

IPVI INSIGHTS

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

February 2019



PRESIDENT'S REPORT

Filiberto Almendarez III

IPVI families, did you ever consider helping others. Have you considered helping yourself. If, so, then you may be interested in volunteering. It's a beautiful way to meet other families who may be in similar situations. It also helps you. Volunteering counters stress, anger, anxiety, depression and makes you happy and provides a sense of purpose. I know your free time is limited and understand how busy you may be attending to your child(ren) not to mention working and maintaining benefits/insurance. But if you have some available time, please think of volunteering and possibly being a board member. It truly is self rewarding and you never know. When you help someone, you might be the only one that does. So give it a thought. Help the community for a worthwhile cause and help improve the lives of others and yourself. Those interested, please reach out. We welcome happy, positive individuals who are willing to help us move forward. Please read the Newsletter every month for amazing articles and supportive information. If there is something you would like to see, just relate. We welcome feedback. We like to know what you are thinking. Help us help each other.

Last but not least, I would like to say Thank You to IPVI Board Members for their tireless efforts on the Newsletter and IPVI Events. Thank You!

Take care and stay warm!





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Pay Dues

The IPVI Board, per changes to our Constitution and Bylaws, have changed our dues period from January 1st through December 31st. The dues are \$25.00. Please send them to

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

Thank you from IPVI.

Board Members

To keep IPVI running as an organization for the blind and visually impaired, we are asking our members, especially those with younger children, to step up with new ideas to contribute. We are in need of a treasurer, VP, and secretary. Any past board members are glad to help guide you, and you can call us at any time.

ANNUAL MEETING

Our 2019 Annual Meeting will be coming up in March. This will also be the time we will need to fill in our board with a vote of the membership present at the meeting as well as presenting the fiscal report and offer ideas to what we can and should be doing to keep IPVI going strong. Ideas will require volunteers, so please search your heart to provide these gifts to our children.

Remember, strength in numbers.



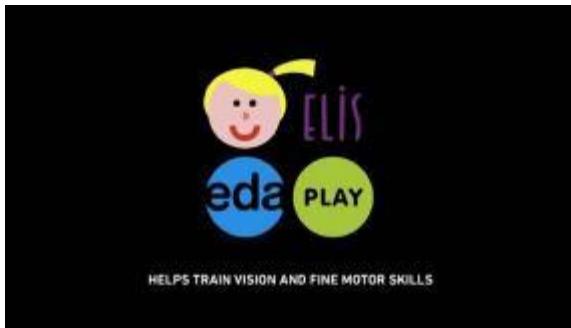


What Can You Do for the Special Needs Mom Who Doesn't Feel Anymore?

By Amber Bobnar

Sometimes it seems like I don't have the time to feel, and I know this isn't a new thing. I've been not feeling for a long time. Is it OK to not feel? [READ MORE](#) at:

<http://www.wonderbaby.org/articles/special-needs-mom-who-doesnt-feel>



Eda ELIS app Review

By Amber Bobnar

EDA PLAY ELIS is an iPad app designed for young children who have low vision or CVI and who are learning how to use their vision. [READ MORE](#) at:

<http://www.wonderbaby.org/articles/eda-play-elis-app-review>



Learning Advocacy When You Have Low Vision

By L. Penny Rosenblum, Ph.D.

L. Penny Rosenblum is a TVI, a parent and student advocate, and has a vision impairment. She writes about what it was like learning to advocate for herself as a child and how to teach these skills to your own children. [READ MORE](#) at:

<http://www.wonderbaby.org/articles/learning-advocacy-when-you-have-low-vision>



Why We Love Music Therapy for Our Blind Son

By Jennie S.

Jennie writes about how her son, Max, responds to music. Other therapies failed Max and often stressed him out, but Music Therapy has been very successful for him! [READ MORE](#) at:

<http://www.wonderbaby.org/articles/music-therapy>

SEEKING PARTICIPANTS FOR INTERVIEW STUDY

Parental Advocacy: Caregivers' Experiences in Early Intervention

Hello! I am Kristen Schraml-Block and I am recruiting caregivers who are receiving early intervention services to participate in an interview study. I am a doctoral student in the Department of Special Education at the University of Illinois at Urbana-Champaign. My advisor is Dr. Micki Ostrosky, and our study focuses on understanding how caregivers advocate for their young children.

About the Project: As a participant, you will

- (a) complete a 10-minute survey so that we can learn more about your family
- (b) be interviewed face-to-face for approximately one hour **AND**
- (c) review a summary of the interview and provide your feedback

Potential Participants: Please consider participating if:

- (a) You are a caregiver of a child (birth to age 3) who currently receives early intervention services

AND

- (b) You are a native English speaker

For sharing your time and story with us, you will receive up to **two \$25.00 VISA gift cards** for completing all components of this study.

