

IPVI INSIGHTS

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

**November
2016**



PRESIDENT'S REPORT

Filiberto Almendarez III

Baseball, the American sport. As I watch the Chicago Cubs go to the World Series and wish them well, I think of our children and I am thankful for the modified version that is visually impaired friendly called Beep Baseball.



The general rules include a beeping ball, beeping bases and involves both visually impaired and sighted players. Only the pitcher and catcher are sighted. On Offense, the batter attempts to hit the beeping ball. If contact is made the batter runs to either first or third base. We know our children are smart, so on operated switches, it will tell them which base will beep. If the batter reaches the beeping base before the ball is retrieved a run is scored. In Defense, the players must locate the beeping ball and lift it before the batter reaches the base. If so, the batter is out. Oh, I forgot to mention the players are blindfolded. It does get competitive, but fun.

My son just finished participating in Beep Baseball. I asked how was it. He said it felt good. He was proud to hit a pitched ball. I responded I was proud, but truly, I have since Monday, December 27, 2004 at 6:51 pm. That's when I was blessed and shortly after held him for the first time. He continues to amaze me.

Parents, I stated before, please reach out if you and your child is interested in gathering and playing a friendly game of Beep Baseball or another sport. Please relate. Also, a big Thank You to the organizations that sponsor events for our children.

Lastly, save the date. Saturday, November 12, 2016. "Play for All" Outing for the Chicago Lighthouse and IPVI Families. WHERE: The Chicago Children's Museum at Navy Pier. Also, the Christmas Party is right around the corner. There will be more information to follow. Take Care, Everyone.

MEMORIES OF
HEIDI MUSSER

Prepared for: IPVI Insights - Issue November 2016

Inside This Issue:

President's Report	1
Memories of Heidi Musser	2
TCL & IPVI Present "PLAY FOR ALL"	3
We Need to Help Each Other	5
Family Connect Website	6
What to Do When Your Child Refuses the Cane!	6
3 Tips to Help Present Bullying...	7
Great Lakes Adaptive Sports Association	8
Santa's Little Helper (Christmas Toy Websites)	9
IPVI Board of Directors	10
Thanksgiving Poem	10
IPVI Membership Dues	11
IPVI Calendar of Events	12

THINK: PARATRIATHLON

I felt thrilled when in the October Report our IPVI President Filiberto Almendarez III invited readers to share their Paralympic story. Here is mine:

Most of us are locked into our inner prison cell by the culture we live in. We live our life according to societal expectations and we have few chances to "escape". Genuine individuality and spontaneity are most frequently lost.

As a totally blind individual from day one of my life, the Chicago Public Schools wanted to lock me into such a prison cell trying to instill into the mind of my parents hopelessness for an education for me. I did not accept the station in life educators and social workers assigned me to. I escaped!

When I attended Chicago Public High School during the school year 1982/83, educators excluded me from athletic activities. They used the "measuring stick" of a sighted person for judging my athletic abilities. Was I boiling with anger? Yes, for sure I was and so was my mother. Together we formed a team to prove to policy makers in education that these rules were WRONG.

On the contrary, the coaches and administrators at the Leaning Tower YMCA in Niles, located close to my home, had for me open arms and an open mind, going back to when I was barely three years old. They deserve high praise. Throughout my childhood and teenager years, they supported me and did what they felt was the right thing to do -- especially, in respect to swimming in the pool.

(Continued on page 4)





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, November 12, 2016

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!!!)



(Continued from page 2) - Think: Paratriathlon

Not until I attended Northeastern Illinois University (NEIU) in Chicago, did coaches in the Physical Education Department discover my potentials as an athlete. Hoorah! Finally! They recommended that I train for participation in the Chicago Park District 2-Mile Swim in Lake Michigan, off Ohio Street Beach, in July 1997. When I exited the water, I was surrounded by the news media.

I picked up renown quickly! Again, the Leaning Tower YMCA came through with enthusiastic support. The LTY coaches started to train me also for running and biking. In summer 1998, I participated as the only physically challenged athlete in the Chicago Triathlon with guide/coach Mark Landeck. The following year, I emerged as the world's first blind female triathlete finishing an Olympic distance triathlon in the 1999 ITU World's Championships in Montreal, Canada.

I continued to participate in triathlons, mostly in California. In 2002 and 2004, my guide/ coach Matt Miller encouraged me to participate in the "Escape from Alcatraz" jumping off a ferry boat and swimming 1.5 miles to shore. I pretty much finished my triathlon racing career with 2005 Iron-man Coeur d'Alene, ID, completing 2.4-mile swim, 112-mile bike and 26.2-mile run.

