

IPVI INSIGHTS

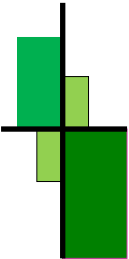


Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities

MARCH 2018

PRESIDENT'S REPORT

Filiberto Almendarez III



IPVI Families I hope everyone is doing great and your child(ren) is happily progressing. With that said, there are several topics that need to be communicated. First, Reminder, if you are interested in being a Board member, please your Annual Meeting will be held at the Double Tree in Oak Brook, 1909 Spring Road 60523 on April 14, 2018 at 11:00am. elate. Secondly, we are changing our accounting period from Fiscal Year to Calendar Year. Currently, IPVI By Laws states "Article IX-Finances, Section 1, The fiscal year shall be September 1 to August 31". The Board will present to amend at the Annual Meeting the following, "Article VIII-Finances, Section 1, The calendar year shall be January 1 to December 31". Also, voting member will have the opportunity to ask questions before vote. Feel free to reach out sooner if needed.

Now, as stated in prior Newsletters, Thank You for the honor of serving as IPVI President. "Sometimes you never know the true value of a moment until it becomes a memory". The memories are deeply treasured. In addition, I have learned "The only disability is a closed mind" and "Your only limit is YOU". So have a wide open mind and reach beyond the unknown. Warm the hearts of others. Let your kindness be felt. Especially with a big smile. Take care IPVI family and I close with a quote from a remarkable child who grew into an amazing woman:

*"The best and most beautiful things in the world cannot be seen or even touched
They must be felt with the heart".*

Helen Keller



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Parenting Preschoolers: Suggestions for Raising Young Blind and Visually Impaired Children

By Kay Alicyn Ferrell
AFB Press

What can I expect?

Expect, first of all, that your child will be like all other children. It does not matter how old your child is, or how handicapped—your child has the same needs as other children for:

- ▶ Love
- ▶ Affection
- ▶ Nourishment
- ▶ Discipline
- ▶ Learning
- ▶ Understanding
- ▶ Patience

Your child may do some things differently from other children—such as getting real close to look at a book—and he may learn some things faster than others—such as memorizing riddles and songs; just remember that your child is an individual. You will no more be able to predict what your child will grow up to be like than *your* parents were able to predict what *you* would be like.

It might help you to put yourself in your child's shoes and imagine what it would be like to be visually handicapped. Close your eyes and just listen for a

few minutes. If you are reading this in bed, maybe all you hear is quite—or maybe you hear your baby breathing, or the clock ticking, or a dog barking outside. But you can probably tell where the sounds are coming from. If you are reading this in a place where there is a lot of noise—the television is on, children are screaming outside, the tea kettle is whistling, dogs are barking—not only is it harder to hear the baby’s breathing and the clock’s ticking, but it is also harder to tell where those sounds are coming from.

Your visually handicapped child will learn about sounds as he grows, but he will need help in identifying them and in understanding which sounds are important to listen to (traffic, voices, news broadcasts) and which can be ignored (the hum of overhead lights, the wind blowing), and when.

Next, try to imagine how you would learn a new sport or game when you cannot see very well. You would not be able to imitate a backstroke if you could not see it. But someone *could* teach you to do it by moving your arms for you.

Visually handicapped children use their hearing, their sense of smell, their own hands and the hands of others to learn about their world. When they have vision, they use that, too. So expect your child to:

- ▶ Be curious
- ▶ Ask questions
- ▶ Listen
- ▶ Get close to objects
- ▶ Need to be shown how to do things
- ▶ Be unaware of what he cannot get close to unless you tell him
- ▶ Do things for himself

and not realize he is visually handicapped—or understand what that means—until you or someone else tells him.



REPRINTED FROM
FAMILY CONNECT WEBSITE



In Early Intervention, We Advocate for Babies and Toddlers Who are Blind or Visually Impaired

By Francesca Crozier-Fitzgerald

We’ve all heard the saying comparing children to sponges—soaking up all the verbal and nonverbal cues from the world around them. Just as a sponge placed in the vicinity of an expanding puddle will inevitably absorb and store the contents into its many pores, so will a child, exposed to various sensory information, have access and capacity to retain and learn from those many sensory experiences. The sooner that exposure starts, the more room there is for improvement and expansion; the more time there is to learn new material. **READ MORE AT: www.familyconnect.org** and click on above article’s name.



