

IPVI INSIGHTS

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

**March
2017**



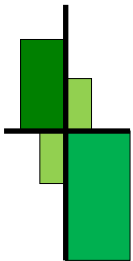
PRESIDENT'S REPORT

Filiberto Almendarez III

Parents, I would like to commend you on your great efforts in taking care of your child/children. Your loving care does not go unnoticed. I know faith, love and hope provides the strength, but who you Are is the foundation that supports your child's future. Despite, challenges and sometimes unknown medical episodes, we must hope for the best and keep moving forward. My family has had it's share of unexpected events. There were long days that seemed like they would never end. You would welcome the next day and say "What a difference a day makes". I reiterate, be thankful for your family, friends, medical professionals, educators and countless others. Their assistance goes a long way. Also, I read a statement on a shelf at a Children's hospital. It said, "Mistakes are proof that we are trying". Let's not be afraid to make positive mistakes and keep on trying as we learn together for our children and their tomorrows.

February was the month for "February Play for All Adaptive Sports" at The Navy Pier Children's Museum. I enjoyed the children and their progression as some walked for the first time. The joy is overwhelming. Great job, children and parents. Also, thank you to the Chicago Lighthouse, IPVI and the Children's Museum for an enjoyable event. This year Menomonee Judo Club provided lessons under the direction of Sensei Brett Wolf. He teaches Judo to all abilities, which includes Visually Impaired. I was amazed by his techniques, energy and big heart. His motivation and determination is amazing. I say thank you for your endeavors and for being an inspiration to our children.

Take care and happy March, Everyone!



IPVI DUES

IPVI Members:

It's a brand new year for IPVI which also brings a brand new year for collecting our \$15.00 dues from all members of IPVI. This will cover the whole year of 2017.

IPVI relies on these dues for fees that have to be paid every year: supplies, our yearly Zoo Outing, and donations for our scholarships. A full itemized list will be handed out at our Annual Meeting.

If we have an email address for you, you'll be sent a reminder that our newsletter is online, so if you don't receive the reminder, please include your email address on your dues check.

You dues are an integral part of our Not-for-Profit organization, and we hope that we can count on you this year, and many years to come.

From your Board Members:

Fil Almendarez
Mary Zabelski
Joan Bielawski

*to all who
have already
paid their
Dues.*

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MEMORIES OF HEIDI MUSSER

Prepared for: IPVI Insights - Issue March 2017

**MUSIC EDUCATION FOR BLIND/
VISUALLY IMPAIRED CHILDREN**

Where would I be without my skills and love playing the piano? Nowhere. It seems to me that it was a divine intervention that Mary Sauer, Principal Pianist, who recently retired from the Chicago Symphony Orchestra after 57 years, took me on as her piano student. I was 9 years old. My life did not change instantly, but starting with my first lesson my life felt on an upward path -- little step by little step. Mary Sauer believed in my potentials and my weekly lessons made me feel more confident and whole! I feel proud to be invited to still attend her Master's classes at the Fine Arts Studio in down-town Chicago on a regular basis.

I have asked myself over and over how I could make it possible for more blind/visually impaired children to take lessons to learn a music instrument and to be introduced to the classical music repertoire? Miss Sauer called my attention to: "A study by researchers at the University of Southern California showing that exposure to music and music instruction accelerate the brain development of young children." Please log on to:

https://

**musiceducationworks.wordpress.com/2016/06/19/
a-childs-brain-develops-faster-with-exposure-to-
music/**

Please join us at the IPVI Annual Meeting on Saturday, March 4, and let's have an open-ended discussion about introducing more blind/visually impaired children to piano playing.

I have myself enjoyed success introducing Elizabeth Sprecher, now 16 yrs. old, to the piano via the Piano Suzuki method. I have asked her to share with IPVI parents her success at the Community Music School at DePaul University on Fullerton Ave. in Chicago.

