

# IPVI INSIGHTS

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

May  
2012



## 2012 11TH ANNUAL MEMBERS ONLY 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, 2012 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 9:30 a.m.; the Zoo opens at 10 a.m.** Tons of activities are available throughout your day! Your IPVI T-Shirt will be your exclusive passport into all the action....parking (south lot), admission to Zoo, pizza lunch, the Great Bears’ Wilderness, the Seven Seas Dolphin Show (with exclusive after show event), Hamill Family Play Zoo, Children's Petting Zoo, etc.



Our speaker at our luncheon at the Discovery Ballroom, will be Bill Jurek, who has been a consultant with The Chicago Lighthouse since March, 2005 and has been working with the Chicagoland Radio Information Service (CRIS) in various capacities, including show host. Most recently, Bill has begun hosting a weekly radio program, The Beacon, which covers topics related to individuals with disabilities as well as issues related to veterans and seniors.

Prior to joining The Lighthouse, Bill spent the last four decades being heard on Chicago radio and television stations. Since 1975, he has been a staff announcer with NBC and has been heard on Channel 5 as well as WMAQ radio during its country music heyday.

Bill’s other radio credits include WGN, WLS, and WIND. In the late 1980’s, he held the fifth highest rating in Chicago for "morning drive" on FM 100. On WLIT radio, he served as community affairs director as well as show host.

In addition to his broadcast work, Bill was also the voice for such clients as Dads Root Beer, Darwin Furniture, Lazyboy Showcase Shops, Fedders Air Conditioners, Serta Bedding, and The Baird and Warner Sunday Morning Home Show, which aired on Channel 7 for several years.

Since losing his vision in 1995, Bill has been a spokesman, advocate, and mentor for blind and visually impaired individuals, particularly those interested in the broadcast field. In addition to working with various organizations serving the blind and visually impaired community, Bill is a graduate field representative for Guiding Eyes For The Blind in Yorktown Heights, NY, one of the premier guide dog schools in the United States from which he has obtained his guide dog.

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Since 1997, Bill has been a guest lecturer for the Taxi and Limousine training program at Harold Washington College in Chicago, as well as Harper College in Palatine, IL and Columbia College Chicago. He has also worked with The Chicago Police Department to produce a training video for cadets and officers concerning the use of guide dogs.

Mr. Jurek has recently been appointed to a two-year term on an FCC (Federal Communications Commission) Video Programming and Emergency Access Advisory Committee (VPEAAC). This is an advisory committee to the FCC that is required by the Twenty-first Century Communications and Video Accessibility Act of 2010.

**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 newsletters and invitations to Parent Rights, Adaptive Technology, and Advocacy seminars.

If you'd like more information on how to attend the 2012 IPVI Zoo Outing, or how to become a member of the "IPVI Family Network", call **Mary Zabelski at the Chicago Lighthouse for the Blind, 312-666-1331 x3675**. The registration form is on page 5.

**PLEASE REGISTER BY JULY 8<sup>th</sup>, 2012**

**Mail Registration Form & your check payable to IPVI to:**

**Mary Zabelski**  
**The Chicago Lighthouse**  
**850 W. Roosevelt Road**  
**Chicago, IL 60608**



## IPVI's 2012 BROOKFIELD ZOO - MEMBERS ONLY OUTING Saturday July 21<sup>st</sup> Registration & Payment Form

Attendance is restricted to currently paid members of IPVI\*\* (check your address). All attendees must pre-register, purchase a 2012 Zoo T-Shirt and show current identification at the Zoo. Attendees may be required to sign Release of Liability & Use of Photographs Form.

Family Name: \_\_\_\_\_ IPVI Current Membership \_\_\_\_\_ (y/n)  
 address: \_\_\_\_\_ city: \_\_\_\_\_ zip code: \_\_\_\_\_  
 e-mail: \_\_\_\_\_ Home #: ( ) \_\_\_\_\_ - \_\_\_\_\_ Cell # ( ) \_\_\_\_\_ - \_\_\_\_\_

1) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 2) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 3) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 4) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 5) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 6) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)  
 7) Name: \_\_\_\_\_ Age: \_\_\_\_\_ T-Shirt: (infant), (small), (med), (large), (X-lg), (XX-lg), (XXX-lg)

The T-Shirt is required & assists Zoo personnel in providing accommodations. Our theme is *“Literacy through Experience at Brookfield Zoo”*.....ask questions, touch the special exhibits, analyze and enjoy the unique sounds, and textures of the Zoo!

Membership Dues (\$15.00/year)		
Total Number of Zoo Admission T-Shirts @ \$9/person		
Donation to IPVI for (IPVI scholarship) or (Zoo costs)		
<b>TOTAL MONEY (included with this form) payable to IPVI</b>		

### REGISTRATION CLOSSES ON JULY 8<sup>th</sup>, 2012

\*\*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.



# IPVI's Matthew Benedict Juskie Scholarship Fund

For students who are blind or visually impaired

Any individual intending to continue his/her education at a college, university or trade school and is interested in being considered for the MBSJF, must meet the following criteria: Illinois resident, blind or visually impaired, undergraduate or graduate student, and an IPVI member.

The candidate's application is processed free of charge. The student must mail or fax a written request to receive a copy of the application from IPVI. Then the student must complete the MBSJF Application Form, provide 3 completed Reference Forms, submit medical records or a letter from the vision specialist confirming the condition, and mail them to IPVI. The applicant may attach a 1-page resume of clubs, offices held, or any other pertinent information concerning his/her activity record.

