

IPVI INSIGHTS



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

AUGUST 2018

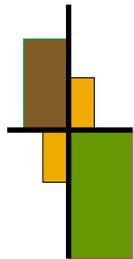
PRESIDENT'S REPORT

Filiberto Almendarez III

What a beautiful day for a family gathering at a celebratory event. The 2018 Brookfield Zoo Outing was a blast. Not even the weather, which was unfriendly at times, could stop the strength and determination of IPVI families. I always say, I know some of the strongest parents around.

Parents, I must say, I truly enjoy sharing your journey and your child (ren's) progress. I am overwhelmed with joy when our children exceed what was expected. As I spoke to parents, one shared how the Outing was held at Lincoln Park Zoo and everyone brought their lunch. Wow, the Outing has changed. It's now held at Brookfield Zoo with entry, parking and lunch too. Plus, this year some of our children were able to touch the dolphins. Thank you Dolphin Show coordinators and staff for incorporating our children as part of the show like everyone else. They felt what others saw, which made the experience more extraordinary. Also, I want to point out, how long some have been IPVI members and the progress we have made. Even if it's an inch a year. We keep moving forward and our children keep growing. It's incredible how they naturally want independence by wandering all over the place. It's simply amazing. You don't need to be perfect to be amazing. Plus, what is perfect?

Finally, I would like to thank our guest speakers from Commissioner Deer's Office and Pam Berman from Guide Dogs for the Blind, the Chicago Lighthouse, our wonderful volunteers, donors, Brookfield staff and countless individuals who work hard behind the scene to make the event possible. In addition, thank you IPVI Parents for all your efforts on coming out to the Zoo. I know it's not easy, but you make it seem easy.



MEMORIES OF HEIDI MUSSER

Prepared for: IPVI Insights – Issue August 2018
 From: Heidi Musser



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Nurtured By Love

Recently, former President Barack Obama travelled to South Africa to commemorate Nelson Mandela’s 100th Birthday. In his speech he quoted the following words from Mandela:

“There can be no greater gift than that of giving one’s time and energy to helping others without expecting anything in return.”

I can honestly say that I have discovered the value of incorporating Mandela’s words in my life. He endured 27 years in prison and felt no bitterness, when he finally was released from prison. I also feel that the Chicago Public Schools educators relegated me into prison not only during my elementary and high school years, but for most of my adult life. *I forgive them; they did not know better.* Their training was based on what I **cannot** do as an individual born totally blind. They had no concept that I had a phenomenal musical ear. Former Chicago Symphony Orchestra Violinist Joseph Golan made the discovery about my having pitch on a sailing boat outing on Lake Michigan with my brother Sig (who was his violin student), when I was nine years old. He contacted former Principal Pianist Mary Sauer; and that was the start of my training as a classical pianist ever since.

Over a period of many years, Miss Sauer has guided me to make piano playing an extension of my heart. I still take weekly lessons from one of her students, who plays with the Civic Orchestra. With honor I look back to have attended Miss Sauer’s regular Masters Classes at the Fine Arts Building on Michigan Avenue.

I also attended group lessons for Suzuki Piano, but I

(Continued on page 7)



IPVI ZOO PICTURES



"Neither rain, nor sleet, nor gloom of night stays these IPVI members from attending our 2018 Zoo Outing!"



Registering



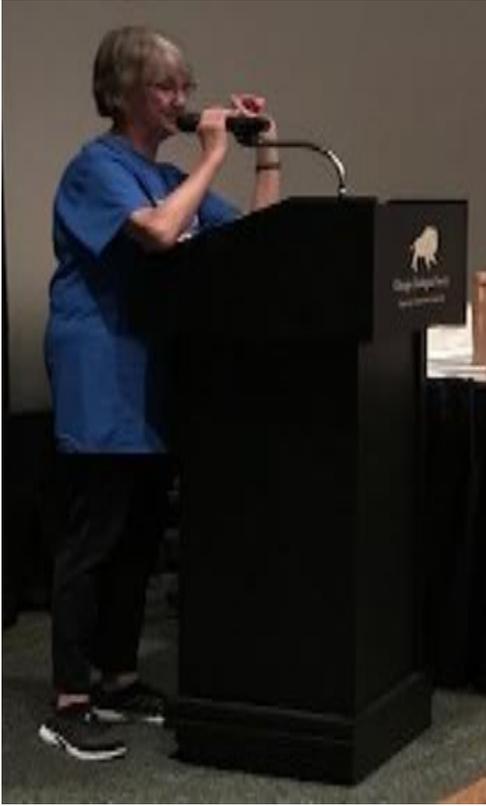
Look out! Spider behind you.



