

# IPVI INSIGHTS

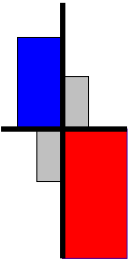
*Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities*

**July  
2017**



## **PRESIDENT'S REPORT**

Filiberto Almendarez III



The 2017 Brookfield Zoo Outing is here. Saturday, July 15, 2017. Come on out and have some fun. I anticipate a big turnout. Just like prior years. Also, please add the Dolphin Show into your schedule. It starts at 2:00 pm. Arrive early for preferential access and seating. Another item to keep in mind is the IPVI group picture. Immediately, following lunch, we will gather directly outside to capture our famous image. The photo will be part of our Newsletter. So, have that beautiful expression on your face, Smile.

Although, we call this an Outing, it is more of a Family Reunion. Getting the whole family together to celebrate being a family. Staying in touch. Families from all over the State of Illinois. Participating in recreational activities, eating together, laughing together and sharing precious life stories. Even IPVI founding Fathers/Mothers attend. Just like a grandparent or aunt and uncle at a family reunion. We may not be the biggest organization, but as the saying goes, "It's not how big the house is, it's how happy the home is". We definitely are one of the happiest. Especially celebrating together. Who would have thought over 30 years ago, there would be an Illinois Association for Parents of Children with Visual Impairments. Thank You to our founding Fathers/Mothers, their little blessings who inspired them and all IPVI members, who Believed. Remember:

*"Nothing is impossible, the word itself says, I'm possible!"*

See You Soon!

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**BROOKFIELD ZOO  
SPEAKERS**

This year's speakers will be the Juan Vaglienty Family. Hello,. My name is Anna Vaglienty. This is my husband Juan Vaglienty, my daughter Amelia, who is 6 years old and my son Maximilian, who is 4 years old.

Amelia was born with a very rare genetic disorder (about 300 cases in the world, about 50 diagnosed cases in the Unites States) called Pallister Killian Syndrome. Amelia is legally blind due to Cortical Visual Impairment (CVI), non verbal and has physical and cognitive impairments.

Maximilian was born with Down's Syndrome. He was also born with a heart defect and underwent an open heart surgery at the age of 5 months. As a result of the surgery, he developed a multitude of medical problems related to his heart and lungs, and subsequently suffered multiple pneumonias and was hospitalized every 3-4 months.

Both Amelia and Maximilian were recipients of the Early Intervention (EI) services. They both received PT, OT, ST and DT.

Amelia additionally received vision services due to her CVI. That is how our connection with the Chicago Lighthouse and IPVI started. Oddly enough, around the same time that Amelia was diagnosed my husband met Rich Zabelski while volunteering at the Polish Legal Clinic called Amicus Poloniae. Juan and Rich started talking and discovered that they had quite

*(Continued on page 6)*



## 2017 IPVI Members' Outing

*"Literacy through Experience at Brookfield Zoo"*

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

**ATTENTION! ATTENTION!** Brookfield Zoo is BIG and the choices are many. **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. Attendees receive free admission, free parking, free lunch and we include two events at no cost. This year's free events will be the **Tram Ride** and the **Dolphin Show—with exclusive after show event and preferential seating.** The show begins at 2:00 so be there by 1:45 at the latest. **IPVI members will receive tickets specifically for the 2:00 show.** There are many other attractions to see, plus animals galore. Some of these attractions are the Hamill Family Wild Encounters, the Hamill Family Play Zoo, the Carousel, and the latest addition, Dinos and Dragons. These are not paid for by IPVI, but would be a rewarding experience for your children. What a wonderful day!

Our luncheon, at the Discovery Ballroom, will include pizza, drinks, and a chance to meet other parents with children of all disabilities. There will be a raffle to win blind or visually impaired items.

**Speakers Continued:** Our children are also involved in outside activities. We are members of Lekotek- a toy lending library, as well as Misericordia Outreach Group. Both children attend swimming classes at Misericordia as well as monthly play groups.

