

IPVI INSIGHTS

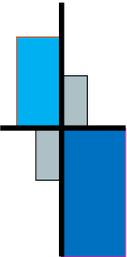


Connecting & Supporting Families Whose Children are Visually Impaired, Including Those with Additional Disabilities

January 2019

PRESIDENT'S REPORT

Filiberto Almendarez III



Happy New Year, everyone. I hope your Holidays were full of health and joy. As we tippy toe into another year, let's continue to move forward with strength and hope. Find peace in your challenges and appreciate the happiness in life with your Family. Start the year on a positive path, even if it means having the same results as the prior year. I know early on I would hope for no changes for my son. That he would maintain the same level of vision and medical stability as the last year. In time, stability was constant and then we moved aggressively taking bigger steps resulting in progress. So IPVI Families, let's move ahead towards an incredible year with glorious expectations. Please keep in mind, IPVI is here for support too. In times of challenges, feel free to reach out. I am here to listen and willing to share my struggles, challenging moments, and positive outcomes.

Also, I would like to share, the IPVI and Chicago Lighthouse Christmas party was a blast. I saw many families and missed a few. Sorry, if I did not get a chance to chat, but was able to say hello, since I was craving and serving the beautiful ham. Wow, it was delicious. Even the kids came back for second servings. Lastly, I send a big Thank You to all who helped and made the event a beautiful success. Thank you!

To all, Happy New Year and remember the past and embrace the coming year. I wish for sweet unexpected surprises to appear and make your heart smile. Take care.

Peace

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Birth to Three Children and Families Enjoy Festive Holiday Party

*Pictures by Fil Almendarez
President, IPVI*

Children enrolled in The Lighthouse's Birth to Three program along with their families enjoyed a festive holiday celebration recently.

Highlights included a visit from Santa (aka Kevin Sullivan) who presented gifts to all the good little boys and girls!

Guests were also treated to a delicious lunch featuring turkey with all the trimmings plus an assortment of tasty cakes, cookies and other items.

In addition, the children and their families had an opportunity to create holiday decorations.

Special thanks to the Chicago Central Lions Club, Chicago Azteca Lions, Illinois Association for Parents of Children with Visual Impairments (IPVI), and Chicago Lighthouse staff members for donating the gifts.

IPVI Members were also involved in helping with the holiday party and IPVI children were also invited to attend.



Snowman and Reindeer are one of the visual highlights of holiday party.



Mary Zabelski and Fil Almendarez, President pose with Santa



Food for the Hungry



Fun with Santa



The Chicago Lighthouse and IPVI Volunteers



**PLAY 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 9, 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 the Chicago Lighthouse,
Please arrive at 8:30 a.m.**



Frederick M. Musser

Aug 23, 1932 - Nov 8, 2018

Frederick M. Musser, age 86, born in Chicago to Mary and Michael Musser and lived for the past 50 years in Edgebrook-Chicago. He received a Bachelor of Science Degree from Northwestern University in 1954. He served as a former President of the Edgebrook Lions Club, participated in Illinois State Swim Meets with the U.S. Masters Gray Sharks of the Leaning Tower YMCA, and worked as a Pre-Trial Officer for the Circuit Court of Cook County in Skokie for 20 years. – Deeply loving husband of Erika A. Musser (born and raised near Vienna, Austria) for 58 years; devoted father of Heidi (classical pianist and U.S. Masters Swimmer, despite being totally blind), Siegfried (research bio-chemist with Ph. Degree from California Institute of Technology) and wife Dr. Cindy Fang, Ursula (MD. Degree from Northwestern University) and husband Dr. C. Blair Harkness, and Fritz (global traveler, who was stabbed in the Caucasus Mountains in the country of Georgia in August 2016 and Rebekah M. Friesen (partner/wife of Fritz and now adopted daughter) from Nova Scotia/Canada. Devoted grandfather of Vincent (15) and twins Ashley and Madeline (13), and Nicholas Lau (30) and Alexander Lau (32), sons of Cindy.

Editor's Note:

I just came upon a website that was sent to me at the time Frederick passed away. Even though this notice is late, I wanted to share this with our IPVI families because the Musser family has been such an integral part of IPVI.

Condolences to the whole family.

