

# IPVI INSIGHTS



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

MAY 2018

## PRESIDENT'S REPORT

Filiberto Almendarez III



**Fil Almendarez**  
**President**  
**Treasurer**



**Mary Zabelski**  
**Program VP**



**Joan Bielawski**  
**Operations VP**  
**Secretary**

## ANNUAL MEETING MINUTES

April 14, 2018

In attendance: Filiberto Almendarez, Mary Zabelski, Joan Bielawski, Bill Bielawski

**Meeting Called to Order** - 11:20 a.m.

**Amendments** - Approved

**Federal and State Filing** – Fil filed AG 990 at Lisa Madigan's office. Federal filing complete. Secretary of State needs names of board to

(Continued on page 3)



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**Foundation Fighting Blindness Celebrates Historic FDA Approval of First Gene Therapy to Treat Blindness**

*Foundation's early investment in LUXTURNA™ boosts vision-restoring treatment for people with RPE65 mutations and will help advance other gene therapies currently in development.*

The U.S. Food and Drug Administration (FDA) approval of voretigene neparvec, to be marketed as LUXTURNA, will be life-changing for patients with vision loss due to mutations in the RPE65 gene and a watershed moment for the inherited retinal disease field, says the Foundation Fighting Blindness. The Foundation was an important early investor in LUXTURNA, providing \$10 million in critical seed funding for the therapy.

The groundbreaking treatment is the first gene therapy for the eye and for any inherited disease to be approved by the FDA. The treatment restores vision by delivering working copies of the RPE65 gene directly into the retina, thereby compensating for the non-functional, mutated genes.

“We are thrilled for the patients whose lives will change dramatically because of this treatment,” says David Brint, Foundation Fighting Blindness chairman. “We are also pleased to have this concrete example of the strength of the Foundation’s strategy of identifying and investing early in promising treatments. Doing so helps attract industry investment that can usher promising treatments through clinical trials and ultimately FDA approval.”

LUXTURNA is the result of more than two decades of research and development at the University of Florida, the University of Pennsylvania, Children’s Hospital of Philadelphia, and Spark Therapeutics. The Foundation Fighting Blindness’ seed investment allowed researchers to take the therapy through the early investigational stages critical to any treatment

(Continued from page 1) - Annual Meeting Minutes

be filed. Must file for last four month's. Then we can have a calendar year of January 1 - December 31.

**Budget** – Fil presented the budget from September 16 through August 31. As noted, our zoo outing has been doubled since we did not get confirmation of the price until our new calendar year.

**Treasury** - The checkbook balance as of 4/12/2018 is \$7,633.90.

**Audit Committee** - Bill Bielawski and Rich Zabelski will audit last year's books.

### **Open Board Positions**

**President and Temporary Treasurer** – Fil will fill these positions until someone comes forth to be the Treasurer

**Program Vice President** – Mary will continue to fill this position.

**Secretary and Temporary Operations Vice President** – Joan Bielawski will hold the Secretary position and will temporarily be the Program Vice President until someone comes forth to be the Program Vice President.

**Scholarship** – We can no longer offer a scholarship. Approved.

### **New Items**

**Summer Zoo Outing** – July 21. Mary will continue to organize our Zoo Outing.

**Gift Cards** – We will give gift certificates to our volunteers.

#### **Seasonal Outings** -

Our Fall outing will be the “Play for All” at Navy Pier.

Our Winter outing will be the Lighthouse and IPVVI Christmas Party

Our Spring outing will be the “Play for All” at Navy Pier.

The meeting was adjourned at 2:10 p.m.

Submitted by Joan Bielawski, Secretary

2018  
**ANNUAL  
MEETING**



**Illinois Association for Parents of Children with Visual Impairments**

P. O. Box 316634 Chicago, IL 60631  
[www.ipvi.org](http://www.ipvi.org) | 1-773-882-1331 | [ipvi@ipvi.org](mailto:ipvi@ipvi.org)

April 14, 2018

**Officers**

**IPVI PROFIT & LOSS**

Filiberto Almendarez III  
**President**  
 Chicago  
 773-693-5713

Beginning Balance

14331.59

**INCOME**

Joan Bielawski  
 Operations

Donation 3274.00  
 Membership 1616.80  
 Zoo Clothing 1118.20

**Vice President**  
 (Temporary)

6009.00 \$6,009.00

Mary Zabelski  
**Services**  
**Vice President**  
 Chicago  
 773-882-1331

**EXPENSE**

Exhibit/Display 350.00  
 TCL Christmas Party 500.00  
 Bank Fee 4.5  
 IL License/Permit/Fee 139.00  
 Scholarship 500.00  
 USPS Postage/Box Fee 203.10  
 Supplies 210.05  
 Double Tree Meeting Room 50.00  
 Double Tree Food 215.03  
 Zoo T Shirts 1954.75  
 Brookfield Zoo Outing 8346.51  
 Zoo Mailing/Printing 241.35  
 Zoo Supplies 40.00  
 Zoo Sweatshirt 44.10  
 Zoo Gift Cards 100.00  
 Newsletter/Publication 528.57

