# IPVI INSIGHTS

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

August 2015



# IPVI ZOO OUTING

7-18-2015





This year's outing at the Brookfield Zoo was one of our most well attended, 175 families. IPVI and it's members would like to give a great big Thank You to the Davis Family and the 100% Foundation for supporting this wonderful experience for IPVI families. We also appreciate The Chicago Zoological Society, Diane Wehrmeister (the zoo catering manager), the zoo's docents, dolphin trainers, parking lot personnel, and the lunch staff for all of their hard work. We also wish to express our gratitude to our vendor, The World of Tees, the Zabelski's, and our wonderful volunteers from the Chicago Lighthouse who did an exceptional job at handling the behind the scenes t-shirt ordering and distribution, as well as for the Lighthouse's donation of raffle gifts.

Diane Wehrmeister

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During our lunch, we had a never-ending pizza as usual. After lunch we took the large group photo.

As we looked across the water at the Dolphin Show we saw our parent members and their family scatter throughout the audience. It was a sea of Orange Shirts "Literacy Through Experience Brookfield Zoo 2015 Members Outing IPVI", Anita Davis said. The Davis Family is our sole private donor. Everyone was smiling in spite of the heated pool area,



the Dolphins were performing, jumping, back flips, splashing, and OH were they splashing! Our members were seated in the front row...the line of fire. Several of our members assisted the trainer with instructions to the Dolphins; some of our kids were able to interact and even touch the Dolphins.

(Continued on page 4)

# MESSAGE FROM THE PRESIDENT

By Lyle Stauder, President

Thanks to all of you who came to the Brookfield Zoo outing. It was extremely wonderful to meet you, and I was honored to be able to speak to you.

I was asked to summarize my presentation for those of you unable to attend. In the nutshell, I told parents to teach their children with visual impairments to be determined to succeed and not let others define them. I told them, I am visually impaired and I own a business, which has supported my family. This happened because my parents taught me to continually work hard for what I want and not to let an impairment stop me. I also told them that I have two sons who have graduated from college and both are visually impaired; and my wife, Anna, and I continually advocated for them throughout their school years.

To avoid being teased and bullied by classmates trying to take his cane, we taught our son to just ignore them. We said to tell them, "Here, take the cane. Go ahead." We said this because one can always get a new cane, but injuries from fights can be hard to mend. Our son listened and did this. He came home that day and said it was funny how no one would step forward to take the cane after he had said that to them. Also no one bullied him again because he took the fun out of it for them.

Additionally, I explained to our members and their families that by teaching our children how to advocate for themselves while they were younger would translate into their being able to do so when they went to high school, college and into the work force.

For example, my son, Anthony, wanted to take a college Computer Robotics class. When he went to his professor at the start of class to explain his eye condition, the professor basically told him he couldn't take his class because Anthony couldn't see. He said if one couldn't see, he couldn't build a robot. Well, my son told him he was taking the class no matter what the professor said. To make a long story short, my son took the class and built a robot. Then, the professor took that robot at the end of class and told Anthony that he wanted to keep it to put it on a shelf in his office. In that way, the professor said he'd always look at it and remember that he should never limit a student with his own biases, especially because that robot was one of the best built robots made in the class that semester.

So parents, we know it's hard to have a child with a vision issue. However, if you teach him or her that everyone has some sort of challenge to work through, it will help you remember to treat your child like you would any other. Have high expectations of achievement and instill this in your child. This will go a long way into helping mold that child into another success story.

(Continued from page 2) - IPVI Zoo Outing





Lyle Stauder really impressed Anita Davis and her twin daughters and their friends with his story about his parents and his experiences and benefits of being an IPVI member. He stated that everyone should say hello with the other families over good food and drink. Networking and sharing experiences and challenges unique to each family is the most valuable benefit of this event. "The event gets better every year.

The new event this year was the "Wild Experience", next to the Hamill Family Experience. It provided hands on experiences with touching and feeding animals", Mary Zabelski, founding member of IPVI, stated.





Rich Zabelski, event chairman announced that the numbers were the highest in quite a few years. With Mary not working at the Lighthouse, communication was a challenge. However, Gloria Udell, Carol Bailey, Gail Patterson and Mary Zabelski recognized the need to call people and personally follow-up with our members. Thank you Gloria, Carol, Gail, Mary, and the Cook County Commissioner Robert Steele, for providing timely and efficient assistance.

