



# HANDS

Summer/  
Fall  
2014

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

## Recap of Family Leaders Weekend

The Illinois Family Leaders Collaboration's 7th Annual Family Conference for adult family members and caregivers of children with disabilities was held in Peoria at the Spalding Pastoral Center in

Peoria. On Saturday, April 5th,



*Seth Harkins (right) new CEO of the Philip Rock Center chats with parent Jeff Antonson before dinner.*

keynote speaker Dr. Jennifer Rosinia gave a day-long presentation entitled *What's With All This Sensory Stuff?* (See story below.)

Parents of children with deafblindness attended additional events just for them organized by Project Reach and IADB. Saturday evening, everyone gathered for a casual group dinner at the Logan's Steakhouse in East Peoria. Later, participants met at the Stoney Creek Inn for an IADB board meeting followed by a Parent Chat. The weekend ended on Sunday morning with an with a relaxation-themed Make and Take session presented by Rose Slaght. (See story on page 2.)

Next year's event will be on March 7th.



## An ExtraOrdinary Endeavor!

*Illinois teen encourages people with extra challenges to be ExtraOrdinary!*

**Aubrie Westmaas** says, "People with disabilities need to be treated ordinary, but they do have some extras." She dreams of a time when all people with disabilities have the power and opportunity to be extraordinary. Aubrie is a 16-year-old high school student enjoying a busy life as an active member of her community. Despite a long list of challenges related to Kabuki syndrome, Aubrie is determined to enjoy the same opportunities and experiences as her peers. She is fully included in her neighborhood school, returns annually to several summer camps, is a top cookie-selling Girl Scout, has received a variety of school awards, is active in her church youth group, and participates in her school drama productions, Quiz Bowl team, chorus and marching band.

Aubrie has been an advocate as long as she can remember. She has visited the state capitol and sat at the governor's desk. She's attended statewide conferences, rallies at the capitol, and even met Temple Grandin. After learning about Martin Lu-

**See EXTRAORDINARY, page 4**

## Thoughts on Rosinia's Presentation in Peoria

### "Sensory Stuff" Takes Center Stage

by Maria M. McCarrick

**Jennifer Rosinia, PhD**, was the featured speaker at the recent Family Leaders Conference in Peoria. A Registered Occupational Therapist with nearly 30 years experience in pediatrics, Dr. Rosinia has a special interest in sensory processing and neuroscience, the role of emotions and the impact of relationships on the developing child.

Dr. Rosinia's presentation entitled *What's With All This Sensory Stuff?* was upbeat, engaging, funny, and filled with useful insights.

We all have sensory needs, the trick is figuring out what they are. Do we need more sensory input or less? Or perhaps you need more of one kind and less of another. You might need more auditory stimulation and less visual—do you close your eyes to listen better? Do you turn off the car radio to read the street signs? Do you put on your glasses to "hear" what



someone is saying? Over time, you've come to know these things about yourself and adjust accordingly. Our sensory needs are different and personal. If it is true for us as adults, it is even more true for our children. The distinction is that children haven't matured as we have. They haven't learned to cope with less-than-ideal sensory situations.

Now, think about the things that bother you. Are you able to focus when the tag

**See SENSORY, page 4**



# JOIN US

## Before Member Costs Increase!

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 currently 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.

## Free Online Parent Training Opportunity

The National Family Association for Deaf-Blind (NFADB) and the National Center on Deaf-Blindness (NCDB) are pleased to announce two online parent training sessions with identical content:

### Open Hands Open Access (OHOA) Module 3: The Role of Interveners in Educational Settings

July 7 – August 11, 2014 or  
 September 8 – October 13, 2014

Choose the one that fits your schedule.

The training will focus on:  
 The role of interveners.  
 The principles of intervention.  
 How interveners function as members of students' educational teams.

For information and registration, visit <https://nationaldb.org> and scroll down to the *NFADB Looking for Parents!! Online Training Opportunity* link. Or you can contact [nfadbinfo@gmail.com](mailto:nfadbinfo@gmail.com).



*Eva Savickas and Rose Slaght work together to fill bags with Himalayan pink sea salt. This salt can be used in both cooking and bathing. It is high in minerals and iron and has many health benefits.*

## Soothing Make-and-Take Session Ends Family Leaders Weekend

Parents who attended the final day of the Family Leaders Weekend in Peoria were treated to a relaxing Make-and-Take session led by our very own Rose Slaght. Rose brought an assortment of herbs, teas and essential oils for participants to sample. She provided handouts with recipes to

try. Each attendee went home with a goodie bag full of samples and literature, and a little less stress in their lives.

