

# IPVI INSIGHTS

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

**June  
2017**



## **PRESIDENT'S REPORT**

Filiberto Almendarez III

Happy June everyone, and July is right around the corner. Our Annual Brookfield Zoo Outing is in the air. I can smell it. I can sense it. I can feel it. I just can't wait. The excitement of being with everyone. Talking, hugging and having fun. Oh, and being with many wonderful children and how they have grown and excelled. I enjoy the children navigating around like any curious child. Plus, the parents/members. Talking to each other, sharing knowledge and experiences. Helping each other out. As we all know, "We can't help everyone, but everyone can help someone". I hope many will attend, but as prior years have shown that would be an understatement.

To IPVI children: Thank You for Inspiring me to be or at least try to be as strong as you. Your strength, courage and beautiful smiles have given me what cannot be seen or touched. I can only explain that it's felt within the heart. I thank you. Our path in life may not always be easy, but from difficulties and challenges we produce change, progress and even what appear as miracles. Choose your Path and don't turn back. Make adjustments if needed, but keep moving forward. Do not let inaccurate perception deter you from dreaming of your reality. "Dreams are our reality waiting to occur". So Live your Dream!

Reminder: Send in your form for the IPVI Annual Brookfield Zoo Outing on Saturday, July 15, 2017. Remember to smile. You never know where your picture may end up. Chances are in our Newsletter.

Looking forward to being Together. Take Care.





DAD

***Inside This Issue:***

<b>President's Report</b>	1
<b>Memories of Heidi Musser</b>	2
<b>Brookfield Zoo Outing</b>	3
<b>Zoo Registration Form</b>	4
<b>Zoo Directions</b>	5
<b>Early Education Parents as Teachers</b>	6
<b>Member Dues</b>	6
<b>Looking Ahead to Our Children's Needs</b>	7
<b>Perth Family Fights for Braille Education...</b>	7
<b>Fall Festival Suggestions</b>	8
<b>WonderBaby.org</b>	9
<b>Helping Your Blind Baby Develop Through Play</b>	9
<b>How to Host a Sensory Play Party...</b>	9
<b>What I Wish Someone Had Told Me...</b>	9
<b>Is My Blind Child Autistic? 1 Parent's Experience</b>	9
<b>Seedlings: Prevent Summer Slide!</b>	10
<b>Prevent Blindness...Health Care Bill</b>	10
<b>Cataract Remains Leading Cause of Blindness</b>	10
<b>IPVI Board of Directors</b>	11
<b>Father's Day Poem</b>	11
<b>IPVI Membership Dues</b>	12
<b>IPVI Calendar of Events</b>	13



DAD

MEMORIES OF HEIDI MUSSER

Prepared for IPVI Insights – Issue June 2017

Dear IPVI Readers,

I have decided to skip preparing an article for the months of June. Too much is happening in my life presently – mostly, unexpectedly good. More and more I realize how educators misunderstood me, because they lacked skillful training to help me as a totally blind individual to be all I could be.

Besides swimming, the study of classical piano playing has taken over in my life. Stronger and stronger within me gnaws the desire to write my own book.

Please rest assured that off and on I will continue to send to our Editor Joan Bielawski episodes to publish in future IPVI Newsletters. In the past, Joan has asked IPVI Parents to send in articles for publication. Please embrace her invitation and do so.

By the way, my mother and I admire our President Fil Almendarez III for his attitude of close family sharing. I loved his quote in the May Newsletter:

*“If a child cannot learn in the way we teach,  
We must teach in a way the child can learn.”*

The meaning of this quote is exactly what I want to explore in my book. Thank you for being my friends.

Please contact me:  
[hmusser@msn.com](mailto:hmusser@msn.com)  
 773-774-7741



## 2017 IPVI Members' Outing

*"Literacy through Experience at Brookfield Zoo"*

Imagine (in the mind's eye) a sensory Zoo experience - listening to the animals, smelling the environment, touching real and simulated animals in their habitat.....well

### Saturday, July 15, 2017 at Brookfield Zoo

is the chance of a lifetime.....the only problem? Are you going to be there?