I'm Free

*Don't grieve for me, for now I'm free
I'm following the path God laid for me.
I took God's hand when I heard the call;
I turned my back and left it all.*

*I could not stay another day,
To laugh, to love, to work or play.
Tasks left undone must stay that way.
I found that place at the close of day.*

*If my parting has left a void,
Then fill it with remembered joy.
A friendship shared, a laugh, a kiss.
Ah yes, these things too I will miss.*

*Be not burdened with time of sorrow;
I wish you the sunshine of tomorrow.
My life's been full, I've savored much,
good friends, good times, a loved one's touch.*

*Perhaps my time seemed all too brief,
don't lengthen with undue grief.
Lift up your heart and share with me -
God wanted me now, God set me free.*



born with serious sight difficulties, your little bundle of joy will not be the only new arrival in your home. READ MORE at:

<http://www.wonderbaby.org/articles/how-work-difficult-doctors-therapists>



Something Happened While I Was Waiting For My Daughter to Tell Me She Loves Me

By Nicole Feeney

I used to long for Shelby to express her love for me, and she has started to, but now I realize that her trust in me is her greatest expression of love for me. READ MORE at:

<http://www.wonderbaby.org/articles/what-happened-while-i-was-waiting-my-daughter-tell-me-she-loves-me>



How to Work With Difficult Doctors and Therapists

By Mary McDonach

You thought you were having a baby. Just one, or maybe twins (or more), but still just babies. Then you realized that because your child was



Family VS Ableism: What I Learned as a Mother of a Child With a Disability

By Nicole Feeney

Is it more important to be worried about how you're presenting yourself and your family to the outside world and the wider disability community, or to focus on the needs of your own family and children? READ MORE at:

<http://www.wonderbaby.org/articles/family-vs-ableism>



The Graco Electric Nasal Aspirator

By Amber Bobnar

Until you can figure out how to blow your own nose, colds are just miserable things. The electric nasal aspirator from Graco makes it easier to clean baby's nose! READ MORE at:

<http://www.wonderbaby.org/articles/electric-nasal-aspirator>

We Need to Help Each Other

By Mary Zabelski

As an IPVI member, I speak to many parents about issues we share since we have children who are blind or visually impaired. This wasn't always the case. When my daughter was little, I didn't know anyone with a child that was blind.

When I first discovered that my daughter was losing her vision and might be permanently blind, I was very distraught. I kept on praying and hoping for a cure, hoping that a miracle would happen. Well, the actual miracle was that I learned how to teach a child who is blind. I learned how to appreciate her as a beautiful little individual with special talents, not as a poor blind child. I discovered that although her eyesight was going, she had four other senses and that she could learn everything other children were learning through these senses.

If someone had connected me to another parent who could mentor or give me information about their child's positive learning experiences, school programs, teachers or just everyday experiences, I would have felt much better. I had to learn by trial and error. When Cara started school at the age of three, her full-time vision teacher in the resource room, was very helpful to me. She worked with me and allowed me to call her at home when I needed to. She even introduced me to some other parents who had children who were blind. That was very important to me. I had to connect with someone else who could understand what I was going through, what my daughter was going through. At this time there were no parent support groups just for parents having children who were blind or visually impaired, deaf-blind or multi-disabled.

Parents who first learn of their child's visual impairment often have to cope with their pain and grief alone and in isolation. Although professional support and related services are often available, the effects of having a child with little or no vision is an overwhelming experience and not often perceived by the "experience", that may try to help. Studies show that parental involvement in the educational process is critical to future success. As a

result the importance of positive parenting practices cannot be overlooked. Yet it is very hard to know if we as parents are doing the "right" thing or not.

We also can connect people with other parents having children with the same eye conditions and other issues. I remember how isolated I felt many years ago, and so I am glad to share information with others.

Please join our IPVI family. Get your relatives and friends to join also. It is so important to get the emotional support and relief from feelings of isolation. IPVI members help each other to acquire information so that we can make better decisions about care, education, and treatment of our children. We assist each other to find and use the best possible resources that are available. Our members communicate and share expertise and empathy which provides encouragement and help.

