.

The next conference will be July 30-August 2, 2012 at the Floridays Resort in Orlando. Visit www.thegfpd.org for more information.

List of 2011 Speakers: Dr. Gerald Raymond of the Kennedy Krieger Institute (KKI), Dr. Nancy Braverman of Canada's McGill University, Hong Brereton of KKI, Dr. Stephen Steinburg of KKI and Johns Hopkins, Dr. Joe Hacia of the University of Southern California, Ann Moser of KKI, Mark Wilkinson of the University of Iowa, Jeff Simmons of Boys Town National Research Hospital of Omaha, Barbara Purvis of the National Consortium on Deaf-Blindness, Dr. William Rizzo of Omaha's Children's Hospital, Shannon Butalla of GFPD, Melissa Gamble of GFPD.

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Educational Videos Available to View On-Line

Perkins School for the Blind has a variety of educational videos available to view on their website. Just go to www.perkins.org, select the "Teaching Resources" tab, choose "Webcasts", and select the video you want to view.

Here are some examples of the great webcasts they have to offer.

CHARGE Syndrome: The Impact on Communication and Learning—By Martha Majors

This very insightful webcast explains the physical, sensory and neurological issues shared by many children with CHARGE and how these issues can affect their success in school. Martha Majors, who has served many children with CHARGE in the Deafblind Program at Perkins, offers guidance for educators in developing an effective educational program that will improve the emotional wellbeing and success in learning for students with this syndrome.

Early Literacy for Students with Multiple Disabilities or Deafblindness—By Deirdre Leech

Students with multiple disabilities, including deafblindness face many learning challenges. They do not learn literacy in typical ways. Often they do not have exposure to books and literacy based materials. Children with hearing loss may not have heard stories read aloud, and may not have used books on tape. The goal for these students is to maximize access using specialized formats.

Families as Partners in the Educational Team—By Dr. Katharine Shepherd & Susan LaVenture

In this webcast, Dr. Katharine Shepherd, Project Director: Parents as Collaborative Leaders Program and Susan LaVenture, Executive Director: National Association of Parents of Visually Impaired Children share their expertise and passion for supporting parents in developing leadership and advocacy skills. As keynote speakers for the Discover Conference, Katie and Susan share their personal and professional experiences to illustrate the powerful role that parents play in children's lives.

Mealtime Skills—By Sue Shannon

Sue Shannon, an occupational therapist at Perkins School for the Blind, describes some of the challenges faced by students who are blind in learning mealtime skills. It focuses on and provides video demonstrations of effective strategies for teaching the skills of pouring, serving, utensil use and cutting. Sue's book, *Help Yourself: Mealtime Skills for Students Who Are Blind or Visually Impaired*, is available in the Perkins Products store.

Company Offers Tactile/Braille Greeting Cards

HeartSight Cards are handmade, print/Braille greeting cards using layers of patterned and textured papers and decorative buttons, ribbons, rhinestones, and other embellishments so that they can be enjoyed with both fingers and eyes. Each card has a simple, occasion-appropriate inside greeting that can be personalized with your own message. Current categories include birthday, thank you, kids, thinking of you, love and friendship, and all occasion. At present there are seventeen different card designs, and new designs will be added regularly. A detailed Braille description is included with each card. HeartSight cards are mailable and affordable, costing \$2 to \$3 less than the competition. Your card order will be sent directly to you or to your special person, usually within one to three days of order receipt. A portion of the proceeds benefit the National Federation of the Blind (NFB). To order, contact HeartSight Cards at 4794 Geneva Avenue, Portage, Michigan 49024 or (269) 779-2216. Their email address is heartsightcards@att.net, and website is www.heartsightcards.com.

IADBD (that's not us) wants to hear your PUNS story

The Illinois Advisory Board for Persons who are Deaf-Blind (IADBD) is looking for families with children or adults who are deaf-blind to share their stories about accessing services in order to evaluate the system of support here in Illinois. Read all about it:

We, (the IADBD), are gathering information from families of people who are deaf-blind about their experi-

ences with the local PAS (Pre Admission and Screening) Agencies. Our focus is on the PUNS (Prioritization of Urgency of Needs for Services). We are hoping to gather Family stories, both positive and negative, in order to more fully address barriers in the current system of choosing who receives services from that waiting list. Our information will go to the State of Illinois, for them to understand the complicated nature of the persons we love and care for, people who happen to be deaf-blind.

