

# IPVI INSIGHTS

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

**January  
2017**



## **PRESIDENT'S REPORT**

Filiberto Almendarez III

Happy New Year! Wishing all a Happy and Healthy New Year. Hope your wishes come true. As for me, I am looking forward to another year with Family and Friends. Speaking of family and friends, I would like to thank the Chicago Lighthouse and IPVI families who came out to celebrate at the annual Christmas Party. Another great turnout. Fortunately, I assisted in carving the turkey and ham, so I had the pleasure of chatting with our beautiful children and their families. I enjoyed the little ones navigating their way around and their smiling faces while sitting on Santa's lap. Thank you everyone for making the event memorable!

For the New Year, I share words of encouragement that were shared with me.

1. Be the reason someone Smiles today
2. Everyday is a second chance
3. Be Somebody, Nobody thought you could be
4. You never realize how strong you are until being strong is the only choice you have
5. Stop saying I Wish and Start saying I Will
6. If it doesn't challenge you, it won't change you
7. Don't be afraid of being different, be afraid of being the same as everyone else
8. The Struggle you're in Today, is developing the Strength you need for Tomorrow
9. You only fail, when you fail to Try
10. Believe in yourself

I welcome another wonderful Year and hope to see you at the next IPVI event. Take Care, Everyone!

**Inside This Issue:**

<b>President's Report</b>	1
<b>IPVI Dues</b>	2
<b>Memories of Heidi Musser</b>	3
<b>News from Matt Juskie</b>	3
<b>WonderBaby.org</b>	4
<b>Vestibular Stimulation...</b>	4
<b>Everyday Activities for Blind Children</b>	4
<b>Development Charts...</b>	4
<b>Potty Training Your Special Needs Child</b>	4
<b>Is Early Intervention Always the Best Approach...</b>	4
<b>Family Connect Website</b>	6
<b>Prevent Blindness Transitional Letter to Donald Trump</b>	7
<b>Making Sense</b>	9
<b>College Scholarships</b>	9
<b>Guide for College-Bound Students</b>	9
<b>Chicago Cultural Accessibility Consortium</b>	9
<b>New Year's Resolution</b>	9
<b>IPVI Board of Directors</b>	10
<b>New Year's Poem</b>	10
<b>IPVI Membership Dues</b>	11
<b>IPVI Calendar of Events</b>	12



**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, (20 copies of 12 pages) of black and white printed newsletters, supplies, and our yearly Zoo Outing. 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

## MEMORIES OF HEIDI MUSSER

Prepared for: IPVI INSIGHTS - January 2017

Oh, how proud I feel of Matthew! Please read his article below. He sounds so self-assured and happy!

I suggest that IPVI appoints him as Ambassador for Illinois Blind and Visually Impaired College Students. I feel confident that he will encourage other blind and visually impaired college students to come forward and share their college experiences to give parents the assurance that they can expect that their sons and daughters will develop independence and receive a college education in their chosen field with good support for their unique needs.

When I attended Northeastern Illinois University from 1990 to 1996, I was not so lucky, because guidelines for support were not laid out for educators - even the ADA was in place.

My heartfelt congratulations, Matthew! Happy New Year!

## NEWS FROM MATT JUSKIE

### **College Experiences For Those With Visual Impairments**

By: Matthew Juskie

Happy New Year, Everyone! I hope it was a wonderful holiday season for all of you. For this column since I am in my third year at Illinois State University (ISU), I was asked to discuss what it is like to be in college with a visual impairment.

First off, many might think that it has to be absolutely miserable and impossible to make friends, but it is exactly the opposite. So many parents are nervous about sending their kids off to college wondering if they will fit in just like in high school. I would have to say it is leaps and bounds easier to fit in on a college campus than in high school. At college, you will find people from all types of backgrounds - from the rural/country to a big city, from large high schools to small high schools, as well as those who are shy to those who are outgoing, and everything in between.

Also, you can re-invent or expand yourself as well. For example, so far I have managed to start my own club, the

Student Disability Network, which really pulls in other like individuals who have various issues. I am the president and this club helps support all students with disabilities. I also joined the Braille Birds Club as its treasurer. This group has allowed me to meet a lot of contacts with visual issues and similar situations to what I am going through.

