

# IPVI INSIGHTS

*Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities*

**October  
2015**



## MESSAGE FROM THE PRESIDENT

*By Lyle Stauder, President*

Dear Parents,

When our first son was born we did not know how much vision he had and the doctors could not tell us. When he was about 6 months old we took his hand and touched it to our ears, mouth and nose to let him learn these parts of the face. Then we would say the word so he could feel the vibration of the words with his fingers on our lips.

We live in a very visual world. As a result, children with low vision or totals need to learn to use their other senses. We had a 0 to 3yr old Vision Teacher working with our child and helping us with suggestions for learning. She told us while we would take walks in our neighborhood to stop and have him feel the shapes of the leaves and smell the flowers along the way. This could also include bark on trees, shrubs, bushes, rocks, sticks, and other natural resources along the way. Also you could teach your child to learn the different building materials such as bricks, concrete blocks, wood, cement, dry wall, as they get older. There are different sports activities to learn. For example we took our children bowling and let them feel the alley, the ball and explain the ball return as well as learning to bowl. There are different smells in a bowling alley such as food, popcorn, etc. that the children are curious about. Another thought is don't be afraid to let them experience climbing, sliding and running around like other children. Beeper balls are a fun activity for low vision. Another game for all children is Goal Ball which gives all children an equal playing field because they are blindfolded. It is so much fun!!!!

Our Vision Teacher suggested, at the age of one and two, to place a noisy

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toy in another room and let him listen and find the toy. This is to increase their listening skills and is a fun game. We took magnetic letters and numbers and let him feel the shapes of each one so he would know what they looked like.

In a lunch meeting with a friend, Alice Post, who was very knowledgeable about raising visually impaired children and being around visually impaired adults, she suggested that a sighted person with the child should describe the new area they are walking into, like the décor of a restaurant or a room, amount of people in the room, and the approximate size of the room.

So in closing let your child experience the world in its fullest and reach for the stars in the sky.



**MS. VIC'S VOLLEYS**  
*Victoria Juskie, IPVI Treasurer*

**MS. VIC VOLLEYS**

**VOLLEY I**

No new members have joined us this month.

**VOLLEY II**

Well, it's October, my favorite month of the year. It has been that way all my life because it's my birth month and Halloween, my two favorite holidays that both happen in October! Growing up there were always two parties in October, both of which were all mine – or at least so I thought. Sure I had to share dressing up in costume with hundreds of other candy-grabbing kiddies; but as long as there were free-flowing goodies for all, what was not to like?

Well, looking back over the last decade or so though, I guess being my birth month isn't as great as it used to be. I seem to be dreading each passing year because it just means I'm getting older and older. I am starting to believe that birthdays are for the younger generations who take their rights of passage with such flair. First you can't wait to be in double digits or even 10 and a half. Then it's becoming a teenager; after that it's 16 so you can drive; 18 so you can vote; and 21 so you can drink. Then the decade celebrations creep up on you so now you're 30, then 40, then 50...and so on.

Sure a lot of you out there are not even close to 40 let alone 50 or 60, but many of us are. I know I don't feel like I'm 57 but, ahhh, I am. I still feel 30 something inside, but on the outside, the wrinkles have piled on, the saggy upper arms seem to flap more viciously, and I tend to take more naps now than ever. You

might ask what my point of this diatribe is because isn't this a forum for stories about children who are blind or visually impaired? Why, yes, it is and so I segue into the true point I wish to make.

Once you have children, you have to make decisions about the future. I don't care how many children you have or if any have disabilities or challenges or not, make out your (s). Get your spouse/other baby parent and both of you become the adults who go to a lawyer and declare how you've planned ahead to take care of your child(ren) should the unthinkable happen. The hardest question that must be answered is "What if you both go at once, who will care for your kid(s)? Now, let's throw that elephant in the room into this equation, too, with the fact that if you're reading this, either you or your family member is affected by low/no vision or other disability. That means assessing the reasonable life spans of the condition(s) with which you're dealing.

If you have someone with low vision who also has low cognitive abilities, your child may need additional care for the rest of his/her life. So I highly recommend going to a lawyer and setting up a trust that would go into effect should both parents pass simultaneously. In that way, your dependent's housing will be established and intact. Many times, people don't put their disabled family member into the "System," feeling that their family takes care of its own. So we drive him everywhere. We do the shopping, cooking, cleaning, manage his medical issues, etc. as I come from that type of family which does that. However, after going to some seminars from **Protected Tomorrows** about establishing the "what if" plan for disaster preparedness, which in my case was "What if my older disabled brother outlives me?", I knew as his guardian, I had to make his future set. So a trust securing that future was established, not only for him but for

our four children as well. In this way, all of the services, which I have been providing, would continue after I'm gone. I came to realize, there is no one out there going to take care of Jim the way I did so any programs he's eligible for, I signed him up. If there are organizations who step in to help potentially, like "Medicare," "Dial a Ride," "Day Therapy," etc., he's a part of them already. This cushion of preparedness has helped take off one more of the potential burdens that may be faced by my family in the future.