Enjoying lunch & camaraderie



Raffle



Speakers: Mary Zabelski

Commissioner Deer's
Office

Pam Berman
Guide Dogs for the Blind



Dolphin Show



Close Enough to Pet the Dolphin



I'm Raising My Special Needs Child With Dignity– Are You?

By Nicole Feeney

Special needs children deserve honor and respect. As parents, we need to maintain their dignity and help them present themselves at their best in public. READ MORE at: www.wonderbaby.org/articles/dignity-surrogate



6 Strategies for Addressing Self-Injurious Behaviors

By Amber Bobnar

Self injurious behaviors are, unfortunately, not unusual for kids with special needs. These behaviors could be anything from biting, hitting or even banging their head on the walls or furniture. READ MORE at:

www.wonderbaby.org/articles/self-injurious-behaviors



Why I Laughed When My Daughter Lost Her Eye

By Gwen S.

Gwen tells funny stories about raising her daughter Ivey who has bilateral anophthalmia. Gwen says it's important for us to learn to laugh at ourselves and our lives and teach our children how to see the humor in everything! READ MORE at:

www.wonderbaby.org/?wpv_view_count=2102-TCPID1000&wpv_paged=6



Make Your Own Play Space for Your Blind Baby

By Sarah Murray

Sarah writes about the journey her family has traveled as they've taught their blind son Lucas to be as independent as possible. And now she wants to start a movement! #blindkidscan READ MORE at:

www.wonderbaby.org/articles/this-blind-boy-can



Repetitive Behaviors in Blind Children: What Are They?

Fourteen-month-old Skyler sat on the floor in the child care room at the synagogue one Friday evening while her parents talked with the woman in charge. When the woman noticed that the toddler was poking her eyes, she bent down toward her, saying, "Oh, you must be tired. Let's get you a quiet place to take a nap." But Skyler wasn't poking her eyes because she was sleepy.

Families of some children with visual impairments may find that their children repeatedly behave or act in ways that can be confusing to sighted observers. Several terms used to describe these behaviors include stereotypical behaviors, mannerisms, self-stimulatory behaviors, and "blindisms." Regardless of what the behavior is called, it's important to understand why it's happening and what you can do about it. Read the whole article at:

<http://www.familyconnect.org/info/browse-by-age/infants-and-toddlers/social-life-and-recreation-iandt/repetitive-behaviors/1235>

Assessments for Students Who Are Blind or Visually Impaired

Before your child begins to receive any kind of instruction, it's important to find out what he needs to learn and the best way for him to learn it. In that sense, assessment—the formal process of finding out someone's strengths and needs in a particular area—is at the heart of all instruction because it al-

lows an appropriate educational program to be planned.

Importance of Specialized Assessment

Your child will undergo some specialized assessments that relate specifically to his visual impairment. These are generally conducted by the teacher of students with visual impairments and are required by the federal law governing special education. Becoming familiar with these assessments and the information that is gathered from each of them will help you to understand the particular recommendations made by members of your child's educational team. Recommendations for services for your child should be based on his needs as determined through assessment. Read the whole article at:

<http://www.familyconnect.org/info/education/assessments/13>

Orientation & Mobility Assessment

An orientation and mobility (O&M) assessment examines a child's ability to travel safely both indoors and outdoors and with or without assistance. An O&M instructor, a professional who has specialized training in how to teach travel skills and concepts such as spatial awareness, will conduct the assessment.

While some teachers of students with visual impairments (TVIs) are dually certified in O&M, others will have some basic knowledge of orientation and mobility, yet are not qualified to assess your child's skills and needs for O&M instruction.

If you have concerns about your child's ability to move safely and independently in her environment and she is not receiving O&M services, discuss your concerns and ask other members of her educational team for a referral for an O&M assessment. Read the whole article at:

<http://www.familyconnect.org/info/education/assessments/orientation-and-mobility-assessment/135>

Back to School for Children With Visual Impairments



www.pathstoliteracy.org

Worldwide · Promoting literacy for children & youth who are blind, visually impaired, or deafblind, including those with multiple disabilities or other special needs

Tips and ideas for getting your classroom set up or preparing your child for school.



www.pinterest.com/pathstoliteracy

(Continued from page 2) - Memories from Heidi Musser

had no idea that one day I would be a Suzuki Piano teacher myself. In the Preface of Dr. Shinichi Suzuki's Book "*Nurtured By Love*", he claims: "*We are born with a natural ability to learn. A newborn child adjusts to his environment in order to live, and various abilities are acquired in the process. My thirty years' experience has proved over and over again that this is true. Many children grow up in an environment that stunts and damages them, and it is as-*

sumed that they were born that way; they themselves believe it too. But they are wrong."

