



HANDS

Winter/
Spring
2015

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

2015 IFLC Conference Focuses on Behavior

Parent Weekend Planned for March 7-8

Join us for a parent training weekend put on by the Philip Rock Center, Project Reach and IADB in conjunction with the Illinois Family Leaders Collaboration Conference. IFLC will hold its 9th Annual Family Conference for adult family members and caregivers of children with disabilities at Peoria's Spalding Pastoral Center on Saturday, March 7th from 8:30 am to 3:00 pm.

Featured speaker, **David Pitonyak, Ph.D.** will present *Beyond "Behaviors": Supporting Confidence, Competence, and Well-Being*. Pitonyak has spent many years working with individuals with disabilities. Much of his work has focused on individuals who exhibit difficult



Project Reach will pay for hotel rooms on Friday and Saturday nights at the SpringHill Suites and mileage for families served by Project Reach coming from outside the Peoria area. Contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or ppausche@philiprockcenter.org.

behaviors because they are misunderstood and/or because they are living lives that don't make sense. Pitonyak is a contributing editor for *The Community Journal*, a disability rights newsletter that focuses on building community. He is also president of the Commonwealth Coalition for Community, a grass roots effort to improve

See PARENT WEEKEND, page 2



Honorees Zach and Austin Savickas

Students Recognized for Tech Achievement

by Eva Savickas of Oak Lawn

On March 6, 2014 the United Cerebral Palsy Seguin of Greater Chicago held the 29th Annual Infnitec Southwest Awards and Dinner Celebration. The goal of the program is to celebrate



the accomplishments of students with various disabilities who have shown great achievement in working past their challenges and accomplishing their goals using technology.

For my two boys, who have vision and hearing challenges, it meant they had to put on nice clothes and go eat food that wasn't McDonald's. Austin was 13 and in 8th grade. Zach was 11 and in 6th. They had been nominated by their teachers from the Eisenhower Cooperative, because they had made great strides in learning to use their iPads, especially the *join.me* program. Austin and Zach really didn't get why they had to put on dress clothes and not eat dinner at home, but reluctantly they did. Then we arrived at the Silver

See TECH HONORS, page 3

The Arc's New Assistive Technology Program

Funding for iPads Available for Qualified Individuals

The Arc of Illinois, through a generous donation, has developed a new Assistive Technology Program. This program will fund, or partially fund, the purchase of assistive technology for individuals with intellectual and/or developmental disabilities, such as an iPad, for social and communication skills. There must be an evaluation/assessment completed by a qualified provider to prove need and reason for the requested device.

The goal of The Arc of Illinois Assistive Technology Program is to enhance and improve the quality of life for persons

with disabilities by providing opportunities for individuals to receive technology to help with education, employment, community living, and independence. With today's technology, there are assistive features on devices, such as iPads, that can really improve learning for students with special needs. One mom recently told us, "I am so excited about the possibility of this program especially for people like my son, who has autism. A device like an iPad would make such a difference to him

See ARC, page 2



Project Reach now on Pinterest



Check out Project Reach: Illinois Deaf-Blind Services on Pinterest. Boards include Literacy for All and Sign Language. See you there!

Parent Weekend *from page 1*

services for people with disabilities and their families in Virginia. Childcare is not provided.

The IFLC Conference is designed 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 Dr. Pitonyak's presentation, IADB will hold our general meeting and elections at the SpringHill Suites where our members are staying. IADB will treat our participants to a pizza dinner and a time to chat. We'll end the weekend on Sunday morning with short presentations by Stacey Borrego who is a certified sign language interpreter, and Kori Olehy who will share her experiences living with vision and hearing loss.

For information and registration, contact Peggy Pausche at the Philip Rock Center (630) 790-2474 or ppausche@philiprockcenter.org.

ARC *from page 1*

in being able to communicate with the people in his life."

The maximum amount funded will be \$500.00 per person or family. Upon approval, the device will be shipped directly to the applicant. Once the device is received, it is the responsibility of that person and/or family to make sure it is used in the appropriate manner and that an evaluation is filled out to assure future funding for this project. There are not many programs like this in the state of Illinois. The Arc of Illinois is overjoyed to be able to provide this much-needed assistive technology for people with intellectual and/or developmental disabilities.

For more information or an application visit The Arc of Illinois at www.hearcofil.org or call the office at (815) 464-1832.