Filiberto Almendarez III  
**Treasurer**  
 (Temporary)

Joan Bielawski  
**Secretary**  
 Naperville  
 630-357-8576

13427.21 \$13,427.21

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[wjbielawski@yahoo.com](mailto:wjbielawski@yahoo.com)

**Net Income**

\$(7,418.21) \$((7,418.21))

**Year End Balance**

**\$6,913.38**



## 2018 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 21, 2018 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 **Seven Seas Dolphin Show after lunch (with exclusive after show event), and tickets to other venues.** Sensory experiences abound!!

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. Our Guest Speaker will be Commissioner Dennis Deer.

**Become an IPVI member!** Dues paying members (\$20) receive free admission and parking at our Members' Only Events — Zoo Outing, Holiday Party, Play For All, etc. — activities intended to provide social and literacy opportunities for children, parents, teachers, professionals and friends.

Paid membership includes newsletters sent by email (so be sure to provide yours on the form), and invitations to various seminars and conferences from various other organizations.

If you'd like more information on how to attend the 2018 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



**2018 BROOKFIELD ZOO - IPVI MEMBERS' ONLY OUTING  
Saturday July 21<sup>st</sup> Registration & Payment Form**

Attendance is restricted to current (paid) members of IPVI\*\*. All attendees must pre-register, purchase a 2018 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 which includes parents, their children only, and grandparents. **ANY OTHER FAMILIES OR FRIENDS OF THE PAID MEMBERS MUST HAVE THEIR OWN ZOO REGISTRATION FORM AND IF NOT A PAID MEMBER, MUST JOIN FOR \$20.00.**

Family Last 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)

7) CHILD: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg)

Admission to the "2018 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 (\$20.00/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>	

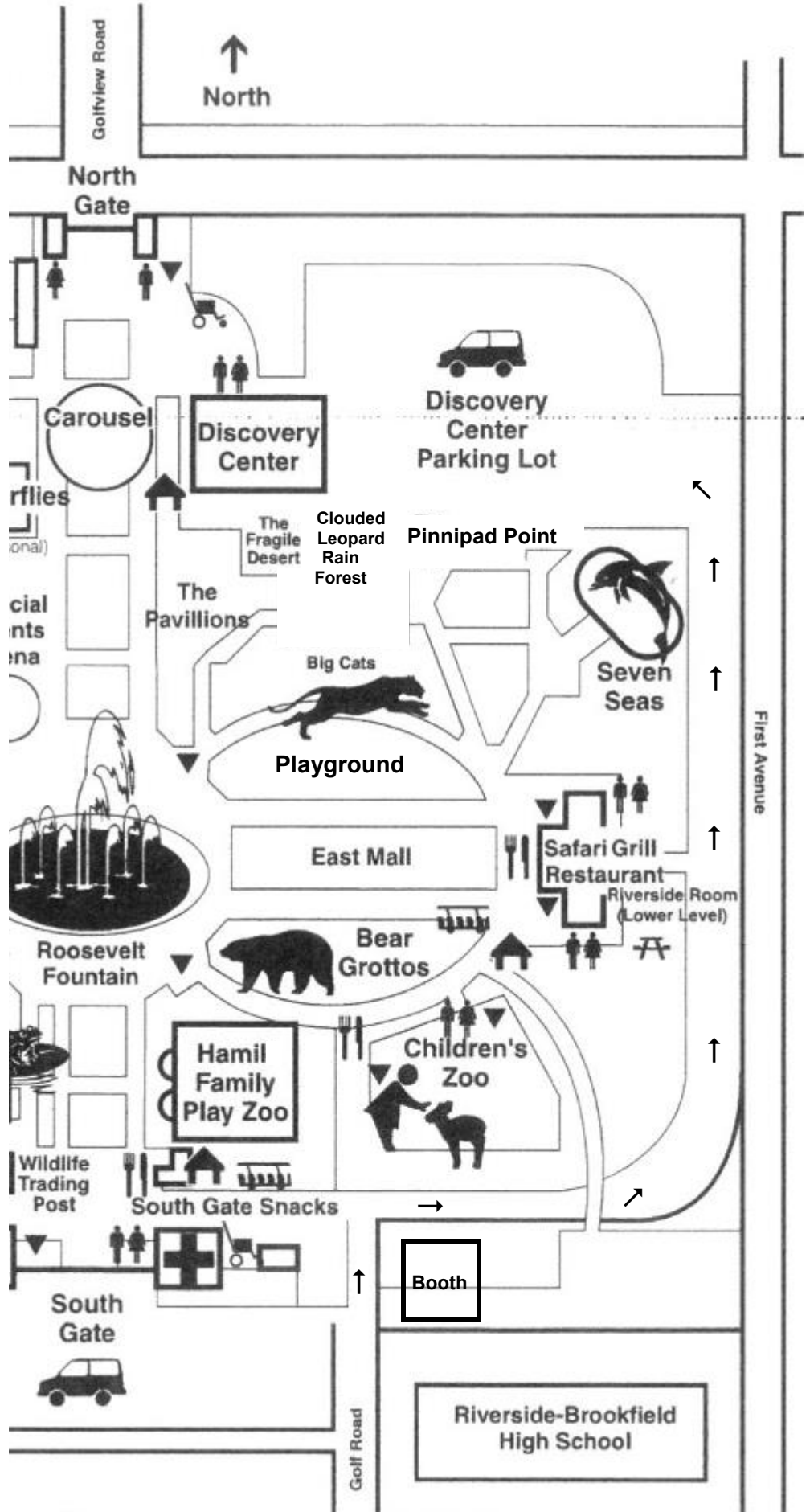
**REGISTRATION CLOSSES ON JUNE 30<sup>th</sup>, 2018**