So my tip of the day is get your house in order now that you're parents/guardians. Don't put off this important matter. Secure the future so you can enjoy the present. Many times we think we're invincible because we're surviving some pretty hard knocks. Let's face it, having low vision sucks (or having any other challenge for that matter), and excuse my crudeness for not being politically correct as I've been watching too many politicians. I should have said "having low vision is troubling," but if I said it that way, you'd know I was scrubbing the language for publication, and not saying how it really feels. So forgive me please for saying how it really feels at times.

I think if you're the parent with the kid going through a life-altering tough time, your heart breaks for your child's loss. Remember though, for those children born with low or no vision, that's all they know; and you don't miss what you've never known. However, we also know that if we don't teach our kids coping skills and other ways to compensate for the lack of vision, their cognitive skills can be adversely affected. Therefore, as a parent or guardian, set up your future security plans. Then get down on your knees and start teaching that baby all sorts of body awareness by asking questions like "Where's is your nose?", and then your touching it or "Where are your ears?", etc. It's up to you as parents

to stimulate and educate the brain cells of your baby into success mode so talk with your child and explain the world to him/her. Then get some birth-to-three guidance so your child will be ready for school where in a few short years they'll be just like typical kids who yell, "Where are my shoes? The bus is coming!" Then you'll smile and realize just how normal everything can be.



By Erika Musser



I just read the IPVI Insights for September 2015 while enjoying my morning coffee. I reflect with respect and admiration how far we have come in our advocacy for our blind/visually impaired children. When totally blind Heidi was a child 3 1/2 years old, the Chicago Public Schools simply wrote her off and made her feel rejected. There was no such thing as taking part in the class room or all school assemblies. I was told to keep her home until she matures.

On a more pleasant note, you may enjoy and value reading the following:

### Teaching Justin

By Heidi Musser

From the Editor: A native of Chicago, Heidi Musser is a triathlete who was nominated for the USA Triathlon Hall of Fame. In recent years she has reduced her training in swimming, biking, and running to focus on classical piano and volunteering to teach blind children Braille, piano, and

swimming. This article is based on a composition she wrote for a class at Oakton Community College.



I have discovered that it is important to help people whom society thinks of as broken--children or adults--by helping them feel accepted, giving them a sense of belonging, and respecting them for who they are and what they have to contribute. The greatest emotional pain is caused by rejection and the feeling that nobody wants you. I experienced rejection and misunderstanding throughout my elementary and high school years.

Justin came into my life in October 2008 when he was twelve years old. I remember distinctly the first day he came to my home. My mother says she fell in love with him as soon as he and his mother walked into our living room. Justin was blind, autistic, and unable to speak. There was very little that he could do or wanted to do. He could walk and move around, but he showed no eagerness about doing anything.

At first I did not know how to interact with Justin. Then I started to play the piano for him. When he heard me play, our relationship started to take off. I played on my grand piano

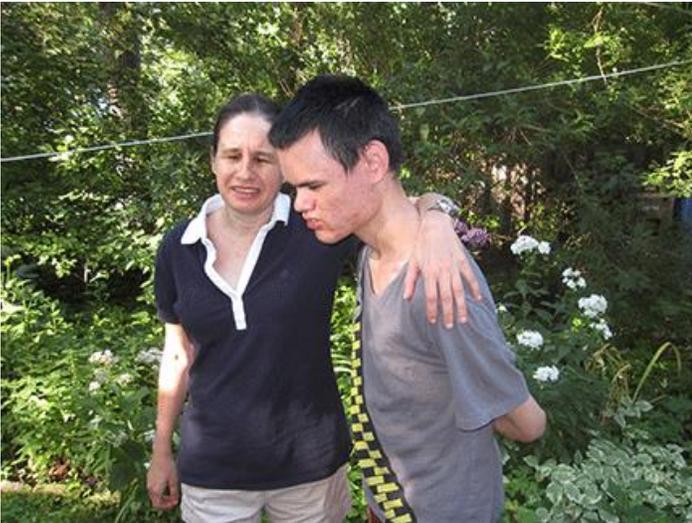
in the living room, and my mother guided Justin to my old upright piano in the dining room. When I pressed the middle C, Justin surprised me by playing the C one octave lower. That told me something! It told me that Justin has a good ear. It did not take long before he could find all seven Cs on the piano keyboard. Right then, my mother and I decided we would like to give him my old piano as a gift. A friend agreed to transport it from our Chicago home to Justin's home in the suburbs for no charge.

Justin started coming to my house once a week. His mother told us that his enthusiasm for daily practicing on the piano soared immediately. He would improvise and sound out songs on the piano by himself. He played songs he knew from school, such as our national anthem. He also played melodies he had stored away in his mind after hearing me play them for him or listening to them on TV, radio, or CDs. He had fun following his creative impulse like never before in his life.

Sitting together on my double piano bench helped Justin and me build a close bond, so important to healing social isolation. Over the next few months, I discovered that Justin could easily follow my hands as I played in major and minor keys. To my surprise, he figured on his own where the sharps and flats needed to be played. The only difference in our playing was that I used my ten fingers, while he used mainly the right index finger and, rarely, the right middle finger. He does not like to use his left hand. I assume this is due to a lack of coordination. I hope I will succeed in getting him to play with all the fingers of both hands in the future. Lately he has surprised me by using the index and middle fingers of his left hand without any coaxing.

