

IPVI INSIGHTS



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

APRIL 2018

PRESIDENT'S REPORT

Filiberto Almendarez III

IPVI families and members, I would like to personally welcome you to our

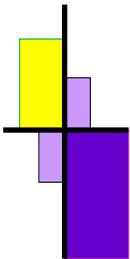
**Annual Meeting on Saturday April 14, 2018
11:00am at The Double Tree in Oak Brook**

Arrive early so we can chat and catch up on our children's progress. Consider the meeting as another outing to spend time together. The only difference is discussing IPVI changes and welcoming new parents taking on the leadership roles as Board members. Also, please review all proposed changes and we encourage your input. As I stated before, if you are interested in being a Board member, please reach out. It's a beautiful way to meet wonderful families and promote a great cause, especially for our children.

Parents, to be a part of your child tomorrow's, you have to be a part of their life today. "Be who you needed when you were young". Help others, help their children. Share strength, courage and hope. Remember, your child believes in themselves, because you as the parent believed in them, first. As you all know, "We have learned about strengths we didn't know we had and tears we didn't know existed".

IPVI families, I thank you for the memories, and fellow Board members I thank you for all your assistance. You all have made my experience amazingly magnificent. Thank You!

See you April 14, 2018. Happy Spring and Take Care!



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FAMILY CONNECT WEBSITE

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AFB American Foundation[®]
for the Blind

Expanding possibilities for people with vision loss



The American Foundation for the Blind (AFB) and the American Printing House for the Blind (APH) Partner for a Future of No Limits for People Who Are Blind

APH to Provide Ongoing Stewardship for Key Programs Founded by AFB

Washington, DC (February 7, 2018)—Today, the American Foundation for the Blind (AFB) and the American Printing House for the Blind (APH) announced a partnership with the mutual goal of generating substantial impact on the lives of children and adults who are blind or visually impaired. APH will become the steward of several key programs founded by AFB and assume responsibility for ensuring their continued impact. AFB will take the work to a new level by investing in policy and programs focused on creating stronger social systems, and ultimately a more inclusive, accessible society for people with vision loss. These complementary strategies will ensure that people who are blind or have low vision can live a life of no limits, recognizing that the future belongs to everyone.

This decision comes following extensive strategic planning by both organizations. The

(Continued on page 4)



PLAY FOR ALL

CHICAGO LIGHTHOUSE *and* 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, June 9, 2018

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!!!

(Continued from page 2) - AFB News

partnership gives APH the opportunity to expand its lifelong learning offerings and gives AFB the opportunity to expand its influence on the research and policies that impact the lives of people with vision loss.

APH will become the caretakers of:

AFB Press—a program that publishes textbooks for college and university programs and professional books for teachers, researchers, and other professionals. The *Journal of Visual Impairment & Blindness (JVIB)* will remain in the care of AFB.

VisionAware—an online program that helps adults who are losing their sight continue to live full and independent lives by providing timely information, step-by-step daily living techniques, and a supportive online community.

FamilyConnect—an online program that gives parents of children who are visually impaired a place to find resources and support each other.

CareerConnect—an online program that provides employment information, career-exploration tools, and job-seeking guidance for individuals with vision loss and professionals who work with them.

BrailleBug—an online program that teaches children about braille through games and activities and provides resources to teachers and parents.

Both organizations are committed to a smooth transition and will be working in close partnership for several months.

“We are proud of what we have accomplished in partnership with so many in the field. This work has brought us to this crossroads where

it is necessary for AFB to assume a stronger and more active voice in decisions that impact the broader world, particularly in the areas of education, employment, and aging and vision loss,” explains Kirk Adams, President and CEO of AFB. “We are excited about our new direction and optimistic about what the future holds for people who are blind or visually impaired. Our partnership with APH is a win-win for the people we serve.”

“Learning is critical to improving the lives of everyone across the life spectrum. Quality information is key for providing opportunities for employment, education, and ultimately, happiness,” says Craig Meador, President of APH. “We are committed to continuing the standards of credibility and excellence established by AFB while evolving and growing these programs to keep them relevant in the 21st century knowledge economy.”

Both organizations are realigning priorities in response to the growing needs of children and adults who are blind and visually impaired. There are more than 25 million Americans with vision loss and those numbers are expected to grow as the population ages. As more people become blind or visually impaired, as schools experience a shortage of teachers trained to teach students with vision loss, as the economy and workforce changes, and as accessibility becomes even more essential to workforce training and technologies, service organizations are relying on new partnerships and sharing resources to provide the necessary supports and systems for people to succeed today and in the future.

The mission of the American Foundation for the Blind (AFB) is to create a world of no limits for people who are blind or visually impaired. AFB mobilizes leaders, advances understanding, and champions impactful policies and practices using research and data. Learn more at www.afb.org.