With this being said, I was very pleased with the accommodation services at ISU. The school has been extremely accommodating for classes, scheduling times, and everything else. Also today's technology really has helped this side of things. For example, ISU has separate testing times and rooms available; they allow visual impaired students extra time; and much more. So I recommend as soon as possible, that you speak with your college intake administrator and inquire as to the special accommodations the school offers for those with disabilities or other medical issues.

The biggest thing I would suggest to you would be don't be too nervous. Enjoy the wide variety of experiences you will have. For example, enjoy the time in the dorms. You will meet so many awesome people there. As much as everyone just wants to hang by oneself, you should socialize with your floor mates. One of my best friends lived two doors down from me freshman year.

Next, take advantage of the campus event(s) that highlight all the clubs and/or sports teams offered at the college. This is a great way to learn about all of the different clubs/sports that are there at one time and in one place. You may just find something you like and stick with or see something that is missing so you go start a club/group yourself!

Lastly, manage your time. It doesn't matter whether you have a visual impairment or not, time management is so important. Don't bite off more than you can chew is important, but you also want to be involved. That's where the happy medium comes into play.

The point I am trying to make is that just because you have a visual impairment or other issue does not mean you should not live college to the fullest! It's a great time to meet new people and learn a lot! You'll grow educationally, independently and socially so enjoy these experiences to the fullest. Good luck! Go Redbirds!



### **Vestibular Stimulation: Making Sense of the Other Senses When Your Child is Blind**

*By Jennifer Stevens*

We all experience the world through our senses: vision, hearing, etc. But have you heard of proprioception or vestibular sense? READ MORE at: **WonderBaby.org**



### **Everyday Activities for Blind Children**

*By Amber Bobnar*

Growing up without sight can be difficult. It can often be hard for your child to fill in the gaps or to fully understand what's going on around them. That's why, especially when they're little, they need your help to explain to them how the world works or how people accomplish simple tasks. READ MORE at: **WonderBaby.org**



### **Developmental Charts for Blind & Visually Impaired Babies and Children**

*By Amber Bobnar*

Watching your child grow and fall behind traditional development charts can be difficult. You understand that it's normal for blind babies to develop at a slower pace, but how slow is normal... and how slow is too slow? READ MORE at: **WonderBaby.org**



### **Potty Training Your Special Needs Child**

*By Amber Bobnar*

Potty training a child is difficult under any circumstances, but when your child has special needs you will need to take their abilities and delays into consideration before you can begin potty training. READ MORE at: **WonderBaby.org**

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### **Is Early Intervention Always the Best Approach for a Blind Baby?**

*By Anastasia*

Your child is born with a very rare condition, he or she is labeled "special needs" and you, after recovering from grief and anger at the world because your child is blind... READ MORE at: **WonderBaby.org**

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FAMILY CONNECT WEBSITE

**Congress Allows NLS to Explore Providing Refreshable Braille Displays**

**Date Posted: 12/01/2016**

By Mark Layman and Mark Schwartz

A change in federal law has put NLS one step closer to realizing its goal of providing low-cost refreshable braille displays to patrons.

On July 29, 2016, President Obama signed into law an amendment to the 1931 Pratt-Smoot Act that allows NLS to provide playback equipment in all formats, not just audio. The law previously authorized NLS expenditures “for [the] purchase, maintenance, and replacement of reproducers for . . . sound-reproduction recordings.” Sponsored by Senator Charles Schumer (D-NY) and co-sponsored by Senator Roy Blunt (R-MO), the amendment reads “for purchase, maintenance, and replacement of reproducers for any such forms,” allowing NLS to explore the possibility of making braille displays available to its patrons.

“Up until now, refreshable braille displays have been quite expensive — \$2,000 and up,” said NLS Director Karen Keninger. “But new products are in the pipeline that promise to be much more affordable. If we can get a low-cost, low-maintenance, refreshable braille display in the hands of our patrons, it would open up worlds of information that currently are not available to them.”