\*\*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!





**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, June 9, 2018**

**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!!!**





### Plants Get Thirsty Too! How Watering Plants Can Teach New Skills

*By Amber Bobnar*

Spring is in the air and we've already got some seedlings growing in the house for our garden. Ivan helped to plant the seeds and is now helping us water them and keep them in the sun. READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### Gardening With a Blind Child

*By Amber Bobnar*

For those of us who live in parts of the world with seasons, there are really only a few months out of the year where you can go outside and plant a garden... and if you like to plant flowers and vegetables then it's also your best chance to have your children learn about plants, dirt and gardening! READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### Play Haven Keeps Everything on Your Child's Tray

*By Amber Bobnar*

It's a problem for all kids, but probably even more so for kids who are visually impaired or have under developed fine motor skills... READ MORE at: [WonderBaby.org](http://WonderBaby.org)



### 8 Simple Ways to be a Happier Special Needs Mom

*By Catherine Rose*

There are a lot of people telling you that your life is hard and I'm not here to say that they are wrong. Your life is hard. I know, because I am living it too. Being a parent in general is probably one of the most difficult things we do, but when you throw disabilities and special needs into the mix life can sometimes become completely overwhelming. READ MORE at: [WonderBaby.org](http://WonderBaby.org)

development.

“LUXTURNA will be life-changing for people with an inherited retinal disease caused by RPE65 mutations. For them, the treatment means a life of independence. Also important is the momentum this approval provides to other gene-based therapies — for the eye and other diseases — now in the clinic,” says Benjamin Yerxa, PhD, Foundation CEO.

Spark Therapeutics, which holds the biologics license for LUXTURNA and conducted the clinical trials that showed its safety and efficacy, will also manage the treatment rollout. Spark has announced that in order to ensure the treatment is safely administered, it will only be available through a small number of centers of clinical excellence across the country. Spark has also expressed its commitment to educating third-party payers about the value of LUXTURNA and to working to help ensure treatment access to all eligible patients.

Anyone in need of more information about LUXTURNA should contact Spark Therapeutics at 1-833-SPARK-PS (833-772-7577). Another resource for information is Spark’s website: [www.Sparktx.com](http://www.Sparktx.com).



Opportunity Works places young adults in subsidized internships; exposes them to viable careers in manufacturing, transportation, distribution and logistics, and information technology; expands their skill sets; and connects them to the training and resources they need to achieve long-term employment in growing industries.