The American Printing House for the Blind (APH) designs innovative lifelong learning solutions for children and adults who are blind or visually impaired. In this fast-changing world, APH levels the learning playing field by providing specialized technology, materials, products, information, and services that are essential for education and life. Learn more at www.aph.org.

For more information, contact:

Adrianna Montague, American Foundation for the Blind

amontague@afb.net

1-212-502-7615

Anne Durham, American Printing House for the Blind

adurham@aph.org

1-502-593-2540



Statistical Snapshots from the American Foundation for the Blind

This page is maintained by the American Foundation for the Blind's **Public Policy Center** at [http://](http://www.afb.org/info/programs-and-services/public-policy-center/12)

www.afb.org/info/programs-and-services/public-policy-center/12

Statistical Snapshots is your one-stop source for statistical facts, figures, and resources about Americans with vision loss. Relying upon the most recently available data, this regularly updated site is always evolving and should answer your most frequently asked questions.

We encourage you to visit Statistical Snapshots often, but we also want your feedback. Tell us about what statistical information you think is missing, unclear, or that you would

like to know more about. To submit your questions or comments and help us enrich this valuable resource, e-mail Rebecca Sheffield (rsheffield@afb.net) and include the word "stats" in the subject line of your message.

Statistical Snapshots provides a wide variety of information and tools addressing the most commonly asked questions. For example, findings from the 2015 National Health Interview Survey (NHIS) data release established that an estimated 23.7 million adult Americans (or 10% of all adult Americans) reported they either "have trouble" seeing, even when wearing glasses or contact lenses, or that they are blind or unable to see at all.

Please note that estimates of the number of people experiencing vision loss differ based on the definitions of vision loss used, as well as on the dates the data were collected, populations surveyed, and other features of data sources. The American Foundation for the Blind urges investigators to pay attention to the detailed background information provided along with each estimate.

House Passes HR 620: Attention and Advocacy Shift to the Senate

The House of Representatives took up H.R. 620, the ADA Education and Reform Act. After debate and consideration of six amendments, four amendments were approved, none of which substantively change the effect of the bill. When the House voted on the bill, it passed 225-192. 213 Republicans and 12 Democrats voted "yea," while 19 Republicans and 173 Democrats voted "nay." Overall, the vote was closer than expected, but we remain disappointed that the House of Representatives chose to advance a bill that makes it harder for Americans with disabilities to exercise their right to full independent enjoyment of

public life.

With the support of more than five hundred organizations and tens of thousands of individuals, the disability community fought hard to encourage members of the House of Representatives to vote against H.R. 620. While our efforts did not succeed in stopping the bill in its tracks, we are pleased that more members voted against the bill than originally expected. Moreover, several Senators, including Senators Casey, Hassan, Duckworth, and Murray, have already expressed their opposition to any bill that weakens the ADA. These successes amplify our belief that, as our attention turns to the Senate, there is still a chance to defeat this bill.

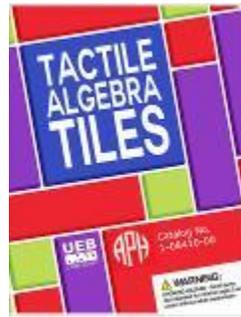
While we do not yet know when the Senate will consider the amended bill, the House's passage of H.R. 620 makes your advocacy even more important! You still have the opportunity to convince your Senators that the ADA is a vital law that protects the rights of individuals with disabilities. In the next few weeks, tell your Senators and their staff that businesses have had 27 years to comply with the law and that any so-called frivolous lawsuits can be and have been dealt with directly by the courts. Tell them to oppose H.R. 620.

Find the names and contact of your Senators at <https://www.senate.gov/senators/contact>

Call the Senate office and tell the staff person who answers the phone that you want your Senator to oppose consideration of HR 620 in the Senate.

For further information, contact:
Sarah Malaier
Coordinator, Programs and Policy
smalaier@afb.net
202-469-6831

APH NEWS

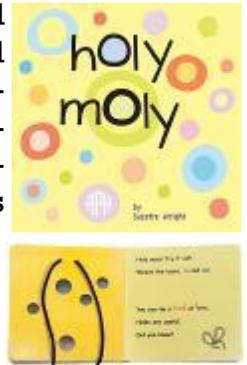


Tactile Algebra Tiles

A mathematical manipulative that provides students with concrete models for approaching abstract algebraic concepts and procedures.

Holy Moly

This colorful tactile board book with rhyming text and interactive components encourages young tactual learners to use their fingers to explore holes in a variety of sizes and locations, lift flaps, weave a cord in and out to tie a knot or bow, count the holes, and, discover that some holes aren't what they seem! (Hint: they're round scented stickers and textured appliques).



