



HANDS

Summer/
Fall
2016

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

Self-Advocacy Takes Center Stage

Parents and Youth Gathered in Peoria for Project Reach/IADB Conference

The Philip Rock Center, Project Reach and IADB in conjunction with the Illinois Family Leaders Collaboration held its annual Parent Leaders Conference in Peoria in April. This year's focus was on self advocacy. Older kids were also invited to attend to learn skills that could help them find their voice and their life's purpose. We were pleased to welcome attendees, young and old, from throughout Illinois.



Featured speakers were the mother/daughter team of **Nancy and Bridget Brown** who led an interactive workshop on Saturday called *Designing a Life with Direction and Purpose*. Bridget presented *Dwell in the Possibilities*. She shared her life story and talked about how she found her voice and learned self-advocacy skills. Hers is a compelling story of empowerment. Bridget is an accomplished young person who pioneered inclusion (along with her mom) in her school district 20 years ago as a young girl. She graduated high school in an inclusive setting and went on to attend college. Along the way she started acting and appeared in t.v.

See **CONFERENCE**, page 2

ASL and Pro-Tactile

Communicating at Parent Weekend



Eliza Ellett, Rose Slaght and Pamela Marshall practice the "cereal" sign.

At the Parent Weekend in Peoria in April we highlighted communication methods for people with deafblindness. IADB hosted a pizza dinner and sign language class presented by Molly Herman, a teacher of preschoolers with hearing impairment. The casual dinner setting gave us an opportunity to learn many signs used during mealtime. The following morning featured an informative and interactive presentation we dubbed *A "Touch" of Pro-tactile Communication* with Bryen Yunashko.



Bryen Yunashko, deafblind activist and speaker, demonstrates the basics of Pro-tactile communication on his translator.

Illinoisans Advocate for Cogswell-Macy Act



Michelle Clyne, Toni Kijowski, Karen Rock, Kaylie Bohl, Rep. Peter Roskam, Krista Bohl and Dr. Olaya Landa Vialard

The push is on to gain support in congress for the Cogswell-Macy Act. The bill (H.R. 3535) will improve access to necessary education services for children who are blind, deaf, and deafblind.

In July, young Kaylie Bohl, who is deafblind, led a delegation of concerned parents and professionals from Illinois' 6th district to lobby their congressman, Rep. Peter Roskam, for the bill's passage.

Proud mom Krista Bohl reported that Kaylie used her voice, shared her experiences with Rep. Roskam, and urged him to support the legislation. Now that is self advocacy!

April 14th was National Call-In Day to support the Cogswell-Macy Act. The date marked the 150th anniversary of Anne Sullivan's birth. IADB encouraged our members to join the effort spearheaded by the American Foundation for the Blind (AFB) to contact elected representatives

See **ADVOCATES**, page 4

Teen Attendee Reviews Peoria Weekend

by Josh Sagez of Jacksonville



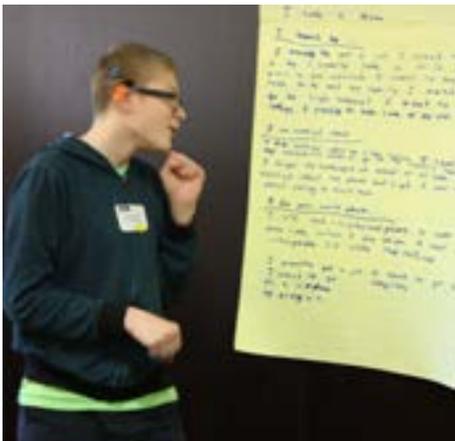
My name is Josh, I am 18 years old and I have Usher's Syndrome. I remember my mom telling me that we were going to a meeting in Peoria for Deaf and Blind people. I didn't

want to go because I thought it would be boring, but mom made me. By the end of the weekend I saw a boy I had gone to Lion's camp together and his brother [Austin and Zach Savickas]. We had a lot of fun talking, watching basketball and hanging out. I also like learning about how to make a plan for my IEP. That was a lot of fun and we each stood up and presented

what we had wrote about us. On the last day Bryen taught us about signing with touching. He was a great teacher and very funny! Now I will make my mom go again next year!



Josh Sagez (right) participates in a co-active signing demonstration with Bryen Yunashko, deafblind activist and Sunday's featured speaker.



Zach Savickas presents his goals and plans during Saturday's session.



Door prize winners: Josh Sagez, Eva Savickas and sons, Austin and Zach.

Save the Date

Parent Weekend 2017

April 28-30

in Peoria

CONFERENCE *from page 1*

shows and movies--one starring Miley Cyrus! She is a polished speaker who went out of her way to engage her audience. At one point during the breakout session, she was signing to communicate to some of the attendees with deafblindness. Nancy's presentation was called *The Love of My Life*. She shared how to be a leader in your child's life and empower them to speak with their own voice. Tyson Bedford, a young man with autism, spoke about his experience attending the University of Iowa in the UI-Reach program. Later attendees were able to work together with each other to map out their own life plans using tools and techniques presented by the Browns as person-centered planning coaches.

