

IPVI INSIGHTS

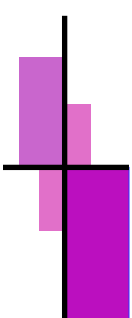
Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities

**May
2016**



PRESIDENT'S REPORT

Filiberto Almendarez III



On Saturday, April 9, 2016, IPVI and the Chicago Lighthouse held an event at the Chicago Children Museum in Navy Pier. Thank you to IPVI members, Chicago Lighthouse employees and Museum coordinators for all their efforts along with the families that came and seized the sunny day.

As we unloaded the buses, I met wonderful families and enjoyed the conversations. Some shared their child's journey, while some parents shared theirs. The children were so happy and excited. Their facial expression said it all with an enormous SMILE. Some who were little last year were now walking all over the museum. The strength and will to do what's possible is amazing. I commend the Children's Museum for offering many activities for all children. Many objects were big and had external texture for touch that were touched and retouched. Our children were learning and having fun.

Our next gathering will be at Brookfield Zoo on July 16, 2016. This event is all day and includes admission, parking and lunch. Please make sure to send your membership dues, which grants access to IPVI events. Hope to see you there!

Lastly, I want to say Thank You to IPVI members who sent warm welcomes. It's nice to hear from you. Also, as you read through our Newsletter, there is much progress in vision and impairment, but have a lot of work to do. Let's bridge our State, so all knowledge and assistance reaches those in need. Again, if you would like to assist, let us know. We welcome YOU.

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Admit One

Save the Date
IPVI ZOO OUTING
Saturday, July 16

Admit One

IPVI ANNUAL



OUTING

Saturday, July 16th

*Free Admission
Free Parking
Free Lunch*

And a day of fun and camaraderie



MEMORIES OF
HEIDI MUSSER

SPEAKING UP

Within me seems to have sprouted the passion to speak up for injustice. I want to speak up for the ones who are given no voice and no choice. During my childhood in Chicago Public Schools, I experienced often the feeling: "Nobody cares about me. There is nothing special about me. It is hopeless to assume that teachers will enthusiastically try to teach me and help me to feel accepted into the group activities of the class."

I was never invited to assemblies or to participate in field trips. Even in the lunchroom, I was often separated from other students in my age group, because I was a slow eater and giggled trying to get attention feeling socially isolated. Now as an adult I have learned to understand why they treated me as an "unwanted" student.

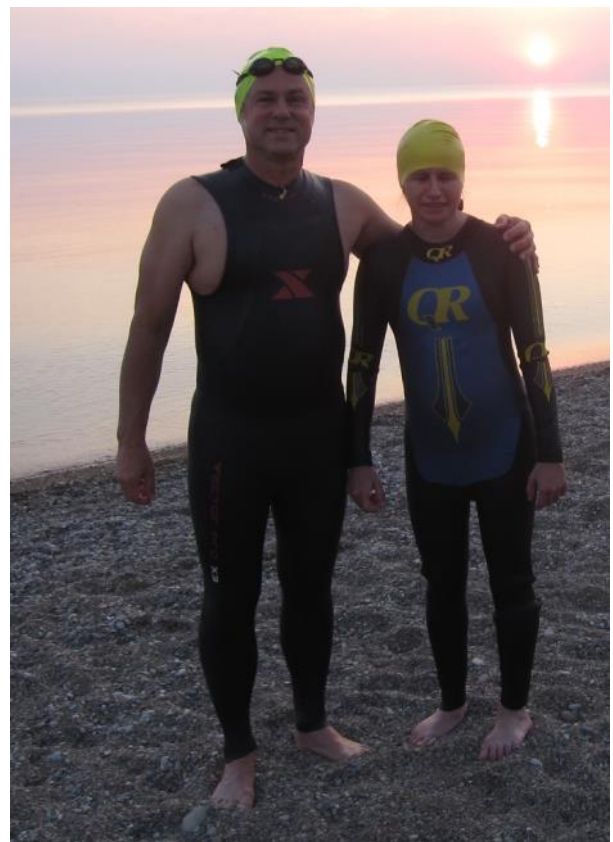
The mode of life we live is largely defined by traditions and social attitudes handed down to us for centuries; in my case, as a blind individual, probably since Aristotle's time more than almost 2500 years ago. Social isolation among blind individuals is widespread even in modern times. As adults, in order to avoid moral aloneness, many give up their own self to appear well-adapted in the eyes of others. Sadly, they give up genuine individuality and spontaneity.

The turning point in my life came, when in August 1997, I completed as the first blind swimmer the Annual Two-Mile Swim in Lake Michigan and in September 1999, I emerged worldwide as the first totally blind female triathlete, when crossing the finish line of the Olympic Distance of the Triathlon World Championships in Montreal, Canada.