Thanks to Rose for sharing her wealth of knowledge and experience, as well as her bags, bins and jars of soothing homeopathic remedies.

### Illinois Advocates for the DeafBlind

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**There is a spot for you on our board!** Your time commitment can be small but your impact can be huge. Contact one of us to join our merry band of advocates to see how you can contribute.

## Moving from Darkness into Light

by Eliza Ellett

July 16th, 2008 our world irrevocably changed, I became a mother to a deafblind child. That's where my mind stayed over the next couple of months, my child is deafblind. I scoured every resource there was. I called agencies. I had people in and out of our home every day those first couple of months, after she came home from the NICU. As I went to sleep, or tried at least, my mind kept going back to that one terrifying word, deafblind. It was the first thing I thought of when I woke up and the last thing I thought of before exhaustion claimed me at night. I can look back at that time and tell you how much I wish I could have told me then, to take a deep breath and forget about the baby in the crib who happened to be deafblind and pick up my daughter, Miranda, and get to know her, not her disability.

The last five years I have been doing that, from the day the Early Hearing

they became invaluable to us, it was heartbreaking when it was over, yet exciting as another chapter was beginning. During those first three years we became involved with Hands and Voices, I started with a Mom's Night Inn when Miranda was barely 6 months old. I definitely was okay with her hearing loss by that point, at least I thought! When it was my turn to speak, my whole composure crumbled, I could barely speak. No one in that room judged me. They *all* had been where I was, some were at the same point in their journey as well. That weekend was wonderful, to be around other moms who just *got it*. Mom's Night Inn has become a yearly event that I look forward to, seeing old friends and meeting new ones.

I approached the Lighthouse for the Blind by the time Miranda was 3 months old, they too accepted us with open arms. They have also served the deafblind community over the years. We started going to the center for Miranda's Vision EI therapy weekly.

I couldn't stop searching. I reached out to Project Reach in the very early morning when sleep eluded me and within a few hours a Family Specialist contacted me, within a few short days she was in our home and over the next five years she became my go-to person for information on deafblindness, she gives her all for the our children.

When Miranda was nine months old, I went

to a training on how to help your blind child become an independent contributor to society, how to turn her blindness into a minor difficulty. The organization was the National Federation of the Blind, run by the Blind for the Blind. I have become more involved with them and their parent's division. I was honored to be chosen to represent Illinois as a parent, at our Washington D.C. conference this last January. I trained alongside other parents

See **MOTHER**, page 5



## Galena Retreat Offers Respite for Moms

by Roseann Slaght

The Galena Mom's Retreat was a fantastic opportunity for moms to take some time for themselves, meet other moms of children with disabilities, get some information, education, and time to themselves.

We enjoyed pizza Friday night and listened to a wonderful presentation about "masks that we wear" from Sandra Geisman, MS, LCPC, NCC, who is also the Social Emotional Consultant for the Child and Family Connections office in Freeport. She is also in private practice.

We painted masks that represented what we were feeling, and took time to share what we learned. It was an enlightening experience.

Saturday morning, we gathered again, shared educational information, and had some time to explore Galena, shop, walk, read, nap, and/or pamper themselves.

We gathered at the Arena of Dreams to meet Dr. Maloney's new staff members who will be conducting some exciting family and therapeutic events at the Arena starting this summer. Details will soon follow.

Rhonda Best, a presenter from Family Matters Parent Training and Information

See **RETREAT**, page 4



My kids Magdalena and Miranda

Detection Intervention (EHDI) made her hearing test possible within 24 hours of her birth, to the NICU nurse who sent our information to Early Intervention (EI), to myself stumbling across Hands and Voices (H&V), and Project Reach the state's deafblind agency websites. Our journey was just beginning and what a journey it has been! EI was in our home constantly, I felt like we were being invaded by therapists. The next three years

## IADB on Facebook



Join Illinois Advocates for the Deafblind (IADB) on Facebook. It's a great way to get timely information and connect with other families. Check it out!