We also had several amateur photographers: Fil Almendarez III (IPVI) and Dominic Calabrese (Chicago Lighthouse). We also thank Jean Lachat Photography 11210 Front Street 2nd Floor, Mokena, IL 60448, 708.263.7269, www.jeanlachatphotography.com.



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

#### MS. VIC VOLLEYS

#### **VOLLEY I**

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

No new members have joined this month.

#### **VOLLEY II**

I was talking to my kid brother, T.J. when he came in town for our family reunion. We talked for hours about lots of stuff. I mentioned to him that when I was young, guys would honk their horns at girls. Now, when a horn honks, people are arming their car alarms. Or if they do notice me now, I know at this age it's because of the car I'm driving like my husband's black Hummer, not me.

"Old age ain't pretty, T.J." I commented now I'm 56. We both laugh at that as he's 54. Just after making this comment, we stopped for ice cream at the Creamery. As we walked back from getting our shakes, a boy about 10 years old with Downs Syndrome was sitting with his mother. As we passed him, he turned and looked at me. I smiled and said, "Hi, how ya doin', buddy?" He gave me a great big smile and replied, "You sure are pretty." I beamed an even bigger smile back, saying "Why, thank you." I turned to my brother when we got back into the car and said, "See, I still got it." Ha. Ha.

For the rest of the day, I was cheered up. Out of the mouth of babes, I thought, meaning when a child tells you something, you pretty much know it's the truth. It reminded me, though, it was the smile that I gave him, wrinkles and all that he responded to. I felt good,

and it wasn't because some guy was flirting with me. I said a silent prayer of thanks to God for reminding me what is really important in life. It's kindness to strangers.

So my tip of the day is to use your smile more. Smiling genuinely at persons with physical issues to some people becomes a little difficult. They want to stare and sometimes even turn away. I purposely make sure I say hello and smile directly to a person in a wheelchair or others, especially children, who have physical, mental, or visual differences. This small gesture seems to make that person feel special, because someone looked them in the eye and made a open gesture of kindness by acknowledging them as they would anyone else. I've never received a bad response from doing this. In cases where the child doesn't answer maybe due to a speech problem or other issue, his or her caregiver smiles at me acknowledging my kindness. However, usually, when I do this, I get a great big toothy smile as a response. Both of us go away feeling just a little better and what could be better than that?

# MBJ SCHOLARSHIP AWARDEE

This year we have awarded a \$250 book grant to a young lady who has been through a tough time with her vision and eye issues, Danielle McCormick. Danielle lives in Oak Park and is attending Concordia University in Chicago. She will be in her second year this fall.

She is majoring in Special Education in order to become a high school teacher with a minor possibly in physical therapy. She is on the Women's Cross Country Team as well as the indoor and outdoor track teams. During her first year at college, she was named "Woman of the Year" on her Cross Country team.

She has been active in her community by being on the Student Advisory Committee of the Oak Park River Forest High School as an executive board member. She was also a Best Buddies member, volunteered for the Northern Illinois Food Bank and volunteered for the Chicago Marathon.

Danielle has strabismus (eyes not aligning in the same direction), nystagmus (pendulum motion of the eyes), ocular torticollis (tilting of the head in order to see), color blindness and congenital gaze paresis (the inability to look at something straight on). Her gaze paresis causes significant difficulty with her saccadic (jerky) eye movements. These issues make it very difficult for her to read. She has undergone three eye surgeries in each eye and is due for a follow up surgery again in each eye. She adopts a chin down head position because she is unable to look up. She cannot participate in ball sports due to the inability to track a ball coming at her as well. While all of these conditions have affected how she sees, she is not legally blind, which is why she has only been granted this allowance.

Danielle wears bifocals, uses enlarged print and magnifiers for reading. She sits in front of the classroom. She avoids glare and uses special lighting to see better. She listens well to memorize what is being said, and this helps her takes notes easier. For testing, including her ACT, she was allowed extra time. gets her texts online so the laptop can read it to her. When asked about what daily living adaptations she has made, she indicated that she utilizes technology a great deal because her eyes' continual movement increases her fatique. When in crowded situations, she has trouble keeping track of her family or friends. What she does to overcome this is to memorize the color of their clothing so she can more readily identify them. Also, she wears very snug sporting glasses when running in order to avoid their shifting, enabling her to focus more readily and helping her avoid headaches.