Throughout its history, NLS has provided its patrons with the equipment they need to listen to talking books, starting with phonographs to play records in the 1930s, then cassette tapes in the 1970s, and now digital cartridges and players. When Keninger became director in 2012, she said one of her goals was for NLS to provide patrons a device to read electronic braille (ebraille) books and magazines. But that couldn’t be done without a change in the Pratt-Smoot Act, the NLS authorizing legislation.

A Government Accountability Office (GAO) report earlier this year recommended that Congress make that change. In its report, GAO said that NLS “is considering whether to adopt several new technologies for delivering braille and audio content to its users which have the potential to improve services and reduce costs. However, in one case — providing refreshable braille devices to its users —

NLS’s efforts are hampered by limitations in its authorizing statute, among other factors . . . Without a change in federal law, NLS will have to forgo the opportunity to provide braille in a more modern and potentially cost-effective manner by distributing refreshable braille devices to its users.” The amendment removed that legal barrier.

Keninger said patrons would benefit in many ways if NLS is able to provide free or low-cost refreshable braille displays. The devices are less bulky to store and carry than the multiple volumes of hard-copy braille books. Also ebraille can be delivered to patrons more quickly and is less costly than hard-copy braille, so NLS could produce more braille books. The GAO report suggested that NLS could actually save money by providing refreshable braille displays. It cited a consultant’s study commissioned by NLS that estimated the total annual cost of producing, storing, and delivering hard-copy braille books and magazines at about \$17 million.

The GAO report suggested that NLS could actually save money by providing refreshable braille displays. But loaning refreshable braille displays to users and replacing hard-copy braille with ebraille could save almost \$10 million per year, the study projected.

“One of the more popular examples my colleagues give to explain savings is the Harry Potter books,” said Keninger. “As the Harry Potter series became more successful, the books grew longer. The Order of the Phoenix book is 13 volumes long or 13 mailed packages. Using a braille e-reader would enable one to download the entire book at once.” Promoting braille is one of NLS’s strategic goals, and as the GAO report acknowledged “braille is the literacy medium for those who are blind and visually impaired . . . Unlike audio, it is a direct corollary to print and displays features of print, such as capitalization and punctuation . . . There is also some evidence suggesting that blind people have better employment outcomes if they use braille.”

“We can now investigate how to provide refreshable braille displays,” Keninger said. “Our patrons could have access to even more of the reading materials that they need to improve their quality of life and increase their engagement with the world. And that is what we’re all about.”

\* \* \*



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PreventBlindness.org

November 22, 2016

Donald J. Trump  
President-Elect  
1717 Pennsylvania Avenue  
Washington, DC 20006

Dear President-Elect Trump:

As you prepare to take office, [Prevent Blindness](#) would like to bring to your attention a largely overlooked, but significant problem facing our country – our collective eye health! Prevent Blindness represents millions of people across the country and is the nation’s leading volunteer eye health and safety organization dedicated to fighting blindness and saving sight, as well as to ensure those living with low vision are able to enjoy a high quality of life. Eyesight is highly valued; it is central to an adult’s employability, a child’s success in school, as well as sustaining independence as we grow older. Eye health problems have a strong correlation to other health concerns (diabetes, smoking, depression, falls, etc.) and in public opinion polls conducted over the past 40 years Americans have consistently identified fear of vision loss as second only to fear of cancer.<sup>i</sup> And yet, a coordinated national approach to interventions, supported by adequate funding is currently not in place.