I feel I have escaped from traditional thinking what as a blind individual I am capable of doing. Sighted educational experts, who are afraid of the dark and fearful of swimming in open water, made life miserable for me as a child.

Now it is my time to speak up and reach out to others, who need a lift to be all they can be. Thank you for supporting me in my mission. Rosa Parks is my inspiration!

I welcome your comments. Please write me at:
hmusser@msn.com



Early morning swim training at Wilmette Beach with guide/coach Don Alsen.

Becoming Your Child's Best Advocate

As your child passes through the educational system, you will need to acquire knowledge and information about the educational issues facing him or her. As a matter of fact, you will need to become your child's "best" advocate. You will find yourself working on behalf of your child, to make sure that the specialized educational services, guaranteed in the federal laws, are actually available in your state or local school district. We want our children to reach their full potential. To do this, they must have equal access to the classroom materials like their sighted peers. In a perfect world, all of the specialized services that the educational and civil rights laws entitle our children to receive, would always be available and easily obtainable. In this real world of ours, the full range of necessary services may not be available unless you actively work on acquiring them or "advocating" for them.

As your child's advocate, you may have to deal or bargain with your child's school district or local school to acquire the necessary services. Services mean the specialized teaching from the special education teacher, vision teacher, orientation and mobility instructor, and other related therapies (e.g., occupational therapy, physical therapy, speech therapy). You may find that you need to arrange for or "negotiate" for services through discussion and settlement of terms with the local educational personnel. Sometimes the services are not readily available and you will have to present your request in writing or through meetings with the educational staff, special education administrator of the district or the principal. The parents' role becomes critical to the success and positive educational experiences that can occur. More importantly, your involvement in decision-making is the key to

developing a positive and meaningful educational program for your child.

You may think that the professionally trained teaching staff automatically knows what is best for your child. This is not necessarily the case. Remember, most pre-school, elementary and high school teachers have no training that helps them to understand what modifications and accommodations students who are blind or visually impaired, deaf-blind or multi-disabled, might need to properly access their textbooks and materials like their classmates. Remember that you have more information about your child's medical issues and the visual/medical diagnosis than the school personnel do.

It is important to recognize that the regular classroom teacher may not be familiar with your child's visual disability and how to provide the specialized services your child needs. When discussing the need for specialized services, the regular classroom teacher and the special education or vision teacher should be present. You may want to ask for a meeting to discuss these issues before the formal IEP meeting.

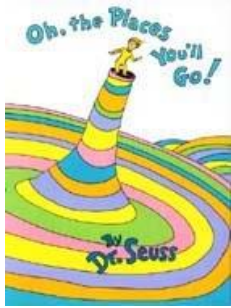
If your child has problems in school because of the lack of specialized services or a need for a change in services, you will need to speak up and negotiate for them. IEPs should be developed jointly, between school personnel, service providers and parents.





Terrific Graduation Gift Ideas!

The #1 GRADUATION GIFT...



Oh, The Places You'll Go

\$17.99, print/braille picture book (in UEB)

Our most popular graduation gift, courtesy of Dr. Seuss!

DECORATIVE MAGNETS!

Slip an inspirational print/braille magnet into a graduation card! \$5.00 each (with free shipping)



For graduation, we suggest these:

- "YOU ROCK."
- "Anyone can be cool, but awesome takes practice." - Lorraine Peterson
- "What lies behind us and

what lies before us are small matters compared to what lies within us." - Emerson

- "Good friends are like stars. You don't always see them, but you know they're always there!" - Old Saying
- "Life isn't about waiting for the storm to pass. It's about learning how to dance in the rain..." - Vivien Greene

See more magnets at National Braille Press

CELEBRATE BRAILLE...



BRAILLE CUFF BRACELETS

Silver- or gold-plated, these adjustable solid brass bracelets have a braille message on the outside, and recessed print inside. Our favorite

message for graduates: Dream Big! (Other messages: Love; Never give up; Walk by faith). \$30 each plus shipping. See more magnets at National Braille Press

Braille "Teach" Apple Pendants



Bright silver-color pendant that says "teach" in braille and embossed print, with a black leather cord. \$25 plus shipping

Braille Alphabet Bangle



This tarnish-free stainless steel bangle (with a hinged opening) features the entire braille alphabet!

Small (6.5") or Large (7.25"): \$32 plus shipping

Braille "Love" and Helen Keller Quote Pendants



This is a 1-7/8" x 7/8" pendant comes in either solid stainless steel (\$25 plus shipping), or dark copper (\$32 plus shipping). They have the word "love" on it in braille, and the following Helen Keller quote in raised letters:

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

TECHIE GRADS: GIVE THIS - WITH A NEW iPhone!?!