Teaching Justin to write Braille was utmost on my mind. Many of the educators did not believe that he was capable of learning, and I was determined to prove them wrong. Justin's

mother accepted my mother's suggestion that she teach herself Braille and then teach her son. In addition to holding two jobs, she became dedicated to helping her son learn Braille. She deserves big applause!



I also was determined to get Justin into the pool at my YMCA. I wanted to introduce him to swimming and physical exercise in the water to improve his coordination all around. Initially, his mother said she was afraid that Justin would catch cold. My mother and I persevered. We discovered that the real reason for her fear was that she was a non-swimmer and afraid of the water in the pool. Justin learned more quickly than his mother, and soon he could put his head underwater. Now they both enjoy swimming in the deep end of the pool. Justin swims length after length with me, holding onto my waist with both hands. He is very relaxed. My mother generally swims next to us to keep close watch. Because his kicking with his legs is still not strong, I help him put a pull-buoy between his thighs. His breathing is surprisingly regular and good. He can hold his breath for an unusually long time underwater.

At the start of the 2014-2015 school year, a new Braille teacher was assigned to Justin. About three weeks into the semester, Justin's

mother informed us with great excitement that his new teacher agreed that Justin is doing well in writing Braille, including contractions. Wow! I have proved that Justin is intelligent! He can reason, and he is capable of learning Braille. His life will be very different from now on. He can express his feelings and wants by typing Braille, learning the correct spelling of words and usage of Braille contractions. That's *big!* He also uses a device called the Fusion that speaks the words he types.

Sadly, only 10 percent of blind children nationwide learn Braille. Couldn't this problem be solved by inviting blind adults who know Braille to come to schools as mentors for blind children? The common bond of blindness did the trick for Justin! Blind teacher/mentors could earn a paycheck working at the schools part-time. Why aren't there more workshops for parents of blind children to learn Braille? Many parents would enjoy helping their children with Braille just like Justin's mother and mine did.

I feel I have my work laid out for me, supporting Justin's Braille teacher. I plan on meeting with Justin in the pool and at my home at least once a week. In my home environment I can give Justin the opportunity to fine-tune his sense of touch. I give him a chance to handle items with which he is not familiar. Through touch blind children need to become familiar with items about which they are reading and learning. For example, during the previous school year, one of Justin's teachers was reading E. B. White's book *Charlotte's Web* to the class. I discovered that Justin had no idea what a baby bottle feels like or how a baby drinks from it. Yet he was expected to answer questions about Fern, the girl on the farm, feeding Wilbur, the baby pig, with a bottle.

What was my formula for success? While the educators made a long list of things Justin cannot do, Justin's mother, my mother, and I add-

IMPORTANT  
ANNOUNCEMENT !

Please be advised that as of 9/1/15, IPVI will be changing its P.O. Box to the following address:

**Illinois Association for Parents of Children with Visual Impairments  
P.O. Box 316634  
Chicago, IL 60631**

We will put in change of address notice in at the post office so it will forward any mail coming in to the old box. Please call 815.355.2098 if you have any questions.

ed up a list of things he *can* do. Six years ago, when we met, Justin's heart was filled with tension, fear, and loneliness. In his book *From Brokenness to Community* (Paulist, 1992, p. 13), Jean Vanier points out, "If a child feels unloved and unwanted, he or she will develop a broken self-image."

When he began visiting my home, Justin started to enjoy being part of a community, a community of my family and his. Often we ate delicious, home-cooked Burmese meals that his mother, who was raised in Myanmar, prepared for us. Justin loved my mother's banana bread and apple pie with lots of freshly whipped cream. We made sure he could take some of our dessert home for his father, proudly carrying the package himself. For Justin's birthday celebrations his father and my father joined us.

Justin's eye rubbing and arm flapping have become less frequent. When he starts a tune on the piano, I figure out what he is trying to play. Then I play back his melody with left hand accompaniment. Sometimes his smiles

are as wide as back to his ears, according to my mother. I never know what he will come up with. Just recently he wanted me to play Verdi's "March of Triumph" from the opera *Aida*. Another time it was parts of the Brahms "Requiem." Most often we end our piano sessions with the Brahms "Lullaby," with which he is well acquainted. His mother sang it to him when he was in intensive care as a baby. He was born premature at twenty-six weeks gestation.

Being part of our community has helped Justin feel that he can contribute to the lives of other people. Justin sure helped me discover the immense joy of giving of myself. He has helped me heal some of the emotional wounds inflicted upon me by teachers who lacked training to work with a congenitally totally blind student and did not value my God-given gift for a classical music education.

American Action Fund for Blind Children and Adults, *Future Reflections* Fall 2015



# IPVI's Matthew Benedict Juskie Scholarship Fund

For students who are blind or visually impaired

Any individual intending to continue his/her education at a college, university or trade school and is interested in being considered for the MBSJF, must meet the following criteria: Illinois resident, blind or visually impaired, undergraduate or graduate student, and an IPVI member.

The candidate's application is processed free of charge. The student must mail or fax a written request to receive a copy of the application from IPVI. Then the student must complete the MBSJF Application Form, provide 3 completed Reference Forms, submit medical records or a letter from the vision specialist confirming the condition, and mail them to IPVI. The applicant may attach a 1-page resume of clubs, offices held, or any other pertinent information concerning his/her activity record.

The IPVI Board of Directors will review all scholarship applications and select the winners. IPVI reserves the right to announce such awards in its newsletters and marketing materials.