**ATTENTION! ATTENTION!** Brookfield Zoo is BIG and the choices are many—arrive early and plan on spending the entire day. **Plan to arrive at 9:30am, the Zoo opens at 10am.** Tons of activities are available throughout your day! Your IPVI T-Shirt will be your exclusive passport into all the action.....into the Zoo, the new **Great Bears' Wilderness, the Hamill Family Play Zoo, and the Seven Seas Dolphin Show—with exclusive after show event**—with preferential seating at the 2:00 show. Be there by 1:45 at the latest.

Our theme is *"Literacy through Experience at Brookfield Zoo"*.....ask questions, touch the special exhibits, analyze and enjoy the unique sounds, smells and textures of the Zoo!

Our luncheon, at the Discovery Ballroom, will include pizza, drinks, and a chance to meet other parents with children of all disabilities.

**Become an IPVI member!** Dues paying members receive free admission and parking at our Members' Only Events — Zoo Outing, Holiday Parties, Picnic, etc. — activities intended to provide social and literacy opportunities for children, parents, teachers, professionals and friends.

Paid membership includes monthly online newsletters and invitations to Parent Rights, Adaptive Technology, and Advocacy seminars.

If you'd like more information on how to attend the 2017 IPVI Zoo Outing, or on how to become a member of the "IPVI Family Network", call **Mary Zabelski at (773) 882-1331**. The registration form is on the following page.

#### Mail Registration & Payment by June 30<sup>th</sup> to

Gail Patterson  
The Chicago Lighthouse  
1850 W. Roosevelt Road  
Chicago, IL 60608



**2017 BROOKFIELD ZOO - IPVI MEMBERS' ONLY OUTING  
Saturday July 15<sup>th</sup> Registration & Payment Form**

Attendance is restricted to current (paid) members of IPVI\*\*. All attendees must pre-register, purchase a 2017 Zoo T-Shirt and show current identification at the Zoo. Attendees may be required to sign Release of Liability & Use of Photographs Form. Registration is limited to one family per IPVI family membership - parents and their children. **EXTENDED FAMILY MEMBERS AND TEACHERS ARE REQUIRED TO PURCHASE SEPARATE IPVI MEMBERSHIPS.**

Family Name: \_\_\_\_\_ IPVI Current Membership [y/n] \_\_\_\_\_

Address: \_\_\_\_\_ city/zip: \_\_\_\_\_

e-mail: \_\_\_\_\_ H ( ) \_\_\_\_\_ - \_\_\_\_\_ C ( ) \_\_\_\_\_ - \_\_\_\_\_

- 1) MEMBER: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)
- 2) SPOUSE: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)
- 3) CHILD: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)
- 4) CHILD: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)
- 5) CHILD: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)
- 6) CHILD: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)

Admission to the "2017 IPVI Members' Only Event" includes parking (enter far South lot), buffet lunch, admission into Zoo, Dolphin Show and Hamill Family Play Area. The T-Shirt is required and identifies your participation and assists Zoo personnel in providing accommodations.

<b>Membership Dues (\$15.00/year per family</b>	
<b>Total Number of Zoo Admission T-Shirts @ \$12/person</b>	
<b>Additional Tax Deductible Donation to IPVI</b>	
<b>TOTAL MONEY INCLUDED - PAYABLE TO IPVI</b>	