The IPVI Board of Directors will review all scholarship applications and select the winners. IPVI reserves the right to announce such awards in its newsletters and marketing materials.

The MBSJF is funded completely from tax-deductible donations from individuals, companies and corporations who support IPVI's goals. Any individuals or groups wishing to donate to this fund, please forward your tax-deductible donations to IPVI. Thank you for your continued support of IPVI.



**To request a scholarship application, please contact the Scholarship Program Coordinator, Vicki Juskie at: 815-464-6162 or [vajuskie@aol.com](mailto:vajuskie@aol.com)**



Experience the invasion of Xtreme BUGS, presented by Dominick's, at Brookfield Zoo beginning Saturday, May 19, and continuing all summer long through September 7. The temporary exhibit of epic proportions will feature everything from Xtra-large animatronic bugs, including a 16-foot-high by 33-foot-long Japanese hornet displayed in the zoo's Roosevelt Fountain, to Xtra-small live insects as part of Harry's Big Adventure: My Bug World! presented by Terminix. The state-of-the-art animatronics were created exclusively for Brookfield Zoo, which is where they will be seen for the first time ever!

"Bugs are a major influence in our history because of their extreme effect on the environment, economics, food, medicine, and pop culture," said Andre Copeland, interpretive programs manager for the Chicago Zoological Society. "This entertaining and educational experience will offer our guests an opportunity to imagine living with gigantic bugs while exploring some of the connections between humans and the small animals that carry the weight of the world on their shells."

Xtreme BUGS will take zoo-goers along a winding trail where they will be able to view more than 20 oversized animatronic bugs, from a fluttering monarch butterfly and ladybug to a praying mantis and a giant Madagascar hissing cockroach. Additionally, there will be nearly 130 larger-than-life stationary insects and flora, some grouped in themed action scenes, including bees pollinating, spiders hunting, ants feasting upon a scorpion, and cicadas hatching.

Along the trail, there will be interactive signs and graphics illustrating amazing facts about some of the smallest creatures. Also, junior entomologists can unearth a variety of replica bugs in JULIE, Inc.'s interactive dig box. Kids will also have fun exploring, crawling, climbing, and sliding down the 10-foot by 20-foot spider web climber. And, throughout the summer, guests can discover bugs' importance during Cultural Connections, featuring Zoo Chats, craft activities, and special entertainment.

Cultural Connections is sponsored by the Sara Lee Foundation.

In Harry's Big Adventure: My Bug World!, guests will have an opportunity to see live creepy-crawlies. The exhibit, located in a 5,000-square-foot tent along the Xtreme BUGS pathway, will immerse guests in the world of bugs, taking them on a journey through the habitats of some of the smallest—yet most important—critters. The interactive habitats feature several ecosystems, such as a cropland, forest, meadow, and swamp, as well as a home scene, to show how insects impact their surroundings, the environment, and human lives. Guests will be able to view live bugs such as water beetles, cockroaches, millipedes, crawfish, ants, emperor scorpions, and a praying mantis.

Young insect fans can pretend to be bug detectives and conduct their own pest inspection, take audio and visual trips into the world of bugs, and even take a photo with a 3D praying mantis named Harry through augmented reality technology.

Special programming will give guests more of a chance to see, touch, and even taste some fascinating bugs. There will be roach races featuring Madagascar giant hissing cockroaches; a bug petting zoo that offers guests up-close opportunities to touch such critters like a giant millipede, Chilean rose-haired tarantula, and vinegaroon; and a chef cooking up some tummy-tickling treats that feature bugs as the main ingredients. (Roach races and bug cooking demonstrations will take place on weekends only.)

As guests exit Xtreme BUGS, they will encounter a gigantic ant farm exhibit, presented by Wells Fargo. The approximately 5,000 harvester ants that live in the 8-foot-wide by 4-foot-high ant farm can be seen digging tunnels.

There is also an Xtreme BUGS call center. Those who have a bug-related myth, rumor, or questionable fact, can call (708) 688-8722, leave their question, and the bug gurus at Brookfield Zoo will expose the Xtreme truth of the matter. Guests can call back periodically to get a variety of debugged messages.

Xtreme BUGS is \$5 for adults and \$3 for children 3-11 and seniors over 65 (half price for Brookfield Zoo members) Children 2 and under are free.



**MS. VIC'S VOLLEYS**  
*Victoria Juskie, IPVI Treasurer*

**VOLLEY I**

Since our last publication, we welcome the following families, individuals, and/or organizations who became members:

No new members have joined during this period.

**VOLLEY II**

We have been asked a few times over the years to help facilitate pen pals. We have another request. There is a 12-year old girl with glaucoma who would like a pen pal. If you are interested, please contact Vicki Juskie at [vajuskie@aol.com](mailto:vajuskie@aol.com) or 815-464-6162 for the address.

**VOLLEY III**

Bonnie Tyler's song – "I Need a Hero" quotes:

"... I need a hero.  
I'm holding out for a hero 'til the end of the night.  
He's got to be strong, and he's got to be fast,  
and  
He's got to be fresh from the fight.  
I need a hero.  
I'm holding out for a hero 'til the morning light.  
He's got to be sure, and it's got to be fast, and  
He's got to be larger than life..."

Who are our heroes to emulate nowadays? Growing up I had Superman, Wonder Woman, Bionic Man, Bionic Woman, and even David Carradine's character Kwai Chang Caine in the Kung Fu television series. (Yeah, I know, I am really dating myself with these.) They all taught us something of value.