The Green Button: A Lesson in Hospital Advocacy Learned From My Sister Who Is Blind, Mayra’s Story

By Ana Cuevas

In one week, Mayra was admitted to the inten-

sive care unit twice. During her first stay, she made use of an intravenous line and a portable heart monitor, a visible and audible reminder of the seriousness of her medical diagnosis. The second time she was sent to ICU two additional pieces of medical equipment were used: a feeding tube and a pain pump. The pain pump would dispense medication continuously to keep the pain under control. If the pain increased, Mayra could push the button that had been attached to the pump for additional medication to be dispensed. The instructions were both easy to understand and easy to follow. The plan initially worked okay; the pain was controlled for a little over 24 hours. During that time, Mayra pushed the button only a couple of times for additional medication. **READ MORE AT: www.familyconnect.org** and click on above article's name.



Pushing Limits and Stepping Back

By Emily Coleman

Eddie wakes up everyday asking what is going to happen next. He likes a schedule, prefers to stick to it, and adding something new can make him uneasy. Children who are blind can be unsure about new experiences. Being unable to predict what will be expected and unsure if they will be successful can be scary. However, we keep pushing him so that his experiences broaden and his ability to participate in life expands. **READ MORE AT: www.familyconnect.org** and click on above article's name.



For the Love of Cellphones: Are There Any Reasons Teens Who Are Blind or Visually Impaired Can Benefit From a Cellphone?

By Samantha Kelly

Chances are your child who is blind or visually impaired is already asking for a cellphone. Somehow the tablets and computers are not enough to quench their desire for technology! As a parent, I try to limit my children's screen time, yet I know technology plays a significant role in the social lives of youth and adults. **READ MORE AT: www.familyconnect.org** and click on above article's name.

Leticia Martinez, Paralympian Swimmer Who Is Blind, Shares Her Story to Encourage Parents

By AFB Staff



[Editor's note: AFB FamilyConnect knows sports and physical education have [benefits aplenty](#) for children who are blind and visually impaired. In an effort to inspire parents of children with visual impairments to encourage participation in sports, we enthusiastically share Paralympian swimmer, Leticia Martinez's story.]

Often time people assume that being blind inhibits them from participating in most activities. However, my parents thought otherwise. **READ MORE : www.familyconnect.org** and click on above article's name.



PLAY FOR ALL

CHICAGO LIGHTHOUSE *and* IPVI FAMILIES

A morning of fun for everyone

**The Chicago Children's Museum at Navy Pier
700 E. Grand Avenue, Suite 127
Chicago, IL 60611**

Saturday, June 9, 2018

Pre-registered families 9:00 - 1:00

General public 10:00 - 1:00+

**To register or for more information, please contact:
Gail Patterson at the Chicago Lighthouse -
(312) 997-3695**

Pre-registration includes:

**Free admission for Chicago Lighthouse & IPVI Families
Free shuttle from the Chicago Lighthouse to Navy Pier**

First 50 people only!!!



Access Living Request for Community Input on ISBE Public Inquiry into CPS' Special Education Practice

In November 2017, Access Living and other education advocacy organizations sent an Open Letter to the Illinois State Board of Education (ISBE) requesting that ISBE investigate Chicago Public Schools' (CPS) Special Education practice. In response, ISBE announced a "Public Inquiry" into CPS's practice. This is great news! But now we are writing to ask for your help.

If you or your child with a disability has been negatively impacted by CPS's special education policies and practices, we need your story.

The ISBE Inquiry Team (IT) would like to hear from individual families as well as teachers and service providers with stories that illustrate CPS's failure to provide necessary service for students with disabilities. If you want to share your story with ISBE so they can improve special education services in Chicago, Access Living will gladly work with you to draft an affidavit that adheres to the format and guidelines given by ISBE.

You are eligible to submit your affidavit if:

1. You are (were) a CPS parent or a CPS student with a disability;
2. You believe that CPS failed to provide necessary services for you or your child with a disability during the time period of 2015 -2017;
 - a. e.g. Delay or denial on approving IEP (Individualized Education Program) plan, failure to provide services in accordance with IEP plan, failure to provide special teachers/aides/therapists, failure to provide transportation, failure to provide language interpretation, etc.

* If you are an individual (teacher, administrator, or advocate) who has information about the above issues, you can contact AL and submit your affidavit.

