

# IPVI INSIGHTS



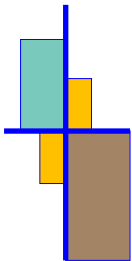
*Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities*

**June 2019**

## IPVI MAY 4TH ANNUAL MEETING

### Agenda with comments

1. Financial Balance  
**Balance \$7,507.54**
2. Change in Federal and State Financial Filing
  - a. New accounting period
  - b. Change in Federal and State Financial Filing/Taxes  
**Our new Filing/Taxes are due in June. Need 2018 Zoo Forms.**
3. Budget  
**Need 2018 IPVI Zoo Outing Forms to complete the Budget.**
4. Volunteering for Board positions  
**None.**
5. Fundraising  
**Mary (Zabelski) and I agreed. We need to determine and Implement Fundraising.**
6. Zoo Outing  
**Mary forwarded the Final copy of the 2019 IPVI Zoo Outing Flyer.**
7. Open Floor (Questions/Ideas)  
**None.**
8. Adjourn  
**Approximately 11:45am**





## Foundation Fighting Blindness National Science Conference Call

Wednesday, May 29th  
3:00-4:00 PM Eastern

The Foundation Fighting Blindness is pleased to invite you to the upcoming National Science Call, our biannual conference call providing a deep dive into the research and clinical trial results that impact the inherited retinal disease community. The goal of this call is to provide scientific updates and answer any questions you may have.

### Foundation Funded Research – The Latest in Clinical Trials

Presented by:  
Ben Shaberman  
Senior Director of Scientific Outreach and Community Engagement  
for Foundation Fighting Blindness

With over 30 clinical trials underway or in the process of being launched, research for inherited retinal degenerative diseases is taking off. Ben Shaberman will share the latest updates on research funded by the Foundation, with a heavy emphasis on those current clinical trials and what they may hold for the future.

There will be a Question and Answer session at the end of the formal remarks. A replay and transcript of the call will also be emailed and available on our website approximately two weeks after the call.

Please register for **National Science Call - Foundation Fighting Blindness** on **May 29, 2019 3:00 PM EDT** at:

<https://attendee.gotowebinar.com/register/8840709403836605196>

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## 2019 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 20, 2019 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.

**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 2019 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



**2019 BROOKFIELD ZOO - IPVI MEMBERS' ONLY OUTING  
Saturday July 20<sup>st</sup> Registration & Payment Form**

Attendance is restricted to current (paid) members of IPVI\*\*. All attendees must pre-register, purchase a 2019 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 "2019 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. Double and Triple extra large shirts available at extra cost of \$1.00/shirt.

|   |  |
|---|--|
| <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>               |  |