Amelia also does hippotherapy (therapy with the horses) on weekly basis. Maximilian started attending sports activities through Chicago Park District (CPD) as of April of 2017. He was in a t-ball, basketball and all sports class. He attended those classes with typically developing peers, but did have a one on one aide. We hope that Maximilian will be able to take piano lessons one day as he really likes striking keys of a piano and enjoys music. Amelia does too.

Activities we do as a family include biking (we recently raised funds and got a Buddy bike for Amelia), going to a playground, library story time and reading as a family. Both Amelia and Maximilian love listening to us read books to them.

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

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.**

**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>	

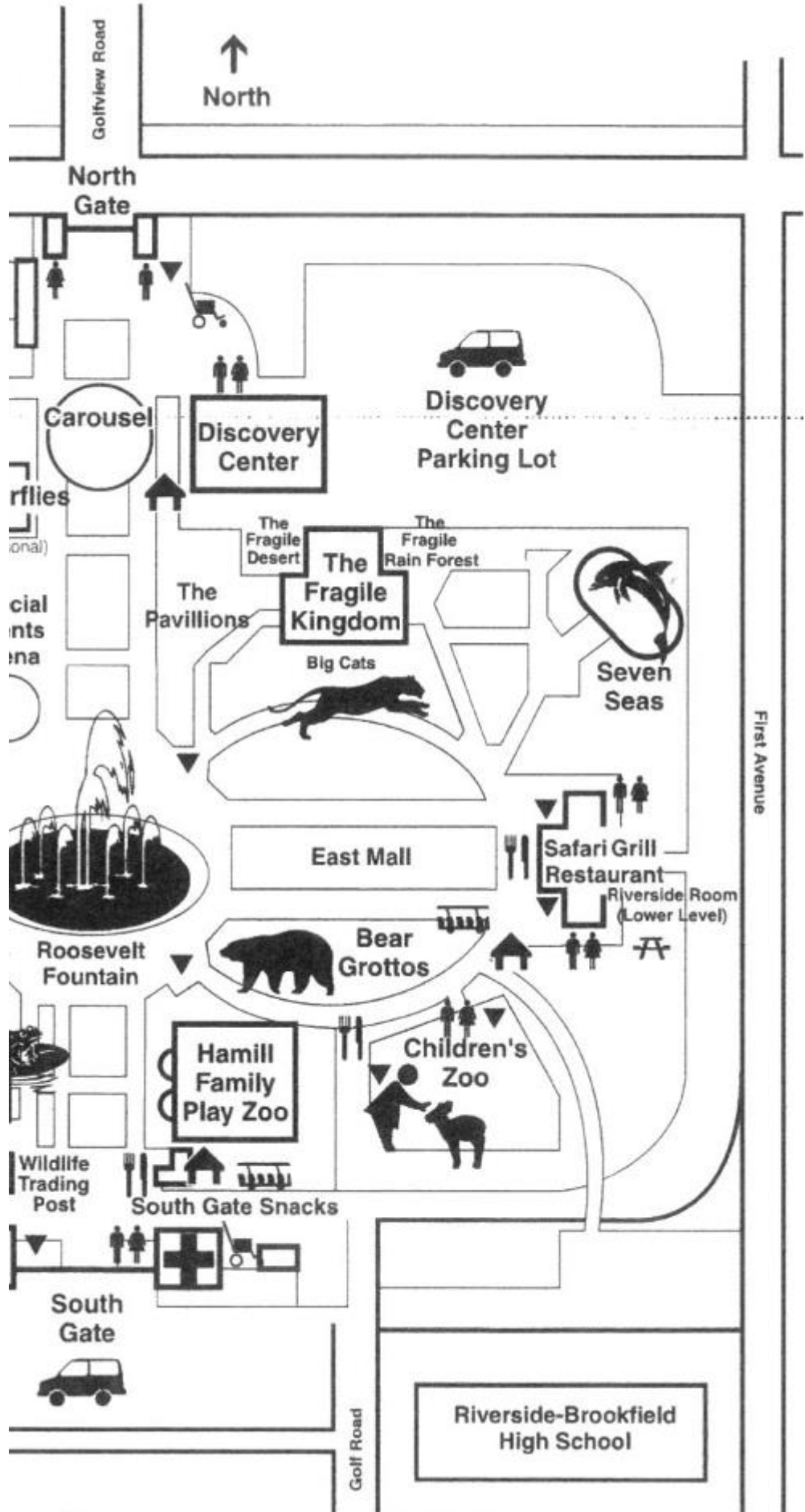
**REGISTRATION CLOSSES ON JUNE 30<sup>th</sup>, 2017**

\*\*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!