She promised me to write an article for the IPVI Newsletter for next month. Also, her sister Aihua cannot anymore imagine a life without piano playing and practicing. Their parents, Alan and Paula Sprecher, openly admit that coming to my home and hear me play got them both hooked.

Please see photo below. We can do it again and possibly raise funds for some blind/visually impaired children to start up with lessons. To work together with conviction and harmony, may help us to accomplish more than we presently hope for.

Also, Miss Sauer was always a strong advocate for Braille reading. I still dream of a regular monthly get-together of blind children and their parents for Braille reading. Debra Bond of Seeding Braille Books for children is heartwarmingly dedicated to provide all blind children with more Braille books. Her determination is not only reaching out to blind children nationwide, but worldwide.

My mother Erika Musser and I hope to see many of you at the IPVI Annual Meeting on March 4. Let us get to know each other.

* * *

**Please write me:
hmusser@msn.com
773-412-4454 (cell)**



**Recital, titled "Children Playing for Children"
at Preston Bradley Hall,
April 8, 2004
(Mary Sauer standing on the far left side holding my hand)**



8 Calming or Stimulating Sensory Activities

By Amber Bobnar

How are you feeling right now? Excited? Agitated? Tired? Bored? READ MORE at: WonderBaby.org



Talking Easter Eggs: Making Easter Accessible for Kids who are Blind

By Amber Bobnar

After we learned our son was blind when he was just a baby, I started wondering about his future and what his life would be like. READ MORE at: WonderBaby.org



My Mistakes Have Made Me: How Learning from Failure Can Help Your Blind Child Grow

By cmellor

<http://www.throughscarlettseyes.com/4322-2/>

One of the most valuable things I gained from studying for two years at a specialist school for the blind was the freedom to make mistakes. READ MORE at: WonderBaby.org



FCC Proposes Increased Audio Description Access

By Amber Bobnar

The FCC proposed rules to expand video description access to blind viewers across the country. READ MORE at: WonderBaby.org



Taking a Blind Child to a Music Festival- Making it Fun and Accessible Top Tips

By cmellor

We kicked off our summer holidays being ambitious by attempting to attend a mainstream medium sized festival. READ MORE at: WonderBaby.org



FAMILY CONNECT WEBSITE

An Introduction to Your Child's Specific Eye Condition

Posted on 2/15/2017
by Shannon Carollo

You are told your child may have a visual impairment; your world halts. You are left with questions and an emotional roller-coaster.

You want to know:

- A description of the possible eye condition
- How it is diagnosed
- If there are treatments
- How it affects one's eyesight
- How one functions with this eye condition
- Resources for families

Where to Turn

If this describes you, it's time to visit AFB FamilyConnect to browse by eye condition. We updated this section from basic definitions of the most common eye conditions to an in-depth look at the most common eye conditions. Our goal was to answer the above questions.

Next, you'll want to read *After the Diagnosis: For Parents of Child Just Diagnosed with Blindness*. You'll learn how to work with your child's medical professionals and how to adapt your home; you'll receive an overview of services for children with visual impairments and a list of helpful products and toys; and lastly, you'll read success stories of those living well with vision loss.

Join the FamilyConnect Community

Join the FamilyConnect community and connect with other families who have children

with the same eye condition as your own. You can choose to receive e-mail alerts for events and activities near you, as well as tips for living with vision loss, new articles, blog posts, and announcements relevant to you and your family.

Connect with others on the message boards—join in the discussions or start a new topic of your own. Track your favorite message boards and blogs by email!

Should My Child with Low Vision Be Receiving Vision-Related Services?

Posted on 2/6/2017
by Shannon Carollo

It's the middle of the school year and your child with low vision (who supposedly doesn't need a Teacher of Students with Visual Impairments) is academically struggling.

While your child could be any age, I wouldn't be surprised if you have a grade schooler and you're seeing the result of standard print size in text books decreasing from approximately

22-point font to **12-point** font.