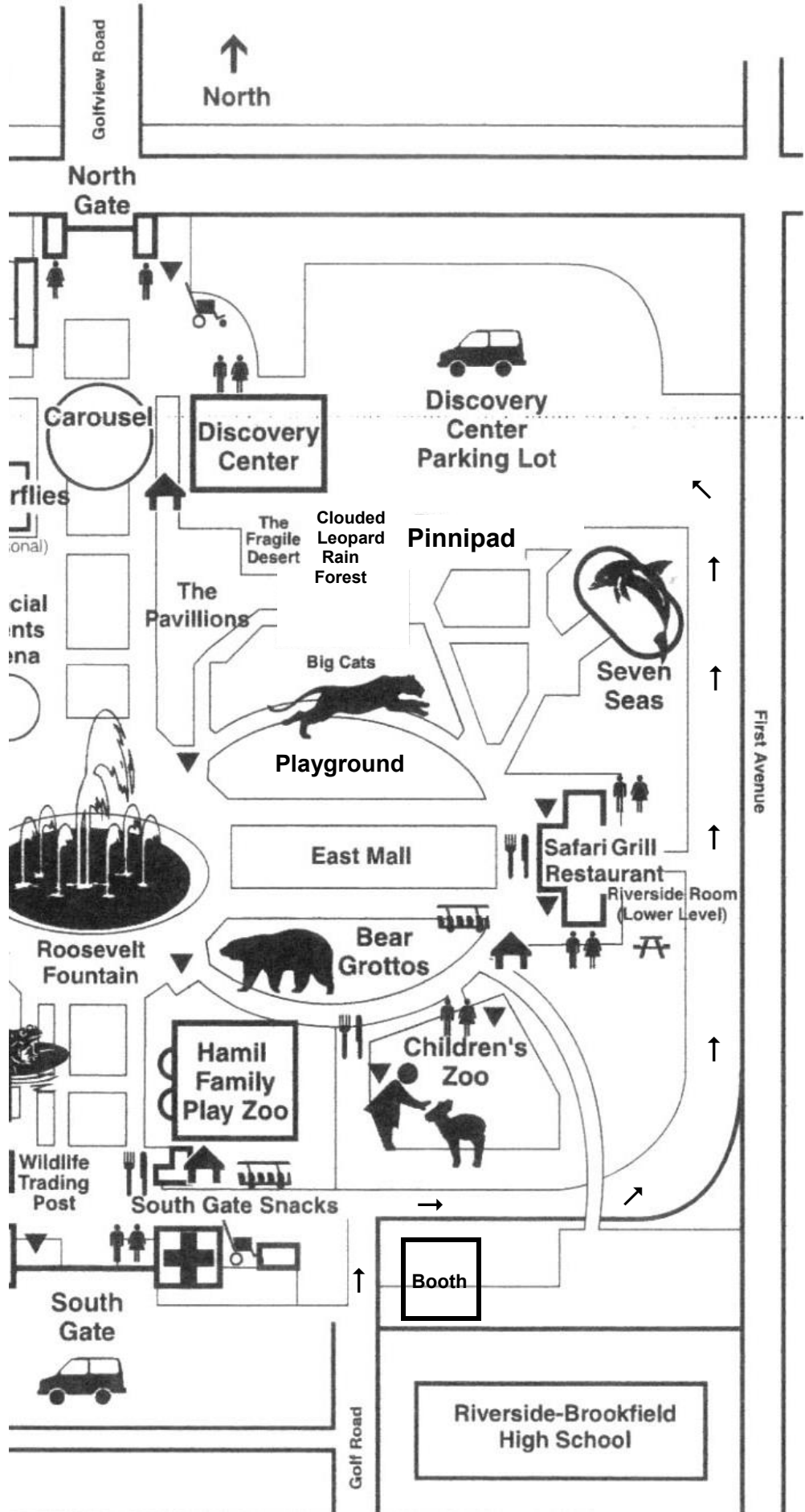
**REGISTRATION CLOSSES ON JUNE 30<sup>th</sup>, 2019**

\*\*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



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!





An important bill has just been re-introduced to the US House of Representatives that has the potential to provide \$1 billion in research funding for blinding eye conditions, including inherited retinal diseases.

Known as Eye Bonds, the bill was introduced last year in July. While your excellent outreach garnered bipartisan support from about two dozen House members – thank you! – the bill needed to be re-introduced with the new Congress, which convened in January 2019. We need to leverage the great momentum we built last year.

To that end, I am asking you again to write or call your member of the House of Representatives to ask him or her to support H.R. 2620, the Faster Treatments and Cures for Eye Diseases Act. Visit [Find Your Representative](https://www.house.gov/representatives/find-your-representative) at <https://www.house.gov/representatives/find-your-representative> to get contact information for your House Member.

If your House Member supported the bill last year, please thank them for being a co-sponsor and ask them to please support the new bill.

If your House Member didn't come on board last year, please reach out again and let them know we need them to get behind this sight-saving legislation.

With the new bill, our lead original co-sponsors are Representatives Sanford Bishop, a Democrat from Georgia's 2nd district, and Cathy McMorris Rodgers, a Republican from Washington's 5<sup>th</sup> district. The other original co-sponsors are: Tom O'Halleran (D-AZ1), Brad Schneider (D-IL10), Steve Cohen (D-TN9), Gus Bilirakis (R-FL12), and Brian Fitzpatrick (R-PA1).