The MBSJF is funded completely from tax-deductible donations from individuals, companies and corporations who support IPVI's goals. Any individuals or groups wishing to donate to this fund, please forward your tax-deductible donations to IPVI. Thank you for your continued support of IPVI.



**To request a scholarship application, please contact the Scholarship Program Coordinator, Vicki Juskie at: 815-464-6162 or [vajuskie@aol.com](mailto:vajuskie@aol.com)**



**PLAY FOR ALL**

**LIGHTHOUSE/IPVI FAMILIES**

**What: A morning of fun for everyone**

**Where: Chicago Children's Museum at Navy Pier  
700 E. Grand Ave., Suite 127  
Chicago, IL 60611**

**When: Saturday, November 14, 2015**

**Time: Pre-registered families 9:00am - 1:00pm  
General public 10:00am - 1:00pm**

**To register or for more information contact:**

**Gail Patterson at the Lighthouse 312-997-3675**

**Pre-registration includes:**

**Free admission for Chicago Lighthouse & IPVI Families**

**Free shuttle from the Chicago Lighthouse to Navy Pier**

**(first 50 people only!!!)**



## Parents of Teens who are Blind or Visually Impaired: The Foundation for Your Child's Transition Goals This School Year

by Shannon Carollo

It feels like yesterday you first laid eyes on your precious one. I know. The days were long, but the years flew. Now it's high school. High school! That means your child's adulthood is rapidly approaching, and it's time to prepare him or her for a satisfying life as a grown-up.

If a "satisfying life as a grownup" truly is the goal, the important questions to ask your son and yourself in your quest to support him are:

- ◆ What leisure activities would my child enjoy as an adult?
- ◆ How can my child be active in his community?
- ◆ Where would my child want to live?
- ◆ What job would be a good fit for my child?
- ◆ Who can be in my child's circle of support in his adulthood? (This includes family, friends, and any support needed to attain a job or independent living.)

Your child may have specific desires and realistic dreams for himself, making his transition from high school to adult life relatively straightforward. In this case, you, your child, and his educational team will meet to establish long-term goals and short-term objectives to prepare your child for his ambitions. For example, transition goals and objectives for the next several years may include:

- ◆ necessary skills for independent life as a person who is blind or visually impaired (such as advanced orientation and mobility and money management),
- ◆ improved social skills,
- ◆ assistive technology skills
- ◆ preparing for college with a visual impairment
- ◆ conducting a successful job search
- ◆ succeeding at work with a visual impairment
- ◆ locating blindness-specific services for adults who are blind.

If your child has additional disabilities that make his desires and dreams unclear and complicated, the transition team should begin by discovering the possibilities for your child. Ideally, a voluntary series of personal futures planning meetings would take place with your son and all who support him now, and those who will continue to support him throughout his adult life. The group of family members, educators, and community supports would aim to understand your child's goals for a satisfying adult life (such as fulfilling employment, a gratifying living situation, leisure pursuits, and a plan for future finances); identify barriers to reaching the goals; and establish a plan to overcome the obstacles. The meetings can continue throughout your child's lifetime.

As you look to the upcoming school year and seek to support your child's shift to adult life, remember to prioritize identifying his goals and desires when creating transition and employment goals. Thereafter, utilize FamilyConnect's "Teenagers' Transition to Independence" section and the tools and resources within AFB CareerConnect to prepare your child for "a satisfying adult life."

Teachers of transition-age students who are blind or visually impaired, please utilize AFB CareerConnect's Lesson Plan Section to teach many transition-related concepts and skills.

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### **Reps. Cartwright, McKinley Champion Comprehensive Bipartisan Legislation to Transform Special Education for Students with Sensory Disabilities**

**Date Posted: 09/18/2015**

Washington, DC – Today, U.S. Congressmen Matt Cartwright (D-PA, 17) and David McKinley (R-WV, 1) introduced the bipartisan Alice Cogswell and Anne Sullivan Macy Act (H.R. 3535), named for two pioneers in the education of deaf and blind students. This landmark legislation would dramatically improve educational results for students who are deaf, hard of hearing, blind, visually impaired, or deafblind.

In 1975, Congress enacted America's federal special education law known today as the Individuals with Disabilities Education Act (IDEA), and the Cogswell-Macy Act would amend and modernize IDEA to address the largely unmet unique needs of students with sensory disabilities. The bill would: ensure that students with vision and/or hearing disabilities are properly identified, evaluated and served, especially when they may have additional disabilities; guarantee that students with sensory disabilities are provided with the full array of special education and related services they must have to truly receive a free and appropriate public education; promote and support teachers and associated professionals who are critical to the delivery of such services; and hold all levels of our public education system accountable for these expectations.

"Upwards of 350,000 students are deaf or hard of hearing, and an estimated 100,000 have blindness or vision loss. Yet less than one-third of those students are reported as having those needs under IDEA. That is completely unacceptable," Rep. Cartwright said. "This legislation would ensure that students who are deaf, hard of hearing blind, visually impaired, or deaf-blind receive an equal and appropriate education and have access to vital services. I look forward to working with my colleagues to guarantee that all children can succeed and achieve their potential."