The IFLC portion of the conference was designed for parents, caregivers and educators of children with any kind of disability. Parents of children with deafblindness attended additional events just for them organized by Project Reach and IADB. (See story, page 1; review, left.)



JOIN US

IADB offers one-year individual or family memberships for only \$20, one-year professional memberships for \$40, and lifetime memberships 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.

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NFADB 2016 Symposium

Illinois Moms Attend National Conference

Maria McCarrick and Maria Reuters, both moms of daughters with deafblindness, attended the National Family Association for Deaf-Blind (NFADB) annual Symposium in Austin, Texas in July.



The three day event was chock-full of helpful sessions and important resources. It also served as a networking opportunity where attendees could meet and talk with other parents as well as professionals from across the country who work with people with deafblindness. Maria McCarrick of Peoria reported feeling simultaneously empowered and overwhelmed by all she learned during her time in Austin.

Highlights for her included inspirational keynote speaker George Stern from Deafblind Citizens in Action (DBCA), Mark Richert who is director of Public Policy the American Foundation for the Blind (AFB), and Robbie Blaha, long-time educator and consultant for the Texas Deafblind Project.

Communication Equipment Available through iCanConnect

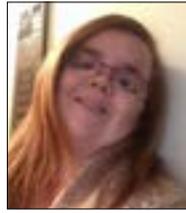
iCanConnect promotes the National Deaf-Blind Equipment Program (NDBEDP). The goal is to get technology into the hands of Americans with combined hearing and vision loss so they can connect with family, friends, and community. Those who qualify receive FREE equipment (braille devices, phones, computers, etc), training and tech support. For more information visit www.iCanConnect.org.

NOTES FROM MY WORLD

On Finding Love

by Kori Longbons of East Peoria

When I first met my fiancé Justin, he didn't know I was deaf and I didn't tell him right away. It took me two weeks before I shared that I was hearing impaired. He was completely shocked when he learned I could read lips. There was dead silence for 20 minutes (not kidding). When the shock finally wore off, he had a lot of questions. I answered them all, addressed his concerns, and we just went on from there.



At times I have trouble hearing him, so I have to ask him to speak up. It happens more than you might think, but he is learning to raise his voice to my comfort level and has figured out what I can hear and what I can't. He is also learning sign language—I am teaching him—to help us communicate better when I don't have my hearing aids on. Justin has been very patient, helpful, and understanding about my deafness, and my other disabilities as well. It's a testament to the caring

person that he is.

I share this with you, because I want others to know that is possible to find love, despite deafblindness. Parents of kids who have dual hearing and vision impairments often worry what the future holds for their son or daughter. Who doesn't want love and happiness for their child? I am here to say it can happen. You can find a true love who is patient and understanding of deafblindness and other disabilities. My hope is that every deafblind person who wants a relationship finds someone just as special as Justin is to me.

As I write this my wedding is just a couple of weeks away. If anyone needs someone to talk to about dating, love, and relationships, please don't hesitate to email, call, or text. I would be more than happy to talk.

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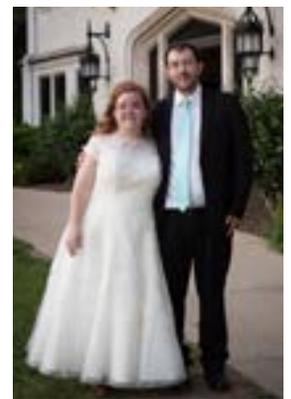
Kori, now a married lady, shares her life experiences and perspective as an adult with deafblindness in this regular column.

Heartfelt Congratulations

by Karen Windy of Peru

In the beginning of 1989, I began a new job, a Deaf-Blind Specialist for Project Reach. I still remember my very first client, a little red-head named Kori. She was quite a little active child who loved to climb up and down the stairs as well as everywhere else while first babbling and talking a mile a minute. She and her parents attended the family weekends we used to have every summer and she personally kept us all entertained. I followed her activities from early intervention to grade school to high school to college, and then to adulthood where she presented to parents with young children who had the diagnosis of Sticker syndrome (Kori's diagnosis) and/or a hearing and vision. I was amazed that she always had a smile

and beautiful laugh. Both as a young child and as an adult she endured multiple life threatening set-backs due to her diagnosis and then surgeries. In this and many other pictures, I see



the most beautiful smile yet on a beautiful woman, both inside and out, as she stands next to Justin, the man that she truly loves and who loves her as much. Congratulations Mr. and Mrs. Longbons! May God bless you and stay with you through all the joys and challenges that lay ahead of you in your life as husband and wife!



Galena Hosts Mom's Retreat

by Rose Slaght of South Beloit

The Mom's Retreat Galena was held May 6-8th, 2016. We enjoyed wonderful accommodations at the 305 North Main Inn and in the Galena Territory owned and operated by David and Dr. Karen. We had 43 attendees this year, who were treated to extra special surprises, thanks to a wonderful grant written by a partner. Some received massages, facials, and pedicures as part of this event.