H.R. 2620 creates new financial instruments, Eye Bonds, which will create \$1 billion of new funding specifically designated for treatments and cures of all

causes of blindness and severe vision loss.

This legislation, which has bipartisan support, would significantly increase funding for the translational biomedical research that will speed development of treatments and cures for all eye conditions, including inherited retinal diseases, from the lab bench to all of us, our family and friends.

The Foundation Fighting Blindness has been a driving force for this critical legislation, and your support now can make it become a reality.

In case you missed the news last year, Eye Bonds and the Foundation's Board Director Karen Petrou, the visionary for the legislation, were featured in the Wall Street Journal (WSJ) in an article titled "[The Woman Who Has a Plan for Wall Street to Help Cure Blindness](#)" at

[https://www.facebook.com/FoundationFightingBlindness/posts/10156769426539917?\\_\\_tn\\_\\_=-R](https://www.facebook.com/FoundationFightingBlindness/posts/10156769426539917?__tn__=-R)

(The link provided is to the Foundation's Facebook post of the story.)

This publicity and visibility for Eye Bonds is wonderful and well-deserved, but at the end of the day, we still need support in the House of Representatives, and you are essential to making that happen.

With your help, we can get these projects the funding they need to advance them towards becoming treatments and cures. Please contact your House Member today and ask him or her to support H.R. 2620, the Faster Treatments and Cures for Eye Diseases Act.

Thank you,

Benjamin Yerxa, PhD  
CEO, Foundation Fighting Blindness

PS: Here are suggestions for contacting your House Member:

- Phone calls or e-mails are both good — you will be counted either way.

- Tell him or her your name, contact information, and where you live in the district.
- Ask them to support H.R. 2620, the Faster Treatments and Cures for Eye Diseases Act, and thank them if they supported the earlier version of the bill.
- If you are comfortable doing so, let him or her know what eye disease affects you and your family, and why cures for blindness are so important to you.
- Mention that Eye Bonds has bipartisan support, will not increase the budget, and can be a research-funding model for advancing cures for other diseases like Alzheimer's and Parkinson's diseases.
- Thank him or her for supporting this critical legislation!

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The Foundation Fighting Blindness is proud to announce the launch of their new website!



The design of the new site symbolizes their leadership role in bringing light and hope to people affected by the entire spectrum of retinal degenerative diseases. It also conveys their commitment to shedding light on innovative research to prevent, treat, and cure these challenging retinal conditions.

Explore a brand new world with enhanced accessibility for seamless browsing, a responsive design for the best view on any device, and updated navigation for clear access to the news and resources most relevant to you.

Here are just some of the many enhancements made to make joining the fight easier than ever before:

- Accessibility at the core of the design. With the Accessibility tool you can adjust the text size, contrast, and also use text to speech capability.
- New features such as "Newly Diagnosed" and "Beacons of Hope".
- Updated "Retinal Diseases" pages with up-to-date content.
- Enhanced areas such as "Eye on the Cure Research News," including the latest news from ARVO:

<https://www.fightingblindness.org/research/arvo-2019-gene-therapy-clinical-trial-for-rp-caused-by-rlbp1-mutations-ongoing-in-sweden-19>

- Be sure to stay connected by signing up for email communications and follow our social media pages.

Their website will continue to shed light on groundbreaking research, provide personal stories as beacons of hope, and more. Please take the time to explore their website and return often to learn what's happening in the news, in the lab, and in the community.

Sincerely,  
Benjamin Yerxa, PhD  
Chief Executive Officer

The urgent mission of the Foundation Fighting Blindness is to drive the research that will provide preventions, treatments and cures for people affected by retinitis pigmentosa, age-related macular degeneration, Usher syndrome and the entire spectrum of retinal degenerative diseases. The Foundation is a beacon of hope for those affected by these blinding diseases. Join the fight and help us accelerate our mission. Welcome to the new Foundation site — supported in partnership with Genentech, A Member of the Roche Group.

