IPVI INSIGHTS

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

January 2016





MESSAGE FROM THE PRESIDENT

By Lyle Stauder, President

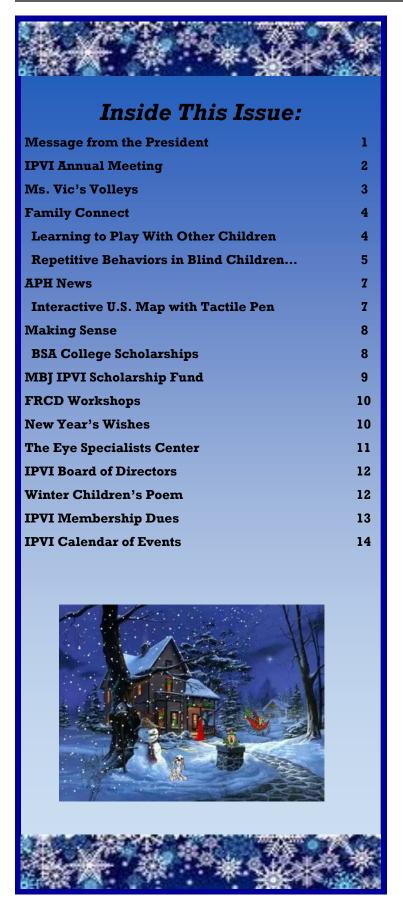
Happy New Year to all of our IPVI members. I trust you had a great Christmas and are looking forward to a great beginning this New Year.

We hope that you try to attend the **Annual Meeting at the** Frankfort Library starting at 12:00 p.m. to 3:00 p.m. on February 27, 2016. The library is located at 21119 S. Pfeiffer Road, Frankfort, IL 60423. We will have food and drinks for all as well as games for the kids to play. Please RSVP to Vicki Juskie at 815.355.2098 so we have a good head count for the sub sandwiches we are going to enjoy.

We will hold officer elections and are asking for anyone who feels like they could volunteer to come forward and help us. Vicki Juskie and I will no longer be Board Members after this year, and we could really use some help keeping IPVI a viable and strong advocacy group for families affected by no vision.

I am looking forward to see you there. Take care and stay warm.





ANNUAL MEETING

Please be advised that IPVI will hold its annual meeting and officer elections at the Frankfort Public Library. The pertinent information is as follows:

WHAT: IPVI Annual Meeting and Officer Elections

WHEN: February 27, 2016 at 12:00 p.m. to 3:00 p.m.

WHERE: Frankfort Public Library

21119 S. Pfeiffer Road Frankfort, IL 60423 815-469-2423

All IPVI families with their children are invited. There will be games and books for the children to occupy themselves while the meeting is going on. Refreshments shall be served.

We look forward to seeing as many of you as possible.

Happy Holidays and Happy New Year!

THE IPVI BOARD

MS. VIC'S VOLLEYS Victoria Juskie, IPVI Treasurer

MS. VIC VOLLEYS

VOLLEY I

No new members have joined us this month.

VOLLEY II

VOLLEY III

Happy New Year, everyone! Now that the holidays are over, we can get ourselves settled into a nice winter routine. Thankfully, so far this winter has not been so bad throughout Illinois so we should be able to enjoy these days, which get dark too early. A happy note to realize though is that since 12/21/15, the days have been getting longer by approximately a minute each day, so that's something to look forward to.

WORK

...if you are poor, WORK. If you are rich, WORK. If you are burdened with seemingly unfair responsibilities, WORK.

...if you are happy, continue to work: idleness gives room for doubts and fears. If sorrow overwhelms you and loved ones seem true, WORK. If disappointment comes, WORK.

...if faith falters and reason fails, WORK. If dreams are shattered and hope disappears, WORK. WORK as if your life were in peril: it really is.

...No matter what ails you, WORK.

WORK faithfully and WORK with faith. WORK is the greatest material remedy available. WORK will cure mental and physical afflictions.

I stopped to contemplate the meaning of this poster and said that it would help segue into a terrific column idea because of its simple truth.