Here's the deal: According to the law, IDEA, if you suspect your child's education is affected by a possible visual impairment (including CVI, a brain-based impairment affecting how vision is processed), your child must be assessed for all blindness-specific services.

Furthermore, if your child was assessed in years past and did not qualify, but you believe your child may now qualify for services, step forward and speak out.

What you're experiencing is not uncommon. While a child whose only disability is total blindness will likely be easily identified as one who requires a Teacher of Students with

Visual Impairments (TVI) and travel training from a Certified Orientation and Mobility Specialist (COMS), a child with low vision or a child with low vision and multiple disabilities may be overlooked for one or both educational services.

You now hold the key to your child receiving services. Know your rights and be an advocate for your child.

If you have a specific question or concern regarding the appropriateness of your child's services, reach out. Seek counsel by posting on the FamilyConnect message boards, commenting on this blog, or by sending a message to our familyconnect@afb.net or FamilyConnect Facebook page. We will respond. With your permission, we will also request counsel on your behalf from other parents and professionals of children who are blind or visually impaired on our Facebook page. (Thank you to the many parents and professionals who have lovingly provided direction, encouragement, and feedback.)

Lastly, the American Council of the Blind has an advocate program. If you call them at 1-800-424-8666, they will pair you with an individual who can advise you on your child's services.

APH NEWS

REVISED! Push Button Padlock **1-03990-01 — \$20.00**

You can have a combination lock that is accessible only to you! Each lock comes with two large print/braille cards listing the combination,



along with large print and braille instructions. Buttons eliminate the worry of losing a key. Just push five buttons and presto, you're in!

Note: This revised lock works in a slightly different manner than our previous model (the discontinued 1-03990-00). Please consult the instructions included with the lock.

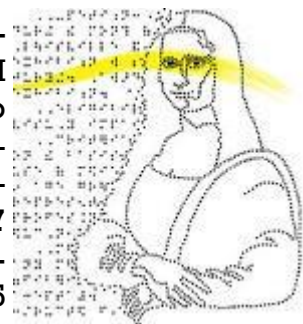
APH Winter Wonderland Sale

Load up a world of savings on selected APH products with APH's Winter Wonderland Sale 2017, January 1—March 31. As always, first come, first served. www.aph.org/sale/



Enter the 2017 APH InSights Art Competition!

DOWNLOAD THE APPLICATION NOW! APH warmly invites artists who are blind or visually impaired, of all ages, to submit artwork for the **2017 APH InSights Art Competition**. For over 25 years, our renowned international contest has delighted the senses, provoked discussion, and most importantly, allowed artists who happen to have vision loss the opportunity to share their creative imagination with the world.



Artists may enter original artwork created in any medium, including (but not limited to) painting, drawing, printmaking, fiber, metal, and wood. This year's deadline for student art-

(Continued on page 13)

AFB American Foundation[®] for the Blind

Expanding possibilities for people with vision loss



Welcome, 2017! For you we have high hopes and elevated expectations. We have gratitude for the renewed energy you bestowed. We needed it! Yes, we'll continue needing it as we put one hopeful, albeit often-weary, foot in front of the other this year.

Parents of blind and visually impaired children, no matter what 2017 brings your way, FamilyConnect wants to support you in your parenting highs and lows. We're here with emotional support, seasonal and age-related suggestions, and resources aplenty specific to parenting a child with a visual impairment.

Let's take a look at our newest content over the past six months, or as I can't resist calling it, FamilyConnect's Fresh Content.