Danielle's hard work ethic is inspiring and she is thought to be very honest with a great deal of integrity. The patience she showed her Best Buddy at school who has autism was a huge asset. She didn't give up on him even though he displayed difficult behaviors. The mom of this student was so appreciative of her persistence and kindness, stating Danielle was always positive and enthusiastic, while modeling appropriate behavior and social skills. These qualities will certainly aid her success later in life. We wish the best for her.

God Bless and continue your hard work. You are truly an inspiration to our children. Congratulations!





# 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 MBJSF, 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 MBJSF 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 MBJSF 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

#### LIGHTHOUSE SCHOLARSHIP

By Matthew Juskie

The Chicago Lighthouse hosted its annual scholarship award ceremony on July 25<sup>th</sup>. It awarded 39 scholarships. I am very grateful to the Lighthouse and to the Robert Gunterberg Charitable Foundation, specifically Mrs. Carol Culiton-Metzer and her husband Dick Metzger for the \$1,000 grant. This money will help with tuition as I continue my quest for a double major in Finance and Insurance at ISU. The first year of college was exciting and difficult, especially in the first semester. I was able to end the school year with 32 credits and a 3.69 average.

At ISU, I was on the Board of A.C.E. during its maiden year as the Chair of the Social Events. This activity group helped students with disabilities mingle with others who also have a variety of concerns and disabilities socially, academically, and in the community at different events.

Additionally, I started my own DJ company called Suburban Sound Machine. I have done gigs for a variety of grade schools as well as with the LWSSA, a group that provides social events for children with disabilities in my hometown in Frankfort. I am also working Saturday nights at "At the Office," a sports bar and grill in Crestwood DJ'ing from 10 p.m. to 1 a.m. If you are in the neighborhood, come by and see me out on the patio.

I also have been working again for the Village of Frankfort at its Farmers Market on the Sundays running its information booth and helping the vendors with set up. I also work in the Frankfort Village office part time during the week assisting in community relations and event planning. On Saturday mornings, I have been running a doughnut vending booth at the Mokena Farmers Market, too. As you can see, it's been a busy year.

Again, I want to thank my parents, the State of Illinois, the IPVI, The Chicago Lighthouse, the Robert Gunterberg Charitable Foundation and the Lions Club for all the help they've given me in making my dreams of getting a degree possible. I couldn't be doing it without all of you. I really appreciate all the help.



(Mr. & Mrs. Metzer, Matthew Juskie, and Adam Metzer)





(Editor's note: Samantha Smolka and Stephanie Collins also received scholarships again from the Chicago Lighthouse and IPVI this year. Congrats to them. Sam was at the ceremony and Stephanie's parents accepted her award as she is was unable to attend because she is taking a class out of the country. Congratulations to Matt, Sam and Stephanie for all their success. God Bless.)

# Hadley Activates New Course on "Transitioning from School Years to Adult Services"

The Hadley School for the Blind is pleased to announce a new online course detailing how parents and professionals working with a child who is visually impaired or has additional disabilities can maximize the child's independence at home, school, work, and in the community. Supported by the Lavelle Fund, the course covers the core areas of education, early intervention and elementary education and methods of advocacy, as well as preteen, adolescent, and adulthood programs, services, and activities. Familiarity with this information can help a person prepare a child for a successful transition to adult services once traditional schooling ends. For more information and to enroll, visit **www.hadley.edu** or call 800-323-4238.

Media contact: Deborah Bloom, Vice President, Development and Communications, <u>deborah bloom@hadley.edu</u>

700 Elm Street, Winnetka, IL 60093 800-323-4238 www.hadley.edu



# NAPVI NATIONAL CONFERENCE



Mary Zabelski received the "Outstanding Service" Award from NAPVI

"The NAPVI National Conference at the Chicago Marriott Medical District/UIC and the Chicago Lighthouse from July 10-12, 2015 was a phenomenal event! Parents were able to network and participate while childcare was provided for young children. Older children attended sports camp and we're able to participate in activities such as goal ball.

The three-day event welcomed parents from across the country and their children of all ages who cope with visual impairments, blindness and other disabilities. Also on hand were researchers, policymakers and exhibitors from organizations and business which serve people with disabilities.

By joining NAPVI you are automatically a member of IPVI, our state affiliate chapter. We have some great pictures thanks to Dominic Calabrese at the Lighthouse."













