

IPVI INSIGHTS

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

**February
2017**



PRESIDENT'S REPORT

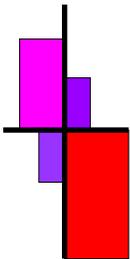
Filiberto Almendarez III

Hello IPVI members, families and friends. Hope everyone is enjoying their winter. It's a time where people help each other more. It's a time to enjoy the outdoors. Just buckle up and experience the snow, sled riding, skiing, ice skating or whatever your warm hearts can image. If you fall, you land on snow anyway (except for the ice part). After the fun, go inside and enjoy some warm Hot Chocolate carefully. Both little and big kids like chocolate. You know, "People don't notice whether it's winter or summer when they are Happy!" So, be Happy in the season.

On another note. The IPVI Annual Meeting is Saturday, March 4, 2017 at the Doubletree Hotel in Oakbrook. Additional information is in this month's newsletter. I would like to personally invite you to the meeting. All are invited including your child/children. Some parents have reached out and expressed interest. Please consider on attending, participating and/or possibly becoming a Board Member. It's an opportunity to meet wonderful families, help our children and make positive changes for their future.

Lastly, IPVI and the Chicago Lighthouse are sponsoring a day at the Children's Museum at Navy Pier on February 11. The Museum is children friendly and has various activities for our children. If you are interested, please call the telephone number in the newsletter to reserve a spot. The gathering is a popular event that fills up quickly. Hope to see you.

Come out and have some fun!





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**IPVI
ANNUAL MEETING**

**Saturday, March 4
Double Tree Oakbrook
1909 Spring Road
Oakbrook, IL 60523
12:00 - 3:00
844-684-0296**

**All are invited to
attend.**

**Please come with an
open heart and
consider volunteering
for a Board position.**



**RSVP:
February 22, 2017**



ADAPTIVE SPORTS FOR ALL CHICAGO LIGHTHOUSE & IPVI FAMILIES

A morning of fun for everyone

**The Chicago Children's Museum at Navy Pier
700 E. Grand Avenue, Suite 127
Chicago, IL 60611**

**Saturday, February 11, 2017
Pre-registered families 9:00 - 1:00
General public 10:00 - 1:00+**

**To register or for more information, please contact:
Gail Patterson at the Chicago Lighthouse -
(312) 997-3695**

**Pre-registration includes:
Free admission for Chicago Lighthouse &
IPVI Families
Free shuttle from the Chicago Lighthouse to
Navy Pier**

(first 50 people only!!!)

MEMORIES OF HEIDI MUSSER

Prepared for: IPVI Insights - Issue February 2017

GIVING BACK TO MY PARENTS

Over the past few months, I have discovered the true meaning of the following words:

*We experience our moments of purest joy at precisely those moments when we are causing it in others.
~ Anonymous ~*

In late August of last year, my Father, Frederick Musser, age 84, was hospitalized with a urine infection that brought about onset of Alzheimer. After he spent two month at a rehabilitation facility after his hospital stay, we welcomed him home again. My Mom's life totally changed; she took on the job of his caretaker. Life at home was not the same anymore; the calm, quiet home atmosphere from the past had changed...

Like through a divine intervention, I suggested to my mother to make contact with HOW (House of Welcome) at the North Shore Senior Center in Northfield, where for the past nine years, I have volunteered to play the piano for their senior residents with memory loss.

When Mom contacted them by phone, they remembered me with fondness! Their respect for me as a totally blind individual playing the piano did the trick to open their hearts and door for my Dad to come in for an interview and be welcomed into their warm family style environment.

My Dad joins them now three times weekly for their day program on Mondays, Wednesdays and Fridays. He happens to love being part of their friendly environment. He has found friends, who accept him and love him just the way he is.

Reflecting on my life, I would never be where I am without the dedication and infinite love of both of my parents. They always supported and loved me, when others did not. They planted within me the happiness and love to help others. They gave me the tools to jump in at the moment when BOTH needed me! I was able to come up with an idea to make life easier for them when my two siblings, who live in different states -- my brother, Dr. Siegfried Musser, in Texas and my sister, Dr. Ursula Harkness, in North Carolina -- could not be with us because of the demands of their own family and career.

I feel that I not only helped my parents, but others through my piano playing. I plan to be more frequently at HOW now, so I can spread the joy of seniors singing together to many more. When I hear the seniors' enthusiastic singing with my Dad among them, I feel that I use my musical gift the way my Creator has probably planned it for me.

