

# IPVI INSIGHTS

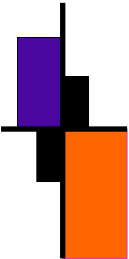


*Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities*

OCTOBER 2017

## PRESIDENT'S REPORT

Filiberto Almendarez III



It's October already and as I bump into others, I never get the chance to wish IPVI members and their families a Happy Birthday; therefore, Happy Birthday and many more. As more birthdays occur while we gracefully age, so does vision. If you think about it, everyone is affected by some form of vision loss. At minimum through aging, the Sun rays and normal wear and tear. "The longer we live the likeliness we will outlive our vision. Most people will have to adapt to some form of serious vision loss at some stage in their lives. Some people must adapt sooner than others for numerous reasons". This may explain why I encountered more people helping others cross streets, find locations and navigating with a cane. However, it's wonderful to watch blind/visually impaired individuals out and about. Tidbit: "White canes are going high-tech. Other countries have equipped white canes with ultrasonic devices that detect obstacles up to nine feet away. Vibrations in the cane's handle warn users of potential hazards in their path". Technology is amazing!

Keep at heart:

You don't need a reason to help someone

When you help other people

You also help yourself

It's impossible to not feel good

When you do good for other people



Last comments: Outing alert. Our outing to the Chicago Children Museum is in November. Also, IPVI is accepting Scholarship applications. So, please send in your application for consideration. IPVI Board Members will review and announce the recipient at the Annual Meeting.

MEMORIES OF HEIDI MUSSER

Prepared for: IPVI Insights - Issue October 2017

## My 15-year Partnership with CAF

The Challenged Athletes Foundation (CAF) was life changing for me! There are thousand individuals worldwide who say the same thing! CAF has helped me to feel *wanted, accepted, needed and to feel proud about myself*. They have helped me to tap my courage, they have instilled in me perseverance and they filled me with hope and Love. With all my heart, I would like that more and more blind/visually impaired children feel the same way about themselves, starting at a young age.

Please log on to [www.challengedathletes.org](http://www.challengedathletes.org) and familiarize yourself with the entire website, and then, click: APPLY FOR A GRANT.

CAF offer grants for many different sports, for numerous different physical disabilities, for both genders, for participation in competitions and coaching, and also equipment needed to participate in sports activities. Last year's grant applicants from 42 countries were funded; the age range was 28 % under 18 years as young as 5 years. You have until December 2017 to apply. All applicants will be notified of their award status in April 2018.

For this year it is probably too late, but try to experience in future years what the SDTC (San Diego Triathlon Challenge) is all about. You probably will want to return every year to the La Jolla Coast. Arrange-

*(Continued on page 6)*

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**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 11, 2017**

**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!!!**

**If leaving from Chicago Lighthouse, please arrive at 8:30am.**



## IPVI'S 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 IPVISF, 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 email a written request to receive a copy of the application from IPVI. Then the student must complete the IPVISF 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 winner. IPVI reserves the right to announce such award in its newsletters and marketing materials.

The IPVISF 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 Board of Directors at: P.O. Box 316634, Chicago, IL 60631.**



### Dear Grandparents of Visually Impaired Children

By Amber Bobnar

As grandparents you are an integral part of both your children's and your grandchildren's lives. You're the rock that keeps the family grounded and your help and support is so important. READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### Using Music to Connect the Generations

By Daria Marmaluk-Hajioannou

*"Grandpa, what songs did you sing when you were little?"*

The answer to that question usually brings a delighted smile to both the grandparent and the young child's face as both get to share a favorite song and a treasured memory. READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### Fall Sensory Art Projects for Visually Impaired Kids

By Amber Bobnar

I've always felt that the best way to celebrate any holiday or season is with crafts! Easter and spring is one of my favorite times for crafts as we decorate eggs and make paper flowers, but fall may be the best time for natural crafts. READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### 20 Apple Themed Books for Kids Who Are Blind

By Hillary Kleck

Summer is coming to an end after all the water play, picnics and outdoor fun. Next, a cool, crisp Autumn is in store along with a ton of sensory activities to enjoy. The leaves will be changing, costumes created, and we'll be giving thanks before we know it. First though, let us celebrate September and all the apples it brings us! READ MORE at: [WonderBaby.org](http://WonderBaby.org)

(Continued from page 2) - Memories of Heidi Musser

ments will be made for staying at luxury hotels in this beautiful resort area – most often, on a complimentary basis – physically challenged participants and their family members. My parents and I did not miss one SDTC event for 15 years, starting in the year 2000.