Member Recommended

Joni & Friends Family Retreat

by Stacey Borrego of Batavia

There is a wonderful, faith-based retreat for those of us who have family member with disabilities. It's a place where everyone can participate. Put on by Joni & Friends Chicago, the retreat is held in Muskegon, Michigan. My family has been going there for seven years now. It is so wonderful, that my children, when given the choice between Joni & Friends or Disney World, chose to go to Joni & Friends! It wasn't even close. Activities include rock climbing, zip lining, rafting, swimming (in the lake and the pool), horseback riding and much more. Check out the details and consider joining us on a Joni & Friends Family Retreat:

Session I: June 8-12, 2015

Session II: June 15-19, 2015

Marantha Bible and Missionary Conference in Muskegon, Michigan, 100 miles west of the capital, Lansing, Michigan, 190 miles east of Chicago

At this family retreat put on by Joni & Friends, persons with disabilities and their families receive encouragement and care in the comfort of a safe and accessible family camp environment.

Enjoy fully-accessible and age-appropriate fun activities, be nourished by hearty home-style meals, and glean from meaningful conversations with a network of families who understand the challenges of a

life with disability. Each family will receive their very own volunteer to assist them for the week.

Our hope is that you will leave physically, emotionally and spiritually refreshed and uplifted.

Joni & Friends offers two Family Retreats sessions held this summer on the sandy shores of Lake Michigan at the beautiful Maranatha Conference Center in Muskegon, Michigan. The seaside theme is repeated throughout the campus and virtually all facilities are barrier free – the staff at Maranatha love our families, and you will feel at home and welcomed to this retreat organized by the Joni and Friends' Chicago team.

The cost is \$335 per person, children 0-2 years are free. Fee includes all lodging, meals and activities. Scholarships are available.

Questions? Contact Michelle Thill, Retreat Director at (630) 640-0584 or michelle.renee.thill@gmail.com or visit www.joniandfriends.org/chicago.



The Borrego family with Joni & Friends founder Joni Ericson Tada

Illinois Advocates for the DeafBlind

President:	Rose Slaght	(815) 389-1077	rojo01@charter.net
Past Pres:	Ken Ready	(847) 965-6597	k-ready@comcast.net
Secretary:	Maria McCarrick	(309) 839-0892	mariamccar@comcast.net
Treasurer:	Eliza Ellett	(847) 530-9809	elizaellett@yahoo.com
Members at Large:	Jayne Wright	(309) 726-1036	jm.wright@mediacombb.net
Membership:	Jayne Wright	(309) 726-1036	jm.wright@mediacombb.net
Newsletter:	Maria McCarrick	(309) 839-0892	mariamccar@comcast.net



Learning from My College Experience

by Kori Olehy of East Peoria

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.

World' Finest Candy Sale Kicks Off in March

IADB's annual World's Finest chocolate bar sale is back by popular demand. We'll be launching the fundraiser at our annual Parent Weekend in Peoria in March (see story page 1). A variety of World's Finest chocolate bars are available for \$1 each: milk, almond, crisp, caramel, and dark almond. Almost everyone on IADB's board of directors come to sell, so you know who to call 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.

My name is Kori, I'm 28 years old and I live in 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 hearing aids). I wear my glasses mostly 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 (ICC) with my Associates in General Education, and I'd like to share my experiences as college student with vision trouble and hearing loss.



I started college in August 2005 at ICC in East Peoria. At 19 years old, I had graduated from Richwoods High School in May of 2005. My plan was to get my General Education Degree. Originally I started out at full-time, but as time went on, I learned I did best taking classes part time. I always had sign language interpreters in all of my classes, and even had note-takers to help me keep up.

With both hearing aids, I was able to hear a lot of what was going on in the classrooms or make out what the teachers were saying. I also relied heavily on the interpreters. In 2007 during my college years I suddenly started going completely blind, with and without glasses. I came to class one day, one minute I was fine, and the next I couldn't read. I immediately got family to come get me and take me to the doctor's office. Later found out I needed cataract surgery as soon as possible. After having both eyes done, not only was I able to see without glasses, but the glasses I had had for 20-something years suddenly didn't work. I was then told I'd need bifocals. My life and vision has completely changed since then.

I made many new friends throughout college, most were accepting of my hearing loss, my vision issues and surgery history. I went to study groups to help me learn more. Even though I couldn't fully hear everything, I still tried to stay

involved the best I could.

One thing I learned being in college is, it is so much different than high school. You have to stand up for yourself and advocate for your wants and needs, not only as a student, but as a student with disabilities. I learned that if I needed help reading something, I would have to speak up. I'd have to speak up if I needed changes to my reading materials, or even homework materials. It took quite some time to get the courage to find my voice, speak up on my own and gain my independence and freedom. Once I did, I felt great about it and I was a better person because of it. I have never let my hearing or vision issues bring me down or make me feel defeated. Now that you've read my journey through college, I only hope that this helps you in your college years. Know that it's okay to speak up when you need help, and it's also okay to stand up for your wants and needs as a college student with disabilities.