### Who is Eligible to Apply?

Young adults ages 16-24 from suburban Cook County are eligible. This program targets southern and western suburbs, but will be open to all of suburban

Cook County, offering sector-specific training in these:

- Manufacturing
- Information Technology
- Transportation, Distribution, and Logistics

### How Do I Apply?

- Apply online now:  
[Opportunity Works Youth Application](https://fs21.formsite.com/res/submit)  
<https://fs21.formsite.com/res/submit>
- To learn more call: (312) 603-7092

## May is Declared Ultraviolet (UV) Awareness Month by Prevent Blindness to Educate Public on Harmful UV Effects on Eyes

*National Non-profit Group Provides Free Information on Best Ways to Protect Vision from the Sun*

**CHICAGO (April 30, 2018)** – Prevent Blindness, the nation’s oldest eye health and safety organization, has declared May as Ultraviolet (UV) Awareness Month to help educate the public on the dangers that UV exposure may have on vision. UV damage may cause immediate effects, such as a corneal sunburn (photokeratitis). Long hours on the water, for example, without proper eye protection can cause this problem.

UV damage has been linked to the development of macular degeneration, cataract, pterygium (a growth on the white part of the eye) and cancer. According to the World Health Organization, different forms of eye cancer may be associated with life-long exposure to the sun. Melanoma is the most frequent malignant cancer of the eyeball, and a common location for basal cell carcinoma is on the eyelids.

Adults and children are at risk from UV damage. However, the risk of sun related eye problems is higher for people who:

- ▶ spend long hours in the sun.
- ▶ have certain retina disorders.
- ▶ had cataract surgery (although some artificial lenses do absorb some UV rays)
- ▶ are on certain medicines, such as tetracycline, sulfa drugs, birth control pills, diuretics and tranquilizers that increase the eye's sensitivity to light.

When purchasing sunglasses, Prevent Blindness recommends consumers always read labels carefully and only buy sunglasses that clearly state that they block 99 to 100 percent of UV-A and UV-B rays. Sunglasses should be worn in conjunction with a brimmed hat. Wrap-around sunglasses are best.

For those participating in outdoor sports activities, Prevent Blindness recommends consulting with an eye care professional on eye protection that both blocks UV as well as protects eyes from injury.

“Consistently wearing effective UV eye protection is a habit that we should practice year-round, not just in the warm-weather months. By wearing UV-blocking sunglasses and a visor, we can help protect our vision today and for years to come,” said Jeff Todd, president and CEO of Prevent Blindness.

For more information on the dangers of UV exposure and how to choose the best UV protection, please visit the Prevent Blindness dedicated Web page at

<http://www.preventblindness.org/protect-your-eyes-sun>

or call (800) 331-2020.



The sun releases energy (radiation) in many forms. The

sunlight we see is one form. The heat we feel from the sun is another. Ultraviolet (UV) rays, a third type, are also invisible to the eye. UV rays cause sunburn. They can also damage your eyes and hurt your vision.

### How Can UV Rays Damage Your Eyes?

There are two types of UV rays: UV-A and UV-B. Over time, the effects of UV rays may help cause a number of eye problems. **Learn more at:**

<https://www.preventblindness.org/how-can-uv-rays-damage-your-eyes>

### How To Protect Your Eyes From UV Rays

You can protect your eyes from UV rays in two important ways: Know the dangers of UV rays. Wear proper eye protection and hats that block UV rays. UV rays can come from many directions. They radiate directly from the sun, but they are also reflected from the ground, from water, snow, sand and other bright surfaces. **Learn more at:**

<https://www.preventblindness.org/how-protect-your-eyes-uv-rays-0>

### Who's at Risk From Eye Damage From the Sun?

Yes, everyone (including children) is at risk for eye damage from UV radiation that can lead to vision loss. Any factor that increases the amount of time you spend in the sun will increase your risk. People who work or play in the sun for long periods of time are at the greatest risk.

**Learn more at:**

<https://www.preventblindness.org/whos-risk-eye-damage-sun-0>

### Choosing UV Protection

Sunglasses help you in two important ways. They filter light and they protect your eyes from damaging UV rays. Mounting evidence shows that exposure to UV rays can damage your eyes. Long-term exposure to UV rays can lead to cataracts, macular degeneration or skin cancer around the eyelids. **Learn more at:**

<https://www.preventblindness.org/choosing-uv-protection>

### UV Protection and Eye Safety

When you or your children play outdoor sports or work outside, you should think about both UV protection and proper safety eyewear. **Learn more at:**

<https://www.preventblindness.org/uv-protection-and-eye-safety>



**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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# 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: \$20 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 \$20/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 9         | Chicago Lighthouse & IPVI Families "Play For All" | Chicago           |
| ▶ <b>July 21</b> | <b>2018 IPVI Members' Outing</b>                  | <b>Brookfield</b> |

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

**Newsletter Deadline for  
June 2018 is May 15, 2018**



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

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