There are numerous events your *disabled* and *non-disabled* children can participate on the weekend of their Annual SDTC. Your *non-disabled* children will learn to *volunteer* and discover the joy of helping out with loud applause from the audience. It's an event like no other event in the world!

You probably have question. So please call my mother, Erika Musser, or me. We will help you with completing the application forms and try to introduce you to our CAF friends based on our many years of friendship with them.

Athletic training is deeply anchored in my body and mind. I am deeply involved with the U.S. Master Swimmers. My deep love is open water swimming with a guide.

Below are some photos of my happy years with CAF participating in swimming and biking!

\* \* \*

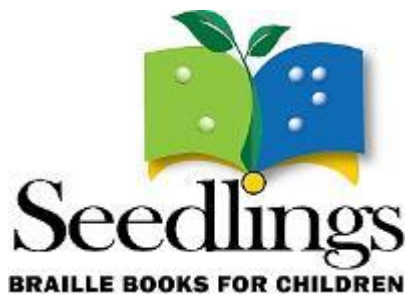
Please contact us:

[eamusser@msn.com](mailto:eamusser@msn.com)

[hmusser@msn.com](mailto:hmusser@msn.com)

773-412-4454 (call)





## A HALF-MILLION BRAILLE BOOKS!

Seedlings produced and distributed its 500,000th book on Tuesday, Aug. 22!

"Our donors and volunteers made this possible. To them, we say thank-you for making a huge difference in the lives of children who are blind," Seedlings Founder/Director Debra Bonde said.

The title of the 500,000th book was *The Boxcar Children*. It was sent to a school in Tampa, Florida, to be enjoyed by students who are visually impaired.

Bonde founded Seedlings in 1984 in Detroit after meeting a little girl who owned only two braille books because they cost more than \$100 each!

Debra began transcribing popular children's stories into braille and charging just for the cost of the paper. That first year, she produced 221 books.

Since then, Seedlings has produced and distributed 500,000 books to blind children in 75 countries! Seedlings gives half of its books away free, and the other half are sold for an average price of just \$10 a book.

Seedlings Braille Books for Children  
[info@seedlings.org](mailto:info@seedlings.org) | [www.seedlings.org](http://www.seedlings.org)

REPRINTED FROM  
FAMILY CONNECT WEBSITE

### Never a Victim, Jake's Story

*By Michael Jake Beausir*



It all seemed normal to me. I was just a little boy who was taking weekly trips to the hospital. It wasn't until I was older that I realized that I was different from everyone else. Something set me apart from my friends. I had cancer.

At nine months old, I was diagnosed with bilateral retinoblastoma. This is a cancer that attacks the retinas in both eyes. I went through months of chemotherapy and countless laser surgeries. When I was not feeling sick, I was the happiest toddler you could meet. I was too young to know that while these treatments were saving my life, they were also helping define who I was as a person: to be brave, confident, and never a victim of my circumstances.

My treatments went on for four more years. When I was five years old, I went in for my last surgery, the one that would remove my left eye. From that point on I was forever to live with a prosthetic left eye and a right eye with minimal vision.

Every teenager wants to fly under the radar and be like everyone else but doing that legally blind and with a prosthetic eye is almost impossible. Instead of focusing on my fears, I looked outward to how I could inspire others. I began volunteering for the American Cancer Society by raising money for Relay for Life. I found my greatest impact was helping children see that they can overcome any of life's

obstacles, and I became a mentor to foster children. I have spent five years working with these children and showing them that being disadvantaged doesn't mean you can't achieve your dreams.