*(Continued from page 2) Brookfield Zoo Speakers*

a few things in common. They became friends and it has been a wonderful experience to have Mary and Rich Zabelski in our lives.

After aging out of EI, Amelia and Maxi have been receiving services through Chicago Public Schools (CPS). They both receive PT, OT, ST and Amelia also receives vision therapy from TVI.

Our children are also involved in outside activities. We are members of Lekotek- a toy lending library, as well as Misericordia Outreach Group. Both children attend swimming classes at Misericordia as well as monthly play groups.

Amelia also does hippotherapy (therapy with the horses) on a weekly basis. Maximilian started attending sports activities through the Chicago Park District (CPD) as of April of 2017. He was in a t-ball, basketball and all sports class. He attended those classes with typically developing peers, but did have a one on one aide. We hope that Maximilian will be able to take piano lessons one day as he really likes striking keys of a piano and enjoys music. Amelia does too.

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## 5 Reasons Why Recreation Is SO Important for Children Who Are Blind or

## Visually Impaired

By Emily Coleman



Summertime is approaching and for many children that means trying new sports or a new activity, hanging out at the park, going camping, and simply having adventures. Children who are blind or visually impaired can often be left out. The following are five reasons why it's so important to include these children in recreational activities.

1. **Physical activity.** Children who have a visual impairment sometimes don't get many opportunities to exercise. We all know that exercising is important to stay healthy, so this reason is obvious.
2. **Hands-on learning.** Sometimes, children with visual impairments simply don't know how to play any sports or participate in activities. They've never been taught, or haven't been exposed to recreation designed specifically for them. By including them in a variety of recreational activities, they can learn how to play, which leads to reason number three.
3. **Finding their preference.** Only after learning about a sport, or an activity, can a person truly decide if they like it or not. By providing children who are visually impaired with lots of recreational opportunities, they can decide for themselves what things they'd like to try again...and what things they'd rather not.
4. **Socialization.** It can be difficult for some children to make friends. Recreation provides a common activity that can start friendships, and maintain them through a shared interest or hobby. Try to see every recreational activity as a chance to meet a new friend, and to be a new friend to somebody else.
5. **Self-esteem.** Children who are visually impaired should be treated like their peers. They are just as capable, and expecting them to participate in recreational activities will build their self-esteem. If they are told that they "can" instead of that they "can't," they'll also expect more of themselves. Through every accomplishment, their self-

*(Continued on page 8)*



## Prevent Blindness Works to Educate the Public on Dangers of Consumer Fireworks

*Non-profit Group Provides Alternative Ideas on Ways Families Can Celebrate Independence Day safely -*

**CHICAGO (June 14, 2017)** – The **U.S. Consumer Product Safety Commission (CPSC)**, estimated that injuries from fireworks sent 8,000 Americans to the emergency room over the Fourth of July holiday. The latest CPSC annual report stated that forty-two percent of the estimated emergency department-treated, fireworks-related injuries were to individuals younger than 20 years of age. Sadly, the CPSC also reported 11 non-occupational fireworks-related deaths.

The **American Pyrotechnics Association** states that Delaware, Massachusetts and New Jersey are the only states that ban all consumer fireworks. Fireworks laws vary from state to state and sometimes, within different counties.

A recent study, “**Effect of Fireworks Laws on Pediatric Fireworks-Related Burn Injuries**,” published in the *Journal of Burn Care & Research*, concluded that the relaxing of fireworks laws in the United States has had a dramatic effect on the severity of the related injuries, resulting in more inpatient admissions and longer length of stay in the hospital.

