



HANDS

Winter/
Spring
2017

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

Promoting Mental Health, Developing Social Relationships

Come to Our Parent Weekend, April 28-30

Join us for a parent weekend in Peoria put on by the Philip Rock Center, Project Reach and IADB in conjunction with the Illinois Family Leaders Collaboration Conference. IFLC will hold its annual Family Leaders Conference for adult family members and caregivers of children with disabilities at Peoria's Spalding



Pastoral Center on Saturday, April 29, 8:30 am to 3:00 pm.

Featured speaker is **Barbara Doyle, M.S.** who will present *Healthy Minds, Healthy Lives: Promoting and Protecting the Mental Health of Children with Disabilities or Other Special Needs*. The IFLC's day program on Saturday is de-

Project Reach will pay conference registrations for parents of families it serves, as well as for hotel rooms on Friday and Saturday nights at the Stoney Creek Inn and mileage for those parents coming from outside the Peoria area. Contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or ppausche@philiprockcenter.org.

signed 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. Following Doyle's Saturday presentation, IADB will host a dinner at the

See **PARENT WEEKEND**, page 3



Charity Concert benefits IADB

Twin Oaks Savings Bank in Marseilles held a customer appreciation concert benefiting IADB on August 25th in the bank's parking lot. The Marseilles community was very generous. The final donation to IADB totaled \$657.68. Twin Oaks patrons and staff contributed \$404 on the night of the concert, then the bank chipped in an additional \$253.68.

Tracie Steider, a teller at Twin Oaks, selected IADB as the charity for the event to honor her son Drew Hood who has Usher Syndrome Type 1. Unfortunately, Drew had been sick all week and didn't make it to his own charity event. IADB board members Maria McCarrick and Eva Savickas (with her two boys) were on hand to thank the community and share information about the work of our organization.

Our thanks go out to Twin Oaks Savings Bank, Tracie Steider, and the entire Marseilles community for their generosity.

Supporting Cogswell-Macy Act

Illinois Advocates Meet with Senator's Staffer



Standing: Rose Slaght, Maria McCarrick, Paul Reina, Krista Bohl, Cindy Burke, Toby Bohl, Karen Rock, and Michelle Clyne.
Kneeling: Elizabeth and Antonina Kijowski.

In October, IADB's Krista Bohl arranged a meeting with Cindy Burke, Senator Mark Kirk's Director of Constituent Services and Advocacy, to discuss the Cogswell-Macy Act, which will improve access to necessary education services for children who are blind, deaf, and deafblind.

Thanks to everyone who came out to the Philip Rock Center to advocate for this important legislation, which continues to make its way through Congress (see story page 4). Thanks also to Dr. Olaya Landa-Vialard and Kaylie Bohl who contributed by video.



The Steider Family comes out to support the concert to honor Drew. Pictured: Noah, Tracie, Mark and Alyson Steider.

Free Online Training Opportunity from NFADB and NCDB

The Role of Interveners in Educational Settings

The National Family Association for Deaf-Blind (NFADB) and the National Center on Deaf-Blindness (NCDB) are pleased to announce another online training for parents and families of children and youth who are deaf-blind on *The Role of*



Interveners in Educational Settings.

The training, sponsored by NFADB and NCDB, runs from March 13 to April

24, 2017. The time commitment is one to two hours per week for about five weeks.

You work on your own at times that are convenient for you. Learn about the role of interveners, the principles of intervention, and how interveners function as members of students'

educational teams.

The format is primarily self-study, but hosts are available to provide assistance. There are several optional online video sessions. Hosts Patti McGowan (NFADB) and Peggy Malloy (NCDB) will provide online support and feedback. The training will use Module 3 ("The Role of Interveners in Educational Settings") from the Open Hands Open Access (OHOA) Deaf-Blind Intervener Learning Modules.

All you need to participate is a computer and a good Internet connection. And, it's free!

For more information contact Patti McGowan (pmcgowan@pattan.net) or Peggy Malloy (malloyp@wou.edu).

To sign up, use the online registration form at <https://goo.gl/forms/S3xg-DjBICibICdU62>.

Welcome Bohl to our IADB Board

Krista Bohl of Glen Ellyn has joined the IADB board as our 4th Member at Large.

Krista has hit the ground running, organizing meetings with legislators to advocate for the Cogswell-Macy Act (see story page 1). She is also the point person for our new NFADB Affiliation (see story page 4). Krista's daughter Kaylie is featured in this issue on page 3.