We Brought You Information, Suggestions, and Resources Specific to Your Child's Eye Condition

In our renovated [Eye Conditions](#) section, you will find the following information on 30+ most common eye conditions:

- Description of the eye condition
- Diagnosis of the eye condition
- Possible treatments for the eye condition
- Description of the eyesight (called the "functional vision") of one with the condition
- Recommendations for your child to best access learning material and his or her environment
- Resources for families with children who have the eye condition

We Concentrated on Orientation and Mobility

We provided the following resources for you to use as you equip your children to understand where

they are in space and travel as independently as possible:

- [Early Orientation and Mobility Concepts for Young Children Who Are Blind or Visually Impaired](#)
- [What to Do When Your Child Refuses the Cane](#)
- [Orientation and Mobility Resources for Your Teen Who Is Blind or Visually Impaired](#)
- [Trick or Treating as an Orientation and Mobility Lesson- Oh Yeah!](#)

We Aimed to Prepare You for the Holidays!

- [Making the Most of Thanksgiving Week with Your Visually Impaired Child or Teen](#)
- [Preparing Our Children for the Holidays](#)
- [Holiday Gifts for Children and Teens with Visual Impairments](#)
- [The Best Holiday Crafts](#)
- [Holiday Travel Tips for Families with Visually Impaired Children and Teens](#)
- [Teaching Our Children With Visual Impairments to Set Goals This New Year](#)

We Blogged, Blogged, and Blogged Some More!

So many topics, so little space. I'll leave you with five posts, but be sure to [visit our blog](#) and subscribe to it to receive an e-mail as each new post is published.

- [Paralympics and Our Newly Motivated Children](#)
- [When You're Second-Guessing a School Placement or Teacher](#)
- [Three Tips for Preventing Bullying In Children with Visual Impairments](#)
- [Understanding Charge Syndrome: Raising My Child Who Is Deaf-Blind](#)
- [Resources for Adopting or Fostering a Child Who is Blind](#)

We Continued to Support Each Other, Our FamilyConnect Community

Don't forget to connect with other parents of babies, children, and teens who are blind or Visually Impaired by [Joining the FamilyConnect community](#). You will be able to:

- Be a part of the FamilyFriends program that will match you with others with the same eye condition and age of child. You will be in total control of who can see your page as you must first accept their request to become friends.
- Request e-mail alerts about events in your area, or new articles relating to your interests
- Follow a blog (such as [FamilyConnect: A Parent's Voice](#)) or [message board](#), and get e-mail alerts whenever there is a new message, post, or reply.

- The FamilyConnect Team



For Parents of Children with Visual Impairments



For many athletes with visual impairments, Dare2tri Paratriathlon Club continually serves as an essential resource for people who pursue a healthy lifestyle, learn about the sport of paratriathlon, and get involved in camps and races.

“Dare2tri does amazing things for both its athletes and volunteers,” said Ashley Eisenmenger, Dare2tri Elite Team athlete. “I would not be the person or athlete that I am today without this organization.”

Dare2tri is an Illinois-based 501(c)3 non-for-profit organization with the mission to positively impact the lives of athletes with physical disabilities and visual impairments by developing their skills in paratriathlon. Dare2tri empowers individuals with disabilities and gives them the opportunity to be physically active, engaged with their community, and helps them set and reach goals. Dare2tri changes lives by boosting individuals’ self-esteem, confidence, and self-worth.

Since 2011, Dare2tri has worked with athletes of all ability levels from beginner to elite by serving youth, adults, and injured service members who have a physical disability such as amputation, spinal cord injury, stroke, spina bifida, cerebral palsy, and those with visual impairments and blindness.

“I am more active at age 49 than ever before in my life, which is because of support from Dare2tri,” said Alberto Guzman, Dare2tri Development Team athlete. “It is great to see me personally improve, and it’s also great to see the spirit and camaraderie within the organization. With Dare2tri, we are out in the com-

munity at large, while strengthening the bonds within our own disabled community.”

Dare2tri hosts weekly practices, and seasonal clinics and camps for people of all ability levels. To learn how to join and participate in upcoming Dare2tri events, visit: www.dare2tri.org or call (312) 967-9874.



