Illinois Association for Parents of Children with Visual Impairments

IPVI INSIGHTS

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

September 2019

PRESIDENT'S REPORT

Filiberto Almendarez III

Hi IPVI Families. I hope everyone is doing well as our Summer dwindles down, which we know what that means. It's time to prepare for another school year. As the school year begins, it brings to mind our children are growing and getting older. What a blessing! As for my family, I am amazed that my son is actually starting High School and will turn 15 years old this year. A bit older with a bigger environment to learn. Especially how to navigate around. I am confident he will adapt and I will patiently wait and support him unless he needs a little encouragement (Pep Talk), which fathers do for their children. Also, to our IPVI children, I wish you a happy and healthy school year. Enjoy the pleasure of doing what someone said you could not do. Tackle the challenges that will add to your interesting life and once overcome, they will make your life a little more meaningful. I know the scary feelings of the new and unknown mixed with excitement in one. Welcome the next step in your life and work hard towards success.

Parents, proudly speak on behalf of your child(ren). Advocate for your child's need and thank all who assist. Make sure you have your IEP information, health records, and request any additional assistance/services that may be needed. Whether it's tools, equipment, an Aid and/or Paraprofessional. In addition, learn how you can lend a hand and get involved with your school to help your child and others. Remember: "An investment in knowledge pays the best interest".

Good Luck, Take Care and Happy Schooling!

Inside This Issue:

FOUNDATION FIGHTING BLINDNESS

A 13-year-old shares her family's story

Hope. Science Fiction. That is what it seems like. Unbelievable, amazing, incredible....that is how everyone describes it now. But it was not always this way, and it was not always easy.

This is my real life story, the story of my sister Ashlyn and me (Kailey).

My mom is an optometrist, and she knew right when my sister was born that her eyes didn't work right. For 9 years it was hard, really really hard. The doctors said she was blind, and would most likely not ever walk, talk or see. They said she had cerebral palsy, and that her future would be hard. I was only three years old when she was born. Now I am 13.

Doctors' appointments, therapies, specialists...that's what I did with my sister. That is what we did as a family, as we all wanted her to get better. I hoped more than anything she'd prove the doctors wrong. Late, everything was late for her. But she pushed through and was soon saying words and running. My sister was legally blind. She couldn't see my face or play with me like other sisters. She always looked up at the light. She couldn't see well enough to keep attention on things.

Mom Didn't Give Up

My sister had many diagnosis that kept changing for her eyes. They called it ocular albinism, then congenital stationary night

(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, October 12, 2019

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!!!

If leaving from Chicago Lighthouse, please arrive at 8:30am.

(Continued from page 2) - A 13-year old shares her family's story

blindness and lots of other things. My mom kept saying it wasn't correct. She was always reading and researching. Here is where it gets amazing.

My mom insisted they do a full genetic work up for my sister at an appointment, and this doctor listened. She told my mom it would take a long time to get results, and insurance may not cover it, and it is very expensive. I remember that appointment. She was 8 then, and I was 10.

"I remember thinking my mom was either smart, or would cost us a ton of money."

Almost a year later they needed more data. They needed a cheek swab from both of my parents. Finally my mom got a phone call that she and my dad needed to see the pediatric geneticist for the diagnosis.

When I got home from school a big name was told to me. "Honey, your sister has something very rare called Leber Congenital Amarosis RPE65, which can make her lose all of her vision," my mom said to me. She said that now that we know what she really has there is more hope. I didn't want my sister to be in the dark when she is a teenager. It's not fair. I was sad, I heard my parents cry, so I knew they were sad too.

Hope, There Is Always Hope

My mom researched and learned that there were clinical trials in Europe for the exact type of LCA my sister has! In the trials, kids have got vision back. Only a few months after my sister was diagnosed, we got the call saying the FDA approved the gene therapy and it will soon be available.