## EXTRAORDINARY *from page 1*

ther King, Jr. in third grade, Aubrie said, “Martin Luther King, Jr. said we should treat everybody equal. But we’re not doing a good job of that!”

In spring 2013, when Aubrie was troubled by hearing the r-word ([www.r-word.org](http://www.r-word.org)) in the school halls, she and her mom created an “End the Word” presentation which they shared with the students at her high school.

Since then, Aubrie has shared “End

## RETREAT *from page 3*

Center shared information about behavior issues, and how our own behavior impacts our children as well. It was wonderful, and we appreciated her time and talents immensely.

Saturday, we shared a delicious meal prepared by Lynn Doolittle and Sandy Valentine. They cooked again for us on Sunday morning. What a treat to have wonderful cooks to share their talents.

Dr. Maloney shared information on what her changes will be for upcoming camps at the Arena of Dreams, and other fascinating and exciting programming she is working on.

We ended the retreat with a fun round of “white elephant” and everyone was happy to return home, renewed, refreshed and ready to do what they do everyday.

Join us for one of our upcoming retreats.



**MOM'S RETREAT!**

**Save the Date for Two Upcoming Events**

**October 17-19, 2014**  
**Bishop Lane, Rockford**

**November 22-23, 2014**  
**Villa Maria, Springfield**

Relax, rejuvenate and connect with other moms of children with special needs. Retreat yourself with weekend away, brought to you by a cadre of service organizations.

Contact Roseann Slaght at [r-slaght@wiu.edu](mailto:r-slaght@wiu.edu) or 815-222-0659.

the Word” with neighboring high school students, local middle school students, and members of the local Rotary Club. When Aubrie received a standing ovation from the Rotarians, a long-time Rotarian said he’d witnessed only two or three standing ovations in all his decades as a Rotarian.

Aubrie compares her life with that of Margaret, a woman institutionalized for nearly 60 years after being placed at the age of two. What a difference a few generations has made! Still, there are obstacles and challenges interfering with quality lives and full community inclusion for people with developmental disabilities. Aubrie says, “I am a person with disabilities. Every time you use the r-word, you are saying that I’m not as good as you. You’re saying that I don’t belong. You’re saying that I don’t deserve a chance. You may not intend to say that, but using that word implies all those things and more.”

Aubrie and her mother, Michele, share their experiences and perspective in order to inspire and empower individuals with

## SENSORY *from page 1*

of your shirt is rubbing the back of your neck, or that seam in your sock is irritating your little toe, or that kernel of popcorn is stuck in your teeth? These are the daily annoyances that take you out of what you are doing, break your concentration, and affect your mood. You, as an adult, can recognize these things and can fix the situation, or choose to cope. Kids don’t yet have the skills to alter their environment to suit their sensory needs, or to simply ignore the distractions and “suck it up”. What do they do instead? They might cry, whine, withdraw, or act out; and you are left to wonder, “What’s your problem?” If you see behavior, think sensory. Recognize that all behavior has meaning. That has been my mantra since the conference, and I’ve applied it to every member of my family, kids and adults alike, in any number of situations.

Everything about Jennifer Rosinia’s presentation was thoughtful and informative. I liked that in the center of every table in the room, Jennifer had placed a bunch of small toys: koosh balls, connector sets, play dough, building blocks and the like. She encouraged us to fidget

disabilities, parents, educators, therapists, and community members to recognize gifts, dream big, and expect the extraordinary. Focusing on self-direction, empowerment, inclusion and high expectations, presentation topics include: End the Word, ExtraOrdinary Self-Directed IEPs, Be the Director of an ExtraOrdinary Life and Expect the ExtraOrdinary. Visit [www.ExpectExtraOrdinary.org](http://www.ExpectExtraOrdinary.org) to learn more.



*Aubrie Westmaas shares disability and special education information at Pittsfield Main Street Family Fun Day in May.*

them as she spoke, recognizing that many people need to have extra sensory stimulation to be able to concentrate and attend. The toys weren’t there as an alternative to listening, but as tools for those who might need that little something to keep them in the right head space to listen, another reminder that everyone has different sensory issues.