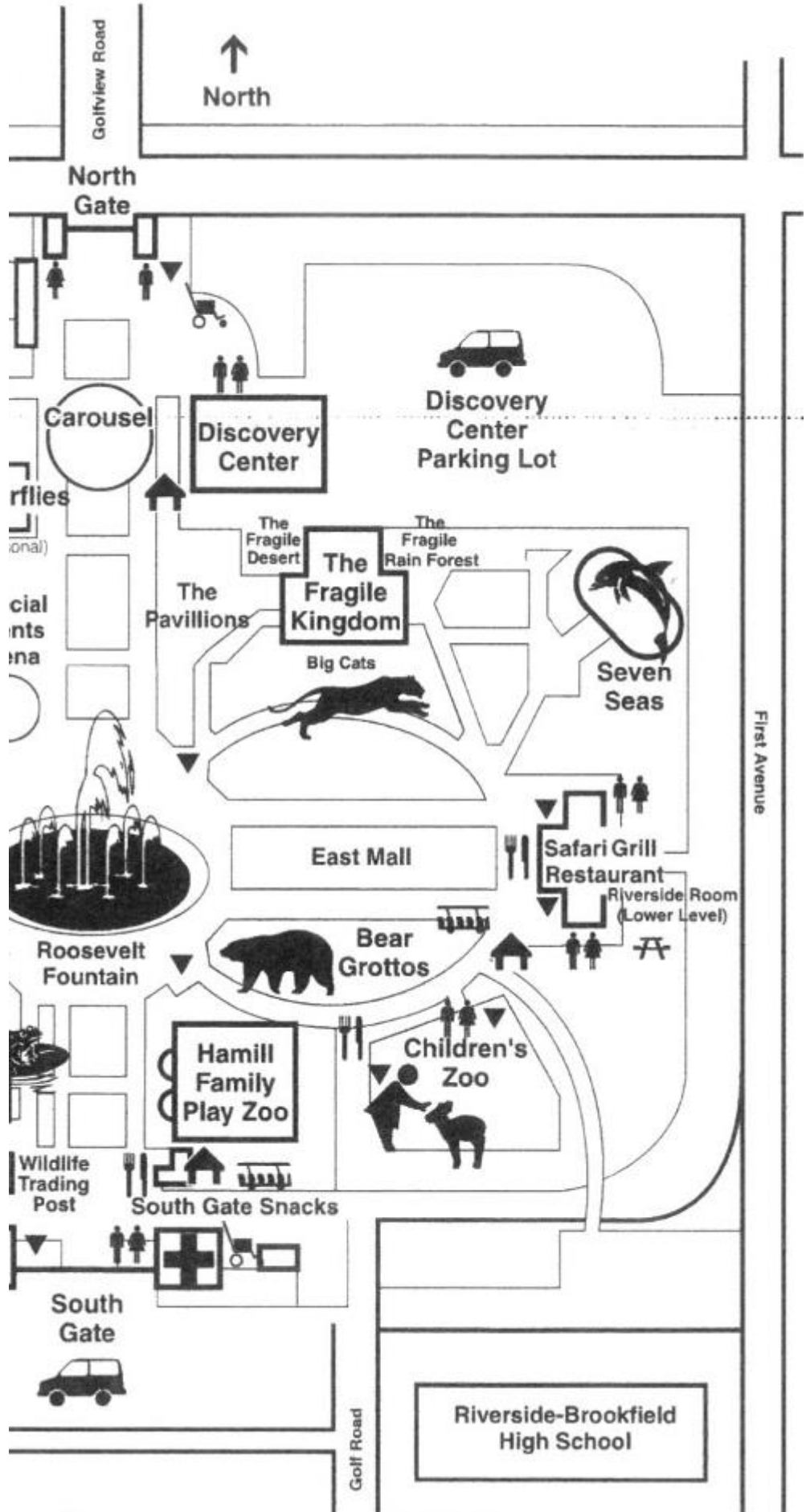
**REGISTRATION CLOSES ON JUNE 30<sup>th</sup>, 2017**

\*\*IPVI is funded from member dues, activity/event participation fees, & private and public donations. IPVI benefits are available to anyone who needs and applies for membership, regardless of their ability to pay. IPVI is an all volunteer organization. We sincerely welcome your participation, support and ideas. We focus on supporting families challenged by visual impairments.