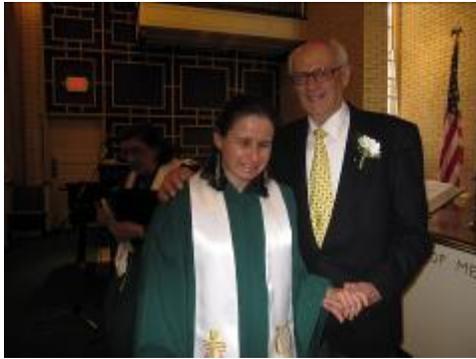
I feel immensely lucky that when I was 9 years old, Principal Pianist Mary Sauer of the Chicago Symphony Orchestra (CSO) took me on as her piano student. She filled my parents with hope for a future for me, when educators wrote me off. This month she will be honored after serving the CSO for 57 years. I wonder, if her love for me also will help plant tiny seeds for more blind/visually impaired children to build a life enriched with classical piano music. Only time will tell.

Our society grows in justice and peace as we allow energies of love and concern to rise up within ourselves.

~ Jean Vanier, Becoming Human"

* * *

**Please write me:
hmusser@msn.com
773-412-4454 (cell)**



My Father with me after singing with the choir at Carter Westminster United Presbyterian Church in Skokie on Father's Day 2015.

MagWin



FROM THIS TO THIS

Are you having problems seeing what is on your computer screen?

MagWin screen reader can help! MagWin reading software enlarges what is on your computer screen. MagWin incorporates our ground breaking screen magnification/reading software into an easy to use software package.

- Works on any computer
- Reduces Glare
- 100% portable
- Font smoothing for clear text
- Mouse enhancements
- Zoom scroll bars
- Windows Vista/7/8/10 compatible



Unlock eye care for 15 million Americans who need it the most.

In the U.S, 1 in 4 kids have a vision problem, and nearly 1 in 10 adults suffer from vision loss. But most cases of blindness can be prevented or treated, beginning with a single visit to an eye doctor.

The problem is, not everyone can access care. And because of that, some members of our most vulnerable communities are losing out on more than just their sight.

Losing your sight means you're less able to succeed in school or keep your job, and the people impacted the most are often the least able to pay. Millions of Americans still unnecessarily experience vision loss or blindness, and many of these cases are preventable.

Loss of vision costs the U.S. \$145 billion a year, but the federal government spends just \$3.8 million on preventive efforts to stop it. That's why, with your help, we are calling on Congress to dedicate another \$6.3 million to prevent blindness in children and adults. With these funds, we'll be able to help **15 million more Americans** live a life with healthy sight.

The House and Senate Appropriations Committees have the power to allocate this funding. Will you help us reach our target of 35,000 people before they start discussions in March.

Learn more about the campaign and go to <http://act.seenow.org/sign/unlock-eyes/?source=PB1> to sign the petition.



Have you ever been given wrong information about your child's vision diagnosis or perhaps steered in the opposite direction of how to help your child reach his full potential? READ MORE at: **WonderBaby.org**



When My School Gave Up on My Child
By Judith Carter

Here's a truth I'm sure you will agree with: Raising a child, any child, is hard. Kids don't come with instruction manuals and we parents are often left wondering if we made the right decisions. READ MORE at: **WonderBaby.org**



Transitioning an Adopted Child to School
By Ellen Nelson

Edy is originally from Guatemala and we adopted him when he was five years old. Edy has three older siblings who are our biological children. READ MORE at: **WonderBaby.org**



Top 8 Misconceptions About Cortical Visual Impairment (CVI)
By Hillary Kleck



Our 20 Favorite iPad Apps for Kids With CVI
By Amber Bobnar

For kids with Cortical Visual Impairment (CVI) there are a few things to keep in mind when helping them use their vision: Keep their environment clutter free, use bright attractive and high-contrasting colors, and accompany visuals with simple movements when possible. READ MORE at: **WonderBaby.org**



My Baby is Blind...What Do I Do?
By Amber Bobnar

When your baby is diagnosed with a visual impairment you may feel lost at first. Like many parents, you've probably never known anyone who was blind and blindness wasn't anything you've ever really spent much time thinking about. READ MORE at: **WonderBaby.org**

IPVI DUES

IPVI Members:

It's a brand new year for IPVI which also brings a brand new year for collecting our \$15.00 dues from all members of IPVI. This will cover the whole year of 2017.

IPVI relies on these dues for fees that have to be paid every year, supplies, our yearly Zoo Outing, and donations for our scholarships. A full itemized list will be handed out at our Annual Meeting.

If we have an email address for you, you'll be sent a reminder that our newsletter is online, so if you don't receive the reminder, please include your email address on your dues check.