Among people over the age of 40, vision related eye diseases are unnecessarily common – cataract (24.4 million); diabetic retinopathy (7.7 million); macular degeneration (2.1 million); and glaucoma (2.7 million).<sup>ii</sup> And uncorrected refractive errors affect 13.6% of the population over the age of 12.<sup>iii</sup> Largely due to our aging population and other changes in demographics, these numbers are likely to increase dramatically in the coming decades.<sup>iv</sup>

Among our nation’s children, more than 12.1 million school-age children, or one in four, have some form of vision problem;<sup>v</sup> and the growing prevalence of these problems begins before a child even enters school, with eye conditions affecting 5 to 10 percent of preschool-age children.<sup>vi</sup>

The financial impact of these problems is enormous. In terms of direct medical costs, eye disorders rank 5<sup>th</sup> among the top eight chronic conditions, with the overall annual cost of vision problems in the U.S. calculated at **\$145 billion**.<sup>vii</sup> **Without significant planning and intervention, our own research suggests this cost could rise to as much as \$717 billion by the year 2050.**



We know that prevention works. And yet, currently, the federal government (through the Centers for Disease Control and Prevention (CDC)) allocates \$3.806 million toward prevention of vision problems – with only \$512,000 funding their overall vision health initiative. This means that for every \$37,720 vision problems are costing our country, we are only allocating a **single dollar** toward their prevention. As you begin to focus on your healthcare plan for the country and consider appointments throughout the Department of Health and Human Services (HHS) – including the CDC, the Health Resources and Services Administration (HRSA), and the National Eye Institute (NEI) – we encourage you to ensure that eye health does not continue to be pushed to the side of the healthcare dialogue.

***Specifically, we ask that you support adequate resources for the Vision Health Initiative of the CDC to enact the surveillance and state grant programs necessary to drive down the costs of adult vision problems, and to advance a children’s vision health program within HRSA that would lead to direct support for state level programs resulting in earlier detection and treatment of vision problems, leading to life-long success in young children.***

The National Academies of Sciences, Engineering, and Medicine's Health & Medicine Division (formerly known as the Institute of Medicine or IOM) recently issued [Making Eye Health a Population Health Imperative: Vision for Tomorrow](#). Throughout this report, there were a number of recommendations that made a direct call for federal government action. Among these were recommendations for the HHS to:

1. Issue a call to action to motivate nationwide action toward achieving a reduction in the burden of vision impairment across the lifespan of people in the United States.
2. Launch a coordinated public awareness campaign to promote policies and practices that encourage eye and vision health across the lifespan, reduce vision impairment, and promote health equity.
3. Create an interagency workgroup to develop a common research agenda and coordinated eye and vision health research and demonstration grant programs that target the leading causes, consequences, and unmet needs of vision impairment.
4. Convene a panel to develop a single set of evidence-based clinical and rehabilitation practice guidelines and measures that can be used by eye care professionals, other care providers, and public health professionals to prevent, screen for, detect, monitor, diagnose, and treat eye and vision problems.
5. Develop, through the CDC, a coordinated surveillance system for eye and vision health in the United States.
6. Build state and local public health capacity, by prioritizing and expanding the CDC's vision grant program, in partnership with state-based chronic disease programs and other clinical and non-clinical stakeholders, to a) design, implement, and evaluate programs for the primary prevention of conditions leading to visual impairment, including policies to reduce eye injuries; b) develop and evaluate policies and systems that facilitate access to, and utilization of, patient-centered vision care and rehabilitation services, including integration and coordination among care providers; and c) develop and evaluate initiatives to improve environments and socioeconomic conditions that underpin good eye and vision health and reduce injuries in communities.

In addition to acknowledging the important – yet underfunded – roles of the Vision Health Initiative at the CDC and the NEI, the report committee acknowledged the HRSA-funded quality improvement work being led by the [National Center for Children's Vision and Eye Health](#) as a leading example of the importance of continuous quality improvement in advancing population health.

Importantly, the report recognizes that for too long vision and eye health have not received the attention and investment they warrant, given their importance to public health. At Prevent Blindness we look forward to working with the upcoming Congress and its [Congressional Vision Caucus](#) to ensure that vision programs currently in place at the CDC will be supported with the necessary resources to turn back the tide of vision problems before us, and to explore opportunities to support the Maternal and Child Health Bureau's interests related to addressing the eye health needs of our youngest citizens through a systems-based approach to ensuring all children have adequate eye care throughout their childhood, and particularly in their youngest years. Your support of these programs will be significant.