2018 Sports Camps

It is that time of year again to start thinking all things camp. [Check out the 2018 listing of camps on the APH Physical Education, Recreation, and Health website.](#)

To read more, go to:

<http://www.aph.org/news/march-2018/>



20 Multi-Sensory Easter Basket Ideas for Kids With Sensory Impairments

By Amber Bobnar

There are lots of ways to make your Easter Basket multi-sensory and accessible for kids of all abilities, including kids with sensory impairments. You might want to throw in some fidgets, chewies or light-up toys, for example (and you can find lots of ideas for [fun small multi-sensory toys here](#). READ MORE at: [WonderBaby.org](#))



The Best Tactile Easter Crafts on the Internet

By Amber Bobnar

When I was a kid, Easter was all about crafts. We'd have big egg-dyeing contests and see who could make the prettiest, most colorful Easter egg. But what fun is a dyed Easter egg if you can't see it? READ MORE at: [WonderBaby.org](#)



Buyer's Guide to Beeping Easter Eggs

By Hillary Kleck

If you're on the hunt for beeping Easter eggs, then you've come to the right place! The search for these often expensive eggs, as well as the commercial talking or noise-maker eggs, can be a headache, and even more so as Easter Sunday draws closer. So to help make the search a little easier this year, we've sifted through the web and browsed our local stores to bring you this list of where to find beeping, talking and noise-maker eggs for your child with a visual impairment. Happy Hunting! READ MORE at: [WonderBaby.org](#)



5 Glowing Easter Egg Activities

By Hillary Kleck

We've rounded up five of the greatest Pinterest ideas for your child to have fun with glowing Easter eggs! Your kids will enjoy going on a glow-in-the-dark Easter egg hunt, exploring sensory bins, and more. The best part is that these activities can also be used anytime of the year at home and school, saving you time and money. READ MORE at: [WonderBaby.org](#)

FOUNDATION
FIGHTING
BLINDNESS

Chicago Chapter Event



Sunday, April 22, 2018

1:30 p.m. Registration

2:00-4:00 p.m. Program

Alexian Brothers Medical Center

Kennedy Conference Center

Entrance #8

800 Biesterfield Road

Elk Grove Village, IL 60007

RSVP by April 18

Mary Ann Subleski

MSubleski@FightBlindness.org

or (847) 680-0100

Learn More About Gene Therapy and Genetic Testing and Meet 2016 Rio Paralympian Sarah Chung

Please join us for light refreshments and get ready to hear from two unique guest speakers: Daniel C. Chung, DO, MA, Clinical Ophthalmic Lead, Spark Therapeutics and Sarah Chung, 2016 Rio Paralympic Participant – Judo. Dr. Chung will provide an overview on Gene Therapy and Genetic Testing. Sarah will share her passion for the sport of Judo.



Mark Your Calendar for This Exciting Event Parent Advocacy Training for Legislative Change

Family Resource Center on Disabilities (FRCD) and the University of Illinois at Urbana-Champaign are offering a FREE training to parents and family members of children with disabilities.

- Participate in the legislative process to change special education policy.
- Become more comfortable speaking to legislators and sharing concerns.
- Develop an understanding of special education policy and practice.

Your participation in this training will build your advocacy skills and provide important feedback that can help guide, expand, and strengthen special education policy. In addition to attending the training, participants will be required to:

- Participate in a focus group to share concerns about special education legislation.

- Complete three surveys to document the effectiveness of the training.
- Be videotaped (less than three minutes) to share your concerns about special education legislation. Your participation is voluntary and your responses will be kept confidential.

To participate, please complete the registration and survey at this link:

<https://www.surveymonkey.com/r/DisabilityAdvocacy>

After completing the survey, you will be notified of your training date. **Training Dates:** May 10 and 17, 2018 or September 18 and 20, 2018. **Location:** Dr. Martin Luther King Service Center/Resource Center for Autism and Developmental Delays, 4314 S. Cottage Grove, Chicago, IL 60653. **Time:** 10 am to 1 pm on both dates. **Please sign up by April 20, 2018.** Food and parking will be provided and each participant will receive two \$10 gift cards.

If you have questions or want to complete the survey over the phone or via hard copy, please contact: Meghan Burke, meghanbm@illinois.edu or 217-300-1226.

IPVI

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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
Children with Visual Impairments**
P. O. Box 316634
Chicago, IL 60631

IPVI CALENDAR

- | | | |
|-------------------|---|------------------|
| ▶ April 14 | IPVI Annual Meeting | Oak Brook |
| ▶ April 22 | FFB Chicago Chapter Event | Chicago |
| ▶ June 9 | Chicago Lighthouse & IPVI Families "Play For All" | Chicago |
| ▶ | | |

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

**Newsletter Deadline for
May 2018 is April 15, 2018**



**Check Out
www.ipvi.org**

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