IPVI also communicates our expectations for our children to federal, state and local service agencies. Because our children are blind or visually impaired, they need very specialized services when they enter into the educational system. Many school districts do not hire enough professional teachers who have the credentials and background to teach Braille, mobility and other skills our children will need to successfully access and navigate the educational system. Through our mentoring and information sharing we can help each other to understand the educational process, the programs our children need and how to positively acquire these services.

JOIN IPVI NOW. WE NEED YOU. WE CAN MAKE A DIFFERENCE.

Join *Need*
Difference

Happy Holidays



Special Needs Chicago Provides
wheelchair accessible transportation for
individuals with mobility and cognitive challenges
throughout Chicagoland.

We would welcome the opportunity to
provide service for you in 2019.

Michelle Dacy

Special Needs Chicago, Inc.

630-668-9999

michelle@specialneedschicago.org

www.specialneedschicago.org

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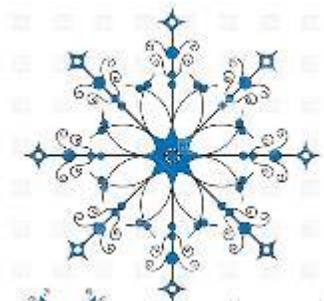
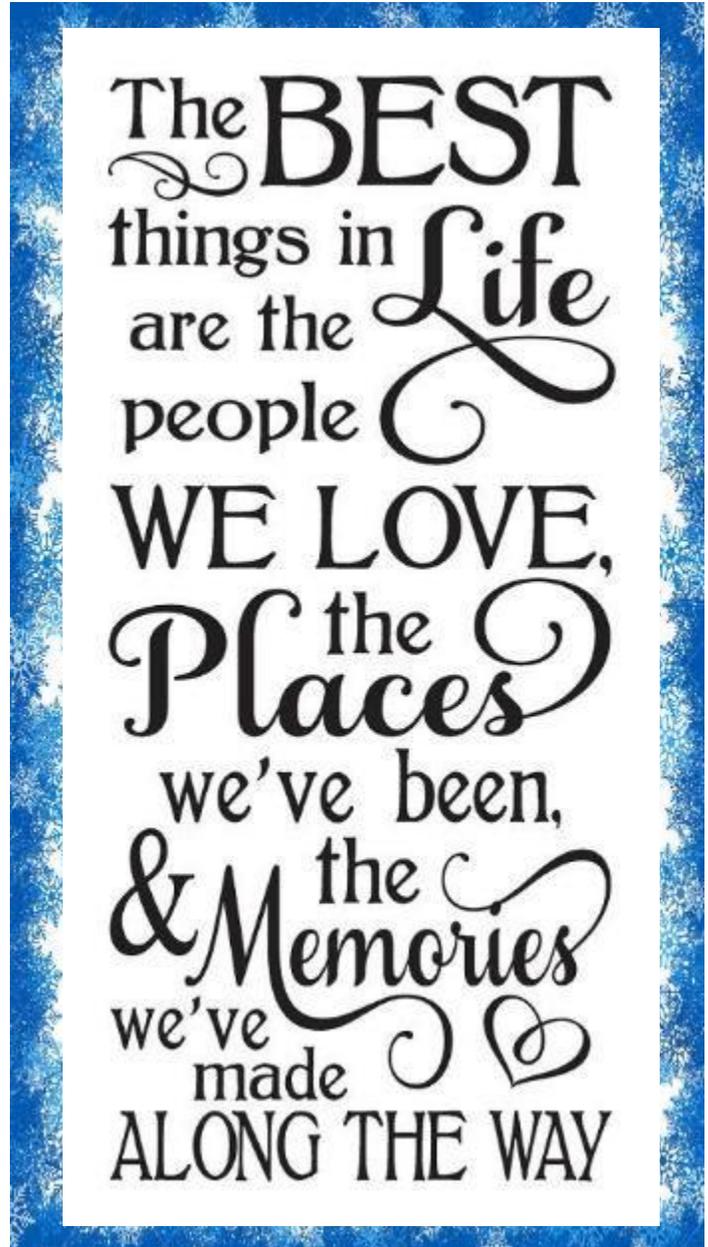
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Join **IPVI** or renew your membership today!

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 9, 2019
PLAY FOR ALL
CHICAGO, NAVY PIER**

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

**Newsletter Deadline for
February 2019 is January 15 2019**



**Check Out
www.ipvi.org**

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