"Americans have made great strides since 1975 toward improving the lives of children dealing with hearing and sight disabilities but there is still more work to be done. We need to ensure the nearly-half a million kids with these disabilities have the same opportunity as other children to learn and develop skills. This is a common sense step to ensure we are helping these children," Rep. McKinley said.

The American Foundation for the Blind and Conference of Educational Administrators of Schools and Programs for the Deaf have endorsed the Cogswell-Macy Act, along with more than 100 other leading national, regional and community-based organizations.

"The introduction of this bill represents a momentous step toward the transformation of this country's special education system in a manner that will truly allow for students who are blind or visually impaired to succeed in a twenty-first century classroom." said Kim Charlson, president of the American Council of the Blind (ACB). "The Cogswell-Macy Act is the most significant national proposal to improve education for students who are deafblind we've seen in decades," said Mussie Gebre, President of the national consumer advocacy group, DeafBlind Citizens in Action (DBCA). "When America's deafblind children and youth have their unique communications and learning needs fully met, are provided with essential supports such as intervener services, and are empowered by our national education system to rise to their full potential, well then just you look out because they're on their way to achieve great things. Just watch us and see for yourself!"

"Our national special education law has been a success at getting kids with disabilities into their neighborhood schools, but what we haven't done yet is to make sure that students with vision loss get the education they deserve once they get in the schoolhouse door," said Mark Richert, Director of Public Policy for the American Foundation for the Blind. "We've waited forty years, and we're not waiting another forty to give kids who are blind or visually impaired an education that is worthy of their tremendous potential. That's why the Cogswell-Macy Act is imperative."

"We expect that the passage of the Cogswell-Macy Act will rectify years of misapplication of IDEA for deaf and hard of hearing children everywhere. Deaf and hard of hearing children continue to experience language and academic delays because their educational environments are not optimal or even conducive to their learning," said James E. Tucker, Superintendent of the Maryland School for the Deaf and President of the Conference of Educational Administrators of Schools and Programs for the Deaf. "Every student's Individualized Education Program needs to be student-driven and focused on the child's language, cognitive, and social development."

NAD President Chris Wagner stated "Every deaf or hard of hearing child deserves access to a quality education, and this Act will be an important step towards reminding states of their accountability regarding deaf, hard of hearing, blind, deafblind, and visually impaired children's needs."

Rep. Matt Cartwright represents Pennsylvania's 17th Congressional District, which includes Schuylkill County and portions of Carbon, Lackawanna, Luzerne, Monroe, and Northampton Counties. Cartwright serves on the House Committee on Natural Resources and the House Committee on Oversight and Government Reform.



## Unified English Braille (UEB) Is Almost Here...Blind Mother

Posted on 9/21/2015

by Scott Truax



**Editor's Note:** Braille is important to everyone who is blind as it provides tactile access to the written word. Holly and Kathryn want you to be aware of the upcoming changes to the braille code, and also assist them by participating in a discussion of families learning braille through online courses.

You may have heard that the braille code, the tactile system used by people with visual impairments to access print, is getting a makeover. In January 2016, blind adults, students, their teachers, and their families will be starting to learn changes to the braille code with which we are all familiar. The revised version is called the Unified English Braille Code (UEB). This is the first in a series of posts designed to help parents and families understand the reasons for these changes and what these changes will mean for you and your child.

### Because Families Are Teachers

We know that parents are the most important influences in the lives of their children. Moms and dads are a child's first and most important teachers. For children with visual impairments, families must take an extra step to learn braille in order to support their child as he or she learns braille at school.

### UEB Resources to Help Families Learn About UEB

There are resources to help families learn the braille code changes. Here are some links:

- ▶ Start with [AFB's braille information](#)
- ▶ Then you may want to check out this [free AFB Webinar, A Brief Overview of Unified English Braille](#)
- ▶ Perkins Scout has a list of [Resources for Learning UEB](#)

- ▶ And The Hadley School for the Blind offers a course called "Transitioning to Unified English Braille"
- ▶ Texas State Leadership Services for the Blind and Visually Impaired will be hosting a UEB Study Group Webinar

But we also realize that not everyone learns best from taking a traditional online class.

### UEB Prep

At Portland State University (PSU) we are developing an online braille learning platform that will incorporate eLearning exercises, educational gaming, and social networking that can be used by both braille readers and their friends and family members. In its first phase, the platform will help people learn some basics about the braille code and the new UEB rules. To learn more about PSU's UEB Prep, contact Holly Lawson at [hlawson@pdx.edu](mailto:hlawson@pdx.edu).

### Share your Experience

As we develop our eLearning platform, we need to know more about the people who will be using the tools. We're asking families to share their experiences with online learning and braille (anywhere from having no experience with braille to being an actual braille reader yourself). In a few weeks we will be sending out an invitation to participate in an online discussion for families about UEB and learning. We hope you'll be able to join us on October 6th at 6:00 PM (Eastern) 3:00 PM (Pacific).

### Contact Information

Holly Lawson  
[hlawson@pdx.edu](mailto:hlawson@pdx.edu)

Kathryn Botsford  
[botsfor2@pdx.edu](mailto:botsfor2@pdx.edu)



**Vision Connect App:** The American Foundation of the Blind (AFB) has released a free accessible iOS app enabling anyone to search through a directory of services throughout the US and Canada for children and adults with vision loss. You can find resources such as computer training, daily living skills training,

braille and reading instruction, guide dog training plus much more. In addition, you'll find personal stories of people living with vision loss, tips for living independently and suggestions for maintaining employment. This app is also helpful for healthcare providers and enables an email to be sent to the patient with resources they have chosen. To learn more, visit [www.visionaware.org](http://www.visionaware.org).