I have always loved sports. Although I am right-handed, I learned to play many sports left-handed to be able to see the ball. I was heartbroken when I had to give up baseball due to my vision. However, I found I could succeed playing golf and put everything I had into becoming the best golfer I could. Making my high school golf team as a freshman sent a booming message. Yes, a legally blind student can play a varsity sport competitively. Although I needed assistance finding my ball, I became one of the top scorers for my team. Being named Captain proved I was a strong leader as well.

I don't like to think of my eyesight as a disability. I like to think of it as a way to show others that I can accomplish anything I want no matter what the situation. I want people to see that it is okay to be different. It just requires more effort and motivation to be great. What does the future hold for me? I can't wait to find out because my past has taught me that I have no limits. In June, I will be attending the University of Central Florida where I have the opportunity to pursue a career in Business and Sports Management. I also have the opportunity to show others that no matter what hardships we have in life, and we all have them, we can choose not to be victims. We can choose to triumph.



Go to [FamilyConnect.org](http://FamilyConnect.org) to read more about Jake and his family.

## Accommodations and Modifications at a Glance: Educational Accommodations for Students Who Are Blind or Visually Impaired

### What Are Accommodations and Modifications?

Children who are visually impaired can do virtually all the activities and tasks that sighted children take for granted, but they often need to learn to do them in a different way or using different tools or materials. For instance, your child may need reading materials in braille rather than in print or may need to examine a live rabbit with her hands to understand what it is, rather than learning from a picture in a book. Other examples might be arranging a classroom to let your child sit close to the science teacher who is demonstrating an experiment or allowing her extra time to complete a test that the whole class is taking.

Depending on your child's abilities and needs, she may need such adaptations to participate in the curriculum and various activities in school, as well as to make use of instructional materials. Your child will most likely learn about such adaptations from his or her teacher of students with visual impairments or orientation and mobility (O&M) instructor.

Such adaptations in school are usually referred to by the terms "accommodations" and "modifications." Different school systems attach different meanings to these terms, but "accommodation" usually refers to a change in the way your child is taught or tested without changing the standard of learning or performance or the requirements that she needs to meet. Some examples include having extra time to complete assignments, using braille or large-print materials, having assignments or tests broken up into smaller parts, or completing assignments in a quiet setting away from



other students. "Modification" commonly refers to a change to what your child is learning or tested on that changes the standards or requirements she needs to meet. Being taught material at a lower grade level or having to complete fewer items on a test are examples of modifications. Because these terms are not used in the same way in all school districts, it will be helpful for you to learn how your school district defines them.

Go to [FamilyConnect.org](http://FamilyConnect.org) to read more about Accommodations and Modifications. There is much more useful information continuing to read this article.

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## Start at the Beginning: The Importance of Early Intervention

*By Mary Zabelski*

As a parent, you may have received the news that your child had a visual impairment right after he or she was born. Or, you may have noticed something unusual about your child's eyes or vision, something no one else noticed, but that you became more and more concerned about. Both of these possibilities are the kind of experiences that parents of visually impaired children typically may have.

### **EARLY INTERVENTION: A DEFINITION**

The term "early intervention" has a literal meaning—intervening in a child's development to provide support at an early time in his or her life. At its best, early intervention identifies a child in need of special services as early as possible in order to support and promote his or her growth and development. Why is this early identification important? Because like all children, youngsters who are visually impaired need to learn about the world around them but are not able to rely on

their sight to the extent that sighted children do. The sooner the process of exploring the world begins, the sooner your child's growth, development, and learning can be encouraged and helped to take place. Often, a child born with blindness or visual impairment may need extra assistance to grow and develop in the ways other children do. An effective early intervention program can help target specific needs or problems, plan positive strategies assisting in development, and help your family to feel comfortable and confident as you raise your child. Expert intervention and appropriate educational and family services during early childhood can help ensure that your child with a visual impairment will enter kindergarten or first grade with the skills he or she needs to start on a successful life in school. For this reason, parents who suspect that their children have vision problems should bring this to the attention of their pediatricians, who should be able to refer them to a pediatric ophthalmologist. Signs of a possible problem include a lack of eye contact, eyes that appear to wander, eyes that do not seem to align, a lack of visual response to lights being turned on, sensitivity to light, and the inability to look at objects placed nearby. Depending on the condition, a child may also need to be examined by a low vision optometrist—a professional knowledgeable about evaluating the need for special lenses and other devices to help maximize the use of vision in people who are visually impaired—who specializes in working with children.