Thanks and Farewell

I've been editing and producing *HANDS*, the IADB newsletter, since 2009. It has been a privilege to bring you timely, important information and resources for the past eight years. My family is moving out of state in June, so it is time to say good-bye. I hope you will continue to support the efforts of IADB to advocate for the needs of people with deafblindness in Illinois. You can make a difference. As Helen Keller once said, "Alone we can do so little, together we can do so much."

Maria M. McCarrick
Editor



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. Members gain access to our Facebook page which provides timely information on events and resources. Members can also apply for IADB stipends to attend meetings, workshops and conferences.

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.

Illinois Advocates for the DeafBlind

Board of Directors

President:	Rose Slaght	(815) 389-1077	rojo01@charter.net
Vice Pres:	Eva Savickas	(312) 972-7167	detaz75@yahoo.com
Secretary:	Maria McCarrick	(309) 839-0892	mariamccar@comcast.net
Treasurer:	Eliza Ellett	(847) 530-9809	elizaellettt@yahoo.com

Members at Large:

	Stacey Borrego	(630) 479-9094	sztaborrego@aol.com
	Toni Kijowski	(630) 910-1668	gkijowski@sbcglobal.net
	Kori Longbons	(309) 437-5505	kmlongbons@gmail.com
	Krista Bohl	(630) 545-0131	kbohl2000@yahoo.com

Membership:	Eva Savickas	(312) 972-7167	detaz75@yahoo.com
Newsletter:	Maria McCarrick	(309) 839-0892	mariamccar@comcast.net

IADB New NFADB State Affiliate

IADB is proud to announce that we are now an official State Affiliate of the National Family Association for the Deaf-Blind.

NFADB is a nonprofit, volunteer-based family association. It is the largest national network of families focusing on issues surrounding deaf blindness.

This partnership with NFADB will help IADB build local, state, and national connections. As an affiliate, we can receive financial assistance to attend NFADB training events. We look forward to sharing ideas and strategies with the national organization as well as other state affiliates. IADB joins four other current affiliates from New York, Pennsylvania, Texas, and Puerto Rico.

Krista Bohl has been named IADB's point person for our NFADB affiliation.



Article spotlights young DB advocate

Kaylie Bohl, daughter of IADB's Krista Bohl and a student at Briar Glen Elementary in Glen Ellyn, was featured in her school district's community newsletter. The article titled "Fifth grader Kaylie Bohl: Local student, national advocate" details her decision to attend to her local public school, the accommodations she uses throughout her day, and her advocacy efforts on behalf of students with deafblindness.



Kaylie has lobbied both her congressman and her senator to support the Cogswell-Macy Act, proposed federal leg-

NOTES FROM MY WORLD

Being deaf in a hearing world... and volunteering

by Kori Longbons of Washington

I wanted to share some challenges I have with my hearing loss and being a school volunteer, for a school with 300 kids.



I volunteer at the John Hensey school here in Washington, Illinois, which is directly across the street from my home. The cool thing about this is I get to walk to work, and don't have to drive anywhere! The funny thing is if the car is in the driveway and I'm not answering the door, many people call me and they're fooled because I'm not even home!

Whenever I go in to work, I am usually there two to three hours. With my hearing loss, I have many challenges when I work. I work in the gym, at the Wildcat store, with my boss who is the school's counselor. It is just him and me for the whole hour or so. The cafeteria/gym we work in gets full for lunch breaks, fast. I can't always hear what is being said in the gym. Most of the time I stay close by my boss, or have him talk louder when we get in the gym. I always try to make

sure I remember when my hearing aid battery was changed. For now, I just have one hearing aid. I normally have two, but my other one doesn't quite work right now. It is awesome having hearing aids, because it takes a deaf person and puts them into a hearing world. Even though there are still struggles and challenges, those can be overcome.

My reason for sharing this is because I do not want others that are deaf to feel like they are the only ones who struggle so much with hearing in public places, especially a school or anywhere. This goes out to any kids as well, you are not alone in the hearing world. There are some people who need to adjust to deaf people around them. Everyone I've been around has always been welcoming and able to adjust to the sound level I need.

One last thing I would like to add, I am always here for anyone who needs to talk, or are having challenges they need help with. I can be reached by email or text, or call. I also have a videophone. I am always open to helping anyone with any obstacle they're facing!