**2016 NASA Internships:** Attention students

*(Continued on page 19)*



## Family Resource Center on Disabilities

Providing Parents of Children with Disabilities with Information, Training, and Assistance

### 11th Annual Illinois Statewide Transition Conference



### Stepping Stones of Transition

The 11th Annual Transition Conference for transition aged youth and young adults with disabilities, their family members and teachers, vocational professionals, caregivers, health care professionals, college students pursuing careers in special education and community advocates will be held at the **Hyatt**

**Regency McCormick Place, 2233 South Martin Luther King Drive in Chicago, Illinois from October 29-30, 2015.**

The conference, titled “**Stepping Stones of Transition**”, invites participants to imagine the possibilities for students with disabilities in the areas of independent living, education and training, employment, community integration, health care, and self-advocacy.

Conference sessions will be organized into 4 tracks: Education, Employment, Community and Healthcare.

Thursday, October 29th features keynote speaker Steve Hopkins, co-founder of 3E Love, and multi-choice Break-Out Sessions with a Welcome Reception at the end of the day. Friday, October 30th concludes the conference and highlights multi-choice Plenary Sessions and Break-Out Sessions in the morning. The conference concludes at 1:00 p.m.

#### Registration

Conference participants are strongly encouraged to register using the **Illinois Transition Conference online registration**, [frcd.org](http://frcd.org). “Go Green” and help conference planners take eco-friendly steps to better our environment by registering online and eliminating paper registration forms. A limited number of hard copy registration booklets will be made available by request only to those that do not have internet access. Contact Family Matters at 866-436-7842.

**20 East Jackson Blvd., Room 300  
Chicago, IL 60604**

**REGISTER FOR YOUR FREE PARENT WORKSHOP TODAY!**



**Illinois State Board of Education**

Gery J. Chico, Chairman  
Dr. Christopher Koch, State Superintendent

FRCD's hour long Lunch and Learn Webinars focus on specific aspects of the special education system in Illinois. All webinars are free.

**IDEA: What Parents Need to Know**  
Wednesday, October 7, 12pm-1pm

**Navigating the IEP**  
Wednesday, October 14, 12pm-1pm

**Do You Understand the Evaluation Process?**  
Wednesday, October 21, 12pm-1pm

**Procedural Safeguards**  
Wednesday, October 28, 10am-1pm

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The Family Resource Center on Disabilities (FRCD) offers parents of children with disabilities birth to 21 years old, their helpers, relatives, professionals, and interested community members no-cost training and workshops, telephone and e-mail assistance, and resources to help claim their role as the child's most effective and significant advocate.

You are invited to contact FRCD for information, resources, support and training.

1-312-939-3513 | [info@frcd.org](mailto:info@frcd.org) |  
[www.frcd.org](http://www.frcd.org)  
20 East Jackson Blvd., Room 300  
Chicago, IL 60604

**IEP Check-Ins**



**Illinois State Board of Education**

Gery J. Chico, Chairman  
Dr. Christopher Koch, State Superintendent

Do you have specific questions about your child's Individualized Education Plan (IEP)? Are you asking the right questions about your child's special education services?

Make an appointment during FRCD's IEP Check-In sessions, and one of our parent trainers will sit down with you and help you comb through your child's IEP.

Thursday, October 8, 4:00pm-7:00pm  
Thursday, October 15, 4:00pm-7:00pm  
Thursday, November 5, 4:00pm-7:00pm

**We ask that you read the IEP prior to your IEP Check-In session and bring a copy for the parent trainer to go through with you.**

**APPOINTMENTS ARE MANDATORY.**

**PLEASE CALL 312-939-3513**

1-312-939-3513 | [info@frcd.org](mailto:info@frcd.org) |  
[www.frcd.org](http://www.frcd.org)  
20 East Jackson Blvd., Room 300  
Chicago, IL 60604

## FRCD



### Family Resource Center on Disabilities

Providing parents of children with disabilities with information, training, assistance, and support.

## Volunteer Advocacy Training Program Registration is Open

Are you a parent of a child with a disability or a community member interested in helping families? The Volunteer Advocacy Training Program is a series of trainings designed to help you navigate the special education process.

### Requirements:

- Willing to attend all 5 sessions
- Willing to complete pre and post survey
- Willing to complete homework assignments prior to class
- Have a passion for helping families of children with disabilities

### Training will Cover:

- The Individuals with Disabilities Education Act (IDEA)
- State law (Part 226)
- The Family Education Rights and Privacy Act (FERPA)
- Section 504
- Advocacy

All trainings and materials are free. The Volunteer Advocacy Training Program is five sessions long and is limited to 15 committed participants. Homework is required and must be completed prior to each session.



The trainings will be held in the fall of 2015 from 10:00 AM to 2:00 pm (CST).