I can't believe how these words are deeply anchored within me. About one year ago, when I was asked by a Philippine mother to teach piano to her 10-year old sighted son Angelo. She came to our home as a nurse for my father on a weekly basis. She loved my playing on my baby grand piano and I said: Yes, I try! Angelo attends a Gifted Program within a Chicago Public School. Immediately, I knew I had a quick learner sitting next to me on the piano bench with deeply dedicated parents supporting him. Needless to say, the experiment worked! Within two months, his best friend Michael wanted to take piano lessons as well. Also, our neighbor from across our street asked me, if I would take his grand-daughter Mina on as a student.

All three of them are doing well. They see the printed score in front of them and I have the score well memorized. Learning to play is mainly based on careful listening by ear. My mother assists by watching off the side, so they have the right fingering. They all practice at home and L*O*V*E to come for lessons. Angelo plays already pieces by Bach and Beethoven from Suzuki Piano Book, Volume II. They give me joy beyond imagination and, most of all, confidence that I have a gift to enrich the life of others.

Here is my message for IPVI parents: Yes, I am willing to try to teach blind/visually impaired students, BUT, the parents need to agree to be supportive for practice in their home environment. Following Mandela's words: No cost.

Looking back, when I was a child, neighborhood children did not feel "comfortable" to play with my three siblings, because they had a blind sister in the home. HOORAH! I planted tiny seeds to change societal attitudes. **Let us work TOGETHER for the common good.**

* * *

If questions, please contact me:

hmusser@msn.com

773-774-7741

Family Income, Ethnicity and Health Literacy May Affect Children's Vision, Eye Care Access

Prevent Blindness and the National Optometric Association Declare August as Children's Eye Health and Safety Month to Help Make Vision Care for Kids a Priority

CHICAGO (July 26, 2018) – August for many children in the United States is the beginning of a brand new school year. According to the recent report from the National Center for Children's Vision and Eye Health at Prevent Blindness (NCCVEH), vision plays an important role in a child's physical, cognitive and social development. And, visual functioning is a strong predictor of academic performance in school-age children.

According to the results from the 2016 National Survey of Children's Health, less than 70 percent of children in the United States are receiving appropriate vision screenings or eye examinations. Children are more likely to receive a vision screening/eye examination as the household income increases.

Minority children are also at increased risk of missing critical steps to ensure healthy vision. The survey found that White, non-Hispanic children are more likely to receive a vision screening or eye examination followed by Hispanics, and Black children. Children who are Native Hawaiian and Pacific Islanders have a much lower rate of preventive vision care.

Health literacy of parents and caregivers is also a factor in children's overall health care. According to the *Pediatrics* article, "Child Health Disparities and Health Literacy," low health literacy is a growing problem for Americans, with studies reporting 90 million adults with a limited understanding of basic health information and services. Half of all parents have difficulty reading and understanding patient education materials, and many struggle to comprehend medical advice that is critical to the care of their child- including their child's vision health.

Prevent Blindness and the National Optometric Association have combined their efforts to declare August as Children's Eye Health and Safety Awareness Month to educate the public on the importance of healthy vision for all kids. Prevent Blindness provides free information on a variety of topics including amblyopia (lazy eye), strabismus (crossed eyes), recommended sports eye protection, and more on its website. A listing of financial assistance programs is also provided to assist parents and caregivers with access to eye examinations and glasses for their children.

"Every child deserves quality eye care," Dr. Sherrol A. Reynolds, president of the National Optometric Association, associate professor at Nova Southeastern University College of Optometry, and volunteer member of the Prevent Blindness Scientific Advisory Committee. "Their future, and ours, depends on their ability to access the resources and services that put them on the path to a lifetime of healthy vision."

Prevent Blindness recommends a continuum of eye care for children that can include both vision screening and comprehensive eye exams. All children, even those with no signs of trouble, should have their eyes checked at regular intervals. Any child who experiences vision problems or shows symptoms of eye trouble should receive a comprehensive eye exam by an eye care provider (an optometrist or an ophthalmologist.)

Some children are more likely to have eye problems. A child's doctor should be aware of the following factors that may make a child more likely to develop a vision problem:

- The child was born prematurely
- The child has a family history of eye problems (Issues can range from childhood cataract to lazy eye [amblyopia] to misaligned eyes or eye tumors.)
- The child has had an eye injury (Problems resulting from childhood eye injuries may develop much later in life.)
- The child has diabetes (Both children and adults with diabetes should have a dilated eye exam at least once a year.)

Children in these high-risk categories should be examined by an eye care provider (an optometrist or an ophthalmologist.)

In support of Children's Eye Health and Safety Awareness Month, OCuSOFT® Inc., a privately-held eye and skin care company dedicated to innovation in eyelid hygiene and ocular health, will make a donation to Prevent Blindness.