Has participation in triathlons changed my life? Definitely, I feel whole as a citizen, and wanted and needed by many. My big love in my life has become playing the piano, participating in open water swim competitions, and helping out teaching blind children Braille and piano, when I can spare the time.

When I learned that there were ten female blind/visually impaired triathletes (Women's PT5), from eight countries and three continents, participating and finishing in the 2016 Rio Paralympic Games, I reflected on the following quote by Nelson Mandela: *"It always seems impossible until it is done."*

Anyone interested in training and competing in triathlon's in Illinois, please make contact with the Dare2Tri Paratriathlon Club in Chicago: info@dare2tri.org or 312-967-9874.

Recently, I learned that 19-yr. old visually impaired Ashley Eisenmenger from Tolono, (Champaign County) IL, has been selected for the USA Paratriathlon Team with sights set on Tokyo 2020. Hoorah! Let's get to know her and support her.

The following quote holds true for ALL of us:

Individuals can affect the world by becoming a model or an example in their small circle of influence. Just as a stone thrown into a pond causes ripples to gradually keep going out until eventually they are very small, so our acts influence the ecology of the entire human race."
~ Anonymous ~

* * *

Please write me:

hmusser@msn.com

773-412-4454 (cell)

I swim and train regularly at the Leaning Tower YMCA in Niles. I would love that you join me sometimes; I would like to introduce you to initial training for swimming, all on a complimentary basis! If you know either Aihua or Rupa Sprecher, please check with them to learn how much they enjoyed learning how to swim there.



WE NEED TO HELP EACH OTHER

By Mary Zabelski, Vice President, IPVI

In 1980, several parents and I, founded IPVI. Over the years, I have been asked to speak of my experiences in raising a child who was blind and also afflicted with cancer. Many of our parents have children with multiple disabilities and struggle to find answers and comfort with unique situations - the uncertainty of their child's future. So I share my experiences in a show of support. I know from my experiences it is very important that we support each other. Back in the day this wasn't my experiences so I gladly assisted in IPVI's early formation; I continue that support today!

At 13 months, my precious little Cara was diagnosed with Retinoblastoma; a very rare infant eye cancer. I was devastated and felt alone. Helen Reddy's "Me and You Against The World" typified those endless early years of my worrying if Cara would survive; would she enjoy her life? Within days of her initial diagnosis, Cara's first eye was removed. Then weeks of chemotherapy and radiation turned into months then years of constant treatment. Immediately after her initial diagnosis, her first eye was removed; I was afraid. Ultimately she lost her second eye at 4 years. Her ophthalmologist SHOCKED me when he said "take her home and love her", (as he confided years later that he believed she would soon die). He also suggested I investigate the state school for the blind in Jacksonville, Illinois. I was DEVASTATED. I had little direction, the unknown and uncertainty of Cara's future was overwhelming. My health was affected. I was hospitalized with a ruptured ulcer.I had no money, no one to encourage me, no one with ideas. But I didn't listen to the naysayers, and treated Cara as a capable, smart adventurous child. Immediately, after she lost her second eye I bought her a bicycle and encouraged her to play with her friends, ride her bike, etc.

Coincidentally, I heard of a Chicago Public School's preschool program at Farnsworth Elementary School, with a fully staffed classroom and resource room for children who were blind or visually impaired. Finally, I had someone to talk to, including a full-time vision teacher who was very helpful to me. She worked with me, giving me tactile books and puzzles and showing me how to help Cara to learn. She also told me about Braille. I signed up for Braille classes through the Hadley School for the Blind and received a free Brailier.

The vision teacher also introduced me to other families with older children who were blind. I realized that Cara was a beautiful, smart little individual with special talents, not a poor blind child. I realized that she wanted to learn everything the other children were learning and it was up to me to find ways to assist. The resources room teacher at Farnsworth Elementary School was a Godsend assisting me and encouraging me to step-up. I realized that Cara had lots of potential. Having the support and encouragement from teachers and other parents made a huge difference in our lives. I was on a roll! My daughter was happy and healthy again. Soon thereafter I met my future husband. To my credit I did not give up!!

When situations need answers, friends; count me in! Join or renew get involved!! We can help each



talk to your support network your NAPVI/IPVI membership and other and our children!!

FAMILY CONNECT WEBSITE

What to Do When Your Child Refuses the Cane!

by Shannon Carollo



As the parent, family member, friend, or teacher of a child with a visual impairment, I'll bet you feel enthusiastic over "White Cane Day" which we celebrate every October 15th. There's something special about the cane, that's for sure.