Elizabeth Frisbie, a reknown mental health professional, was the keynote speaker and provided educational and personal growth opportunities for all. We ate, shared stories, learned, walked, laughed, and got to relax and rejuvenate. It's amazing to see the bonds that form, ideas shared, and supports shared among the ladies.

Thanks to Patti Mook from Chicagoland Easter Seals and Bank of America for all their wonderful support. It is truly another family leader collaborative event with supports from STARnet Regions 1 and 3, Child and Family Connections (CFC) #1 and #3 administered through Regional Office of Education (ROE #8), the ARC of Illinois' Family to Family Health Information Center (F2F), Illinois Advocates for the DeafBlind (IADB), Carein' Connections and the Arena of Dreams.

Mark Your Calendar for Upcoming Mom's Retreats

Rockford Sept. 9-11
Springfield Nov. 19-20

Contact Rose Slaght for details
at 815-389-1077
or rojo01@charter.net

Progress Update on Cogswell-Macy

In July, Interveners.org posted on Facebook an update on the Cogswell-Macy Act (H.R. 3535) which will ensure delivery of high quality special education and related services to students who are DeafBlind, Deaf and Blind.

According to Interveners.org, H.R. 3535 now has 36 cosponsors--28 Democrats and 8 Republicans. Some advocates for the bill visited these folks in Washington, D.C. in March as part of the National Coalition on Deafblindness (NCDB) Capital Advocacy Day. They were very persuasive. Thanks to these congressmen and women for supporting this important legislation and to the advocates who persuaded them. You may notice that Illinois is conspicuously absent from this list, so there is more for us to do.

WE ARE STILL LOOKING FOR A REPUBLICAN LEAD IN THE SENATE. Please contact your Republican senator (Mark Kirk, here in Illinois) using the letter found at <http://intervener.org/cogswell-macy-act/> (At the bottom of the page, see "Click here for a message to Senate Members"). If you sent a letter before, feel free to send it again and get others to sign on with you.

SPONSOR:

Rep. Cartwright, Matt [D-PA-17] (Introduced 09/17/2015)

CO-SPONSORS:

Rep. McKinley, David [R-WV-1] 09/17/2015

Rep. Takano, Mark [D-CA-41] 09/17/2015

Rep. Cardenas, Tony [D-CA-29] 09/17/2015

Rep. Castor, Kathy [D-FL-14] 09/17/2015

Rep. Grayson, Alan [D-FL-9] 09/17/2015

Rep. Honda, Michael M. [D-CA-17] 09/17/2015

Rep. Huffman, Jared [D-CA-2] 09/17/2015

Rep. Ryan, Tim [D-OH-13] 09/17/2015

Rep. Kaptur, Marcy [D-OH-9] 09/28/2015

Rep. Jolly, David W. [R-FL-13] 10/02/2015

Rep. Eshoo, Anna G. [D-CA-18] 10/20/2015

Rep. Crowley, Joseph [D-NY-14] 10/28/2015

Rep. Israel, Steve [D-NY-3] 11/16/2015

Rep. Swalwell, Eric [D-CA-15] 11/18/2015

Rep. Welch, Peter [D-VT-At Large] 12/10/2015

Rep. Napolitano, Grace F. [D-CA-32] 01/07/2016

Rep. Brady, Robert A. [D-PA-1] 02/03/2016

Rep. Delaney, John K. [D-MD-6] 02/09/2016

Rep. Sanchez, Loretta [D-CA-46] 03/07/2016

Rep. Murphy, Tim [R-PA-18] 03/07/2016

Rep. Larson, John B. [D-CT-1] 03/07/2016

Rep. Schiff, Adam B. [D-CA-28] 03/07/2016

Rep. Doyle, Michael F. [D-PA-14] 03/14/2016

Rep. DelBene, Suzan K. [D-WA-1] 04/29/2016

Rep. Donovan, Daniel M., Jr. [R-NY-11] 04/29/2016

Rep. Thompson, Mike [D-CA-5] 04/29/2016

Rep. Edwards, Donna F. [D-MD-4] 04/29/2016

Rep. Hastings, Alcee L. [D-FL-20] 04/29/2016

Rep. Thompson, Glenn [R-PA-5] 05/16/2016

Rep. Peters, Scott H. [D-CA-52] 06/08/2016

Rep. Fattah, Chaka [D-PA-2] 06/13/2016

Rep. Hanna, Richard L. [R-NY-22] 06/14/2016

Rep. King, Peter T. [R-NY-2] 06/15/2016

Rep. Cummings, Elijah E. [D-MD-7] 07/05/2016

Rep. Fitzpatrick, Michael G. [R-PA-8] 07/05/2016

Rep. Tsongas, Niki [D-MA-3] 07/05/2016

ADVOCATES *from page 1*

in Congress to urge them to sponsor the bill which is so important to our deafblind community.

Several members who attended IADB's annual general meeting in Peoria in March pledged to make calls promoting the bill: Krista Bohl, Penny Sagez, Eliza Ellett, Maria McCarrick, Eva Savickas and Rose Slaght. Thanks for letting your voice be heard and keep advocating for Cogswell-Macy. It's will make a huge difference for our kids, and for those who come after.