**NAPVI** 

## **NAPVI 2015 Conference**

By: Filiberto Almendarez III IPVI Vice President

The 2015 NAPVI Conference was held in our very own Chicago, Illinois. Not only did I meet wonderful parents and children from various states and countries, but I attended sessions related to Vision, Health, Sports, Financial planning for our children's future, and especially in Education.

In the meantime, our children were interacting and participating in activities such as Goal Ball, Beep Baseball, Beep Kickball and Judo. Their joy was overwhelming.

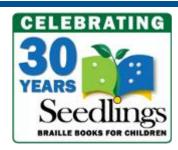
Thanks to our Parent Organization, NAPVI, for supporting IPVI and making the experience possible for our members and other Illinoisans.







# Seedlings Braille Books for Children Offers Free Books!



Seedlings Braille Books for Children invites braille readers and pre-readers from ages 0 to 21 in the United States and Canada to register to receive two free braille books per year.

This amazing program called the Book Angel Program was originally called "Anna's Book Angel Project" and was named in memory of our Director's 19-year-old daughter who was tragically killed by a drunk driver in 2001. Each year, blind children who were registered received one free book in Anna's name, but now we're doing even more.

Thanks to Seedlings' generous donors, blind children in the U.S. and Canada can receive **two** free braille books per year!

Seedlings offers 1,300 titles, from contemporary literature to well-loved classics and continues to add new titles each year so that visually impaired children have the opportunity to read the same books their sighted peers are reading.

The Book Angel Program is a wonderful way to introduce a visually impaired child to the marvel of braille literacy.

Here's a testimonial from a parent who ordered her first braille books for her son from the Book Angel Program, "Alex has always been a curious boy and loves to read anything he gets his hands on. He received his first Braille book from Seedling's Book Angel program when he was a baby and the print/braille format allowed me to read to him while he could touch the Braille just as a sighted child would look at the words as he listens to bedtime stories. Thank you!"

To order free books for your child or student fill out the form located on the Seedlings website: http://www.seedlings.org/bkangel2009.php.

Note: This is a continuing program, but registration is required each year to participate since book choices must be communicated to Seedlings.

Seedlings Braille Books for Children | 14151 Farmington Road | Livonia MI 48154 | Phone: 800-777-8552 | website: seedlings.org



Your favorite House Walk is coming.

# Please save the date for our 29th Annual House Walk: September 9, 2015

The houses will be spectacular. The gardens will be in late bloom. And the cause continues to be meaninful, supporting programs that benefit children and adults who are blind or visually impaired.

# We hope you plan to attend, volunteer, or both!

# **Registration/Ticket pick-up:**

9:30 am – 1:30 pm

North Shore Congregation Israel (1185 Sheridan Rd, Glencoe, IL)



10:00 am-3:00 pm with **last entry** into homes at 2:45 pm

Tickets purchased in advance: \$65 Tickets purchased at the door: \$85

For more information, contact Lighthouse Coordinator: Melissa Wittenberg 847.510.2060

Melissa. Wittenberg@chicagolighthouse.org



## Lunches are \$15 each

Lunch options provided by LYFE Kitchen – Love Your Food Everyday All lunches include dessert & bottled water.

# **Sharing A Vision Conference**

Join Us!

# Crowne Plaza Springfield, IL September 28-30, 2015

Sharing A Vision brings together thousands of Illinois' early childhood educators, administrators, policy makers, advocates, families and many more. This three day, information packed event will connect you with experts who will provide new ideas and best practices to help you reach your goals.

http://sharingavision.org/index.html





## **Request for Presenter**

The Sharing A Vision (SAV) Presenter Committee is excited to accept proposals for presentations for the 14th Biennial Conference. Proposals are due January 31, 2015. http://sharingavision.org/conf/2015/presenters.html

## **Exhibitor and Sponsorship Activities**

Connect and grow your business by registering as an exhibitor and learn about sponsorship opportunities.