Yet despite the thousands of injuries and consumer firework-related deaths, some state government representatives are moving to lift restrictions on consumer fireworks. In fact, in Iowa, **a new law enacted in April** allows retail sales of consumer fireworks in permanent buildings between June 1 and July 8, and again between Dec. 10 and Jan. 3.

As a public health-based organization, **Prevent Blindness** supports the development and enforcement of bans on the importation, sale and use of all fireworks and sparklers, except those used in authorized public displays by competent licensed operators. The national non-profit group, including its affiliates, works with leading organizations to educate the public on the dangers of consumer fireworks and endorses legislation to help protect adults and children from needless injuries from fireworks.

The CPSC states that burns from fireworks are the most common injury to all parts of the body, except the eyes, where contusions, lacerations, and foreign bodies in the eyes occurred more frequently. According to the **American Academy of Pediatrics**, approximately one third of eye injuries from fireworks result in permanent blindness.

Prevent Blindness, the nation’s oldest volunteer eye health and safety organization, offers alternatives to celebrate the holiday safely:

- Make 4<sup>th</sup> of July rockets by using paper towel rolls, paint, streamers and paper cement.
- Make pinwheels or wind socks with an Independence Day theme.
- After the sun goes down, wrap flashlights in colored cellophane to provide fun shades of light.
- Purchase non-toxic glow-sticks, ropes and jewelry that can safely light the night for kids.
- Using yarn, craft sticks, paint and construction paper, families can make the United States flag.
- Have children design and decorate their own t-shirts and hats using glow in the dark paints. Add puffy paints and glitter to make them sparkle.

“The Fourth of July can still be fun without fireworks,” said Hugh R. Parry, president and

CEO of Prevent Blindness. "By attending on-ly fireworks shows run by licensed profes-sionals, and being vigilant, we can celebrate our nation's birthday with family and friends, not in the emergency room."

For more information on the dangers of fire-works, please call Prevent Blindness at (800) 331-2020, or visit [preventblindness.org/prevent-eye-injuries-fireworks](http://preventblindness.org/prevent-eye-injuries-fireworks).

**Sarah Hecker**  
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**Prevent Blindness**  
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F 312.363.6052  
[www.preventblindness.org](http://www.preventblindness.org)

Christine Spence, a doctoral Candidate from the Department of Special Education at the University of Illinois at Urbana-Champaign, would like to understand more about the out-comes of early intervention (EI) for families and how EI therapists helped to achieve those outcomes. She is inviting parents to complete a survey and participate in an in-terview describing your experiences in ear-ly intervention.

You are eligible to participate if your child has received early intervention services for at least six months. They can still be partici-pating in early intervention or discharged from early intervention services within the past six months.

The interview can be scheduled at a time and place that is convenient for you. The to-tal time commitment is approximately an hour to an hour and a half.

**You will receive a \$25 gift card in appreci-ation for your time and input.**

**Please contact Christine Spence at [cspence@illinois.edu](mailto:cspence@illinois.edu) or 217-244-6742 with questions or to schedule a time to meet for the interview.**

*(Continued from page 6) - 5 Reasons Why Recreation is SO Important...*

esteem will improve, leading to greater independence.

For all children who are blind or visually impaired, inde-pendence is the greatest goal. This is worked on during the school year through academics, but sometimes ig-nored during the summer. For the reasons listed above, I suggest you continue teaching independence throughout the warmer months by promoting recreation. Not only will it benefit your child this summer, but also for many summers to come.



**Family Resource Center on Disabilities**  
*Parent Training and Information Center*

The logo for the Family Resource Center on Disabilities is circular and features a colorful city skyline with a purple arc above it. The text "Family Resource Center on Disabilities" is written around the top inner edge of the circle, and "The Association for Parents of Children with Special Needs - Helping Families Since 1999" is written around the bottom inner edge.