Please feel free to email me your experiences, or call me if you'd rather. I will ask you questions, not to be in your business, but in order to figure out what may be occurring for you and your family. We will maintain confidentiality, and if you choose to share your personal information, we can call on you in the future, if the State has questions that they want to ask you. The power is in your hands.

The main goal is to show through our experiences, how complex and complicated some of the needs of our children and adults who are deaf-blind are. We need supports that other families may not need or other decision makers have no clue that we need.

I look forward to hearing from you.

*Roseann Slight
815-222-0659
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Mom's Night Inn: Join other mothers of children with hearing loss and let your hair down...

MOMS NIGHT INN NORTH 2012

February 11-12 at the Holiday Inn in Itasca, Illinois.

MOMS NIGHT INN CENTRAL 2012

March 3-4 at the Hilton in Springfield, Illinois.

Featuring massages, manicures, dinner, sweets, conversations, soul searching and crafts. Brought to you by Hands & Voices, a parent driven, non-profit organization dedicated to providing unbiased support to families with children who are deaf or hard of hearing. Contact www.ilhandsandvoices.org or 877-350-4556.

CHARGE *from page 1*

began with registration and it was a day dedicated to the professionals. Friday, after breakfast the CHARGE children and siblings went to Camp Discovery and Camp Explorer and the excitement and the anticipation began for the parents. Some of the breakout sessions included: Fathers Forum, CHARGE 101 (for all the new families), Technology for Learning & Fun, Problems with Self Regulation, Transition into Independent Living, Cochlear Implantation Studies with Children who Experience Deaf-Blindness, and new updates on genetics. The day ended with the 2nd annual CHARGE Syndrome Conference Idol and talent extravaganza. This event showed how intelligent and amazing our children are. It was inspiring to see what they are capable of and how much they have achieved. Some of the Saturday sessions were: Special Needs Planning Program, Social Skills, Creating Calm from CHARGE chaos, Educating Children in Local Schools, Toilet Training, Early Transitions, Identifying the P (pain in CHARGE), Heart & CHARGE, ENT & CHARGE, and Growth/Puberty. The most interesting session that I attended on Saturday was LAMP (Language Acquisition through Motor Planning) presented by John Halloran, who is a speech language pathologist and Senior Clinical Associate for the Center for AAC and Autism. He talked about neuroplasticity and understanding how we learn through our senses. The benefit of multisensory integration on learning through assistive technology was also presented by him. The night ended with a CHARGE-A-Palooza: dinner, carnival, and silent auction which was a big success this year. On the last day, Sunday,

after two busy days of networking and seminars, it all came to an end.

The entire conference was such a morale booster and a major battery recharger. I felt full of hope for the future, had peace in my mind, healing in my heart, and more confidence in my child. David Brown, who is an education specialist from California Deaf-Blind Services, closed the conference and reflected on the last three eventful days. There were hundreds of people who listened to his inspiring and moving presentation. He compared the conference as a journey of hope, life experience, and pilgrimage through our difficult road to make our kids independent and be active members of society. By the end of the meeting, emotions were running high and we all had a new image of our children and what they are capable of overcoming.

There is so much information to absorb and so much to do, but we all know that we have support from our big CHARGE family. It was fantastic to meet so many wonderful people and renew friendships, and finally nice to put a face to a name. At the end we all had this hunger for the next conference which will be in 2013 in Scottsdale, Arizona. For those who could not attend this conference please visit the CHARGE website (www.chargesyndrome.org) to obtain free materials to download about the conference. This phenomenal experience wouldn't have happened without our presenters, sponsors, exhibitors, interpreters, volunteers, advisors, and board members. I'm pleased to share that the new president of the CHARGE Syndrome Foundation is Illinois' own David Wolfe.



IADB members from central Illinois enjoy lunch at Famous Dave's in Bloomington before heading to State Farm Park. The rain-shortened regional event took place on August 13. Thanks to Karen Olehy for organizing this popular annual outing.



JOIN US

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.

We have much to learn from one another, and joining IADB or renewing a current membership will enable our goals to be met. 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
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Glen Ellyn, IL 60137