If you are interested in participating in this study or if you would like more information, please contact:

Kristen Schraml-Block, schraml2@illinois.edu, 703-609-6905

OR

Dr. Micki Ostrosky, ostrosky@illinois.edu, 217-333-0260



Share your Insight About Early Intervention



The Early Intervention Clearinghouse (EIC) at the University of Illinois at Urbana-Champaign (UIUC) is conducting focus groups with families of young children with disabilities. We want to learn your perspectives about needed: supports, information, and services.

Specifically, you will also be asked to participate in a focus group discussion for 60-90 minutes. At the beginning of the focus group meeting, you will complete a 20 minute questionnaire about your family and experiences with early intervention services. Next, you will participate in a focus group discussion, which is similar to a roundtable discussion. After the focus group, you will have the opportunity to share your phone number and/or email address if you are interested in a follow-up contact. During the follow-up you will be asked to review a brief summary of the focus group discussion and provide comments.

To participate you must be:

The parent or family member of a young (aged 0-8) child who received early intervention services.

Your participation is voluntary and your responses will be kept confidential. In appreciation for your time, you will receive a \$10 gift card and a package of resources.

To participate, please contact:

Meghan Burke, 217-300-1226 or meghanbm@illinois.edu

The focus groups will be held in English and in Spanish at locations, dates, and times throughout Illinois.



Healthy Sexual Relationships for Individuals with Disabilities Webinar Series

Wed, Feb 13, 2019 11:00 AM - 12:00 PM CST

Wed, Feb 20, 2019 11:00 AM - 12:00 PM CST

Wed, Feb 27, 2019 11:00 AM - 12:00 PM CST

Family Matters PTIC is hosting a webinar series about healthy relationships, setting boundaries, sexuality and safety.

The speaker, Sean Black, is the assistant director of the Illinois Coalition Against Sexual Assault.

This is a VERY important series of topics for our kids!! And honestly, even if you don't have a kid with a disability, the webinars will have good information for all parents and teachers, etc.

Even if you can't make it at the time of the webinars, go ahead and register and Family Matters PTIC will send you the links for the recorded webinars for you to watch on your own.

To learn more and to register, go to:

<http://www.fmptic.org/node/4277>

<https://register.gotowebinar.com/register/384889939240260865>



Dear Friends,

As we begin 2019, I am delighted to present the Foundation's new logo, depicted at the top of this message.

The image, a beacon of light projecting over the words "Fighting Blindness," symbolizes our leadership role in bringing light and hope to people affected by the entire spectrum of retinal degenerative diseases. It also conveys our commitment to shedding light on innovative research to prevent, treat, and cure these challenging retinal conditions.

Also note that the words "Fighting Blindness" are large and prominently positioned — appearing front and center — with "Foundation" positioned vertically to the left. This arrangement places additional emphasis on our core mission: fighting blindness.

I hope the symbolic image is inspirational for you as we move into the new year, but equally important is it more strongly conveying our mission and message to those newly acquainted with the Foundation.

I wish you a happy, healthy, and successful 2019. Thank you for all you do to bring an end to blinding retinal diseases.

Sincerely,

Ben Yerxa, PhD
Chief Executive Officer
Foundation Fighting Blindness

Illinois Association for Parents of Children with Visual Impairments

IPVI

P.O. Box 316634, Chicago, IL 60631

1-773-882-1331 • Email: ipvi@ipvi.org • www.ipvi.org

PRESIDENT

Filiberto Almendarez III
5323 N Delphia Ave #124
Chicago, IL 60656
(773) 693-5713
falmendareziii@yahoo.com

OPERATIONS VP

Joan Bielawski
(Temporary)

SERVICES VP

Mary Zabelski
6153 N. Nettleton Avenue
Chicago, IL 60631
(773) 882-1331
maryzabelski@hotmail.com

TREASURER

Filiberto Almendarez III
(Temporary)

SECRETARY

Joan Bielawski
421 Applegate Court
Naperville, IL 60565
(630) 357-8576
wjbielawski@yahoo.com

SPANISH TRANSLATOR

Noelia Gaminio
708-655-2747

NEWSLETTER EDITOR

Joan Bielawski
421 Applegate Court
Naperville, IL 60565
(630) 357-8576
wjbielawski@yahoo.com

VOLUNTEERS

are just ordinary people with

*extraordinary
HEARTS.*

They offer the gift of their time

to teach, to listen, to help,
to inspire, to build, to grow, to learn.

They expect no pay,

yet the **VALUE** of their work knows
no limit...

They've known the *unexpected joy*
of a simple hug.
They've planted the tiny
seeds of love in countless lives.

VOLUNTEERS

are just ordinary people who reach out
and take a hand
and together

MAKE A DIFFERENCE
that lasts a *LIFETIME*.



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.

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

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
1-773-882-1331

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

IPVI CALENDAR

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

**Newsletter Deadline for
March 2019 is February 15, 2019**



**Check Out
www.ipvi.org**

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