The training dates are:

**October 10<sup>th</sup>,  
October 17<sup>th</sup>, October 24<sup>th</sup>,  
October 31<sup>st</sup>**

To register online, visit [www.frcd.org/news/vatp](http://www.frcd.org/news/vatp)  
For more information contact Paula Wills at [paula.wills@frcd.org](mailto:paula.wills@frcd.org) or call 312-939-3513.  
**SPACE IS LIMITED!**

*For more information about FRCD resources, support and publications, please contact the Family Resource Center on Disabilities at 312-939-3513, visit us online at [www.frcd.org](http://www.frcd.org), or email us at [info@frcd.org](mailto:info@frcd.org).*

FOUNDATION  
FIGHTING  
BLINDNESS

Share



I am pleased to announce that the Foundation Fighting Blindness (FFB) will be joining forces with the Foundation for Retinal Research (FRR) to enhance our research efforts to find treatments and cures for retinal degenerative diseases. The merging of FRR into FFB will officially take effect on January 1, 2016.



FOUNDATION  
FIGHTING  
BLINDNESS

For the past 17 years, FFB Board member and Officer, David Brint, his wife Betsy, and other family members have dedicated themselves to organizing, informing, and supporting individuals and families across the country affected by retinal disease. FRR has played a vital role in advancing the field of research in congenital blinding disorders, as has FFB, through large investments in this area of research over the past two decades.

As scientific progress in our field continues to accelerate – there are now roughly 20 clinical trials focused on retinal disease treatments – it is increasingly clear that greater collaboration is, and will be, needed in order to fund later stage projects and de-risk them sufficiently to draw commercial partners from the pharmaceutical, biotech and investments sectors. We have taken the initial steps, but there is still a great deal more work to be done. We believe that the joining together of FFB and FRR will increase our capacity to attract commercial investment.

We welcome the FRR families to the FFB and look forward to the amazing dedication and passion that has been such a defining characteristic of FRR. FFB, in turn, is committed to providing information and support at the same high standard that has been set by FRR. Most importantly, we share a laser-like focus on finding treatments and cures for retinal diseases.



Sincerely,

*Bill* William T. Schmidt  
CEO, Foundation Fighting Blindness

[www.FightBlindness.org](http://www.FightBlindness.org)

7168 Columbia Gateway Drive, Suite 100, Columbia, MD 21046 | (800) 683-5555

Connect with us:



*(Continued from page 14) - Second Sense*

with disabilities interested in the STEM fields, NASA has internships available! These paid internships are ten and six weeks long (college and high school respectively) and students must carry a 3.0 GPA. Interested students can begin the application process after November 1st for the 2016 summer program.

To learn about all the available opportunities, visit <https://intern.nasa.gov>, call Kenneth A. Silberman at 301-286-9281 or email [kenneth.a.silberman@nasa.gov](mailto:kenneth.a.silberman@nasa.gov).

*Reprinted from MAKING SENSE, September & October 2015, Second Sense, Beyond vision loss, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, [www.second-sense.org](http://www.second-sense.org).*

**FOUNDATION  
FIGHTING  
BLINDNESS**

## Chicago Chapter Speaker Series

Sunday, October 18, 2015

Registration: 1:30 pm

Program: 2: 00-4:00 pm

### Speakers:

#### **Gerald Fishman, M.D.**

#### **“Treatment Strategies for Inherited Retinal Diseases.”**

Dr. Fishman, a nationally-renowned ophthalmologist, research and academic specializing in inherited retinal diseases, directs the Pangere Center. Dr. Fishman has counseled thousands of people to better understand their unique conditions, including early onset macular degeneration, various night blinding diseases, and causes of unexplained visual loss.

#### **Gregg C. Pusateri, O.D., M.Div.**

#### **“Low Vision Rehab From the Inside Out ”**

Dr. Pusateri is the Assistant to the Executive Director of Spectrios Institute. The Institute empowers children and adults with vision loss, regardless of income, to optimize their visual capabilities and independence through the use of prescriptive tools, technology, rehabilitative training and inspiration. Spectrios strives to educate the world to see the potential in every person with vision loss.

#### Location:

Alexian Brothers Medical Center  
Kennedy Conference Drive  
800 Biesterfield Road  
Elk Grove Village, IL 60007

We will also preview the Spring 2016 Chicago VisionWalk!

RSVP: [mdigaetano@FightBlindness.org](mailto:mdigaetano@FightBlindness.org) or call 847-680-0100

*This Chapter Speaker Series is presented without charge and brought to you by The Chatlos Foundation Public Health Education Program of the Foundation Fighting Blindness.*



**Physicians**

**Benjamin H Ticho, MD** - Pediatric ROP & Adult Ophthalmology  
**Jonathan S Buka, MD** - Ophthalmology-Glaucoma & Lasik Surgeon  
**Alexander J Khammar, MD** - Pediatric ROP Ophthalmology  
**Karl Ticho, MD** – Ophthalmology  
**E. Michael Cassidy, MD** - Ophthalmology  
**Roshni A Vasaiwala, MD** – Cornea Specialist  
**Hassan A Shah, MD** – Oculofacial Plastic, Orbital and Ophthalmic Surgery  
**Megan Allen, OD** – Optometrist  
**Birva K Shah, OD** – Optometrist

**Visit our Locations**

10436 Southwest Hwy., Chicago Ridge, IL 60415  
P: 708-423-4070 F: 708-423-4216

600 Ravinia Ave., Orland Park, IL 60462  
P: 708-873-0088 F: 708-873-5224

333 Chestnut Street, Suite 104, Hinsdale, IL 60521  
P: 630-323-4202 F: 630-323-6588

7001 W Archer Ave., Chicago, IL 60638  
P: 708-423-4070 F: 708-423-4216

801 Mac Arthur Blvd. Ste. 302, Munster, IN 46321  
P: 219-836-7990 F: 219-873-0175

## IPVI

P.O. Box 316634, Chicago, IL 60631

1-815-355-2098 • Email: [ipvi@ipvi.org](mailto:ipvi@ipvi.org) • [www.ipvi.org](http://www.ipvi.org)



I would like to introduce you to a wonderful website, **WonderBaby.org**.