What I see on television today though are

**SHARING THE VISION,  
PARENT TO PARENT**

Let's have a dialogue. Do you have a question? One of us may have an answer or at least a suggestion. Submit questions and responses for the IPVI Newsletter to Pam Stern, NAPVI Region 3 Representative:

[pamstern3@gmail.com](mailto:pamstern3@gmail.com)

**MAY QUESTION**

**What are the most important factors in developing/maintaining a beneficial working relationship between professionals and parents?**

Parent/VI professional:

When it seems like professionals don't understand, remember how you felt about not knowing what to do. As a parent with a new baby, you're also new to the professional; be patient as communication develops.

--

Parent of an older child:

Say "thank you" when things are going well; celebrate success. Try phrasing, "how can we do things better or differently," instead of, "this is wrong."

--

Professional:

- Acknowledge that you're not going to be happy with what is said all of the time.
- Prioritize, know your task and stay on task until completed.
- Use a scribe to take notes in meetings.
- Know the facts (laws).
- Don't think that being nice is going to get you what you need.

*(Continued on page 10)*

shows like Family Guy and the Simpsons that have become popular. I shake my head and ask "How can children learn any type of family values with trash like this?" Laughing at morals and wholesome family values or screaming at your parents all foul-mouthed and inanely. Let's not get me started.

I have also found that other than few family movies, it's almost impossible to have our children watch a movie on TV. The proliferation of swearing, nudity or innuendo regarding sex abound on almost all but a few channels. Other than removing the TV from the house altogether, what does a parent do? I have found limiting access and adding parental controls is helpful. However, eliminating TV access altogether is only used as a punishment. Also, for each show, other than those on the Disney Channel, we have trained our children to ask permission to watch because, as I alluded to above, you can't even trust cartoons any more.

Anyway, recently, I saw the Captain America movie. I thoroughly enjoyed it because even though the premise was unrealistic, the thought behind it was not. It's that we all need heroes who teach us morals and to do the right thing in our lives. Lately, I have been looking for and finding these types of heroes in lots of places. Besides the obvious ones such as the police, fire fighters, and armed forces personnel defending our country, who I thank wholeheartedly for their dedication to duty, the heroes I speak of today and want to thank are the doctors who help our children; the teachers who show us how to instruct them during the birth-to-three age range and thereon; the sports, music and Braille coaches our kids have had the luck to know; and the countless others who give them positive reinforcement, including family, friends and other loved ones.

They say it takes a village to raise a child. When your child has special needs, you may have to expand your village to include vision

specialists, fine and gross motor skill therapists, mobility instructors, and various others who help medically and therapeutically assist your child.

These daily heroes in our lives help us find our way through the complicated mess we find ourselves immersed in when our child is diagnosed with a vision impairment or other ailment. First we feel so lost because all of a sudden we are thrust into an unknown world with lots of questions, fears, and frustrations. Why my child? Why our family? Vision impairments are low incident occurrences. How come we won this lottery? Those answers may never be available. We must learn to accept this and go on.

The biggest thing I have learned from all of this is that it is **not** the end of the world. Life does go on, albeit with more challenges. You must realize that humans are amazingly adaptive. We have the unique quality of being able to cope with adversity in a variety of ways. We find ways to enjoy the good things our lives offer, not just concentrating on the crappy stuff (pardon my explicitness) by learning to laugh at things again; smiling at the accomplishments our children attain -- even though they may have taken longer than typically; and overall, realizing we can't control everything in life, vision loss or no.

Remember, too, that we parents are heroes to our children. We love them, mold them, and teach them about life. How we respond to adversity is how they will learn to respond. Even when you're not feeling it, be positive in front of your child. Help him or her to become as independent and accomplished as possible. God works in mysterious ways and, until we meet our Maker, we may not understand why He chose this path for us.

So my tip of the day is to remember my spin on this paraphrased old Indian proverb,

*“Walk a mile in another man’s moccasins and you’ll gladly come back yours and feeling better about them.”*

Enjoy the here and now with your child. Love them completely even though this affliction hurts and makes them different. You see, the thing I’ve found after my first half century of life is that nearly everyone is different in some way or another. There are few who go through life unscathed by something. It’s just not as obvious when it’s on the inside. So don’t forget, you’re okay and so is your child just the way you both are, and it just doesn’t get any better than that. God Bless.



## ASK M@



Hey, everyone, I hope all are doing well. Some crazy weather, isn't it? Anyway, this month I would really like to talk to you about how it is so important to keep a positive mental attitude, as I call it, because the way you must think is that it could always be worse.

I have found this to be true by actually taking driving lessons at Marianjoy Rehabilitation Hospital. I take required lessons there due to my bioptics\* used while driving. I also will try to keep this short, using less words than it could be. (We all know how I can ramble on.)

Now at this hospital, they teach anyone with any type disability to drive, whether this requires special hand controls or any other adaptive device along this line. Basically eve-

ry time I set foot into one of their cars that is equipped with hand controls, I feel blessed that I am able to drive the traditional way. But this statement can be used the other way as well, such as, if you needed the hand controls, then you could feel blessed that you don't need bioptics to drive. This is just one of many instances that can be reversed.

Now, the second manner that I feel this way is when I am sitting there waiting for the instructor. I see people of all ages coming in and out with so many diverse disabilities. It is just very sad to think that every one of them has to deal with something and cope with it. Basically, the main idea I am trying to convey to you is that whenever you may be feeling down due to your eye issue, just think about all the possibilities on how it could be worse. I really like to think of it as, "Man, I am so lucky, I have the ability to walk, move, and have that sense of independence." This then makes me think of how it could be "worse," at least how we think of it.