Now when I spend an extra minute or two searching for that favorite pen that feels right when I write, or adjusting the pillows ever so slightly in my most comfortable chair, or doodling when I’m on the phone, I get it. It’s all sensory...part of the way I self-soothe and get along in the world. I need to recognize that my kids, like me, have their own sensory needs and behaviors that help them. I am more mindful of the stimuli that affect my kids (in good ways and bad). Now I try to help them find right environmental mix to give them best chance to succeed at whatever it is they are doing. It might be as simple as turning the radio on or dimming the lights. A literal light-bulb moment for me, one of many I had during Jennifer Rosinia’s presentation.

from across the country. We learned how to engage our children, how to advocate for them, and how to push ourselves to the front of change for our blind people and teach them to do that for themselves. I went to Capitol Hill to speak to our state legislators on the importance of passing bills to give equal rights, accommodations, and pay to people with blindness. It was a breath-takingly humbling experience. New friends and advocates were definitely made that week.

Miranda wasn't quite two years old when Project Reach directed me to the Illinois Advocates for the DeafBlind. IADB was the answer to my yearning to be with others that understood both sides of Miranda's struggles. The absolute most amazing people were introduced to me that weekend. One thing that was said to me made every fiber of my being relax (finally) was when Miranda was pulling herself between people, getting extremely close to everyone, touching them, exploring their faces, hands, and laps! I was slightly embarrassed by her being so intrusive of their personal space, I apologized. Everyone chuckled and said they completely understood, but one woman turned to me and very seriously and kindly said, "Never apologize for your daughter, especially with us." Of course I teared up and not once have I felt a need to apologize for her need to communicate and comprehend her surroundings, maybe for her slobbering on you and stepping on your foot, but never for her. Two years later I joined the board to continue the involvement in our deafblind community.

By the time Miranda was almost three, we belonged to quite a few organizations, each giving us something to learn from. When a Parent Guide position within Guide By Your Side, Illinois opened up, I debated on if I should apply. Guide By Your Side (GBYS) and H&V had the same beliefs I held, "What works for your child is what makes the choice right!" I wanted to finally give back, to be the person to help someone else along their personal journey. When I was hired, I thought I was the luckiest person and I was right. I was so excited and so nervous, what was I going to say to these parents? Well "these parents" needed exactly what I needed and every parent I know needed. They needed another parent that was going through

a similar experience that they had been through, to let them know they weren't alone. We would be there to help find resources, to help them empower themselves for their family, and to offer an ear when they needed to just talk. Sometimes I think I get more out of my role as a Parent Guide, than our GBYS families do. I learn something new from every parent I meet, new experiences to help another family as well as ours.

To sum up, the last five and a half years have been difficult. What started with devastation, has become something else entirely. I've gotten to know one of the most important people in my life, Miranda, who happens to be deafblind (it will never define her again), and become closer with her amazing sister Magdalena, who has been instrumental in Miranda's progress and care. It caused strain on my spouse and me in the beginning, yet I think it has made our relationship stronger now. I have met some of the most wonderful people along the way. I know that if Miranda wasn't born extra special, I never would have met these people, many of whom have become our closest friends.

Life is brighter now, quite sunshiny even. There have been cloudy days, weeks, and even months, but as they say, "There's always a rainbow at the end." Miranda has flourished; she is the definition of a 5-year-old little girl. My family and I have sat and discussed if we could "change" Miranda, would we? The answer was and is a resounding no. Her sensory losses are a part of her, they are part of her uniqueness and we wouldn't want a different little girl than what we have been blessed with. Our family wishes all of you the best on your family's journey.



**PHILIP J. ROCK  
CENTER AND SCHOOL**  
"Together for Independence"

<http://www.philiprockcenter.org>

Check out the new and vastly improved website for the Philip Rock Center and Project Reach. You'll find lots of new content, including issues of our own HANDS newsletter!



## **Kori Olehy** *in her own words*

My name is Kori Olehy, I'm 27 years old and I live in East Peoria (central Illinois) with my parents and our two dogs. I am hard of hearing, and I wear glasses. I am deaf in my right ear, but hearing in my left (with the help of my hearing aids for both ears). The glasses are mostly just for reading. In 2007, I had cataract surgery on both eyes and now I can see 20/30 in my right and 20/20 in my left without glasses on. I graduated from Illinois Central College with my Associates in General Education, but I'm considering going back to school this fall, to become a Sign Language Interpreter for the Deafblind.