This website was started by Amber Bobnar when her son, Ivan, was diagnosed with **Leber's Congenital Amaurosis (LCA)**, and later on with **Joubert Syndrome** and **Landau Kleffner Syndrome**.

In 2011 WonderBaby teamed up with Perkins in order to provide more features and support for families through the internet.

Under the Parenting section there is:

### Advice for Parents

- Adoption
- Advocacy
- Conferences & Fundraising
- Helpful Organizations
- Parenting
- Support

The articles on this website are the best I've read, for all ages of children and many topics that parents would be interested in. Please view this site and you won't be disappointed.

Joan Bielawski, Editor, IPVI Insights

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Northbrook, IL 60062  
847-217-7590  
[pamstern3@gmail.com](mailto:pamstern3@gmail.com)

### SPANISH TRANSLATOR

Noelia Gamino  
708-655-2747



# Join **IPVI** or renew your membership today!

The *Illinois Association for Parents of Children with Visual Impairments* is a state-wide, non-profit organization that enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities.

## Your IPVI membership dues or generous contributions help to support all of our ongoing efforts:

- Regular communications which include: workshops, conferences, training seminars, legislative issues, organizational announcements, products, and advice about raising a child who is visually impaired.
- Offers several \$500 college scholarships each year.
- Publishes a resource catalog which includes anything and everything to do with visual impairment.
- Conducts training and support sessions where parents share experiences and ideas.
- Holds fun outings adapted for children with visual impairments at athletic, cultural, educational, and entertainment settings.
- Represents parents of children with visual impairments at conferences, public hearings, and on committees.

## What does IPVI do?

- Promotes and provides information through meetings, correspondence, publications, etc., which will help parents meet the special needs of their children with visual impairments.
- Facilitates the sharing of experiences and concerns in order to provide emotional support and relief from feelings of isolation for parents and their families.
- Creates a climate of opportunity for children who are blind in the home, school, and society.
- Fosters communication and coordination of services among federal, state, and local agencies and organizations involved with providing services to people who are visually impaired.
- Advocates on a statewide level for services to children who are visually impaired and their families.
- Keeps members informed about current proposals and actions which impact on children with visual impairments and their families.

Check one:

Parent/Guardian Membership: \$15 per year.

Child(ren)'s Names: \_\_\_\_\_

Birthdate(s) of my visually impaired child(ren): \_\_\_\_\_

My child(ren)'s eye condition: \_\_\_\_\_

I give my permission to release my name to other parents.

Group/Agency Membership \$50 per year.

Extended Family/Friend Assoc. Membership \$15/year.

Medical Specialist \$50 per year.

Scholarship Fund \$10.00

Donation: \$ \_\_\_\_\_ (tax deductible)

New Membership

Renewal

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (\_\_\_\_\_) - \_\_\_\_\_

Email: \_\_\_\_\_

Please enclose this form along with your payment by check to:

IPVI • P.O.Box 316634 • Chicago, IL 60631

**Have questions or need more information?**

**Call us at  
1-815-355-2098**

Illinois Association for Parents of  
Children with Visual Impairments  
P. O. Box 316634  
Chicago, IL 60631

Please contact IPVI to see if you are  
up-to-date on your dues at the  
address on the left or  
1-815-355-2098  
Email: [ipvi@ipvi.org](mailto:ipvi@ipvi.org)  
[www.ipvi.org](http://www.ipvi.org)

## IPVI CALENDAR

- |                  |   |                          |
|------------------|---|--------------------------|
| ▶ 10/10,17,24,31 | <b>FRCD Volunteer Advocacy Training Program</b>                             | <b>Chicago</b>           |
| ▶ 10/8,15,11/5   | <b>FRCD IEP Check-In Session for IEPs</b>                                   | <b>Chicago</b>           |
| ▶ 10/18          | <b>FFB Chicago Chapter Speaker Series</b>                                   | <b>Elk Grove Village</b> |
| ▶ 10/29-30       | <b>FRCD 11<sup>th</sup> Annual Illinois Statewide Transition Conference</b> | <b>Chicago</b>           |
| ▶ 11/4           | <b>Chicago Children's Museum Trip at Navy Pier</b>                          | <b>Chicago</b>           |

Please call  
**1-815-355-2098**  
for any questions, concerns,  
or comments that IPVI can  
help you with.

**Newsletter Deadline for  
NOVEMBER 2015 is OCTOBER 15**



**Check Out  
[www.ipvi.org](http://www.ipvi.org)**

Calendar of Events!  
News and Updates!  
Useful Links to Web Sites!  
And more...