For more information on children's eye health and safety, the NCCVEH, or financial assistance programs, please call Prevent Blindness at (800) 331-2020 or visit preventblindness.org.

About Prevent Blindness

Founded in 1908, Prevent Blindness is the nation's leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight. Focused on promoting a continuum of vision care, Prevent Blindness touches the lives of millions of people each year through public and professional education, advocacy, certified vision screening and training, community and patient service programs and research. These services are made possible through the generous support of the American public. Together with a network of affiliates, Prevent Blindness is committed to eliminating preventable blindness in America. For more information, or to make a contribution to the sight-saving fund, call 1-800-331-2020. Or, visit us on the Web at preventblindness.org or facebook.com/preventblindness.

About the National Optometric Association

The National Optometric Association (NOA) was founded in 1969 in Richmond, Virginia, as a not-for-profit corporation. The NOA is comprised primarily of minority optometrists from throughout the United States. The recruitment of minority students into the schools and colleges of optometry and their placement into appropriate practice settings upon graduation are two priorities of the NOA. Coincident with these priorities is the underlying purpose of the NOA — advancing the visual health of minority populations through the delivery of effective and efficient eye and vision care services to the minority community, a shared priority with Prevent Blindness. The NOA is committed to reducing visual impairment and blindness by increasing awareness, education, community outreach and screenings in urban areas, and partnership with the Prevent Blindness network of affiliates. More information about the NOA is available online at: <http://www.nationaloptometricassociation.com/>

FOUNDATION
FIGHTING
BLINDNESS

CALL TO ACTION

An important bill was just introduced to the US House of Representatives that has the potential to greatly increase research funding for blinding eye conditions, including inherited retinal diseases. To that end, I am asking you to write or call your Member of the House of Representatives to ask them to support H.R. 6421, the Faster Treatments and Cures for Eye Diseases Act. Co-sponsors of the bill are: Pete Sessions (TX), Sanford Bishop (GA), Fred Upton (MI), and Gus Bilirakis (FL).

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.

Visit [Find Your Representative](#) to get contact information for your House Member.

H.R. 6421 creates new financial instruments called 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. These funds would be backed by a limited federal guarantee. Given current federal deficits, this guarantee has been carefully constructed to ensure that it works for all of us and should have no material impact on the deficit. See FFB's [press release](#) for more details on the bill.

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. 6421, the Faster Treatments and Cures for Eye Diseases Act.
- 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!

Thank you.



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

The *Illinois Association for Parents of Children with Visual Impairments* is a state-wide, non-profit organization that enables parents to find information and resources for their children who are blind or visually impaired, including those with additional disabilities.

Your IPVI membership dues or generous contributions help to support all of our ongoing efforts:

- Regular communications which include: workshops, conferences, training seminars, legislative issues, organizational announcements, products, and advice about raising a child who is visually impaired.
- Offers several \$500 college scholarships each year.
- Publishes a resource catalog which includes anything and everything to do with visual impairment.
- Conducts training and support sessions where parents share experiences and ideas.
- Holds fun outings adapted for children with visual impairments at athletic, cultural, educational, and entertainment settings.
- Represents parents of children with visual impairments at conferences, public hearings, and on committees.

What does IPVI do?

- Promotes and provides information through meetings, correspondence, publications, etc., which will help parents meet the special needs of their children with visual impairments.
- Facilitates the sharing of experiences and concerns in order to provide emotional support and relief from feelings of isolation for parents and their families.
- Creates a climate of opportunity for children who are blind in the home, school, and society.
- Fosters communication and coordination of services among federal, state, and local agencies and organizations involved with providing services to people who are visually impaired.
- Advocates on a statewide level for services to children who are visually impaired and their families.
- Keeps members informed about current proposals and actions which impact on children with visual impairments and their families.

Check one:

Parent/Guardian Membership: \$20 per year.

Child(ren)'s Names: _____

Birthdate(s) of my visually impaired child(ren): _____

My child(ren)'s eye condition: _____

I give my permission to release my name to other parents.

Group/Agency Membership \$50 per year.

Extended Family/Friend Assoc. Membership \$20/year.

Medical Specialist \$50 per year.

Scholarship Fund \$10.00

Donation: \$ _____ (tax deductible)

New Membership

Renewal

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Phone: (_____) - _____

Email: _____

Please enclose this form along with your payment by check to:

IPVI • P.O.Box 316634 • Chicago, IL 60631

Have questions or need more information?

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

**Illinois Association for Parents of
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P. O. Box 316634
Chicago, IL 60631**

IPVI CALENDAR

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

**Newsletter Deadline for
September 2018 is August 15, 2018**



**Check Out
www.ipvi.org**

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