Reach me at 309-437-5505 or kmlongbons@gmail.com.

islation which would increase availability of resources and services for students like her, services including interveners. Kaylie has an aide, Jennifer Bradfield, who assists her with any vision or hearing needs. With Bradford as her intervener, Kaylie gets access to information she wouldn't otherwise get, access that all students deserve.

Of her advocacy work, Kaylie says, "Words are powerful. When you say something, people hear it."

Congratulations, Kaylie, on your well-deserved recognition. Keep advocating for yourself and others!

Parent Weekend *from page 1*

Stoney Creek Inn in East Peoria where our members are staying. After dinner, we'll have a parent panel discussion and IADB general meeting. We'll end the weekend on Sunday morning with a special presentation for our DB families by Barbara Doyle titled *Developing Social Relationships: Goals, Strategies and Teaching Tips*.

Registration packets have been mailed. For more information contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or ppausche@philiprockcenter.org.

Seroogy's Chocolate Sale Kicks Off in April



IADB's annual candy sale is back by popular demand. We're trying out a new candy brand this year: Seroogy's. We'll be launching the fundraiser at our annual Parent Weekend in Peoria in April (see story page 1). A variety of premium Seroogy chocolate bars are available for \$1.50 each: Milk,

Dark, Chocolate Meltaway, Chocolate Crisp, Peanut Butter Crisp, Chocolate Mint, Almond Meltaway, Mocha Meltaway, and Shock Rock Meltaway. Almost everyone on IADB's board of directors will have some to sell, so you know where to go 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 Eliza Ellett at elizaellett@yahoo.com or (847) 530-9809.

Retreat Yourself

Mark your Calendars for Upcoming Moms' Retreats

Family Matters Parent Training and Information Center FMTIC has planned four Moms' Retreats:

Carbondale	March 11-12
Galena	May 5-7
Champaign-Urbana	July 14-16
Rockford	October 6-8
Springfield	TBA

For more information visit www.fmtic.org or contact Rose Slaght at (815) 389-1077 or rojo01@charter.net.

Advocacy Opportunities

IDEA Funding Threatened

There is a bill in the House of Representatives that will decrease funding to IDEA by 25% which includes personnel preparation. This is particularly detrimental to students with special needs, who require teachers and staff with specialized training (think interveners). An alert and call to action from the National Family Association for the Deaf-Blind (NFADB) was posted on IADB's Facebook page in December. A sample letter was posted directly below it in the comments section. There is still a need for advocacy. Contact your representative in Washington to urge them to prioritize the funding for Personnel Prepara-

tion IDEA FY2017 at the FY2016 level of \$83.7 million, the level of the Senate Bill.

Cogswell-Macy Act Reintroduced in Congress

Alice Cogswell and Anne Sullivan Macy Act (formerly H.R. 3535) has been reintroduced in Congress as of February 2nd. It is now known as H.R. 1120 and has been referred to the House Committee on Education and the Workforce. H.R. 1120 is sponsored by Reps. Matt Cartwright, with fifteen original co-sponsors. Contact your Representatives and let them know you support this bill.

Illinois mom, advocate attends CMV Conference in Texas

Thank you IADB for funding me to attend 2016 CMV Public Health & Policy Conference in Austin, Texas. It was an information-packed event, with sessions presented by parents, researchers, medical personnel and state agency providers.

I learned about what's happening in the world of congenital cytomegalovirus (CMV), which before was unknown to me. There have been gains, with the use of antivirals at first when babies are born positive, whether or not the onset symptomatology is not suspect.

Meeting many parents from other states and countries was a wonderful experience, and although their children were quite young, it was interesting to see what techniques and educational experiences they could share.

Illinois does have one of the first laws on the books for identification, treatments and education of families who experience CMV and the ravages it can present if its unchecked and allowed to continue to destroy young healthy children.¹

Having the opportunity to learn and converse with researchers, medical people and other parents and providers is such a valuable experience. I cannot thank IADB enough for the critical financial support,

without it, I certainly would not have been able to attend.

Of course my son Donnie will benefit from my attending the conference. He is relatively healthy compared to many family stories shared. I can only try to share what I know.

--Rose Slaght of South Beloit

1. Reference for the law:
<http://www.ilga.gov/legislation/publicacts/fulltext.asp?Name=099-0424>

REGISTER TODAY

**IADB Parent Weekend
April 28-30
Peoria, Illinois**

Project Reach or IADB will cover expenses for first 20 families-- hotel, conference registration, most meals, mileage.

Register by March 15th.

See story page 1.