We are gathering in the Discovery Center. We are to park in the Discovery Center Parking Lot. We need to enter at the SOUTH Entrance, not the main entrance. To get to the South Entrance, take 1st Avenue to Ridgewood Road (the first traffic light south of 31st street). Go west on Ridgewood to Golf Road. Turn right on Golf Road to the South Entrance Parking Booth (See map).

At the South Entrance Parking booth, say that you are with IPVI and you will not have to pay for parking. After the south parking booth, stay to the right and tell the next gate guard that you are with IPVI and they will let you on to the road leading to the Discovery Center parking lot. Come to the Discovery Center to check in and get your shirts and Zoo map. See you all there!



## Early Education Parents as Teachers

As a parent, you are your child's first and most important teacher from infancy through the preschool years. Just about all your interactions—playing, talking, putting on clothes, feeding—are natural teaching experiences for you and learning opportunities for your child in your role as teacher. Keep in mind that:

- Every child, whether visually impaired or not, is a learner.
- The family is the most significant influence in the life of a young child.
- Children have different learning styles and, therefore, effective teaching approaches should be geared to their individual needs.

What makes you a natural teacher?

- **You know your child** better than anyone else does and have a better idea of what he or she is ready to learn
- **You spend more time with your child** than anyone else does. Therefore you're able to take advantage of the many ordinary events—things that happen throughout the day in the normal course of family life—that are opportunities to teach your child something.
- **You give your child toys** and common, everyday objects to help him or her learn in natural situations that can be applied to other situations outside the home.
- **You provide opportunities** for your child to practice what he or she has learned and a chance to experience the world under your guidance.
- **You act as a role model.** By starting early, you teach your child behaviors and good habits that will last a lifetime.
- **You involve your child in family life** so that friends and relatives learn how to interact with your visually impaired child and he or she learns how to act with others.

Visually impaired children learn by touching, listen-

ing, smelling, tasting, moving, and using whatever vision they have. You teach your child by talking, touching, and playing during natural interaction times. You are also teaching when you give your child toys and ordinary household objects that vary in texture, weight, smell, sound, and color. The more sensory experiences you provide—experiences that have your child use his or her senses and learn how to obtain information through them—both one at a time and simultaneously, during everyday routines and special family occasions, the better. Your creative, on-the-spot teaching is an essential part of your child's education.

Early intervention services can help you expand your natural teaching skills to help your toddler or preschooler be ready for more formal learning experiences in school. But do not underestimate the value of your own everyday, natural activities with your child. Every moment you spend with your child is a teaching moment. It might be playing, or talking, or running errands, or just being—but you are teaching your child just the same.

Reprinted from K. A. Ferrell, *Reach Out and Teach: Meeting the Training Needs of Parents of Visually and Multiply Handicapped Young Children* (New York: American Foundation for the Blind, 1985), pp. 10-11.

MEMBER  
DUES

Please remember to  
send in your member-  
ship dues of \$15.00 to:

Mary Zabelski  
P.O. Box 316644

**Our Zoo Outing is coming up on July 15th, and we are planning a Fall Festival at a Pumpkin farm in Autumn. We hope one of these outings peaks your interest. You must be a dues paying member to attend. Thanks so much!**

**From  
A Parent's  
Perspective**

**LOOKING AHEAD TO  
OUR CHILDREN'S NEEDS**

When my daughter, Cara, was entering the seventh grade, I asked if she could learn to write her name in cursive handwriting. Since she was totally blind, no one had ever attempted to teach her handwriting skills. She wrote and read braille.

Evidently, nobody thought that handwriting skills were necessary for her. However, I thought that as she grew up and became more independent, she would need to sign her name to a variety of documents, such as her voter registration form, apartment, lease, checks, credit card receipts, and other everyday items. Her teacher of students with visual impairments told me that she was overloaded with students on her caseload and would try to work on this skill when she could. She wasn't sure she could get to it. I let it pass. The whole school year went by, and the skill was never introduced. My attempts to teach Cara were not successful; she had too much homework after school. As it was, I was often her reader, her library research assistant, and her proof-reader. She had no extra time for me to teach her handwriting.