Please Note

1. Submitting your affidavit for the ISBE Public Inquiry WILL NOT resolve a specific grievance pertaining to a particular student and/or parental complaint. The purpose of collecting these affidavits is to examine whether there is a systemic issue with CPS special education practice.
2. If your affidavit contains a specific student's information, you MUST submit a Record Release Authorization form with the affidavit.
3. ISBE may call you to present oral testimony. Scheduled hearing dates are: March 20, March 21, and March 27.

If you have any questions, please feel free to contact Chris Yun at (312) 640-2134 or cyun@accessliving.org.

MAKING SENSE

New Arrival in Our Product Center: We are now stocking an ADA-inspired padlock by Master Lock. This padlock has a spring mechanism making it easy to operate. The lock comes with four keys and two oversized key heads for easy gripping. The lock is great for school, gym or employee lockers. To order, call Brian or email

brian.hollandsworth@second-sense.org.

Guide Dog O&M Immersion Program: Did you know the most common reason a person is not accepted into a guide dog program is due to poor orientation and mobility skills? Guide Dogs for the Blind is helping people master the relevant skills and nuances of guide dog travel in their new immersion program. The program builds on previous O&M skills and emphasizes the non-tactile information important for successful guide dog travel. The week-long program takes place at the San Francisco Lighthouse with transportation, meals and lodging at no charge to the student. Students receive 20 to 25 hours of training, working one-on-one with an O&M Specialist from the San Francisco Lighthouse who has received special training in guide dog travel. This immersion program is designed for those who are strongly motivated to becoming an independent guide dog traveler. Some prerequisites are required. To learn more, contact Marc Gillard at mgillard@guidedogs.com or 800-295-4050 ext. 4061.

Scheigert Scholarship Program: College students with low vision are invited to apply for the Fred Scheigert Scholarship program. Three awards of \$3,000 are awarded to deserving, full-time college students with low vision who meet the academic and visual acuity guidelines. The online application, most recent transcripts, two professional or aca-

demical letters of recommendation and verification of low vision are due by March 15, 2018. For more details and to access the application, visit <http://cclvi.org/scheigert-scholarship>.

Protecting Your iPhone from the Cold: It's cold out there this winter and when you're traveling outdoors, your iPhone is cold too! Apple designs their phones to operate in temperatures 32 degrees Fahrenheit and above. When temperatures get below that, you may experience your phone quickly running out of its battery charge, shutting down completely, having display problems or even developing a shattered glass screen. Here are a couple of tips to protect your phone when you have to be out in these arctic temperatures: First, keep your phone in your pocket, as your body temperature will help keep it warm. Don't leave your phone in a parked car without heat for an extended period of time. Use a special insulated case. Don't charge your phone when it is cold as this can cause further damage.

Fashionable Medical ID Bracelets: After being diagnosed with cancer and going through some complicated medical experiences, Abbe Sennett, a local jewelry designer, saw a critical need to protect people in medical emergencies. She saw too many people not wearing medical bracelets because they were not very attractive and drew too much attention to very personal conditions. Abbe designs custom-sized medical ID bracelets in designer stainless steel, precious metals and beautiful beads. She calls every customer to make sure each bracelet is a perfect fit for their lifestyle with all critical medical information properly included. For more information, call 847-638-2223 or visit www.medicalidfashions.com.

Reprinted from MAKING SENSE, February 2018, Second Sense: Beyond vision loss, 312-236-8569, www.second-sense.org.



17 Braille Innovations that Don't Exist Yet...but should!

By Amber Bobnar

Assistive technology and innovations for visually impaired users are moving fast! There are so many new ideas for accessible orientation and mobility devices, wearable technology and updated apps and software. Just check out these new [navigational tools](#) from Verizon. Wow! READ MORE at: **WonderBaby.org**



What Does It Really Take to Make a Home Accessible?

Hint: It May Have More to Do With Changing your Thinking Than Your Furniture

By Nicole Feeney

What really makes your home an inclusive space for your special needs or blind child? Is it the furniture? Or is it the way you think? READ MORE at: **WonderBaby.org**



The Hidden Truth About Special Needs Resources: It Doesn't Need to Be This Complicated

By Nicole Feeney

Do you ever feel like you're tied up in knots looking for support and resources for your special needs child? Maybe it doesn't have to be this way! READ MORE at: **WonderBaby.org**



Do You Have the Courage to Redefine Disability?

By Lesley Potgieter

What does disability look like to you? How do people with disabilities interact with the mainstream world? What can you do to help? READ MORE at: **WonderBaby.org**



You're Invited

Conferences for Illinois Parents of Children with Vision Loss

Parents of children ages birth through twenty-one are encouraged to join us for in-depth discussions of useful topics. Learn from experts in the field as well as from fellow parents.