1. We are proud of the youngster who has a visual impairment.
2. We are excited about the white cane and the independence it represents.
3. We are thankful for the protection the white cane offers.

Yes, white canes and White Cane Day have a way of invoking our emotions.

Your Child's Emotions and the White Cane

School-age children and teens also have emotions stirred up over the white cane.

1. They usually feel embarrassed at the attention the cane evokes.
2. They usually feel it's a nuisance because "they don't need it."
3. They usually feel angry because it symbolizes they are different.

If this describes your child, you are oh so not

alone.

What To Do When the Cane is Refused?

So, what is the recommended approach when a child refuses to use his or her cane?

- Ask why he or she doesn't want to use the cane. Don't tell him his reasons are silly or unsubstantiated; just listen and understand, putting yourself in his or her shoes.
- Ask if he or she thinks there could be a good situation to use the cane.
- Let your child know you will give him or her increased independence as cane use increases. (This is true of all parents and children. As children demonstrate consistent safe travel skills and road safety, they can play more independently.)
- Introduce your child to others his age with visual impairments who also emotionally struggle to use the cane.
- Introduce your child to others with visual impairments who understand the importance of cane use.
- Allow your child to decorate the cane.
- Have your child name the cane.

You have to give your child room to fall. When a child or teen realizes it's better to use the cane than run into objects or fall off a curb, he'll be convinced a cane is a tool worth using...and celebrating!



3 Tips to Help Prevent Bullying in Children with Visual Impairments

by Shannon Carollo



As a teenager I was bullied quite badly, which of course left me devastated, fearful, and stressed. That painful season did change me and give me eyes to see the lonely and marginalized—so truly, beauty rose from the ashes—however, I would have much rather learned empathy in a less agonizing manner!

Now, as a parent and a teacher for students with visual impairments, I am painfully aware that our children can encounter the same ridicule I did years ago, and I recognize the importance of doing what we can to prevent our children from becoming victims of bullying.

You see, according to the [National Bullying Prevention Center](#), children with disabilities are two to three times more likely to be bullied than their nondisabled peers. I believe this is because a bully feels powerful by mocking, physically hurting, harassing, or embarrassing someone who he or she notices is isolated and who will willingly comply. All too often this describes one with a disability.

Therefore, to help prevent our children from becoming victims of bullying, we must remove our children from the bully radar by:

- Teaching our children to be assertive, which includes advocating for their own needs and using assertive language. Assertive people are willing to stand up for themselves and others by being honest, direct, kind, and respectful; they aren't passive (downplaying their own desires and feelings) or aggressive (making demands of others).
- Encouraging our blind children to build friendships, from the preschool years to the teen years.
- If your child is not developmentally able to assert him or herself, perhaps you can talk to the school about pairing your child with an assertive and friendly peer who would like to both mentor your child and look out for your child, particularly at times when adults are not immediately available—such as on the bus, at lunch, or before/after school. Look for ways this relationship can be mutually beneficial; your child could listen to the buddy read, help hold the backpack of the buddy, or thank the buddy with an occasional note and small gift.

If your child is the victim of a bully, please visit [What Should You Do if Your Blind or Visually Impaired Child Is Bullied?](#) and [stopbullying.gov](#) for help.

Please contact IPVI to see if you are up-to-date on your dues at
1-773-882-1331
Email: ipvi@ipvi.org
www.ipvi.org

“Let NO ONE Sit on the SIDELINES”

GLASA provides integrative Paralympic, recreational and competitive sport activities for youth, teens and adults who have a primary physical or visual disability.

Judo

(For the Blind and Visually Impaired)

When: Tuesdays, Thursdays & Saturdays

Sept. 1—Dec. 17

Tues & Thur 6:00-7:00pm
Saturdays 10:00-11:00am

Where: Gurnee Judo Club
4411 Old Grand Ave.
Gurnee, IL

No Program Dates: November 24

Goalball

When: Fridays

Sept. 23, 30, Oct. 14, 28,

Nov. 4, 18, Dec. 2, 9

6:30 - 8:00 PM

Where: Rockland Elementary School
160 W. Rockland Rd.
Libertyville, IL 60048

Personal Training

When: Beginning October 1

Saturdays, 9:00-10:00am

Mondays, 5:00-6:00pm

Where: Saturdays - GLASA Office
Mondays - CrossFit Kilter

Swimming

When: Saturdays

October 1 - December 10

*1 hour time slots from 1:00-4:00 PM

*Program Director will coordinate scheduling of program time slots. Space is limited.

