



# HANDS

Summer/  
Fall  
2015

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

## Our Cochlear Implant Experience

*When that hoped-for “viral video” moment doesn’t happen*

*by Eva Savickas of Oak Lawn*

I am a sucker for videos that people share on social media. I cry at almost every one, from military homecomings to marriage proposals.



*Zach Savickas recovers from surgery.*

And then I share and pass them on to others.

My son Zach is 12. Diagnosed at age three, he wore two hearing aids for about six months. Then he lost all hearing on his right side. He has spent the last nine years with just his left ear aided and has done great. Last year, we decided it was time to explore a cochlear implant for his right ear. I did my homework. I researched everything, from the companies, to the pros and cons, costs and rehabilitation needed, and so on. I spoke with other parents who had kids with implants, got their advice, experiences, etc...I

See **IMPLANT**, page 2

## *Proposed Legislation*

### Cogswell/Macy Act to Benefit Deafblind

The Alice Cogswell and Anne Macy Sullivan Act which aims to reform education for children who are blind or deaf is making its way through Congress. The newest version of the bill includes Title III, which was added to specifically address the needs of children with deafblindness:

- Designates intervener services in the “related services” listing
- Reflects the need for the recognition of and training for teachers of deafblind
- Adapts the federal definition of deafblindness

See **ACT**, page 3



*Elizabeth Frisbie, MA, MSEd. stepped in for snowbound speaker David Pitoniak.*

## *GDFR at the GFPD Conference*

### An Honest (and Slightly Immature) Look at PBD

*by Corin Chapman of Bloomington*

In July, Todd, Max, and I attended the Global Foundation for Peroxisomal Disorders (GFPD) Family and Scientific Conference in Omaha. The conference is meant to bring together families from around the world that have children diagnosed with Peroxisomal Biogenesis Disorders (PBD).

All the best PBD doctors were there and available for you to talk with. You could have these great non-rushed conversations about different issues – hearing aids or co-



chlear implants, are vitamin supplements necessary, etc. and know you were getting advice from doctors that really understood the needs of PBD kids.

The conference was a whirlwind of emotion that I feel like I’m still recovering from.

First and foremost, there was the joy. The joy that there are other families out

there like ours. Good, normal, loving families that are having to deal with this terrible disease. Families that didn’t do anything “wrong” other than having a

See **GFPD**, page 4

### An Eventful Family Leaders Weekend

The Illinois Family Leaders Collaboration’s 9th Annual Family Conference for adult family members and caregivers of children with disabilities was held in Peoria at the Spalding Pastoral Center in March.

Organizers were thrown a curveball when a late-season East Coast blizzard stranded scheduled keynote speaker David

See **WEEKEND**, page 4



## 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. **IADB offers several membership options: one-year individual/family for only \$20, annual professional for \$40 and lifetime individual for \$150.** To join or renew your membership, please make checks payable to IADB and mail to: IADB Membership; 818 DuPage Blvd.; Glen Ellyn, IL 60137.

## IADB Election Results

The votes are in! Congrats to IADB's **new** and returning members of our board of directors: Roseann Slaght, president; **Eva Savickas**, vice president; Maria McCarrick, secretary; and Eliza Ellett, treasurer. Our members-at-large are **Stacey Borrego, Toni Kijowski, Kori Olehy**, and Jayne Wright. Thank you for contributing your time and talents to IADB.

Meet the newest members of our board of directors:



Eva Savickas



Stacey Borrego



Toni Kijowski



Kori Olehy

## IMPLANT *from page 1*

knew what would happen during each step of surgery. I knew how long recovery was. Remarkably, some kids went home that same night! I knew when we had to come back for a post op check-up. I knew the activation date. I shared everything with family and friends. I watched all these videos of recipients on their activation day, laughing, smiling, and crying tears of joy! We were so excited! I was prepared... or so I thought.

Ok, so just a small hiccup in the plan hit a few hours after Zach came out of surgery on January 13th. He was extremely sick from the anesthesia. His head hurt so badly, he was crying like a two year old again. The medicine given for his headache made his stomach worse. He was vomiting, sweaty, and just in pain. That is one of the worst feelings you can experience as a mother—not being able to help your child. After two nights in the hospital, we were able to go home. No biggie...