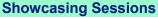
http://sharingavision.org/conf/2015/exhibitors.html



## **Art Gallery Submissions**

Showcase artwork from children (birth to eight) attending your program in the Creative Expressions Gallery.

http://sharingavision.org/conf/2015/gallery.html



Showing Sessions are an effective forum for the exchange of information and research, and to present innovative ideas.

http://sharingavision.org/conf/2015/showcasing.html



<u>Hotel Accommodations:</u> http://sharingavision.org/conf/2015/hotel.html

<u>Tips for the First Time Conference Attendees</u>: http://sharingavision.org/tips.html

Jeanette McCollum Nominations: http://sharingavision.org/conf/2015/mccollum.html

Contact Info: https://illinois.edu/fb/sec/6925927

STAR NET | 6020 West 151st Street | Oak Forest | IL | 60452



# **Family Resource Center on Disabilities**

Providing Parents of Children with Disabilities with Information, Training, and Assistance

## 11th Annual Illinois Statewide Transition Conference



# Stepping Stones of Transition

The 11th Annual Transition Conference for transition aged youth and young adults with disabilities, their family members and teachers, vocational professionals, caregivers, health care professionals, college students pursuing careers in special education and community advocates will be held at the **Hyatt** 

Regency McCormick Place, 2233 South Martin Luther King Drive in Chicago, Illinois from October 29-30, 2015.

The conference, titled "**Stepping Stones of Transition**", invites participants to imagine the possibilities for students with disabilities in the areas of independent living, education and training, employment, community integration, health care, and self-advocacy.

Conference sessions will be organized into 4 tracks: Education, Employment, Community and Healthcare.

Thursday, October 29th features keynote speaker Steve Hopkins, co-founder of 3E Love, and multi-choice Break-Out Sessions with a Welcome Reception at the end of the day. Friday, October 30th concludes the conference and highlights multi-choice Plenary Sessions and Break-Out Sessions in the morning. The conference concludes at 1:00 p.m.

#### Registration

Conference participants are strongly encouraged to register using the <u>Illinois Transition Conference online registration</u>, frcd.org. "Go Green" and help conference planners take eco-friendly steps to better our environment by registering online and eliminating paper registration forms. A limited number of hard copy registration booklets will be made available by request only to those that do not have internet access. Contact Family Matters at 866-436-7842.

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

# REGISTER FOR YOUR FREE PARENT WORKSHOP TODAY!





Space is limited; registration is mandatory Please visit **www.frcd.org** or call 312-939-3513 for registration and workshop or webinar location.

#### **Lunch and Learn Webinar**

Transition to Adulthood Tuesday, August 18, 12pm-1pm

The Family Resource Center on Disabilities (FRCD) offers parents of children with disabilities birth to 21 years old, their helpers, relatives, professionals, and interested community members no-cost training and workshops, telephone and e-mail assistance, and resources to help claim their role as the child's most effective and significant advocate.

You are invited to contact FRCD for information, resources, support and training.1-312-939-3513 | info@frcd.org | www.frcd.org

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

# APH NEWS

# Back by Popular Demand! Brailon® Paper

1-04630-00 -- \$55.95

Note: Brailon IS available on Quota!

A plastic-like paper developed specifically for use with Thermoform machines. Brailon® paper has a slightly



matte surface, is non-toxic, moisture-proof, and classroom safe. Brailon® is reliable, durable, and is an inexpensive way to create exact duplicates and diagrams. It has been the Thermoform industry standard for 50 years.

Size: 11  $1/2 \times 11$ , Weight: "Regular," 19-Hole Punch, 500 sheets per box.

Brailon is a registered trademark of American Thermoform.

# MAKING SENSE

New in Apple's App Store: The American Foundation for the Blind has recently recognized Apple for accommodating its software for those with vision loss. To celebrate this accomplishment, Apple has created a new section in the App Store to showcase 26 apps that are accessible with VoiceOver. Some of the apps included are YouTube, Flipboard, BBC News, DropBox and Shazam, plus Apple's own Pages, Numbers and Keynote. Check it out in the App Store.

Free Telephone Directory Assistance: We often receive calls at Second Sense about free directory assistance to avoid the high charges of traditional "411" service. You can call 800-373-3411 to access residential, commercial and government listings. You will need to listen to an advertisement before getting to the prompts. This number is voice activated and doesn't require pressing any numbers on your telephone keypad.