At her eighth grade IEP meeting, I was prepared. I explained that every other student in the class could write their names and that it was an essential skill. I insisted, in a pleasant but firm manner, that acquiring handwriting skills should be put into the IEP, and it was. Cara learned how to write and sign her name because I was there to advocate for this skill. The regular classroom teacher would never have thought of teaching this skill, nor would this person have any knowledge of how to teach it. The teacher of students with visual impairments had the training but did not have the time. Many teachers are not going to look ahead to the skills that a person who is blind or visually impaired may need to become a successful working adult. We as parents must look ahead to the future, and to the skills our children need for their successful transition into adulthood.

*Mary Zabelski, Mother of an adult daughter with retinoblastoma*

**Perth Family Fights for Braille  
Education for Vision-Impaired Twins**



© Provided by ABC News Raquelle Hannen-Williams has high aspirations for her daughters Bethany (left) and Caitlin.

Perth twins Caitlin and Bethany Hannen-Williams have faced many challenges since they began losing their sight four years ago but one battle their mother did not predict was a fight for them to be taught braille.

The girls are going blind due to a degenerative condition called optic neuropathy and Raquelle Hannen-Williams believes learning braille could give her daughters the best chance to achieve their goals in life.

She lobbied the WA Education Department intensely for braille lessons for the girls, but they were offered short-term lessons of only one hour a week

The department's assessment of Caitlin, who is now 12 and legally blind, states "to introduce braille at this time would create an unnecessary burden for her and would prevent her from achieving her potential in the classroom".

"So I think to myself, how many other children in WA are in the same position? Ms Hannen-Williams said.

In frustration, Ms Hannen-Williams began teaching Caitlin braille herself - despite not

knowing the script - and later secured some funding from the National Disability Insurance Scheme.

This has enabled Caitlin to study braille before school via FaceTime with a teacher in New South Wales, but this funding runs out in August.

For many blind and vision-impaired people, braille is an important tool for leading an independent life, from going into the correct toilet or selecting a floor in an elevator.

Australia's former disability discrimination commissioner Graeme Innes was born blind and began to learn braille at the age of three.

He said braille was a critical literacy skill which taught spelling and punctuation.

Mr Innes said he had come across many highly intelligent vision-impaired people whose careers had been held back by poor spelling because they had learned via audio, not braille.

He supported Ms Hannen-Williams' efforts in preparing her daughters for a future where they would need to use braille to study and work.

"I don't want her to think that just because she's going blind, she's only able to do menial tasks," she said.

"I don't want her [Caitlin] sitting at home on a disability pension. I expect that just because she's lost her sight she's still the same person she would have been if she still had her sight."

Always at the back of her mind is the reality that Bethany - who has lost only 25 per cent of her vision - will also need to start learning braille.

Ms Hannen-Williams said Bethany was "in denial" about her failing eyesight. Although she had witnessed her sister struggle to adjust, having to give up competitive swimming and accepting she will not be able to drive a car.

But today Caitlin is highly motivated to learn braille, loves reading Harry Potter books and wants to be a film actress when she grows up.

"It's up and down. It's a rollercoaster," Ms Hannen-Williams said.

But there could be a glimmer of hope. After being contacted by the ABC, the WA Education Department said it expected Caitlin's braille services would be increased when she was reassessed next month.

"I think from what you've described, there's no doubt that this child needs more access to braille and I'm sure that's what will be organized," executive director of statewide services Lindsay Hale said.

The department said there were 17 students learning braille in WA, with 25 teachers qualified to teach the script. Students can have up to 4.5 hours of tuition a week.