You dues are an integral part of our Not-for-Profit organization, and we hope that we can count on you this year, and many years to come.

From your Board Members:

Fil Almendarez
Mary Zabelski
Joan Bielawski

*to all who
have already
paid their
Dues.*

FOUNDATION
FIGHTING
BLINDNESS

Save the date for the **CHICAGO**



Vision Seminar
February 11, 2017
8:00 am-12:00 noon

Foundation Fighting Blindness Presents the Chicago Vision Seminar

Please join the Foundation Fighting Blindness for a **FREE** informative seminar on age-related macular degeneration, retinitis pigmentosa, and related diseases. Leading researchers and specialists will be presenting information on the latest research advances and current treatments for these diseases as well as valuable information on vision enhancement and rehabilitation.

WHEN:

Saturday, February 11, 2017
8:00am – 12:00 noon

WHERE:

[The Stonegate Conference and Banquet Centre](#)
2401 West Higgins Road
Hoffman Estates, IL 60169

SEMINAR TOPICS INCLUDE:

- Age-related macular degeneration
- Retinitis pigmentosa
- Current treatments
- Clinical trials
- Research advancements
- Low-vision rehabilitation

Attending the seminar and parking are **FREE**. Seating is limited, so advanced registration is requested. A continental breakfast will be served. On-site vendors will exhibit low-vision products and services. **Questions?** Call 866-602-9964 or visit www.FightBlindness.org/ChicagoSeminar.

FAMILY CONNECT WEBSITE

Winter Weather Orientation and Mobility (Oh My!) for Children and Teens with Visual Impairments

By Shannon Carollo



Now I don't know where you live, but I am freezing here in Delaware and most certainly have winter weather on the brain! Bring it on, winter! Well, actually...go easy. Please, I'm begging you, go easy.

In thinking about preparing for winter, it occurred to me that we should discuss cold weather preparations and skills for children and teens with visual impairments.

Winter Gear Is a Necessity

If your child is spending time outdoors in cold weather, snow, and/ or ice, of course winter gear is a necessity. To purchase the most appropriate gear, consider the following:

- A beanie is considered the best style of winter hat for folks with visual impairments, as it can lay or be folded above the ears. Ear muffs, winter headbands, and the like will impede your child's ability to listen to environmental clues.
- When considering hand warmth (and I'm glad you are, as holding a cane or dog guide harness means one hand is exposed to the harsh elements), knit mittens are the gold standard. Alternatively, mittens you've adapted or tube-shaped wraps

over each hand are on point. Each allows optimal feedback while providing warmth.

- To minimize slipping on icy surfaces, ensure your child's shoes are designed to provide traction. You can also purchase and attach "trax" (such as **YakTrax**) for increased stability in the snow or on ice.
- Glare is brutal where snow abounds; be prepared with good sunglasses (likely amber tinted lenses will be recommended) and a visor.
- The best mobility cane for freezing conditions is one that doesn't collapse. There are not only no joints which can freeze, but it also holds up well if it is leaned on in icy conditions.
- The best cane tip for snow conditions depends on the technique your child is using. If your child is poking snow which has been iced-over, a thin tip is best; if your child is gliding over soft snow, a broad tip is best.

Winter Weather Mobility Techniques

That about covers winter gear (minus thermal layers and a great jacket); now let's talk mobility techniques, skills, and strategies used in the snow and ice:

- Your child will learn a light cane touch for fluffy snow and a heavier touch for icy conditions. Additionally, your child will learn to poke the snow with the cane to gauge its depth and consistency.
- Your child will learn to choose a route that has been recently plowed (when possible).
- Your child will learn to ask for assistance to navigate around icy terrain.
- Your child will learn to call for a taxi or call a friend if conditions worsen and it is no longer safe to travel.
- Your child will learn to leave the house with ample time when weather conditions

are poor.

- Your child will learn to utilize a GPS, a particularly helpful tool when landmarks are unrecognizable.



YakTrax

You're Not Alone: Starting College When You Are Blind or Visually Impaired

From the FB Press Book College Bound: A Guide for Students with Visual Impairments, Second Edition by Ellen Trief



Starting college can be overwhelming, but if you find yourself feeling this way, you're not alone. Just about everyone finds that going to college means making many big adjustments all at once. At the same time, the transition to college can be the widening of your world. It can be the beginning of finding out who you are, what you want to do with your life, what really interests you, and who your friends and contacts will be for many years to come. Expect to feel confused and lonely sometimes, but remember that this is all a process and an ongoing journey.