The next news we got was great. The post op checkup was wonderful. His incision was healing great, and we even got the activation date sooner than I expected. I will say that our doctor did prepare me for the fact that there might not be any benefit from the implant. I knew to only be slightly optimistic about the long term effects. But there were more videos to watch and share!

Activation day is here! We are ready to take pics and videos of this amaz-

ing day to share with everyone! As we start, Zach is nervous, as expected. But then...I see him getting sad, and looking down, and then looking up with tears in his eyes. He is not answering anyone. He is only looking at me, and then he starts to sob. As the tears roll down his face, I am in shock. This isn't what I saw on the videos. Why isn't he smiling? Why isn't he happy? Why isn't he hugging us and high-fiving the audiologist? Something is wrong. He yells, "Stop! I need to go to the bathroom!" That is his way of telling me "get me out of here NOW." As he bolts out the door and runs down the hallway, I realize he is scared and in shock as well. There was no stimulation on his right side for nine years, and then suddenly there is. Of course he would freak out! How did I as a mom not know that? He doesn't even want to go back into the room. But after several minutes and a good talk, he agrees. The mood in the room has changed without anyone saying a word. Voices are softer, less upbeat. I think it hits all of us that this was going to be different. I am sure that the professionals had experienced this before, and I feel their support in their glances, but also I feel a bit of pity. It kind of reminds me of that moment when they tell you your child has a hearing loss. After a few minutes, we are done and ready to go home. My wonderful husband looks at us, and says, "I knew that reaction was a possibility. I watched a video about it."

### Illinois Advocates for the DeafBlind Board of Directors

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# Lifetime Nat'l Park Pass for Disabled

Making vacation plans soon? Get an Access Pass to National Parks and Federal Recreation Lands for people with disabilities. The Access Pass is a free (\$10 processing fee by mail) lifetime pass available to United States citizens or permanent residents, regardless of age, that have a permanent disability. The Pass can be used at over 2,000 Federal recreation sites across the nation, including National

Parks, National Wildlife Refuges, and many National Forest lands. For more information, visit [store.usgs.gov](http://store.usgs.gov)

## ACT from page 1

- Requires each state to specifically address deafblind issues in the development of its state plan

The Cogswell/Macy Act needs a Republican co-sponsor.

For more information The Cogswell/Macy Act with Title III, check out the whole story at [intervenor.org](http://intervenor.org).



## Galena Retreat Offers Respite for Moms

by Roseann Slaght of South Beloit

A wonderful retreat for moms of children with special needs was held on May 1-3 in Galena. We enjoyed the *Arena of Dreams*, where June Blunk presented a wonderful program on taking care of yourself, creating a sacred space in your home, and how to work at limiting the negative thoughts in your head.

We had great conversations, networked, and enjoyed Sandra Geiseman's presentation on memories on Sunday morning. We were treated to home-cooked meals thanks to Sandy Valentine and Lynn Doolittle.

We give many thanks to Dave and Karen who open their doors to all who need help, and continue to marvel at the good and innovative ways that they support people with exceptional needs. You can check out their website at <http://www.careinconnections.com>



Looks like "rain" at the basic sign class led by Molly Herman, teacher of children with hearing impairments.

## Basic Sign Language Class Ends Family Leaders Weekend

Parents who attended the final day of the Family Leaders Weekend in Peoria were treated to a lively and informative basic sign language class. Molly Herman who teaches students with hearing impairments at Vlaska Early Childhood Program in Peoria demonstrated common signs used in everyday activities.

Participants were able to practice signs and learn adaptations and variations that could help them improve communication with their family members with deafblindness. Herman provided attendees with take-home packets containing illustrated vocabulary lists of more than 100 basic signs. In addition, she demonstrated other helpful signs, taking



Kristi Dysart gets Christopher's attention by signing "toys."

requests from those in attendance.

Herman suggests these websites to explore sign language further:

- [www.signingsavvy.com](http://www.signingsavvy.com)
- [www.aslpro.com](http://www.aslpro.com)
- [www.lifeprint.com/asl|101](http://www.lifeprint.com/asl|101)
- [www.signingtime.com](http://www.signingtime.com)

## Notable Upcoming Events

### Moms' Retreats

October 16-19, 2015 in Rockford  
December 5-6, 2015 in Springfield  
Contact Roseann Slaght  
[r-slaght@wiu.edu](mailto:r-slaght@wiu.edu) or 815-222-0659

### Statewide Transition Conference

October 29-30, 2015 in Chicago  
[illinoistransitionconference.org](http://illinoistransitionconference.org)

### IFLC and Project Reach Family Leaders Conference

April 8-10, 2016 in Peoria  
Contact Michelle Clyne  
[MClyne@philiprockcenter.org](mailto:MClyne@philiprockcenter.org)  
or 630-790-2474

## GFPD *from page 1*

case of bad luck. I mean, I knew there were PBD families like us out there, but to be able to meet these people and look each other in the eye and think – you GET IT. It truly was an instant bond.