Summer 2018. This is crazy. I helped my sister get into her hospital pajamas. They had tigers all over them and were big on her. I was scared stiff as my parents left me and they went to put her under anesthesia. It was the longest 4 hours of my life, when the surgery was happening. She was the first girl in the U.S. to get this surgery. I hoped it would turn out well. She went back a week later for the second eye surgery.

This Part Sounds Like Science Fiction

A month later my sister could see! She was talking about everything. "What's that?" she would ask, as she pointed. She was so happy. The process was hard. She was on steroids so her body would accept the gene.

"I told my dad I thought she lost her mind. She ate a lot of beans. She was super hyper. But she could see."

One of the last trips to the hospital before coming home she pointed across the road and read "call your mom" on a sign. It was magical. When she held my face and said "I see your eyes, what color are your eyes? Blue." to me I was overjoyed. She laughed so hard when she saw her shadow. She can now see the moon and clouds. She is starting to read print instead of Braille.

Every day with her is a miracle. Her future is different, and so is mine. I want to be an ophthalmologist and do surgery. I want to change lives, like they changed hers and my family's. I want to give kids sight. Hope, it all started with hope.

Sincerely,
Kailey Reichardt

Please support the amazing work the Foundation Fighting Blindness does to make sure more kids like Ashlyn don't go blind.

https://give.fightingblindness.org/give/244807/#!/donation/checkout

WonderBaby.org
Perkins School for the Blind

Home Sweet Group Home?

By Shiri Ronen-Attia

When is the right time to move your special needs child out of the house and into a group home? READ MORE at:

http://www.wonderbaby.org/articles/home-sweet-group-home

How Access to an iPad Can Change a Blind Child's Life

By Phia Damsma

For children who are blind or visually impaired, iPads represent multi-purpose, portable Assistive Technology devices that can replace expensive AT devices. READ MORE at:

http://www.wonderbaby.org/articles/ipad-access

Fall Sensory Art Projects for Visually Impaired Kids

By Amber Bobnar

Choose from five wonderfully crafty art projects adapted for blind children that celebrate fall! Make prints and wreaths with apples and leaves, create your own tree, or decorate pumpkins! READ MORE at:

http://www.wonderbaby.org/articles/fall-art-projects

Play a Game of Pumpkin Bowling With a Braille Twist

By Hillary Kleck

Maybe you've been bowling, but have you ever been pumpkin bowling? This multi-sensory game is perfect for Fall and makes a fun Halloween party game, too! READ MORE at:

http://www.wonderbaby.org/articles/pumpkin-bowling

IATP Statewide Conference And Expo

Presented by

Illinois Assistive Technology
Program

WHEN: Friday 9/13/19 - 8:00 TO 5:30, Saturday 9/14/19 - 8:00 TO 3:30

WHERE: Crowne Plaza • 3000 South Dirksen Parkway - Springfield, IL 62703

Discover The Possibilities Assistive Technology in
EDUCATION * EMPLOYMENT * COMMUNITY LIVING
CEUs WILL BE OFFERED

Expo Free And Open To The Public
FRIDAY 11:30 - 5:30 SATURDAY 9:00 - 3:30
Explore And Try The Latest Assistive Technology
Free Makers Day On Saturday At 2:30
Create Devices To Take Home

Register by August 15, 2019

Registration for the 15th Annual Illinois Statewide Transition Conference on October 17-18, 2019, at The Gateway Center in Collinsville, Illinois.

"Stepping Stones of Transition" invites participants to imagine the possibilities for students with disabilities in the areas of independent living, education and training, employment, community integration, health care and self-advocacy. It features

- 64 breakout sessions
- 80+ speakers
- CE, CPDU, CRC credits available upon request

The conference is aimed at transition-aged youth, parents, caretakers, vocational professionals, healthcare professionals, educators, college students pursuing careers in special education and community advocates. Participants will come away with valuable tools, resources and contacts to put transition-aged youth with disabilities on the path to success and achieving their dreams.