In those moments when you do feel at a loss, here are some suggestions that may help:

- While you're trying to make new friends and form a new social life, emotional support from people who care about you is helpful. Touching base with your friends from high school and your community, your parents, your siblings or other family members, and trusted individuals such as former teachers can boost your spirits and reinforce your feelings of acceptance and self-worth.
- Joining groups, or maintaining your membership in them, is another way of staying connected with people who can offer you information, tips, help, and camaraderie. Sports, web-based interest groups, and campus activities are just some possibilities.
- Consider volunteering, contacting professional and student membership organizations, and exploring mentoring arrangements such as [CareerConnect](#), the employment and careers mentor database maintained by the American Foundation for the Blind.
- Social media can provide you with a network of people and resources. You can bounce ideas off them, turn to them for help, and express your interests and needs.
- Your college and its campus and national organizations in the field of visual impairment and blindness (see Appendix B) also offer resources, including staff that can provide useful information and a friendly ear. Counselors in academic, disability, placement, and psychological services on campus are all good sources of assistance and support if needed. So are outreach and hotline operators at national organizations.
- Keep in mind that this is just the start of a rewarding transition. For now, you're just learning the ropes, but soon you'll be moving into another, more informed and self-assured phase of your life.

For more information about helping students prepare for their new life in college, develop useful skills, and negotiate for and coordinate appropriate services check out the AFB Press book *College Bound: Practical Steps for Students Who Are Blind or Visually Impaired*, available in the AFB Store at www.afb.org/store or by calling 1-800-232-3044.

Teaching Our Children with Visual Impairments to Set Goals this New Year

By Shannon Carollo



I'm not one to establish an annual "New Year's resolution". I realize if I don't have the motivation to challenge myself or change a habit during the year, I unfortunately won't mystically attain it come January 1. I don't like setting myself up for failure!

When it comes to setting goals, I'm less motivated by the first of the year and more motivated by both internal rewards (we call this intrinsic motivation) and natural consequences.

Internal rewards: It feels satisfying to have a clean bedroom, so I put items and clothes where they belong.

Natural consequences: If I eat too much chocolate, I feel sick. Therefore, I (mostly) limit myself.

So while I'm not one for New Year's resolu-

tions, I do realize we all have New Year's Day and resolutions on the brain—it seems a natural time to talk with our children about setting goals. Let's share with them why we choose to pursue goals (boiled down to feeling good or to avoid feeling bad) and what goals we choose to pursue. Share a few successes and share a few failures, as well as how you handled them. They need to know how to handle both.

Next, help them recognize goals they already pursue to feel pleasant and goals they already pursue to avoid unpleasant outcomes.

Take it a step further. Help your child realize what he or she is motivated to change and teach your child to **problem solve** a solution. The solution can then be refined into a main goal and accompanied mini objectives. This is key; substantial goals are overwhelming, while mini objectives are achievable.

Tell them our lives are like train cars and the train tracks are the goals we choose to pursue. Without them, we're without a course and where we end up is haphazard.

No need to leave our destinations to chance. While we're not in full control of every outcome, we can decide where we want to be and set goals to get there.

Goal-Setting Suggestions

- Reading and writing development in pre-schoolers
- Learning screen-magnification software
- Acquiring the skills needed to make friends
- Job-exploration for blind adolescents

Happy goal-setting and a very happy New Year!

Overview of Services for Children Who Are Blind or Visually Impaired

When your child is born with a visual impairment, or acquires one through illness or injury, you may feel shocked, bewildered, and frightened. You may also find that your immediate family members, local doctors, and neighborhood schools are unfamiliar with the impact of visual impairment on a child's learning and education. But you're not alone.

National, State, and Local Organizations

A number of national organizations are dedicated to the well-being of visually impaired children, and they're important sources of information and support for you. Other sources include:

- The supervising agency for early intervention services for children **under the age of three** in each state. The lead agency in each state may be housed in state departments of education, health, human services, or rehabilitation, although some are in agencies outside the state system. These agencies, also called Part C early intervention agencies, usually provide referrals to local programs.
- Special education professionals in state education departments that oversee education for children with disabilities, and the state vision consultant, if your state has one, who is involved in coordinating the efforts of teachers who specialize in working with visually impaired children. Your state's department of education can tell you whether there is one in your state.
- Special schools—sometimes referred to as residential or state schools or schools for the blind—and their experienced staff.
- You may also call your local school district for assistance in receiving services. The district may have an office of special edu-

cation or their main switchboard can assist you in starting the process for receiving services.

You'll find information on how to connect with these resources on this site.