The Conference Program

- **Technology**
Technology is forever changing as is Assistive Technology. Learn more about low tech and high tech supports for visual impairment.
- **Social/Emotional**
This session will discuss social/emotional issues specific to families and children with vision loss. It may include issues such as bullying, making friends, impact on families, acceptance of adaptive equipment, etc.
- **Special Needs Planning**
Come learn and discuss some issues that you might have questions on. What is Guardianship? Is it right for my child? What other issues might I need to think about as my child turns 18. (We hope parents of children of all ages will benefit from this discussion---not just parents of older children.)
- **Panel of Parents**
Several parents of children with Visual Impairments will be led by a moderator to discuss topics such as family dynamics, advocacy, social/emotional issues and/or things that work for their family and things that have not worked.

(Sessions are subject to change without notice)

Southern Illinois Vision Conference
Saturday, March 03, 2018
Mt. Vernon Primary Center
401 N 30th Street
Mt. Vernon, IL 62864

Northern Illinois Vision Conference
Saturday, April 21, 2018
SASED Administration Center
2900 Ogden Ave.
Lisle, IL 60532

Time: 9:00 Check-in, 9:30 – 3:15 Conference Program

Planning committee: Delta Gamma Center for Children with Visual Impairments; Northwestern Illinois Association; Rockford Public Schools; Four Rivers Special Ed District, The School Association for Special Education in DuPage County (SASED); Crystal Lake Elementary District 47; parents of children with vision impairment; and the Illinois School for the Visually Impaired.

AFB American Foundation®
for the Blind

Expanding possibilities for people with vision loss



Cortical Visual Impairment
An Approach to Assessment
and Intervention
Second Edition
Christine Roman-Lantzy

AFBPress
American Foundation for the Blind

AFB Press is excited to announce a brand-new edition of our best-selling text, *Cortical Visual Impairment: An Approach to Assessment and Intervention*, by Christine Roman-Lantzy!

This new and revised content brings the book

up-to-date with new research and insights into CVI, its development and progression, and the best approaches to assessment and intervention with children affected by this condition. It also provides the viewpoints of parents and service providers, all of whom use the CVI Range from the perspective of their own situation or specialty.

As in the previous edition, assessment forms, including the CVI Range and CVI Progress Chart, provide a comprehensive method for evaluating the functional vision status of, and program planning for, children with CVI.

Whether you are a student, educator, therapist, physician, or parent of a child with CVI, this revised edition is a must-own for your professional collection.

Cortical Visual Impairment: An Approach to Assessment and Intervention is available in the AFB Store in print, e-book, and online subscription. Order now at www.afb.org/store or by calling 1-800-232-3044.

MOPD

Mayor's Office for
People with Disabilities

Work Incentive Planning & Assistive Staff

Save the Date
March 17, 2018
10:00 am - 1:30 pm

The Mayor's Office for People with Disabilities' Employment Services Unit SSA Work Incentive Planning & Assistive Staff and collaborating Community Program Partners, which include city, state, federal agencies, case managers, counselors, job developer & employers will work with young adults to:

- Improve job readiness job search
- Resume writing skills
- Accessing adult services

Location:
2102 West Ogden Avenue
Chicago, IL 60612

Register by calling: (312)746-5743
Fax: (312)746-5749
Ticket to work help line: (866)968-7842

**Counseling to parents & students to understand the impact SSI and SSDI benefits may have on education and work will be offered during this time.*

IPVI

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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: \$20 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 \$20/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
1-773-882-1331**

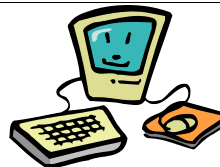
**Illinois Association for Parents of
Children with Visual Impairments**
P. O. Box 316634
Chicago, IL 60631

IPVI CALENDAR

- | | | |
|-------------------|---|------------------|
| ▶ March 17 | Work Incentive Planning & Assistive Staff | Chicago |
| ▶ April 14 | IPVI Annual Meeting | Oak Brook |
| ▶ April 21 | Conference for Illinois Parents of Children With
Vision Loss | Lisle |
| ▶ June 9 | TLC & IPVI "Play for All" | Chicago |

Please call
1-773-882-1331
for any questions, concerns,
or comments that IPVI can
help you with.

**Newsletter Deadline for
April 2018 is March 15, 2018**



**Check Out
www.ipvi.org**

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