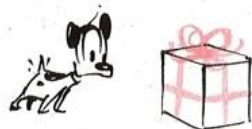


Getting Started with a new iPhone!?!

Sending your new graduate off to college, or to a new city? Make a plan to keep in touch! Get them an iPhone and this book - Anna Dresner's soup-to-

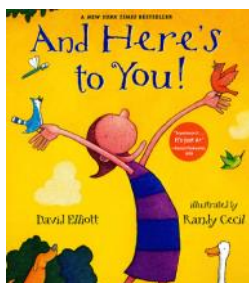
nuts tutorial for beginners. In braille (2 vols.), BRF, Word, DAISY, or ePub: \$24

The Gift of Nothing



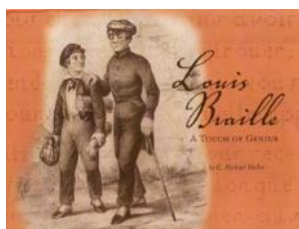
\$14.99, print/braille picture book
A simple and beautiful book about the true meaning of friendship.

And Here's to You!



\$6.99, print/braille picture book (in UEB)
Perfect for a young grad, David Elliott's infectiously joyful poem invites us to celebrate the world's vast diversity - and feel pretty happy with our place in it, too.

Louis Braille: A Touch of Genius



\$35.00 plus s/h in full-color print (only). Inspire your graduates with the only full-color biography of Louis Braille to include 31 of his surviving letters. Author Mike

Mellor has beautifully woven the story of Louis's life around the context of his family and business correspondences, and more than 120 illustrations related to his life and times.

To order any books, send payment to: NBP, 88 St. Stephen Street, Boston, MA 02115-4302. Or call and charge it: toll-free (800) 548-7323 or (617) 266-6160 ext 520. Or order any of our books online at

<http://www.nbp.org/ic/nbp/publications/index.html>

National Braille Press
88 Saint Stephen St
Boston, MA 02115
www.nbp.org



Speaker Series and VisionWalk Launch

“Is The Bionic Eye (ARGUS II®) Right For You?”

**11th Annual Chicago VisionWalk
June 12, 2016**

Since 2006, VisionWalk has raised over \$35 million to support the mission of the Foundation. VisionWalk is a fun, family-friendly walk complete with music, food, kids activities, bounce house and more! Join people like you who are committed to changing the future for their friends and family members affected with retinal degenerative diseases.

Busse Woods

Ned Brown Meadow
Elk Grove Village, IL

Registration and Fun begins at 9:00am
Stage Presentation begins at 10:00am
Walk begins at 10:30am
RSVP deadline: April 9, 2016

Contact Michele DiVincenzo at 847-680-0100 or MDivincenzo@FightBlindness.org

Visit www.FightBlindness.org/
ChicagoVisionWalk
FOUNDATION
FIGHTING
BLINDNESS

FREE SPECIAL EDUCATION
TRAINING FOR PARENTS

FRCD



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

Lunch and Learn Webinar: School Closings & Restructuring: What Parents of Children with Disabilities Need to Know

Wednesday, May 11, 12-1pm

Six Principles of IDEA

Saturday, May 14, 12-1pm

Lunch and Learn Webinar: Assistive Technology and the IEP

Wednesday, May 18, 12-1pm

Navigating the IEP Process

Saturday, May 21, 10am-1pm

NEXT STEPS: Adult Life: Accessing Services

Saturday, May 21, 2-4pm

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

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

1-312-939-3513 | info@frcd.org | www.frcd.org
20 East Jackson Blvd., Room 300
Chicago, IL 60604

PARENT SURVEY

Examining Parent-Teacher Agreement
Regarding the Transition to
Employment Process

Kimberly Patton, a doctoral student in Special Education at the University of Illinois at Urbana-Champaign and under the advisement of Dr. Meghan Burke, are looking for participants for an exciting research project that focuses on parent and teacher perspectives of the transition to employment process for individuals with significant disabilities.

About the Project: As a participant, you will complete an online survey that should take about 20 minutes to complete. At the end of the survey, we will also ask you to provide contact information for your child's primary transition special education teacher. The goal is to determine the extent that parents and teachers agree about their views of the transition to employment process for individuals with significant disabilities. We believe that the information you provide through this study will help to inform transition-related practices involving individuals with significant disabilities, their families and their teachers.