You might think, "Well, how does this help the visually impaired and those who are blind together with their families reading this column?" My answer is simply that the premise applies to everyone, whether they have an affliction or not. It reminds us that we need to instill into our children that they have to work hard all the time to succeed. Yes, I know that when you have a child who's blind or visually impaired, you may feel as though there may be no work that they can do. Please believe me when I say, you're wrong.

Every child, no matter how capable or disabled, must feel like s/he can do something that makes the world a better place. Those who are capable must be pushed to learn well and perform their best all of the time. This creates strong character and responsibility for one's actions. For those children who struggle in some way, it is up to us parents to help that child become proficient at something and have them also perform to the best of their abilities. Many times, one might say because someone can't see well, they won't be able to become gainfully employed. Well, I'm sure Helen Keller, Louis Braille, Ray Charles, Claude Monet, Harriet Tubman and Franklin Delano Roosevelt would beg to differ. All of

these people were affected by blindness or low vision.

So my tip of the day is, do not set the bar too low for your child affected by low vision or blindness. Push them to become as independent and capable as they can be. Early intervention is one of the best places to start learning how to do this, Moms and Dads. We have to be the parents who know that we will not always be around, so we must teach our children while they are young. This way, when they become adults, they understand they have to also pull their weight in the world to the best of their abilities. The rest of the world really doesn't given anyone a break so we might as well instill the courage to do their best so that they, too, will become productive members of society. You will be amazed years later when you look back at how far you and your child have come, and it will be this way because both of you did the WORK to get there.

God bless all of you and have a great New Year!



FAMILY CONNECT WEBSITE

Learning to Play with Other Children

The First Year

Children as young as a year old begin to be interested in other children. Although they don't usually play with one another, they may play near each other and watch each other. At this stage you won't see them taking turns with a toy or imitating each other. They're more focused on learning about their world and are very much caught up in themselves.

Even if your baby isn't ready to play with other children yet, you can help her prepare for that next step. When there are children about her age nearby, watch how they play. Since your baby may not be able to observe this, she'll need you to show her what you're seeing—how to use a toy, play peek-aboo, or do a simple game of taking turns banging blocks together. When you show your baby how to play with a toy, it's a good idea to sit behind her and use either the hand-under-hand or hand-over-hand approach.

Playing with Other Toddlers

All toddlers have a lot to learn when it comes to playing with other children their age. Sharing toys and taking turns in a game aren't instinctive. These are skills children need to learn, and your toddler will probably need some help from you to understand and practice those behaviors. Start with one activity, such as sharing a toy. You can model the behavior when the two of you are together by asking to take a turn playing with one of her toys, then offering her a turn with the toy after you've played with it for a minute or two. When she's with another toddler, remind her to share her toy with the other child. But don't be surprised if your child's playmate is reluctant to return the favor and needs to be encouraged to continue sharing back and forth.

Parallel Play

You can use the same approach to help your toddler learn to play the way other children do—again working one- on- one with her first to give her practice. Ideally, have two of the same or a similar toy, one for each of you. Follow her lead as she plays with the toy—a truck, for example. Then encourage her to do on her own what you're doing with the truck, perhaps rolling it up an incline while making "motor" sounds. This is called "parallel play," since the two of you are playing side-by-side but not necessarily together

A local park or playground is a likely place for your toddler to hear other children at play and begin to learn how to be part of their activities. If a child nearby is playing with a toy, describe what he's doing if she can't see him clearly and help her do the same with her toy. You might ask him to tell her what he's doing. If the two of them seem comfortable playing with their toys side-by-side, it's time for you to sit back and just keep an eye on them.

Let's Pretend

Older toddlers often begin to use imaginative play—such as pretending to go grocery shopping. For sight-ed children, the things acted out in pretend play are often based on experiences they've had and things they've observed. The more experiences your child has at home and in the community, the more she'll have to draw on when beginning to play with other children. You can help her understand and have fun with pretend play by giving her some practice. For example, give each of you a role and act out a scene that might be based on one of her storybooks or on an imaginary shopping trip. You might want to play it one way first and then exchange roles, with your child playing the grownup and you playing the toddler. Many children find that great fun, which is what playtime is meant to be. Once your child is comfortable playing "let's pretend," you may want to invite another child to join your little girl and you in pretend play.