Ashley Schrader, M.S.
Marketing & Public Relations Manager
p / 815.970.3144
w / www.dare2tri.org
ONE INSPIRES MANY

LIGHTHOUSE, IPVI, DARE2TRI PLAY FOR ALL

A great big thanks to all of those who visited The Chicago Children's Museum for our 5th Annual Adaptive Sports Event with Dare2tri. We hope all those in attendance had an excellent experience. We would love to hear any feedback to continue providing dynamic programming for all! Please go to <https://goo.gl/forms/c35NTUUPGfBxRcyO2> to fill out a quick survey.

Melanie Moore
Partner Services Coordinator
Chicago Children's Museum
Navy Pier • 700 East Grand Ave., Ste. 127 • Chicago, IL • 60611
p: 312.464.8249

DESIGNDANCE
MOVE OTHERS. MOVE YOURSELF.

AND



..... INVITE YOU TO

PLAY FOR ALL

Adaptive Dance *and* **Family Get-Down**
WITH DESIGN DANCE

March 11
9 am - 12 pm

Chicago
Children's
Museum

WHAT: Come and dance with us! We invite students, siblings, parents and caregivers to take part in this adaptive dance opportunity. Students are invited to sing, clap and use movement to explore their physicality in space through directive songs, story time and solo and partner activities. Using creative movement and imaginative play, all will feel welcome as we take part in the joy of movement and creative expression!

WHO: The first 250 children and families with disabilities who register will receive free admission. The museum opens one hour early, at 9am, for Play for All guests.

Please call 312-464-8249 to request a free bus or to register for a group visit (18 or more visitors).

REGISTER:

PlayForAll.eventbrite.com





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

- **Social Emotional Issues**

In this session you will hear and discuss emotional issues specific to vision loss. This presentation and discussion may include adjusting to “fitting in,” accepting the need to use adaptive materials, socialization. Parents have asked a lot of questions in the past on this topic...we hope to cover some of them.

- **Orientation and Mobility**

How does my child get around safely without full vision? How do I encourage safe movement for my child? How can I promote independence in my child?

- **Life Skills**

Discussion and demonstration of how to adapt everyday tasks for someone with a visual impairment. Personal management (brushing teeth, selecting cloths, etc.) and household tasks/chores will be demonstrated. You might even be able to try it yourself!

- **Panel of Students**

Students with Visual Impairment will talk about how they perform Independent Living Skills—everyday tasks, i.e., laundry, cooking, cleaning, money and time management

Southern Illinois Vision Conference

Saturday, March 11, 2017

Mt. Vernon Primary Center

401 N 30th Street

Mt. Vernon, IL 62864

Northern Illinois Vision Conference

Saturday, April 8, 2017

Center for Sight & Hearing

8038 MacIntosh Lane

Rockford, IL 61107

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

Planning committee: Center for Sight & Hearing; Delta Gamma Center for Children with Visual Impairments; Northwestern Illinois Association; Rockford Public Schools; Illinois Talking Book Outreach Center; South Macoupin Association of Special Education; Region III Special Education Cooperative; Crystal Lake Elementary District 47; Southwest Cook County Cooperative Association for Sp Ed; Parandoe Special Education District; parents of children with vision impairment; and the Illinois School for the visually Impaired.

Registration Form

Conferences for Illinois Parents of Children with Vision Loss

Please mark which conference you wish to attend:

Southern Illinois Vision Conference

Northern Illinois Vision Conference

Saturday, March 11, 2017

Mt. Vernon Primary Center
401 N 30th Street
Mt. Vernon, IL 62864

(Registration Deadline March 9, 2017)

Saturday, April 8, 2017

Center for Sight & Hearing
8038 MacIntosh Lane
Rockford, IL 61107

(Registration Deadline April 3, 2017)

List all who will be attending and their relationship to the child with vision loss. If the attendee is a child, please list their age. Notice: **Children must be at least 12 years old to attend.**

Name _____ Relationship _____

Name _____ Relationship _____

Name _____ Relationship _____

Address _____

Street

City

State

Zip

County

Phone _____ Email _____

Check here if you would like registration information via US mail rather than Email.