So, instead of a quote this time, I would rather send you off with a thought/call to action. Remember, sometimes life gets hard, and as we all know, it is not fair; but you must keep a positive mental attitude. When that time comes along and you get down on yourself, just be thankful for what you do have.

I really hope everyone is able to go ahead and do this, and until next time, SO LONG! M@

*(Editor's note: Bioptics are where a telescopic lens is attached to a regular pair of glasses, and this can improve low vision in some sufficiently to allow them to drive. The Chicago Lighthouse for the Blind as well as Spectrios and other low vision practitioners offer these types of lenses.)*







The Chicago Lighthouse North is pleased to offer

## Fit and Fun Family Night

Monday, May 21, 2012, from 6:30 to 8:00 pm  
at 222 Waukegan Road, Glenview



Come and hear about how The Chicago Lighthouse has partnered with GLASA (Great Lakes Adaptive Sports Association) and Adaptive Adventures to provide kayaking, tandem cycling, track and field, sailing, waterskiing and more. Enjoy a hands-on kayak experience and learn more about the summer activity schedule.

To RSVP,  
call or email

Pam Stern, Manager of Youth Programs,  
at (847) 510-2054 or

[pam.stern@chicagolighthouse.org](mailto:pam.stern@chicagolighthouse.org)

by Thursday, May 17, 2012

(Continued from page 6) - Sharing the Vision, Parent to Parent

- The relationship is ongoing.
- Both parents should attend meetings.
- Be happy with small gains.
- Share with duties.

--

Parent/VI professional:

- Open-mindedness of all parties.
- Open communication; no holding back.
- Refrain from being "high and mighty" "know-it-all" and "talking down."
- Avoid threatening the utilization of a chain of command; districts will become intimidated in this long-term relationship.

--

Parent:

- Openness on both sides; avoid close-mindedness.
- Know my child first before deciding what's best.

--

Parent:

- Be honest. Be specific about when something will happen, i.e., skill-development, a service.
- Don't delay. The ophthalmologist needs to learn the importance of Early Intervention; don't delay until school age.

--

Professional:

Remember that you're equal partners. Don't assume that you know more. Don't make unreasonable demands. Talk about the child's uniqueness and individual needs. Mutually agree on what's best for the child.

--

Professional:

Trust and respect, allow reciprocal, good communication.

--

Professional:

Keep up-to-date with family concerns (said to other professionals) Give them (the family) other resources. Trust and honest communication are first and foremost; you don't have to personally like each other. Be reliable and follow-through; don't schedule and cancel. Apologize for coming to a meeting late.

--

Parent/ VI Professional:

Parents must genuinely love their child and see beyond the disability.

--

Professional:

Have frequent contact with each other. Thank professionals for the good things that happen.

### **JUNE QUESTION**

**Which of the following Expanded Core Curriculum components do you feel your child could use the most help with?**



**Newsletter entries will be published maintaining the anonymity of all unless otherwise approved.**

SAVE THE DATE JUNE 14, 2012



11TH ANNUAL  
**ARTISTRY OF WINE**

perfect pairings  
food & wine tasting

BENEFITTING THE  
FOUNDATION FIGHTING BLINDNESS

Please Join the Foundation Fighting Blindness for the

**11th Annual Artistry of Wine - Perfect Pairings**  
Food & Wine Tasting

Thursday, June 14, 2012  
6:30 – 9:30 p.m.

Green Acres Country Club  
916 Dundee Road  
Northbrook, IL

Sample delicious signature dishes prepared by Chicagoland's premier chefs and perfectly paired with a selection of wine and spirits. We also invite you to participate in our silent auction, featuring items from our generous local and national in-kind supporters.

Participating Restaurants Include:

Bridie McKenna's  
Francesca's North  
Whole Foods Market  
Wildfire  
Carnivale  
Bluegrass Restaurant  
M  
Cake Bite Girl  
The Cooking Chicks Chicago

For sponsorship information, tickets or additional event information, please contact Kristi Snuttjer at (847) 680-0100 or [KSnuttjer@fightblindness.org](mailto:KSnuttjer@fightblindness.org).

CONFERENCES

# VISIONS2012

THE NATIONAL CONFERENCE OF THE FOUNDATION FIGHTING BLINDNESS  
JUNE 28 - JULY 1, 2012 | HYATT REGENCY MINNEAPOLIS, MN

The conference will feature valuable sessions geared specifically toward individuals affected by retinal degenerative diseases. Science and information sessions will focus on the latest advancements in research, new and exciting treatment options, current and upcoming clinical trials, and practical skills for living and coping with vision loss. In addition, you will have the chance to ask some of the world's best retinal researchers and clinicians your own questions in "The Doctor Is In" sessions.

VISIONS 2012 also offers you the opportunity to meet and network with individuals from around the country, and even the world, who are affected by similar diseases. And you can discover the latest low vision products, services and resources from the vendors in our Exhibit Hall.

### What's New in 2012

Since VISIONS is all about you, our guests, we've added some features based on past attendee feedback. Here's what's new in 2012:

- Extended Exhibit Hall Hours
- Beginner & Advanced Level Research Sessions
- Sessions for Adolescents & Young Adults
- More Networking Sessions
- Closing Research Session on Sunday Morning
- Mall of America Bus Trip

Learn more about these exciting new features on the [VISIONS 2012](http://VISIONS2012) website and in our future e-blasts! [www.FightBlindness.org](http://www.FightBlindness.org)



July 27-29, 2012, Boston, MA

An international conference covering all aspects of raising a child with a visual impairment, the 2012 Families Connecting with Families Conference will include:

- Interactive sessions and panel discussions to address parents' most pressing interests
- Networking with other families and professionals
- FREE daycare program for children, and activities designed especially for teens
- Fun for the whole family with special receptions and events

The opening general session for the conference begins on July 27, Friday early evening and ends at noon on Sunday, July 29. The NAPVI Board will also be hosting a parent leadership seminar for NAPVI Affiliate parent leaders on Friday during the day, July 27.