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.

These behaviors, which can differ among children, include:

• Eye poking or pressing — some visually impaired children repeatedly poke or press their hands or fingers on or in their eyes. Before trying to change that behavior, make sure it's not happening because your child's eyes hurt. Find out from your eye care specialist if there's a possible medical explanation.

- Hand flapping some children flap their hands when they're excited and stop after a little while as they
 calm down. This can happen repeatedly for no apparent reason.
- **Rocking** a child may rock back and forth or from side to side either while sitting or standing. For some children the behavior increases as they become more excited.
- **Light gazing** light is very stimulating for some children. They may enjoy staring at a lamp or a sunny window and may also flick or wave their fingers in front of their eyes to cause the light to make patterns.
- Head shaking a child may shake his head from side to side repeatedly even though he's not saying "no." Some babies are especially prone to do this when lying in their crib or on their back on the floor.

Why do Children Who are Blind or Visually Impaired Exhibit These Repetitive Behaviors?

There is no one agreed-on theory about why some visually impaired children engage in stereotypical behavior, which is also sometimes seen in children with a variety of other disabilities. One theory is that a child may not be getting as much stimulation from the environment as sighted children do. Since he can't see everything a sighted baby sees, he seeks stimulation from within himself. Another theory is that some visually impaired children don't play with toys or socialize the way sighted babies do, so behaviors that all babies engage in from time to time become more of a habit. Once that happens, it's difficult to change or redirect the behavior and help the child learn more socially acceptable ways of expressing excitement or boredom.

What You Can do to Help Your Child Change Stereotypical Behavior

Most people engage in some behavior that's self-stimulatory that they do without thinking—jiggling their knees or cracking their knuckles, twirling their hair or clicking a pen repeatedly. People tend to do this when they're bored, nervous, or worried. Often we don't realize we're exhibiting these behaviors, and others may not either, because they fall into the "socially acceptable" category. But the stereotypical behaviors some visually impaired children engage in aren't seen as socially acceptable and may be considered highly unusual by many people. It may be helpful to work with your child to replace that behavior with another that's viewed as more socially acceptable.

Babies need pleasurable physical activity. One way to change your baby's stereotypical behavior is to help him find stimulation in acceptable ways. For example, when you introduce him to a <u>variety of toys</u>, give him a reason to use his body, particularly his hands, to explore and play with these new objects. Once he's involved in a stimulating activity, he's less likely to think of poking his eyes or shaking his head. Refocusing your baby's attention from stereotypical behavior to a different, pleasurable activity can help to wean him from that habit. Toys aren't the only useful distractions—you might sing a song together, tickle him, or play patty-cake.

Try not to scold your baby if you see him engaging in self-stimulatory behavior. He may quickly learn that he can get your attention, even if it's negative, by doing that. Instead, try to redirect his behavior.

Remember to give your child attention and praise when, for example, he isn't rocking or poking his eyes

while waiting to pet the pony at the petting zoo. Giving him a big hug and telling him you're proud of the way he's waiting his turn is a good way to reinforce that behavior.

As your child becomes more aware of other children, let him know that most others don't have the habit you're trying to break him of. Let him know, in some way that doesn't make him angry or embarrassed, how others respond to his behavior. "There's a little girl in the sandbox who looks scared because you're waving your hands around. If you keep them still she might come and play with you." It can be hard for young children to understand how others perceive them, so your child may not be ready for this type of feedback.

Ask family members and friends not to encourage your child's self-stimulatory behavior because that will make it harder for him to break the habit as he gets older. At the same time, make it clear that you don't want them to scold or tease him about it. They can help distract your child from these behaviors by playing with him or in some other way engaging him in an activity. If they're interested in finding out more about these behaviors, you might want to suggest that they take a look at FamilyConnect.

APH NEWS

NEW! Interactive U.S. Map with Talking Tactile Pen

1-01150-00 — \$259.00 + shipping

Optional Item

Stereo Headphones with Ear Cushions and Volume Control

1-18986-01 — \$14.50

The Interactive U.S. Map with Talking Tactile Pen is a fun, dynamic learning tool for accessing information about the 50 states!