## Study



**Has your child participated in early intervention?**





### 13 Summer Must Have for Special Needs Kids

*By Amber Bobnar*

Summer means long days at outdoor music festivals or carnivals, trips to the beach or maybe a day out picking plums and peaches at a local farm. Summer can be a trip to the zoo, a family picnic or a day spent at the water park. **READ MORE** at:

**WonderBaby.org**



### 36 Fun Summer Activities for Kids Who Are Blind or Multiply Disabled

*By Amber Bobnar*

During long breaks from school we're always looking for something fun (and preferably educational) for Ivan to do. I like to search through Pinterest and parenting blogs looking for fun summer-time activities, but it can be very difficult to find projects or outings that are appropriate for a young child who is blind and has multiple disabilities. **READ MORE** at: **WonderBaby.org**



### No Therapies for a Month? Taking the Summer Off With Your Special Needs Child

*By Amber Bobnar*

When kids are out of school and therapies slow down, what do you do? Do you plan a vacation? Go fishing or take the family to a ball game? Or do you feel guilty that your child may not be getting the services and therapies that he needs to keep up with his development? **READ MORE** at:

**WonderBaby.org**



### Make Your Own Tactile Summer Memory Book

*By Mary McDonach*

Tactile memory books are a fun way to incorporate language development, social skills and good old fashioned arts and crafts all into one activity, and tactile memory books about summer vacation are an easy way for your visually impaired child, verbal or nonverbal, to share with his class and teachers about his holiday when he gets back to school in the fall. **READ MORE** at: **WonderBaby.org**

## Prevent Blindness Offers Free Information to Protect Eyes During Upcoming Solar Eclipse

*- Non-profit Group Provides Tips on How to View Historic Solar Event Without Damaging Eyes -*

Across North America on Monday, August 21, 2017, a solar eclipse will be visible to millions of people. According to the [National Aeronautics and Space Administration](#) (NASA), a solar eclipse occurs when the moon blocks any part of the sun. As part of this eclipse, some parts of the United States will experience a brief total eclipse, when the moon completely blocks the sun's face for up to 2 minutes, 40 seconds.

However, looking directly at the sun can be very harmful to the eyes. In fact, exposing eyes to the sun without proper eye protection during a solar eclipse can cause "[eclipse blindness](#)" or retinal burns, also known as solar retinopathy. This exposure to the light can cause damage or even destroy cells in the retina (the back of the eye) that transmit what you see to the brain. This damage can be temporary or permanent and occurs with no pain. It can take a few hours to a few days after viewing the solar eclipse to realize the damage that has occurred.

Prevent Blindness, the nation's oldest volunteer eye health and safety organization, has established a [web page](#) and [fact sheet](#) with information about an eclipse, potential related dangers to vision, and how to protect your eyes from injury during the event.

Prevent Blindness offers the following tips on how to view the eclipse safely:

**Pinhole projection:** This is the safest and most inexpensive way of watching a solar eclipse. This helps you avoid looking directly at the eclipse by using a projected image. This do-it-yourself project includes making a pinhole in a cardboard paper with the sun on one side and a piece of paper to project the image on the other side. Keep in mind not to look through the pinhole at the sun.

**Welder's glass:** Number 14 welder's glass provides effective protection and can be found at a local welder's supply store. This glass will reduce the harmful rays that are emitted during the eclipse. Do not use if there are any scratches or damage to the glass.

**Mylar filters:** Aluminized Mylar plastic sheets are available as eclipse vision glasses or can be cut and made into a viewing box. Do not use if there are any scratches or damage to the sheet.

**Other ways:** Other ways to safely watch a solar eclipse are on television or at a planetarium.

In addition, Prevent Blindness warns against using the following methods:

**Smartphone:** Watching a solar eclipse on your smartphone camera can put you at risk of accidentally looking at the sun when trying to line up your camera. It could possibly also damage your smartphone camera. Don't take the risk.