The 2012 Conference will be held at:

Boston Marriott Newton, 2345 Commonwealth Avenue, Newton, Massachusetts 02466

This beautiful hotel is also an ideal family vacation destination, featuring special discounted hotel rates for the Families Connecting with Families Conference.

Contact NAPVI, [www.familyconnect.org](http://www.familyconnect.org)

Pam Stern  
Region 3 Representative  
NAPVI  
847-433-0809  
[pamstern3@gmail.com](mailto:pamstern3@gmail.com)

WORKSHOPS

FRCD MAY 2012 WORKSHOPS

Sessions

(10:00 AM-1:00 PM)

20 E. Jackson Blvd. Room 300  
Chicago, IL 60604

Phone Trainings

- 5/22 Accessible Instructional Materials (AIM/Assistive Technology)
- 5/29 Effective Parent Advocacy

(For your convenience we are holding 1 hour training sessions over the phone)  
(12:00 Noon-1:00 PM)

Sessions

(10:00 AM-1:00 PM)

20 E. Jackson Blvd. Room 300  
Chicago, IL 60604

- 5/28 Transition to Post Secondary to Transition with Autism Society of Illinois

You must register in advance in order to get your materials in the mail.

Please call us at 312-939-3513  
or  
You may register online at:

[www.frcd.org](http://www.frcd.org)

To view the training calendar go to [www.frcd.org](http://www.frcd.org) and click on Events/Training-Upcoming Events. To register for FRCD's Upcoming Trainings, contact us by phone at 312-939-3513, Monday-Friday, 9am-5pm, or drop us an email at [info@frcd.org](mailto:info@frcd.org).



The Chicago Lighthouse Vision Rehabilitation Center welcomes Dr. Cary Supalo Ph.D. Inorganic Chemistry, Penn State University

Saturday, June 9, 12:30pm-4:30pm — FREE

RSVP required. Please call Pam Stern at 847-510-2054



*"My experience with developing these access technologies has taught me that blindness need not be a barrier in the pursuit of one's ambitions to achieve whatever goals he or she aspires to achieve."*

Founder of Independence Science, Cary Supalo Ph.D. is developing access technology to empower a new vision for students with visual impairments in the science laboratory. Since his research at Penn State University and the ILSAB (Independent Laboratory Access for the Blind) project, he has assembled the Talking LabQuest and Talking Logger Pro Lab Solutions that are breaking down barriers in science education for the blind. His research works to increase student confidence and comfort with science procedures, field studies, and lab experiments. Research shows a hands-on learning environment is necessary for greater concept development and interest in academic material.

**Please join Dr. Supalo at this workshop to learn cutting edge techniques and methods for teaching STEM fields of study to students with visual impairments.**  
Learn more at [www.IndependenceScience.com](http://www.IndependenceScience.com)

SPORTS

**The Chicago Lighthouse & Great Lakes Adaptive Sports Association**



Summer is coming, and that means fitness and fun in the sun!

- WHAT:** Kayaking and Tandem Cycling  
**WHERE:** Skokie Lagoon  
**WHEN:**  
6/19: Kayaking 3pm-4pm  
Tandem Cycling 5pm-7pm  
7/24: Kayaking 3pm-4pm  
Tandem Cycling 5pm-7pm  
8/21: Kayaking 2pm-3pm  
Tandem Cycling 5pm-7pm  
**COST:** \$6 Kayaking, \$8 Tandem Cycling  
\$12 for both  
**WHO:** Middle School and High School Students



USABA Announces New Sponsor Vanda Pharmaceuticals and 24Sleepwake.com . USABA is proud to announce our newest sponsor Vanda Pharmaceuticals and 24Sleepwake.com which are conducting an awareness campaign for a sleep-wake disorder commonly experienced by people who are blind.

If you or know someone who is totally blind and suffers from irregular sleep patterns, we want to hear from you. Vanda Pharmaceuticals is conducting a study that is evaluating an investigational treatment. The study does not require any overnight stay in a lab and participants are compensated for their time and travel expenses. For more information on the clinical trials and to complete a survey to better understand the condition and determine if you may be eligible to participate, call 1-888-389-7033, Email [info@non24registry.com](mailto:info@non24registry.com) or visit [www.non24registry.com](http://www.non24registry.com).

**Inability to Maintain a Good Night's Sleep May be a Sign of an Under-Recognized Circadian Disorder**

More than 50 percent of individuals who are totally blind may suffer from an under-recognized condition which prevents them from maintaining a regular sleep pattern; impacting their health, lifestyle and relationships.

Known as Non-24-Hour Sleep-Wake Disorder (Non-24-Hour), the condition can push the timing of an individual's body clock off the 24-hour clock, making them unable to maintain a regular schedule of sleep and wakefulness. Those with the condition may experience bouts of severe insomnia, sleep deprivation and excessive daytime sleepiness during the day, all on an irregular and rolling basis.

"Sometimes I fall asleep and stay asleep,"

says Dan Roy, a Braille translator for Horizons for the Blind in Des Plaines, Illinois who is congenitally blind and has experienced recurring bouts of troubled sleep and daytime fatigue since childhood. "Other times I wake up after a few hours and can't get back to sleep." At work, Roy adds that he must "...try to fight through my sleepiness" in order to maintain productivity.