**IPVI**

**P.O. Box 316634, Chicago, IL 60631**

1-773-882-1331 • Email: [ipvi@ipvi.org](mailto:ipvi@ipvi.org) • [www.ipvi.org](http://www.ipvi.org)

**PRESIDENT**

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

**OPERATIONS VP**

Joan Bielawski  
(Temporary)

**SERVICES VP**

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

**TREASURER**

Filiberto Almendarez III  
(Temporary)

**SECRETARY**

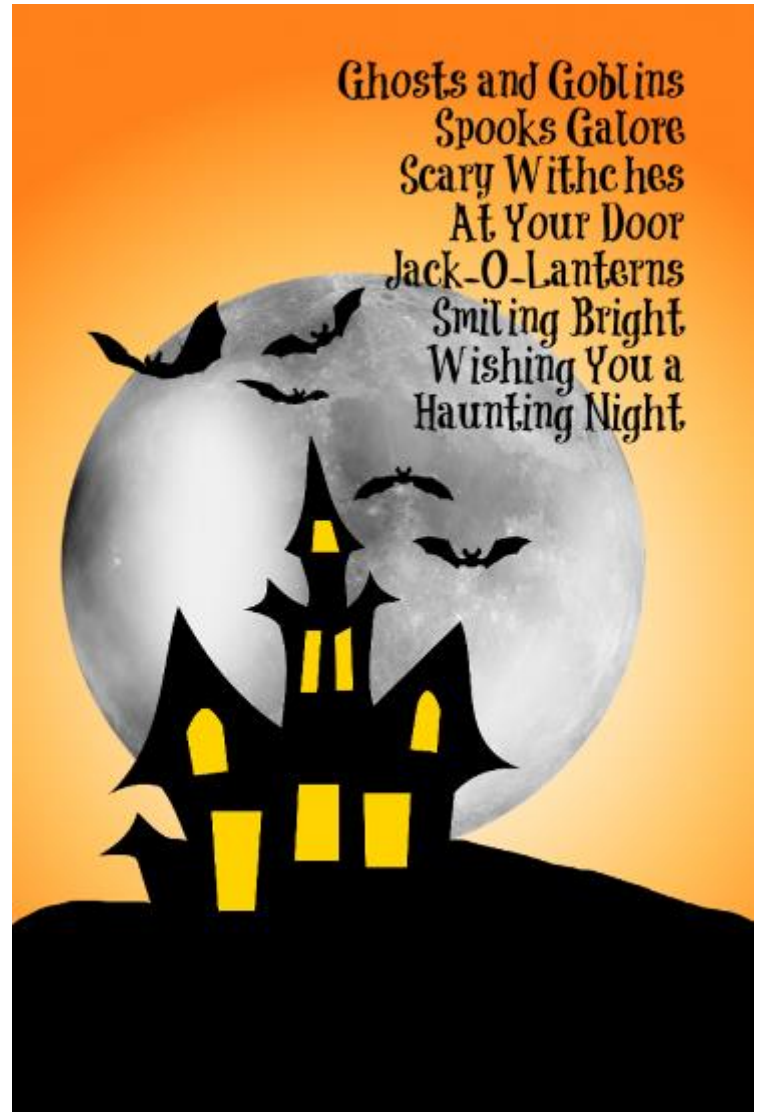
Joan Bielawski  
421 Applegate Court  
Naperville, IL 60565  
(630) 357-8576  
[wjbielawski@yahoo.com](mailto:wjbielawski@yahoo.com)

**SPANISH TRANSLATOR**

Noelia Gamino  
708-655-2747

**NEWSLETTER EDITOR**

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

▶ **11/11**      **LIGHTHOUSE/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  
November 2017 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...