To begin the survey, go to:

[https://illinoislas.qualtrics.com/SE/?](https://illinoislas.qualtrics.com/SE/?SID=SV_56Ltk4HYBQ7IlpP)

[SID=SV_56Ltk4HYBQ7IlpP](https://illinoislas.qualtrics.com/SE/?SID=SV_56Ltk4HYBQ7IlpP)

Potential Participants: Please consider participating in this study if:

- (a) You are the parent or guardian of a transition-aged youth (i.e. between the ages of 14.5-22) with a significant disability (i.e., intellectual disability, autism, or multiple disabilities) who also participates in the alternate assessment,
- (b) You are willing to identify and provide contact information for the primary special education teacher for their child, AND
- (c) You are from the state of Illinois

If you choose to complete the survey, you will be asked to enter your email to receive a \$10 Amazon gift card in appreciation of your participation in the research study.

For more information, please contact Kimberly Patton (kagentry@illinois.edu).

Lunch and Learn Webinars Guest Presenters from Legal Aid Foundation and IATP



Lunch and Learn Webinar: School Closings & Restructuring: What Parents of Children with Disabilities Need to Know

School closings have impacted urban school districts across the nation. There are important things that parents of students with disabilities should know if their child's school closes. State and federal law unquestionably require that the needs of the student drive special education services and instruction-no matter what changes are happening at the school or school district level. This presentation provides an overview how this issue impacts students with disabilities along with strategies for students who have been or will be affected by a school closing or other form of district restructuring.

Wednesday, May 11, 2016

12pm - 1pm

Webinar (Link to actual webinar will be emailed to you.)



Lunch and Learn Webinar: Assistive Technology and the IEP Webinar

The appropriate implementation and use of assistive technologies has the ability to increase abilities and provide greater accessibility to educational opportunities for eligible students with disabilities. Assistive technology devices and services can be used to extend physical, social and communication skills and provide the means for academic inclusion. Many students with disabilities have successfully used assistive technologies to minimize barriers to gain access to a free and appropriate public education (FAPE).

Wednesday, May 18, 2016

12pm - 1pm

Webinar (Link to actual webinar will be emailed to you.)

Register online at www.frcd.org or call Family Resource Center on Disabilities at (312)939-3513.

Interested in Working This Summer???
Apply for a Summer Job Through
One Summer Chicago!



ODLSS

Office of DIVERSE LEARNER
SUPPORTS + SERVICES

Students interested in earning money and gaining valuable work experience should apply today.

Where: Different locations throughout the Chicago area

When: Begins the last week of June for 6 weeks.

How: Apply online.

<https://www.onesummerchicago.org/SummerJobs/>

forming arts, and field trips to various cultural sites. Activities may include sailing, yoga, bowling, beep baseball, and swimming. Headed by a vision teacher or rehabilitation teacher, the program runs from 9:00 in the morning until 2:00 in the afternoon, five days a week. For more information contact Bill Green at bgreen@blindservicesassociation.org or call 312-236-0808.

Blind Service Association is located in Chicago's downtown Loop at:

**17 North State Street
Suite 1050
Chicago, Illinois 60602**



PATHWAYS SUMMER YOUTH PROGRAM

In June and July, Blind Service Association sponsors a six-week program open to blind and visually impaired students aged 10 to 18. Pathways includes training in daily living skills, such as cooking, house cleaning, shopping, cane travel and money management. Kids also enjoy sports, recreation, per-



Summer Camps For Children Who Are Blind or Visually Impaired

Parents will find listings for day camps, summer camps, and other recreational programs that welcome children with disabilities, including some that serve campers with blindness or visual impairment exclusively.

You may also wish to browse the [state listing for Sports Camps](#), compiled by American Printing House for the Blind (APH).

Please go to the following site to learn about more camps and recreation:

<http://www.perkinselearning.org/scout/summer-camps-children-who-are-blind-or-visually-impaired>

IPVI

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SPANISH TRANSLATOR

Noelia Gamino

My handprint

Here is my handprint,
Five fingers in all,
Outside they are short,
But the middle is tall,

You will find them on windows,
You can find them on the wall,
They will make a big mess,
For something so small.

One day I will grow
And leave them no more,
My hand prints will be missed,
Of that, I am sure!

So here is one now,
That you can't wipe away.
My present to you,
This Mother's Day.





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

- ▶ **June 3** **TCL Seeing What's Possible Dinner** **Chicago**
- ▶ **June 12** **FFB Speaker Series and Vision Walk Lunch** **Elk Grove Village**
- ▶ **5/11 & 5/18** **FRCD Lunch and Learn Webinars**
- ▶

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

**Newsletter Deadline for
JUNE is MAY 15**



**Check Out
www.ipvi.org**

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