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**IPVI**

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(Temporary)

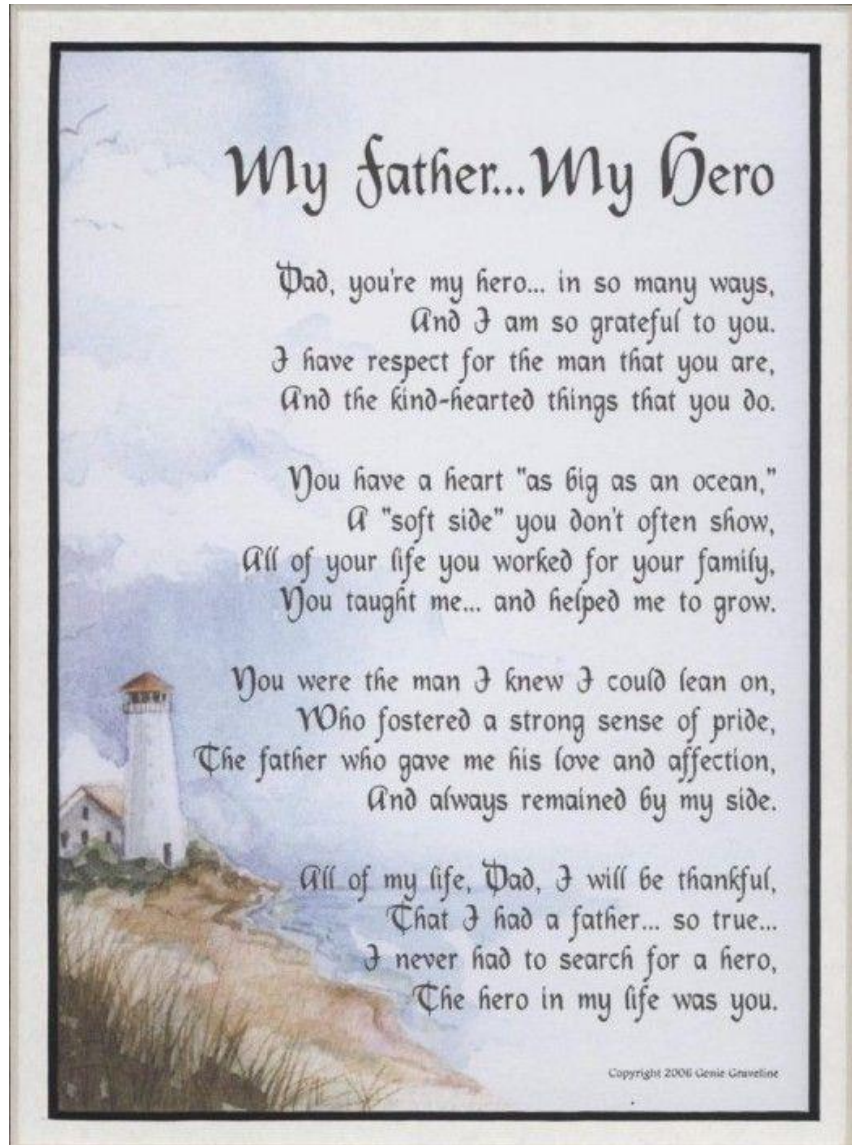
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# Join **IPVI** or renew your membership today!

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.
- Holds fun outings adapted for children with visual impairments at 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: \_\_\_\_\_  
 \_\_\_\_\_

- 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.  
 Donation: \$\_\_\_\_\_ (tax deductible)  
 New Membership       Renewal

Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: (\_\_\_\_\_) - \_\_\_\_\_

Email: \_\_\_\_\_

Please enclose this form along with your payment by check to:  
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**Have questions or need  
 more information?**

**Call us at  
 1-773-882-1331**

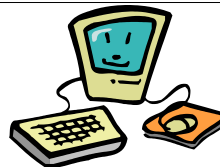
**Illinois Association for Parents of  
Children with Visual Impairments  
P. O. Box 316634  
Chicago, IL 60631**

## **IPVI CALENDAR**

### **2019 IPVI Members' Outing Saturday, July 20, 2019 at Brookfield Zoo**

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

**Newsletter Deadline for  
July 2019 is June 15, 2019**



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

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