Tech Honors *from page 1*

Lake Country Club and they saw all the people dressed up, and Zach said to me, "See Mom, I'm glad I decided to wear my fancy clothes." There, they saw all the staff from school, and were very impressed how beautiful everyone looked. After the welcome speech and a video highlight presentation, we were served dinner. I think that was the highlight for my boys. Next came the presentation of awards. Each of them was called up to the front of the room and made a short speech, thanking mom and dad and grandma for coming. They received a beautiful award, a teddy bear, and best of all, McDonald's gift certificates!

To have your kids singled out--not for being different, because they wear glasses and hearing aids, use magnifiers and large print everything, and use sign language as well as speak unclearly, but because they have accomplished something despite all that has been set upon them--is one of the greatest joys I have experienced as a parent. I know this won't be the last time they will have to wear "fancy" clothes.

ABLE Act Becomes Law

The Achieving Better Life Experience Act or "ABLE" Act was signed into law in December. It allows Americans with disabilities to save money, tax-free, for certain expenses without endangering their Social Security or Medicaid benefits. Before ABLE, people with disabilities could only have money in special trusts set up for them or risk losing their government benefits. Now citizens with disabilities can earn paychecks, deposit them in their own accounts and save for long-term expenses not covered by Medicaid and SSI, like education, transportation, housing, or a job coach.

Call for Nominees: IADB to Elect New Board

Interested in becoming more involved in IADB? We will be holding elections for our Board of Directors at the general meeting on March 7th at the SpringHill Suites in Peoria.

The current slate of nominees include: **Rose Slaght** for president, **Eva Savickas** for vice president, **Eliza Ellett** for treasurer and **Maria McCarrick** for secretary. Member at Large nominees are **Jayne Wright**, **Stacey Borrego** and **Kori Olehy**.

We need four Members at Large for a complete board. We welcome any other members who would like to serve, in whatever role they choose. Contact Maria McCarrick at mariamccar@comcast.net or (309) 839-0893 home or (734) 634-8417 mobile.

Important Upcoming International Meetings

CHARGE Syndrome Foundation
Conference

July 30-Aug 2 in Chicago, IL

GFPD Family & Scientific Conference
for Peroxisomal Disorders

July 17-21 in Omaha, NE

SOFT Foundation Conference
for Trisomy 18, 13 and Related Disorders

July 8-12 in Salt Lake City, UT

Usher's Syndrome Coalition Symposium
and Family Conference

July 10-12 in St. Louis, MO



October Mom's Retreat in Rockford

by Rose Slaght of South Beloit

Moms of children with disabilities of all ages met at Bishop Lane Retreat Center in Rockford, Illinois on October 17, 18 and 19. We enjoyed activities, laughter, information, ideas and fun. There were pampering services such as massages, reflexology, manicures and fun things to do like shopping, learning about nutrition and essential oils. We had sessions on Tai Chi and Meditation too.

Sandra Geiseman presented on the *Masks We Wear*, then we painted our own masks. Elizabeth Frisbee presented on behavior issues and how we can proactively deal with our children. Tom Sullivan showed us how to make healthy foods.

We had a bonfire, and white elephant gift exchange. Lots of networking and conversations were going on all weekend, and the participants were fed well.

We all returned home with renewed strength and fresh information to continue supporting all the ones we love, and especially our family members with different abilities.

Maybe you should check one out in the future.

Want to know more about upcoming Mom's Retreats? Contact me, Rose Slaght at (815) 389-1077 or rojo01@charter.net.

Illinois Hands & Voices Moms Night Inn

May 2-3, 2015

Hilton Hotel Lisle/Naperville, 3003 Corporate West Drive,
Lisle, Illinois

Moms and female caretakers of children with hearing loss come together to bond and relax together. This event is for moms and female caretakers of children of ALL ages, no one is excluded from Moms Night Inn.

Brought to you by Illinois Families for Hands and Voices, a parent-driven, non-profit organization dedicated to supporting families that have children who are deaf and hard-of-hearing without a bias toward communication modes or methodologies.

For more information visit ilhandsandvoices.wordpress.com.



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Join IADB on Facebook for timely information and news of interest to people with vision and hearing loss. Connect with other members throughout the state and stay up to date on all the happenings.