Name of child you are representing _____ Age of child _____

Child's diagnosis _____

Please explain any translation or ADA accommodation needs during this conference: *(Accommodations request must be submitted three weeks prior to conference)*

Choose appropriate format for handouts: Regular print Large print Braille Electronic

I give permission for photos of all people in my party to be taken at the conference for future educational use.

Register:	Online:	www.isvi.net
	Email:	jason.crotchett@illinois.gov
	Phone:	217-479-4436
	Fax:	217-479-4433
	Mail:	Illinois School for the Visually Impaired, 658 East State Street, Jacksonville IL 62650

SAVE THE DATE!

Illinois Statewide Transition Conference



Stepping Stones of Transition

Illinois Statewide Transition Conference
Prairie Capital Convention Center
in Springfield, Illinois from

October 23-24, 2017

This year's 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 Prairie Capitol Convention Center in Springfield, IL from October 23-24, 2017.

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.

Family Resource Center on
Disabilities | (312)939-3513 |
info@frcd.org | www.frcd.org

(Continued from page 6) - APH News

ists from preschool through high school is **March 24, 2017**. The deadline for adult artists is **March 31, 2017**. **Complete rules and entry forms are available on the APH website**. We are always deeply inspired and grateful for the unique, artistic expression from each artwork, every year.

We look forward to your participation in our contest. For more information, please e-mail insights@aph.org, or call Rob Guillen, at 502-899-2242.



MAKING SENSE

Free Children's Braille Books: Braille Trails is sponsored by the American Printing House for the Blind (APH) in partnership with the Dolly Parton Imagination Library. Children five and under can receive six free braille and large print books up to their sixth birthday. Braille and large print books are great for the child who is blind and also a parent or grandparent with vision loss. Everyone can enjoy these books as the braille text is printed on clear labels and applied directly to the print copy of the book. Applications are taken on a first come, first serve basis. To apply visit:

www.aph.org/dolly-partons-imagination-library-apply/

or contact Hannah Ozmun at 502-899-2387.

Reprinted from MAKING SENSE, February 2017, *Second Sense, Beyond vision loss*, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, www.second-sense.org.



IPVI

P.O. Box 316634, Chicago, IL 60631

1-773-882-1331 • Email: ipvi@ipvi.org • www.ipvi.org

PRESIDENT

Filiberto Almendarez III
5323 N Delphia Ave #124
Chicago, IL 60656
(773) 693-5713
falmendareziii@yahoo.com

OPERATIONS VP

Joan Bielawski
421 Applegate Court
Naperville, IL 60565
(630) 357-8576
wjbielawski@yahoo.com

SERVICES VP

Mary Zabelski
6153 N. Nettleton Avenue
Chicago, IL 60631
(773) 882-1331
maryzabelski@hotmail.com

TREASURER

Filiberto Almendarez III
(Temporary)

SECRETARY

Dawn Wojtowicz
9188 161st Place
Orland Hills, IL 60487
(708) 590-6447
deeder0477@aol.com

SPANISH TRANSLATOR

Noelia Gamino
708-655-2747

NEWSLETTER EDITOR

Joan Bielawski
421 Applegate Court
Naperville, IL 60565
(630) 357-8576
wjbielawski@yahoo.com





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
1-773-882-1331**

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

IPVI CALENDAR

- | | | |
|---------------------|--|--------------------|
| ▶ March 4 | IPVI's Annual Meeting | Oakbrook |
| ▶ March 11 | PLAY FOR ALL Adaptive Dance & Family Get-Down | Chicago |
| ▶ March 11 | Southern Illinois Vision Conference | Mt. Vernon |
| ▶ April 8 | Northern Illinois Vision Conference | Rockford |
| ▶ Oct. 23-24 | Stepping Stones of Transition | Springfield |

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

**Newsletter Deadline for
April 2017 is March 15**



**Check Out
www.ipvi.org**

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