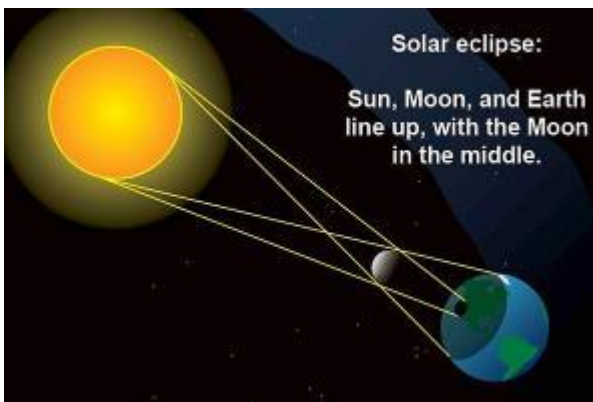
**Camera viewfinder:** Never look at a solar eclipse through the optical viewfinder of a

camera. It can damage your eyes in the same way as looking directly at it.

**Unsafe filters:** Unless specifically designed for viewing a solar eclipse, no filter is safe to use with any optical device (telescopes, binoculars, sunglasses, etc.).

Prevent Blindness strongly recommends that anyone who plans on viewing the solar eclipse consult an eye care professional to determine the safest viewing option. Anyone who experiences changes in vision or worsening eye pain after viewing the eclipse should seek treatment from an eye doctor immediately.

“By wearing the proper eye protection, everyone can enjoy this amazing spectacle of nature safely,” said Hugh R. Parry, president and CEO of Prevent Blindness. “We want to encourage the public to take the right precautions in advance to safeguard their eyes from the sun’s powerful rays.”



MEMBER  
DUES

Please remember to send in your membership dues of \$15.00 to:

Mary Zabelski  
P.O. Box 316634

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!



Fall Festival

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

**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)

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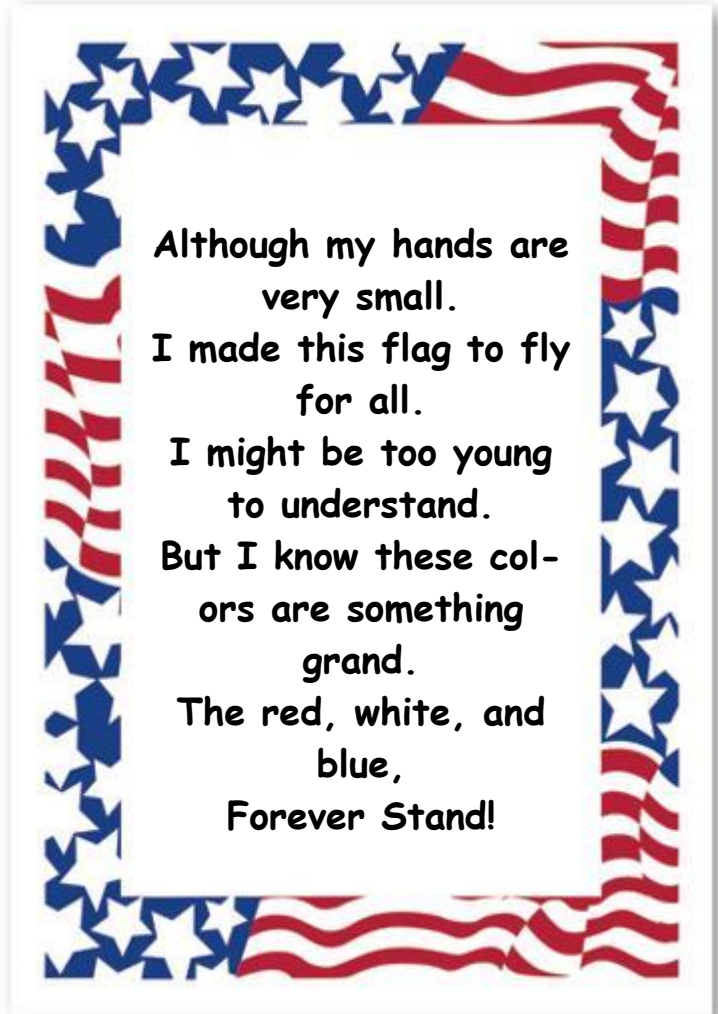
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# Join **IPVI** or renew your membership today!

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**

**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  
August 2017 is July 15**



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

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