### **What is the Cause?**

For individuals with no light perception, the lack of cues for daylight can cause the sleep cycle, one of many circadian biological rhythms, to be out of synch from the 24-hour clock, gradually shifting their body's perception of when it is day versus when it is night over the course of weeks and months.

Extensive research is underway to learn more about the cause and possible treatment of the condition. One organization, Vanda Pharmaceuticals, is conducting a series of nationwide clinical trials of people with total blindness. These studies continue to recruit eligible participants and Vanda has screened more than 1,400 individuals for potential participation to date. Recently reported results from one of the trials demonstrated the ability to reset the body clock and align it to a constant 24-hour day in people with Non-24-Hour who are totally blind.

### **What is the Impact?**

For some totally blind individuals the condition can have significant impact on their social and occupational lives. "You can be in the middle of a sentence and fall asleep for 30 seconds or so just because your body needs that time so badly because it's not sleeping at night," says Mindy Jacobsen of Brooklyn, New York, who lost total light perception 15 years ago and began experiencing symptoms of Non-24-Hour almost immediately. The unpredictability of Mindy's sleep pattern forced her out of full time employment, though she now

maintains several part time jobs.

### **What can I do if I have these Symptoms?**

If you are experiencing an irregular sleep pattern you can reach out to your primary care physician and ask whether the symptoms are an indication of Non-24-Hour. They may recommend a referral to a sleep specialist for further information. Maintaining a sleep diary to include timing, duration and quality of sleep, as well as a record of consumption of caffeine, alcohol and other medications may help guide your conversations with a physician.

Totally blind individuals experiencing symptoms of Non-24-Hour may also be a candidate to participate in the clinical trials led by Vanda Pharmaceuticals. The studies are evaluating an investigational treatment and do not require any overnight stay in a lab and participants are compensated for their time and travel expenses. For more information on the clinical trials and to complete a survey to better understand the condition and determine if you may be eligible to participate, call 1-888-389-7033, Email [info@non24registry.com](mailto:info@non24registry.com) or visit [www.non24registry.com](http://www.non24registry.com).

## HADLEY SCHOOL FOR THE BLIND

### **Hadley Family Education Courses Now Available on eReaders**

The Hadley School for the Blind now offers three courses in its Family Education Program in a new medium—eBook. Upon enrollment, students will receive a link to the download page, where they can select a format appropriate for their eBook reader. Hadley eBook courses are compatible with Amazon Kindle, Barnes and Noble Nook, Sony Reader, iBooks app for iPhone/iPod/iPad, and any other eBook reader that accepts ePub or MobiPocket file formats.

## Illinois Association for Parents of Children with Visual Impairments

The courses include You, Your Child and Your Community, Beginning the Special Education Journey and How to Be Your Child's Advocate. Hadley's Family Education courses are offered tuition-free to parents or grandparents of a blind or severely visually impaired child as well as spouses, adult daughters or sons, or adult siblings of a blind or severely visually impaired adult. The eBook format is especially convenient for busy parents on the go.

Hadley has provided tuition-free distance education courses to its blind and visually impaired students and their families and affordable tuition courses to blindness professionals since 1920. Since 2002, the school has offered online courses.

"We have now been offering online courses for ten years. As we pass this important milestone, we move into the next phase of online education—mobile learning, or mLearning—which offers students the ability to complete coursework from their mobile devices, thus enabling them to on the go, on demand. I am excited to on the cutting edge of this important trend in technology and distance education," says Hadley President Chuck Young. For more information about Hadley's courses available on eReaders or the school's mLearning initiative, please visit [www.hadley.edu](http://www.hadley.edu).

For more information, visit [www.hadley.edu](http://www.hadley.edu) or call 800-323-4238.



### MISCELLANEOUS



### CHICAGO CHAPTER ANNOUNCEMENT

Come and share your thoughts, experiences,

and advice with those affected, family members, and friends. Also, learn about the **Foundation Fighting Blindness'** great research and upcoming activities. Join us for a Coffee Social in one of the following Chicagoland locations:

#### **Frankfort/Orland Park**

Wednesday, May 30<sup>th</sup>

2:00 p.m. - 4:00 p.m.

Panera Bread

11069 West Lincoln Highway

Frankfort, IL 60423



### **Brand New ONYX PORTABLE/ VIDEO MAGNIFIER W/ CAMERA**

Easy to use & delivers magnification in 3 distinct viewing modes, distance view, document view & mirror- image self-view.

Includes a 19 inch flat panel monitor which has a camera mounted to it that rotates 360 degrees as well as the unique telescopic arm allowing the ability to look in any direction for ultimate flexibility. It also comes with a durable carrying case on wheels which makes it easy & convenient for transporting.

So if you want to make seeing printed type, pictures, handwriting or just small details easier, then this device is exactly what you need! If you are interested, please feel free to contact Michelle @ 630-460-3747.



# BRIDGES: Illinois Early Intervention Vision AND Hearing



June 25 and 26, 2012  
ISU Alumni Center, Normal

Fax or email registration to Amber Gaddis  
[Amber.gaddis@illinois.gov](mailto:Amber.gaddis@illinois.gov) or Fax 217-479-4328

Name:

---

Address:

---

Email:

---

Cell Phone:

---

Dates Attending:

---

ADA Accommodations:

---

CPDU and EI Credit

## Registration:

FREE! Max 100

[www.morgan.k12.il.us/isd/hveio](http://www.morgan.k12.il.us/isd/hveio)

Register separately for both days!