New College Success Program: Learning Ally has developed a research-based college support program designed especially for students with vision loss pursuing two— and four-year degree programs from an accredited institution. The program helps students identify their strengths and provides resources to improve weaknesses. The curriculum covers assessing technology skills, participating in extracurricular activities, advocating with professors, learning effective study habits and much more. Mentors are also available for additional support. The program is free. To learn move, visit

# www.learningally.org/ CollegeSuccess.aspx

Online College Guide: Affordable Colleges Online has recently developed an accessible guide for students with vision loss who want to attend an online college. The guide helps students by providing information on navigating the online environment with technology, provides resources and services for students and families, lists available scholarships, accredited colleges, majors and lots more. To learn more, visit

# www.affordablecollegesonline.org/colleges-helping-visually-impaired-students/

Attention Writers with Vision Loss: The San Francisco Lighthouse is looking for writers with vision loss to contribute to their literary journal on a paid, free-lance basis. They are

looking for first-person stories about not only living with vision loss, but what it takes to survive and thrive. Novices or professionals are encouraged to submit personal essays, travel writing, commentary, general humor, useful lists, or anything that is dynamic and honest. You can submit articles or ideas to <a href="mailto:wbutler@lighthouse-sf-org">wbutler@lighthouse-sf-org</a> or to learn more visit <a href="mailto:www.lighthouse-sf.org/blog/submit/">www.lighthouse-sf.org/blog/submit/</a>.

Reprinted from MAKING SENSE, August 2015, Second Sense, Beyond vision loss, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, www.second-sense.org.

# Parents: Add "Get an Eye Exam" to Back-to-School Checklist for Kids

Back-to-school preparations are well underway for many parents. But one of the best ways to help ensure a child's success in the classroom this year is to make sure they can see clearly!

Prevent Blindness, the nation's leading volunteer eye health organization, is asking parents to have their child's eye checked before the school year begins and has declared August as Children's Eye Health and Safety Awareness Month. The non-profit offers a variety of eye health information and programs, the Affordable Care Act, and more, to get children on the path to a lifetime of healthy vision. In fact, Prevent Blindness has been helping to protect children's vision since 1908!

And, through the Star Pupils program, teachers can download no-cost curriculum and materials to help students learn about their eyes and how to take care of them.

Sarah Hecker, Director, Media Relations

Prevent Blindness
211 West Wacker Drive Suite 1700
Chicago, Illinois 60606
T 312.363.6035
F 312.363.6052
www.preventblindness.org

# Summer Challenge to END BLINDNESS

Throughout our <u>2015 Summer Challenge</u>, an anonymous donor will match your gift dollar-for-dollar to fund more cutting-edge research. **That means your impact on vision-saving work will be doubled!** 

The Foundation invests only in those researchers whose work shows great promise. Researchers like Dr. Shannon Boye.

Dr. Boye is a gene therapist and mother of two who empathizes with parents desperate to save their children's eyesight.

As part of our Summer Challenge Researcher Spotlight, you can read more about the treatments Dr. Boye is currently working on.

Dr. Boye is helping develop a gene therapy for Leber congenital amaurosis caused by a defect in the GUCY2D gene. Gene therapy, the practice of replacing a mutated gene that causes the disease with a healthy gene, is increasingly being used to treat patients in clinical trials.



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One aspect of Dr. Boye's work would represent a "paradigm shift" by providing patients with a gene-delivery system that's gentler, and less invasive, than those currently used in human studies.

Today, your gift through our Summer Challenge Campaign will be doubled to increase the promise that gene therapy holds and, ultimately, the funds available to researchers like Dr. Boye.

Beyond hope for a cure, we are ending blindness. Thank you for joining us.



Sincerely,

William T. Schmidt
Chief Executive Officer

www.fightblindness.org









# Join The FOUNDATION FIGHTING BLINDNESS

# **TELL CONGRESS:** PROTECT VISION RESEARCH



This is an exciting time for vision research, with recent breakthroughs giving hope to millions of people facing vision loss.

With that in mind, now is the time to accelerate funding for vision research, both in the private AND public sectors.

Unfortunately, funding for the National Eye Institute at the National Institutes of Health has not kept pace with the demand for retinal research. In fact, it's been scaled back in recent years.

If allowed to continue, this situation could have a devastating effect on the health and economic vitality of the nation, as well as negatively impact current and future researchers.

Tell Your Senators **Make Sight-Saving** Research a Priority

But as part of our Summer Challenge to End Blindness, it is easier than ever to tell Congress that sight-saving research needs to be a priority.

I ask that you take one minute to add your name in support of additional funding for research advancements. You can use the sample message we started for you and simply hit SEND, or you can edit the message to add your personal story and thoughts.