The Interactive U.S. Map's combination of tactile, visual, and audio feedback contributes to a versatile learning experience that allows for independent, self-guided study by visually impaired and blind students and adults, as well as by sighted peers.

The Talking Tactile Pen consists of a non-writing stylus, a tactile Power button, an audio jack, and a micro-USB connector (for recharging the pen after long periods of use). The audio content can be heard through the pen's tiny speaker, however, standard headphones (headphones sold separately) or external speakers can provide better sound quality for the synthetic speech and sound effects.

The pen serves as a personal "tour guide" that gives the reader information about each location

visited on the map via multiple layers of audio recordings. The reader is allowed to "drill down" layer by layer via consecutive pen taps to learn about each state.

17 Pen Layers Include: State name; State abbreviation, State capital; Ten largest cities; Surroundings (land & water); Land area, water area, state water percentage; Highest point (elevation); Major rivers; Population estimate; Statehood year; State nickname; State symbols (bird, flower, tree, and song title); State motto; Famous people; Points of interest; Interesting facts; Spelling of state name

Includes

- Foldable tactile/large print map of the United States
- Modified Livescribe™ Echo™ Smartpen with audio content, 3.5mm headphone jack, and mini-USB port
- USB charging cable
- Storage pouch for pen and charging cable
- Carrying box to store components
- Large print instruction booklet
- Braille instruction booklet UEB Compliant

Livescribe[™] is a trademark of Livescribe Inc. The Talking Tactile Pen is a modified version of the Livescribe Echo[™] smartpen. All components of the Interactive U.S. Map with Talking Tactile Pen are copyrighted by the American Printing House for the Blind, Inc. and Touch Graphics, Inc.

Recommended ages: 8 years and up.

WARNING: Choking Hazard—Small Parts. Not intended for children ages 5 and under without adult supervision.

MAKING SENSE

BSA College Scholarships: Looking for a way to pay for college? Blind Service Association (BSA) is offering scholarships to help offset college expenses for legally blind students who are enrolled, or planning to enroll, in graduate or undergraduate school, community college, or trade school. Last year students received awards as high as \$4,000! Applications can be obtained after January 1, 2016 by contacting Bill Green at 312-236-0808 or email

bgreen@blindserviceassociation.org

Reprinted from MAKING SENSE, January 20146 Second Sense, Beyond vision loss, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, www.second-sense.org.





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

REGISTER FOR YOUR FREE PARENT WORKSHOP TODAY!





FRCD's hour long Lunch and Learn Webinars focus on specific aspects of the special education system in Illinois. All webinars are free.

Lunch and Learn Webinar: Evaluation Process under IDEA in Illinois

Wednesday, January 20, 12-1pm

Navigating the IEP Process Saturday, January 23, 10am-1pm

Lunch and Learn Webinar: Procedural Safeguards

Wednesday, January 27, 12-1pm

Skills For Effective Parent Advocacy Saturday, January 30

El ¿qué?, y ¿por qué? y ¿cómo? de "respuesta a la intervención" (RTI)/Sistema de apoyo Multinivelado (MTSS)

Saturday, January 30, 10am-12pm

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



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



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

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SPANISH TRANSLATOR

Noelia Gamino 708-655-2747



You welcomed me into your home When I was very small, And I stepped into your heart With smiles and mud and all.

But everyday I am growing And I'll be big someday, And all those muddy footprints Will have been washed away.

My hands are very small now Busy exploring everyday, Always leaving you reminders Of the things I do and say.

So here's a little welcome mat
To clean the messy feet,
Because I know that folks like you
Just simply can't be beat!!



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):	
Child(tell) s Ivames)	
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 316634 • Chicago, IL 60631	•

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 316634 Chicago, IL 60631

IPYI CALENDAR

2/27/16 IPVI Annual Meeting Frankfort

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

Newsletter Deadline for FEBRUARY is JANUARY 15, 2016



Check Out www.ipvi.org

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