## Sponsors:

ISU EI Graduate Certificate Program,  
Hearing and Vision Early Intervention  
Outreach, Philip Rock Center Project  
Reach, DSCC

Announcing a combined summer event for Early Intervention professionals in BOTH hearing and vision! (*Note: There will not be a separate DTV Summer Mini Camp*).

## Invited from Early Intervention:

- DTH's and Deaf Mentors
- DTV's and DTO&M's
- Individuals working on EI credential in any of above disciplines
- Designated Service Coordinators

**Keynote June 25:** Kevin O'Connor, CSP  
Getting Ready for the Next Right Step

**Special Guests:** Illinois EI Training Team

## Sessions:

Baby Brain

Adult Learning Styles

Bag Free Therapy

BAHA technology/Unilateral Hearing Loss/ Atresia,

Dr. Machinski/ Ask the Optometrist

HV/EIO and DSCC Update

Session Plans and Planning

## Round Tables Discussions

Box Lunches Available



**June 25 — 26, 2012**

## **Parent-Infant Institute**

at the  
Illinois School for the Visually Impaired

The dead line for applications to the 29th Annual ISVI Parent Infant Institute: Opening Doors is May 15th!! We already have 16 families registered and can accept 14 more! Please continue talking to your families about this. If any of them needs assistance completing the application, please encourage them to contact myself or Janet McGovern.

- 1) Each family will have a Developmental Therapist Vision (DTV) assigned to them throughout institute as their "go to" person. That DTV will call them in before, and again afterwards, to make sure all of their questions are addressed. Over 80 staff will on hand to ensure that this event runs smoothly for your families. The attached letter to parents lists the many topics that will be addressed through informational sessions for the parents. Evaluation teams will be present to provide optional O&M and Functional Vision evaluations. We have exciting keynote/featured speakers lined up!!
- 2) We are aware of a few families who need transportation because they don't have a car. When we are aware of this situation, we may be able to provide or arrange transportation for them using vans and drivers from ISVI. En-

courage them to talk to us if they need assistance. Each family will also receive a modest check to assist them with some of their travel expenses. Registration, housing and meals are all FREE! Siblings up to age 5 are welcome to attend (but must be registered!).

- 3) Dr. Michael Zost is doing two sessions. One is an informational presentation, the other is in a "ask the doctor" format. Parents can get their questions answered!
- 4) Besides the keynotes (see attached), we are also bringing in Nancy Birkenmeier, Sleep Specialist with the St. Luke's Sleep Medicine and Research Center in St. Louis. This was a topic that many parents have been requesting!

Gail Olson, Coordinator  
Hearing and Vision Early Intervention Outreach  
Illinois School for the Deaf  
125 Webster Avenue  
Jacksonville, Illinois 62650

Phone: 217-479-4320

Fax: 217-479-4328

Email: [gail.olson@illinois.gov](mailto:gail.olson@illinois.gov)

URL: [www.morgan.k12.il.us/isd/hveio](http://www.morgan.k12.il.us/isd/hveio)

Facebook search: Hearing and Vision Early Intervention Outreach

[http://www.facebook.com/pages/  
Hearing-and-Vision-Early-Intervention  
Outreach/128802893816523](http://www.facebook.com/pages/Hearing-and-Vision-Early-Intervention-Outreach/128802893816523)





**The Foundation Fighting Blindness'  
7th Annual Chicagoland VisionWalk**

**Sunday, June 10, 2012**

We hope you can join us for this free event to kick off our 7th Annual VisionWalk.

**Who:** All Team Captains, individual walkers, their friends, family and colleagues. We would also like to welcome anyone who has not participated previously and wants to learn more about the event.

**What:** VisionWalk will take place on Sunday, June 10, 2012, at Busse Woods in Elk Grove Village, IL.

**Why:** More than 10 million Americans are affected by blinding retinal diseases, such as macular degeneration, retinitis pigmentosa and Usher Syndrome. The Foundation Fighting Blindness is working to find treatments and cures for these devastating diseases. Funds support cutting-edge research in areas such as genetics, gene therapy, transplantation, artificial retinal implants and pharmaceutical and nutritional therapies.

**Contact:** RSVP by Friday, April 6, 2012, to Michele DiVincenzo at 847-680-0100 or [mdivincenzo@fightblindness.org](mailto:mdivincenzo@fightblindness.org). For more information on VisionWalk, please go to **[www.visionwalk.org](http://www.visionwalk.org)**.

Join Us at the Walk!

7th Annual Chicagoland VisionWalk  
Sunday, June 10, 2012  
Busse Woods



Find us on Facebook 

## An Accessible Rubik's Cube—Not Too Puzzling to Adapt!

Do you have an off-the-shelf Rubik's Cube handy? If so, there are several easy ways to adapt it for use by a person with visual impairment or blindness using one of the following APH products:

a) Apply a tactile "Point Symbol" sticker to each color square. Select a unique point symbol to represent each color. For example, apply a raised outline circle to each green square, a V-shape symbol to each orange square, a raised bump to each blue square, and so forth. Assorted tactile Point Symbol stickers are available in two separate packages of **Feel 'n Peel Stickers** [Catalog Nos. 1-08846-00 and 1-08868-00].

b) Would you rather have textures applied than tactile point symbol stickers? Cut and apply small textured squares from the assorted textured sheets included in **Carousel of Textures** [Catalog No. 1-08863-00] and/or **Textured Paper Collection** [Catalog No. 1-03275-00]. Assign a unique texture to each color square—soft to blue, rough to red, bumpy to yellow, and so forth. Don't forget that you can leave one color smooth!