Over the years, I have had over 30 surgeries. Most of them were craniofacial surgeries, to reconstruct my face. I have also had a few other surgeries, not related to my face. I have had both my knees scoped, my wrists done, (from tendonitis) and I had emergency surgery on my stomach to figure out what was causing me pain and making me so sick. At that surgery, they removed the adhesions they found, and my appendix. At the present time, I thought I was done with surgeries. I just had a tooth pulled in May 15 and I'm looking at my gallbladder having to come out, and that surgery date is to be determined. I am still waiting to see the surgeon for that one.

I have overcome many challenges as far as my hearing and vision goes. For

**See KORI, page 6**

# celebrate!

## 15 Years on the Job



My name is **Paul Reina** and I have worked at Walmart In Beloit, Wisconsin for fifteen years, beginning my junior year in high school. I have a job coach who acts as my eyes and ears, as I work as a cart pusher in the parking lot. A very non-traditional job for someone who is deaf-blind like me.

Don't be afraid to try lots of jobs. My first job was in a deli, but it wasn't a good fit for me. I need lots of help to maintain my job, someone who is patient, kind and signs. It helps me when I get to practice things, and safety is one of them.



We want to hear from you. Have you found a helpful resource? Do you have some news you'd like to share? Did you attend a workshop or conference that was particularly informative? Let us know! Contact HANDS editor Maria McCarrick at [mariamccar@comcast.net](mailto:mariamccar@comcast.net) or (309) 839-0892.

## KORI from page 5

nearly 20 years, I was totally blind without glasses. But now, thanks to my cataract surgery, I can see great. Before I had them removed, I was completely blind without my glasses on, and with my glasses on I was going blind. I pretty much needed the cataract surgery done ASAP to save my vision, and I am very glad I did it. Being able to see without my glasses has been life changing. I have been driving for over 10 years now, and I don't let my hearing trouble or physical disabilities get in the way. I really wanted to be independent when I was younger, and I had always hoped for my driver's license. I got it while in High School, (at the age of 16) and I have been driving ever since. For many years, I had the Coke-bottle glasses (super-thick lenses), and I was completely blind without them. Growing up, I used them for everything. For a while I had to use them while driving – about four years. I love my current glasses, and even more, I love the fact that I passed my driver's vision test *without* my glasses on. I can see perfectly now without them. All I really need my glasses for now is reading.

I graduated from Sterling Middle School in 2001, and then when I finished high school at Richwoods High School, I graduated in 2005. Throughout my school years I always had a sign language interpreter. That continued into my college years. I would always go to meetings with my advisor to set up interpreters for my classes, and note takers, and such. I graduated college in 2009 with my Associates in General Education, a very proud accomplishment for me.

I live at home, with my parents and our two schnauzers. I live in East Peoria, but due to my hearing loss I had to go to Peoria/District 150 schools. I would get on the bus every morning and one way to school was 20 minutes. I had always hoped to be able to go to school in East Peoria, but at that time ADA laws were not highly-respected or followed. I completed all my schooling in Peoria, and then went to Illinois Central College in East Peoria.

I have many hobbies. I *love* to write, (I'm working on an autobiography about myself) and read, crochet, do different crafts, play with my dogs, spend time with the family, and so much more. I have my own craft page on Facebook, where I show many of the crafts I do, and

even sell different things on there. I love to volunteer, and help others too. I have recently started volunteering with CIRT (Central Illinois Riding Therapy) in East Peoria, which helps kids with disabilities to be able to ride horses. My "position" there would be to help the children get on the horse, or get off, and help them to ride as well. The reason I try to do so much with volunteering is because I *love* to help others. I am also planning to turn in my application to volunteer with Pekin Hospital.

I love to text, and love to talk on the phone, and hang out with my family and friends. I have Facebook (which I'm on all the time) and I also recently started a WordPress Journal, so that anyone out there who would like to can keep up with my daily (or every now and then) updates. I always check my Facebook, and always have my phone with me. I am the type of person/friend who loves to be there for others, to encourage them, and to help them. I love giving advice and being the support a person or friend needs. I have been through so much medically in my 27 years of life, that talking about anything medically does not scare me. I like to consider myself the type of friend who you can call on, day or night, to talk.

If you'd like to keep in touch, you're welcome to add me to Facebook, follow my WordPress Journal, or even text me.

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### Mark Your Calendar

The date for next year's Family Leaders' Conference has been set:

### March 7th in Peoria

The focus will be Behavior as Communication. Watch for Details in our next issue!