**I would like to ask our members for help to suggest a Pumpkin Farm to visit in the fall.**

**I'd like one in the Chicago/close suburban areas that you may have visited and had plenty to do that would include our blind/visually impaired children. This may include pony rides, hay ride, maze, animals to pet, etc. I have found a great one but it is in Oswego. Please email me at:**

**wjbielawski@yahoo.com  
Thanks so much. Joan Bielawski**





### Helping Your Blind Baby Develop Through Play

*By Amber Bobnar*

Every day your baby is getting bigger and older... but is he getting stronger? ...is he getting smarter? As the parent of a visually impaired child, I'm sure you worry about your baby's development, both physically and cognitively. But how can you be sure that you're doing all that you can? We'll help you create a **Baby Workout Program** that will cover all the bases! READ MORE at: **WonderBaby.org**



### How to Host a Sensory Play Party For Visually Impaired Kids

*By Amber Bobnar*

Sensory Play and Multi-Sensory Activities are such buzzwords these days. Early educators and special needs moms alike know how important it is to engage a child's senses during play in order to encourage learning and development. But have you ever noticed that most sensory play activities are designed for one kid to play alone, usually while sitting nicely at a table? READ MORE at: **WonderBaby.org**



### What I Wish Someone Had Told Me When My Child Was First Diagnosed With a Disability

*By Amber Bobnar*

When Ivan was born, we were in the NICU for a week. His breathing was irregular and he aspirated when feeding. He was run through a battery of tests, but essentially sent home with a shrug. Our doctor's message wasn't inspiring: "There's something wrong with your baby, but we don't know what it is." READ MORE at: **WonderBaby.org**



### Is My Blind Child Autistic? One Parent's Experience

*By Mary McDonach*

I can only ever write about my experience with my child and I always write from that perspective first. In this article I would like to address the relationship between blindness and autism, but I do not wish to step on any toes or take issue with what another parent has experienced or lives with daily. READ MORE at: **WonderBaby.org**



## Prevent Summer Slide!

**On average, students lose 2 months of reading skills over the summer. Don't let that happen to your child!**



**Summer slide is real, and cumulative. By the end of 6th grade, children who lose reading skills over the summer are on average 2 years behind their peers regardless of ethnicity, socioeconomic level or previous achievement.**

***But you can PREVENT SUMMER SLIDE!***

**Children who read just four or more books over the summer fare better on reading comprehension tests in the fall than their peers who read no books or one book.**

***Order our LOW-COST braille books and learning aids today***

**to keep your child's reading skills on track!**

Seedlings Braille Books for Children  
800-777-8552  
[info@seedlings.org](mailto:info@seedlings.org)  
[www.seedlings.org](http://www.seedlings.org)



## Prevent Blindness Makes Recommendations for Health Care Bill

In its recommendations for healthcare reform, Prevent Blindness urges the Senate to maintain the essential health benefits, which includes vision screenings and eye examinations for children and chronic disease management for adults, as defined under the Affordable Care Act (ACA), to maintain Medicaid as expanded to ensure a vital lifeline to our nation's most vulnerable, and to implement income-based tax credits as opposed to age-based tax credits to ensure that aging Americans prioritize their vision and eye health. **Read the full text of the Prevent Blindness Letter to the Senate Finance Committee at <http://www.preventblindness.org/prevent-blindness-makes-recommendations-health-care-bill>**

Prevent Blindness will hold the sixth annual Focus on Eye Health National Summit on Wednesday, June 28, 2017 from 7:30 a.m. – 3:30 p.m., at the National Press Club in Washington, D.C



## Cataract Remains Leading Global Cause of Blindness

Cataract is a clouding of the eye's lens which blocks or changes the passage of light into the eye. Cataracts usually form in both eyes, but not at the same rate. They can develop slowly or quickly, or progress to a certain point, then not get any worse. Prevent Blindness has declared June as Cataract Awareness Month to educate the public on risk factors, symptoms and treatment options. For those considering surgery and their caregivers, Prevent Blindness offers a free online guide at:

**<http://www.preventblindness.org/cataract-surgery>.**

**IPVI**

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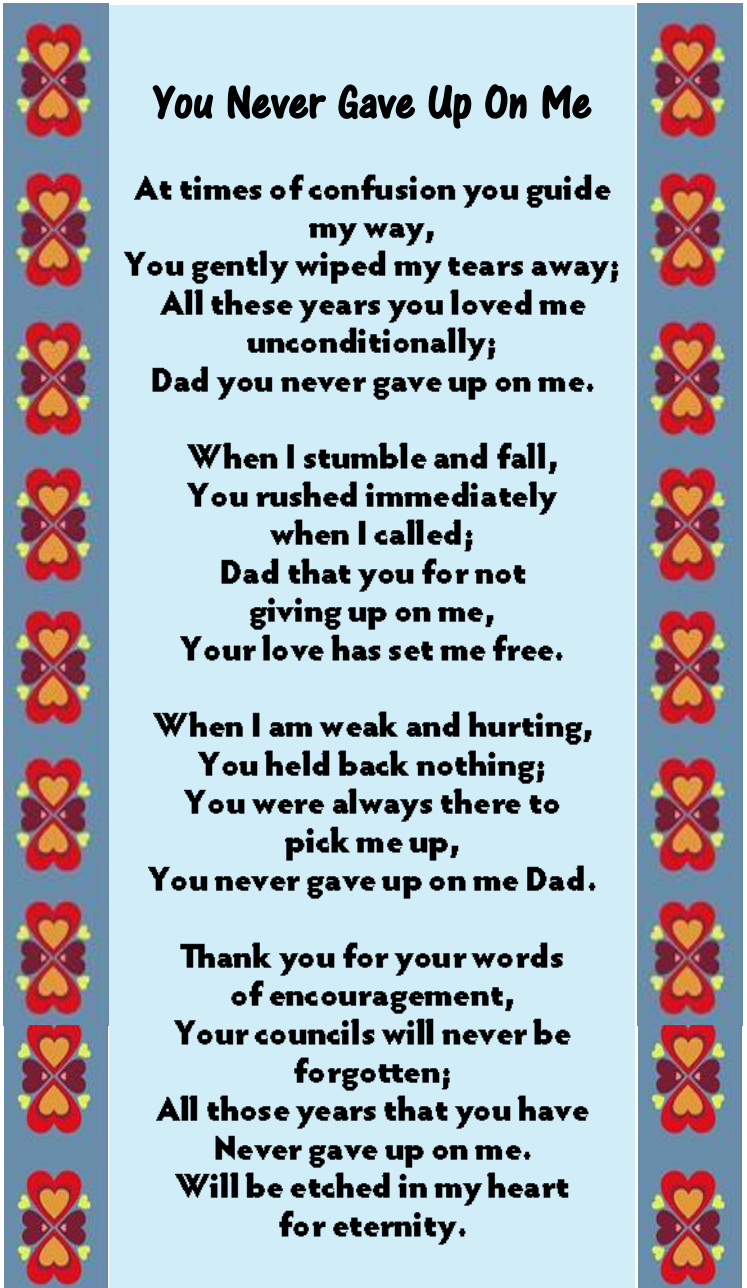
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***You Never Gave Up On Me***

**At times of confusion you guide  
my way,  
You gently wiped my tears away;  
All these years you loved me  
unconditionally;  
Dad you never gave up on me.**

**When I stumble and fall,  
You rushed immediately  
when I called;  
Dad that you for not  
giving up on me,  
Your love has set me free.**

**When I am weak and hurting,  
You held back nothing;  
You were always there to  
pick me up,  
You never gave up on me Dad.**

**Thank you for your words  
of encouragement,  
Your councils will never be  
forgotten;  
All those years that you have  
Never gave up on me.  
Will be etched in my heart  
for eternity.**





# 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**

**July 15**

**Annual Brookfield Zoo Trip**

**Brookfield**



**Fall Festival**

**Pumpkin Farm Outing – TBD**

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

**Newsletter Deadline for  
July 2017 is June 15**



**Check Out  
[www.ipvi.org](http://www.ipvi.org)**

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