We look forward to working with you and your Administration to address these challenges and to ensure that no one should needlessly go through life without optimal vision. Please feel free to utilize Prevent Blindness and our National Center for Children's Vision and Eye Health as a resource throughout your transition period and beyond. For any assistance, please reach out to Jeff Todd, Chief Operating Officer (312.363.6026; [jtodd@preventblindness.org](mailto:jtodd@preventblindness.org)) or Kira Baldonado, Director of National Center for Children's Vision and Eye Health (312.363.6038; [kbaldonado@preventblindness.org](mailto:kbaldonado@preventblindness.org))

Yours in partnership,



Hugh R. Parry  
President & CEO



Richard L. Sanchez  
Board Chair



Torrey DeKeyser  
Chair, Government Affairs Committee

MAKING SENSE

**College Scholarships:** It's time to get those essays and applications ready to apply for college scholarships! Here are two you'll want to investigate. The National Federation of the Blind (NFB) offers 30 scholarships ranging from \$3,000 to \$12,000 for legally blind, full-time college students (high school seniors included). You'll find all the application requirements by visiting

[www.nfb.org/scholarships](http://www.nfb.org/scholarships)

or via email at [scholarships@nfb.org](mailto:scholarships@nfb.org). Deadline is March 31, 2017.

Blind Service Association in Chicago offers scholarships as high as \$4,000 to legally blind students enrolled, or planning to be enrolled, in graduate school, undergraduate, community college or trade school in the fall of 2017. Applicants must live in Chicago or the surrounding counties. For an application and more details, call Bill Green at 312-236-0808 or email [bgreen@blindserviceassociation.org](mailto:bgreen@blindserviceassociation.org). Deadline for submission is April 1, 2017.

**Guide for College-Bound Students:** Making the transition from high school to college is a big step for any young adult. This turning point in life has different and additional challenges for the student with vision loss. College-Bound: A Guide for Students who are Blind or Visually Impaired by Ellen Trief has recently been revised and provides important information and tips for preparing for college. The book helps students develop useful skills to advocate and negotiate for accommodations and services. The large print guide and companion webinar give tips on organization, time management, assistive technology and the college application process. To purchase this valuable resource, visit the American

Foundation of the Blind store at [www.afb.org/store](http://www.afb.org/store) or call 800-232-3044.

**Chicago Cultural Accessibility Consortium:** You may have noticed that several cultural institutions in Chicago are offering accessible programming and events. These accessible events are a result of the efforts of the Chicago Accessibility Consortium, a volunteer-run group of cultural administrators and people with disabilities who believe all should have access to Chicago's renowned art and theatre scene. They have created the CCAC Access calendar with over 200 upcoming accessible theatre performances and museum events from 30 different cultural institutions in Chicago. The online calendar can be found at [www.chicagoculturalaccess.org/calendar](http://www.chicagoculturalaccess.org/calendar). Let's applaud the CCAC's dedication to accessibility and support these events with your attendance!

**New Year's Resolution - Get Fit:** It's time to start working out to help lose those holiday pounds. Don't want to hit the gym? BlindAlive Eyes Free Fitness has the answer! They have created fully accessible, audio-described, fitness workouts you can do in the comfort of your home. Choose from a variety of workouts including beginner and advanced levels of cardio, Pilates, yoga, whole body workouts and stretches. Check out their blog and favorite product picks, too. Workouts are fully described, tested by people with vision loss and come in a variety of formats including digital download, flash drive or SD card. To purchase your new fitness routine, visit [www.blindalive.com](http://www.blindalive.com).

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May Light always surround you;  
Hope kindle and rebound you.  
May your Hurts turn to Healing;  
Your Heart embrace Feeling.  
May Wounds become Wisdom;  
Every Kindness a Prism.  
May Laughter infect you;  
Your Passion resurrect you.  
May Goodness inspire  
your Deepest Desires.  
Through all that you Reach For,  
May your arms Never Tire.





## 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:

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**Have questions or need  
more information?**

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

**Illinois Association for Parents of  
Children with Visual Impairments  
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Chicago, IL 60631**

## **IPVI CALENDAR**

*Annual Meeting Coming Soon*  
*More Information in the February Newsletter*

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

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



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

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