The environment of inclusion there was also amazing. Never did I have to “explain” Max. Everyone knew Max had feeding and vision and hearing issues, because they dealt with the exact same thing every day! That IS their normal. You were given the opportunity to leave your child in the child care room, which was manned by the most loving, amazing women – most who had substantial experience with special needs kids. I’m not sure that Max has ever gotten as much loving as in that room. I basically wanted to bring everyone in there home with me.

There was also hope. I saw these amazingly, loving kids doing so much – talking and walking and giving amazing hugs and I found hope that Max would be able to do

## WEEKEND *from page 1*



*Special guests Nicole and Harmony Rendelman leave IADB’s pizza dinner hand-in-hand.*

Pitoniak in Baltimore. The IFLC planning committee had to scramble to find a last-minute replacement. Elizabeth Frisbie, MA, MSEd. (who was originally unavailable to speak when approached last fall) graciously stepped in and was able to give an informative and entertaining day-long



these things. Of all the emotions I’ve felt over the past few months, the hardest and most destructive one has been hopelessness. There is no reason to feel hopeless.

However, there were also some blows that I’m still recovering from.

There was frustration. When Dr. Braverman, a leading researcher of PBD, explained that being able to test a combination of Betaine and an additional drug, which is thought to have the ability to improve peroxisomal production in these children, is still five years and \$1 million away, you could actually feel the air being sucked out of the room.

There was sadness. I knew that PBD kids struggle with hearing and vision

loss, but I didn’t realize what a foregone conclusion vision and hearing loss would be. Max will be blind and deaf, it’s just a matter of time. That’s hard.

But the worst is that I learned that Max will pass. I know, I know – it’s a terminal disease and I knew that it was. But there’s this part of my brain that said – well certain kids might pass away, but not Max. I mean look at him – look how healthy and happy he is. Unfortunately, I learned that there were a lot of parents that had PBD children that were healthy, until they weren’t. It’s degenerative and this journey is only going to get harder.

Parents who have lost their children are invited to attend the conference as well. This may seem odd, but, as I said, there is a special bond among PBD families. These parents are there for many of the same reasons we’re there – for support from others who understand. During the sessions about the latest treatments, these families meet with each other in the grief counseling room– affectionately known as the “scary room.” I don’t want to go to the scary room.

On the last day, we gathered outside and each child’s name, both living and deceased, was read and reflected upon. Then, we released balloons into the air. It was very moving and then I went back to the hotel room and wept. I had held it all in for the previous days, not wanting to be the crazy new girl that can’t keep it together, and when I finally hit the release button the tears came like a fire hose. And afterwards, I felt better. And then I took my puffy eyes downstairs and drank beer with my new PBD Mom friends and even though there was sadness and frustration and PBD itself is just awful, the conference was actually kind of perfect.

*Corin Chapman originally published this on her blog: <http://persucksisomalbiogenesisdisorder.blogspot.com>*

*For more information about PBD visit [www.thegfpd.org](http://www.thegfpd.org).*

presentation: “I’m trying to tell you something!” *Understanding & Responding to Children’s Challenging Behaviors.*

Parents of children with deafblindness attended additional events just for them during the weekend organized by Project Reach and IADB. Friday evening, families gathered for a casual social hour in the lobby of the SpringHill Suites hosted by Karen Windy, a deafblind specialist from Project Reach: Illinois Deafblind Services. On Saturday evening, IADB hosted a pizza dinner at the hotel, followed by a general meeting and election. The weekend ended on Sunday morning, first with a basic sign language class lead by Molly Herman, a teacher of students with hearing impairments at Peoria’s Vlaska Early Childhood Program (See story, page 3). Finally, **Kori**

**Olehy** shared her experiences living with dual vision and hearing loss.

The next Family Leaders Weekend will be April 8-10, 2016 in Peoria.