Both tactile adaptations can provide a novel design for sighted peers as well!

For some interesting photos and description of other adapted Rubik's Cubes, visit <http://puzzleuniverse.com/posts/view/238>

## NEW! Test Ready: Plus Reading

### Book 3, Teacher Guide:

- **Large Print: 7-00521-00 -- \$18.00**
- **Braille: 5-00521-00 -- \$18.00**

### Book 3, Student Book:

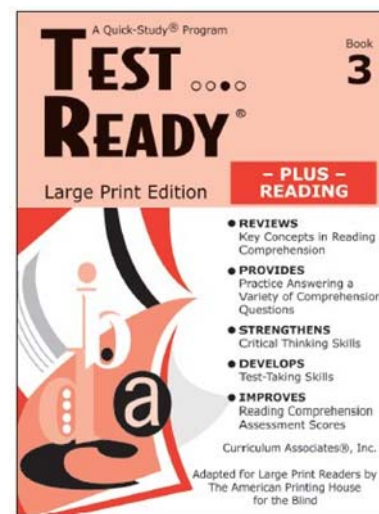
- **Large Print: 7-00522-00 -- \$35.00**
- **Braille: 5-00522-00 -- \$46.00**

### Book 4, Teacher Guide:

- **Large Print: 7-00523-00 -- \$18.00**
- **Braille: 5-00523-00 -- \$18.00**

### Book 4, Student Book:

- **Large Print: 7-00524-00 -- \$35.00**
- **Braille: 5-00524-00 -- \$46.00**



**Note:** Test Ready: Plus Reading grades 5–8 and Advanced (High School) available soon.

This test prep series offers practice for today's standards-based assessments for grade levels 3 through 12.

Test Ready®: Plus Reading provides preparation and review, in as little as two weeks before testing day. It also provides a program of instruction and remediation.

Students practice test-taking skills for:

- Recalling information
- Constructing meaning
- Evaluating literary forms
- Interpreting fact & opinion
- Evaluating & extending meaning

Test Ready: Plus Reading is a review program that provides practice in test-taking skills in reading comprehension and open-ended writing tasks.

In just 14 days, students can be test ready with:

- Timed pretest to diagnose skills gaps
- Standards-based skill-specific lessons
- Timed mixed-practice post-test, mirroring pretest to show growth

### **Accessible Formats**

The APH Teacher Guides and Student Books are available in several accessible formats, so that the entire class can work on math together in a multi-media approach. The large print and braille editions include a CD with an .html file and a Digital Talking Book (DTB) file with built-in player.

The large print student edition includes a specially formatted large print answer document. However, it is recommended that each student have a book in his or her preferred reading medium, and should feel free to mark answers in the test books. Used this way, the student books become consumable items.

**Note:** Copies of regular print Teacher Guides and Student Books are available from the publisher at: Curriculum Associates, Inc., 153 Rangeway Road, North Billerica, MA 01862-0901, 800-225-0248, Fax: 800-366-1158, [www.curriculumassociates.com](http://www.curriculumassociates.com)

**COMING SOON!** Test Ready: Language Arts

## IPVI

P.O. Box 2947, Naperville, IL 60567-2947

Toll-free: 1-877-411-IPVI (4784) • Email: [ipvi@ipvi.org](mailto:ipvi@ipvi.org) • [www.ipvi.org](http://www.ipvi.org)



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HILTON/PERKINS  
PROGRAM AND (IN PART) FROM A  
GRANT FROM THE FAMILY RE-  
SOURCE CENTER ON DISABILITIES**



# 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 2947 • Naperville, IL 60567-2947

**Have questions or need more information?**

**Call us at  
1-877-411-IPVI (4784)**

Illinois Association for Parents of  
Children with Visual Impairments  
P. O. Box 2947  
Naperville, IL 60567-2947

**FREE MATTER FOR THE BLIND  
or PHYSICALLY HANDICAPPED**

**ADDRESS SERVICE REQUESTED**

**THE TOP LINE... of your address label indicates whether your dues are "Paid" or if they are "Due." Please send your annual dues in each year.**

## **IPVI CALENDAR**

▶ May 21	<b>Fit and Fun Family Night</b>	<b>Glenview</b>
▶ June 9	<b>TCLN Vision Rehabilitation Center - Dr. Cary Supalo</b>	<b>Glenview</b>
▶ June 10	<b>FFB's VisionWalk</b>	<b>Schaumburg</b>
▶ June 14	<b>11th Annual Artistry of Wine - Perfect Pairings</b>	<b>Northbrook</b>
▶ 6/19...	<b>Adaptive Sports - 6/19, 7/24, 8/21</b>	<b>Skokie</b>
▶ June 25-26	<b>ISVI Parent-Infant Institute</b>	<b>Jacksonville</b>
▶ 6/28-7/1	<b>VISIONS2012</b>	<b>Minneapolis</b>
▶ 6/30-7/5	<b>Braille Monitor Convention/Scholarships Available</b>	<b>Dallas, TX</b>
▶ July 21	<b>IPVI's 2012 11<sup>th</sup> Annual Members Only Outing</b>	<b>Brookfield</b>
▶ 7/27-7/29	<b>Families Connecting with Families</b>	<b>Newton, MA</b>

Please call  
**1-877-411-IPVI**  
for any questions, concerns,  
or comments that IPVI can  
help you with.

**Newsletter Deadline for  
MAY is APRIL 10<sup>th</sup>**



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

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