# Please, email your members of Congress today.

A cure is in sight, but not unless the research continues. We can't do it alone.

Thank you,

Stephen Rose, Ph.D. Chief Research Officer

P.S. Our list of the top research advancements of 2014 is impressive, but imagine where we can go from here. Tell Congress today: We need to continue funding sight-saving research!









# **Physicians**

Benjamin H Ticho, MD - Pediatric ROP & Adult Ophthalmology
Jonathan S Buka, MD - Ophthalmology-Glaucoma & Lasik Surgeon
Alexander J Khammar, MD - Pediatric ROP Ophthalmology
Karl Ticho, MD - Ophthalmology
E. Michael Cassidy, MD - Ophthalmology
Roshni A Vasaiwala, MD - Cornea Specialist
Hassan A Shah, MD - Oculofacial Plastic, Orbital and Ophthalmic Surgery
Megan Allen, OD - Optometrist
Birva K Shah, OD - Optometrist

# **Visit our Locations**

10436 Southwest Hwy., Chicago Ridge, IL 60415 P: 708-423-4070 F: 708-423-4216

600 Ravinia Ave., Orland Park, IL 60462 P: 708-873-0088 F: 708-873-5224

333 Chestnut Street, Suite 104, Hinsdale, IL 60521 P: 630-323-4202 F: 630-323-6588

> 7001 W Archer Ave., Chicago, IL 60638 P: 708-423-4070 F: 708-423-4216

801 Mac Arthur Blvd. Ste. 302, Munster, IN 46321 P: 219-836-7990 F: 219-873-0175

# **IPVI**

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

1-815-355-2098 • Email: ipvi@ipvi.org • www.ipvi.org

#### **PRESIDENT**

Lyle Stauder 41 Groton Springfield, IL 62702 (217) 787-9728 astauder@springnet1.com

## **OPERATIONS VP**

Filiberto Almendarez III 5323 N Delphia Ave #12 Chicago, IL 60656 (773) 693-5713 falmendareziii@yahoo.com

#### SERVICES VP

Mary Zabelski 6153 N. Nettleton Avenue Chicago, IL 60631 (773) 882-1331 maryzabelski@hotmail.com

# **TREASURER**

Vicki Juskie 21170 Deerpath Road Frankfort, IL 60423 (815) 464-6294 vajuskie@aol.com

#### **SECRETARY**

Dawn Wojtowicz 9188 161<sup>st</sup> Place Orland Hills, IL 60487 708-590-6447 deeder0477@aol.com

### **NAPVI REGION 3 REPRESENTATIVE**

Pam Stern 1912 Mission Hills Lane Northbrook, IL 60062 847-217-7590 pamstern3@gmail.com

#### **SPANISH TRANSLATOR**

Noelia Gamino 708-655-2747

THIS PUBLICATION IS SUPPORTED
(IN PART) BY THE NATIONAL
ASSOCIATION FOR
PARENTS OF CHILDREN WITH
VISUAL IMPAIRMENTS (NAPVI)
HILTON/PERKINS
PROGRAM AND (IN PART) FROM A
GRANT FROM THE FAMILY RESOURCE CENTER ON DISABILITIES



# Join IPVI or renew your membership today!

The Illinois Association for **P**arents of Children with **V**isual 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.

Check one:		
☐ Parent/Guardian Membership:	\$15 per year.	
Child(ren)'s Names):		
Dinth data(a) of mary reignally	ring pained abild(nep).	
Birthdate(s) of my visually	impaired child(ren):	
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# 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.

Have questions or need more information? Call us at 1-815-355-2098 Illinois Association for Parents of Children with Visual Impairments P. O. Box 2947
Naperville, IL 60567-2947

Please contact IPVI to see if you are up-to-date on your dues at the address on the left or 1-815-355-2098

Email: <u>ipvi@ipvi.org</u> www.ipvi.org

# IPVI CALENDAR

▶ 9/9 TCL 29<sup>th</sup> Annual House Walk

Glencoe

**▶** 9/28-30

**Sharing a Vision Conference** 

Springfield

**▶** 10/29-30

FRCD 11th Annual Illinois Statewide Transition Conference

Chicago

Please call
1-815-355-2098
for any questions, concerns,
or comments that IPVI can
help you with.

Newsletter Deadline for SEPTEMBER 2015 is AUGUST 15<sup>th</sup>



Check Out www.ipvi.org

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