No Program Dates: Nov. 26

Where: Recreation Center of Highland Park
1207 Park Ave West
Highland Park, IL

60035



Save the Date!

GLASA's Annual Holiday Party

Friday, December 16th

Lake Forest High School—West Campus

GLASA's Holiday Party is for ALL current and past participants!

New comers are also welcome to come check out GLASA!

Wheelchair basketball, adaptive tennis, goalball, and more!

Feel free to bring a dish to pass!

Some food and drinks will be provided.

Contact Nicole at nverneuille@glasa.org or

847-283-0908 for more information.



Santa's little HELPER

WonderBaby.org
Perkins School for the Blind

The Best Christmas Toys for Blind Children!

Go to:

<http://www.wonderbaby.org/articles/best-christmas-toys-blind-children#baby-toys>



Sensory University

"Learning should be fun. It just makes sense."

While we maintain our core special needs product line, we now offer many products geared towards the everyday cardiovascular, gross motor, sensory, and strength development of all children.

Go to:

<http://www.sensoryuniversity.com/>



amazon

Suggested Toy List for Blind and Visually Impaired Children

Go to:

amazon.com

and do a search for the green title above

Fat Brain Toys



Vision Impairment

Go to:

https://www.fatbraintoy.com/special_needs/vision_impairment.cfm

Compare⁹⁹

HOT DEALS

Visually-Impaired-Toys

from various stores and online

Go to:

<http://www.compare99.com>

IPVI

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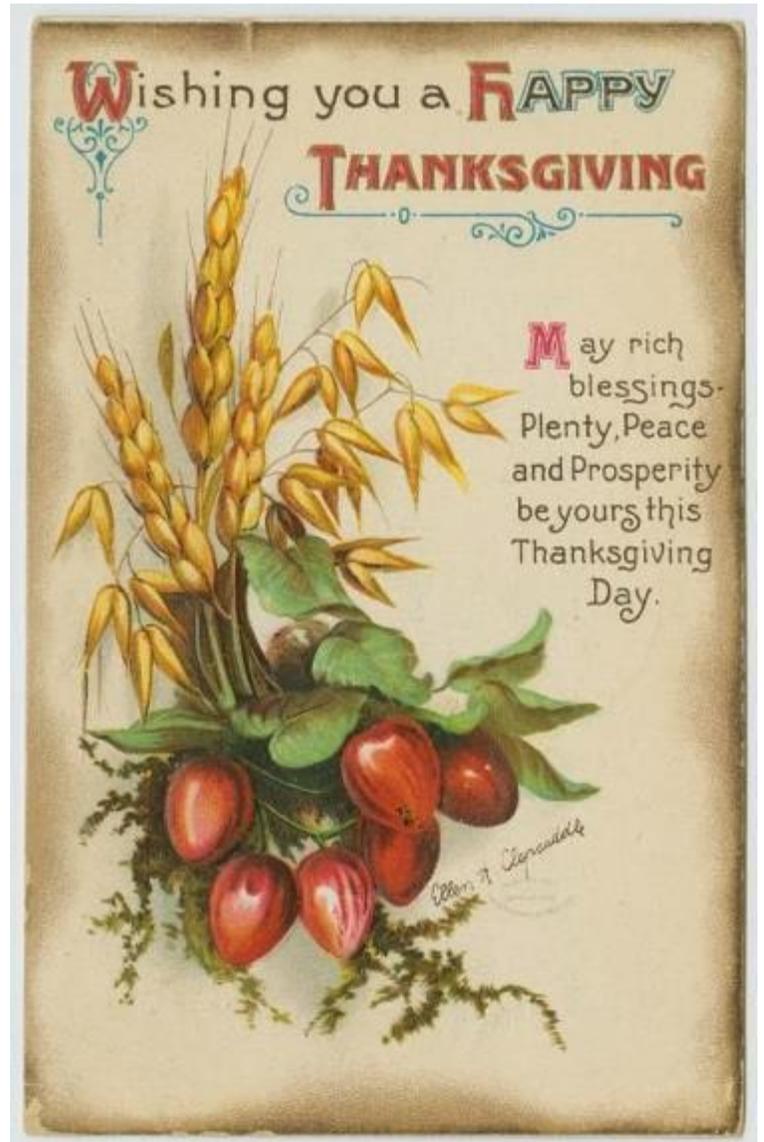
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Join **IPVI** or renew your membership today!

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: \$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

► **11/12** **PLAY FOR ALL** - Chicago Lighthouse and IPVI

Chicago

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

**Newsletter Deadline for
December is November 15**



**Check Out
www.ipvi.org**

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