Register early! Registration for this conference will close on September 13 or when we reach 600 attendees, whichever comes first

IPVI

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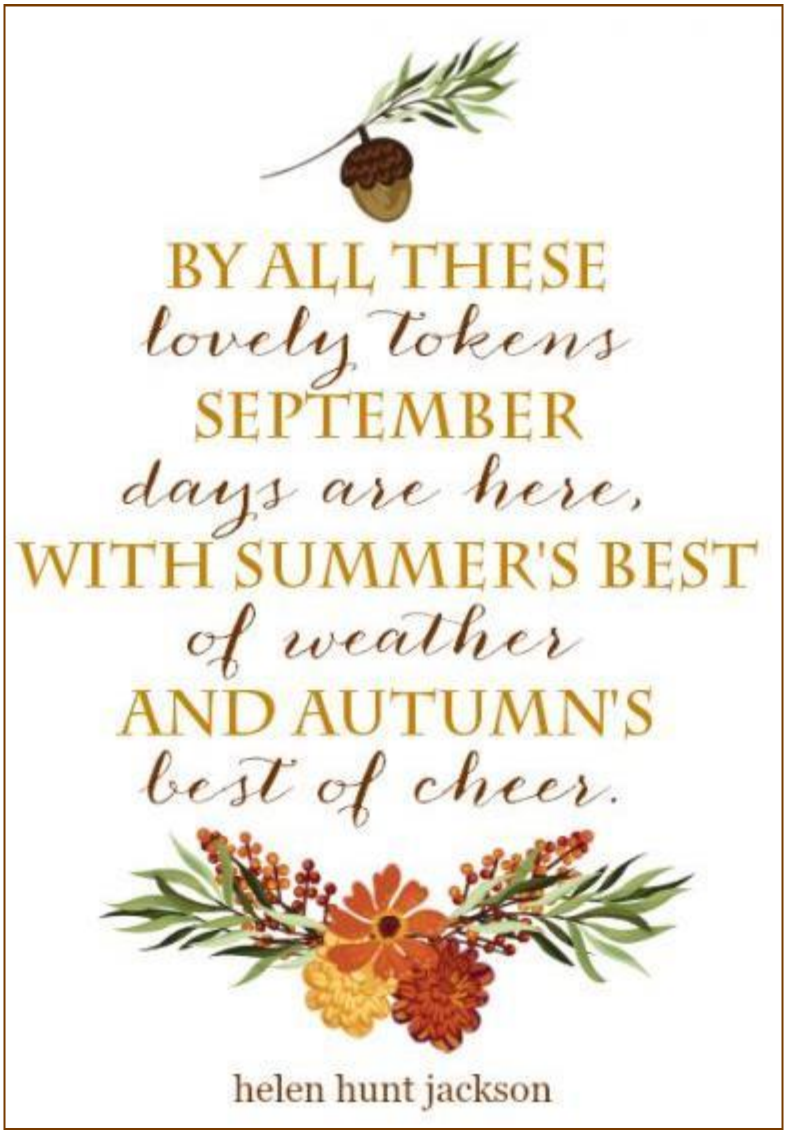

Join **IPVI** *or renew your membership today!*

The ***I****llinois Association for* ***P****arents of Children with* ***V****isual* ***I****mpairments 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.
- Holds fun outings adapted for children with visual impairments at educational and entertainment settings.
- Represents parents of children with visual impairments at conferences, public hearings, and on committees.

Check one:

☐ Parent/Guardian Membership: $20 per year.
Child(ren)'s Names):______________________________
____

☐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.
☐ 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**

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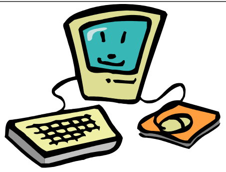
Children with Visual Impairments
P. O. Box 316634
Chicago, IL 60631

IPVI CALENDAR

October 12	**The Chicago Lighthouse & IPVI** **"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
October 2019 is September 15, 2019



Check Out www.ipvi.org

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