Parent Groups

At times it may seem as if the only people who understand what you're going through are people who have been there too. Other parents of visually impaired children, either individually or in organized groups, can offer advice based on firsthand experience, good information, and ongoing support. [The National Association for Parents of Children with Visual Impairments \(NAPVI\) www.napvi.org](http://www.napvi.org), and other parent organizations mentioned in the [Overview of the Service System for Children http://www.familyconnect.org/info/after-the-diagnosis/overview-of-services/overview-of-the-service-system-for-children/23](http://www.familyconnect.org/info/after-the-diagnosis/overview-of-services/overview-of-the-service-system-for-children/23) can help you to network with other families.

A Thankful Mom

*By Alicia Wolfe
Teacher of the Visually Impaired
and AFB Content Consultant*

This article can be found at:

<http://www.familyconnect.org/info/browse-by-age/teenagers/teens-voices/a-thankful-mom/1235>

As this article is rather long, please go to the website above and read this heart-rending story of triumph over all.



IPVI

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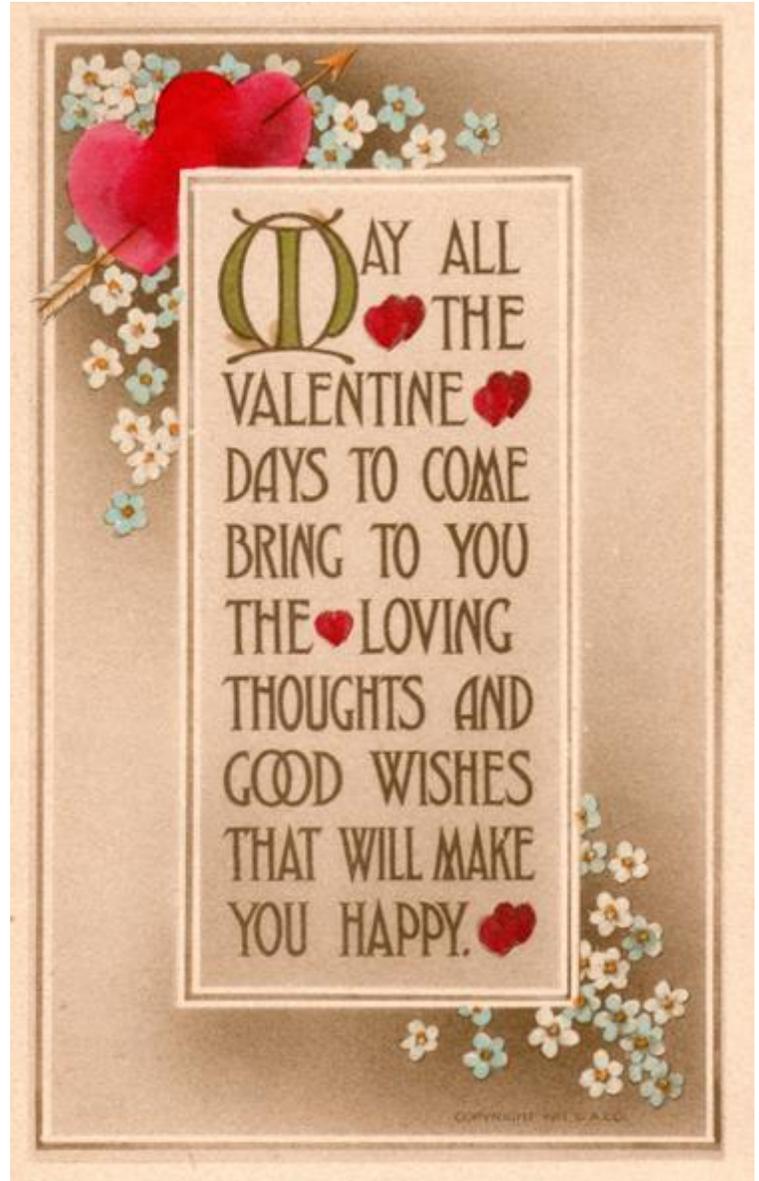
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Join **IPVI** or renew your membership today!

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: \$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 316634 • Chicago, IL 60631

Have questions or need more information?

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

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

IPVI CALENDAR

- | | | |
|------------------|---|------------------------|
| ▶ February 11 | Adaptive Sports For All | Chicago |
| ▶ February 11 | The Chicago Vision Seminar (FFB) | Hoffman Estates |
| ▶ March 4 | IPVI's Annual Meeting | Oakbrook |

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

**Newsletter Deadline for
March 2017 is February 15**



**Check Out
www.ipvi.org**

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