

IPVI INSIGHTS

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

**August
2016**



PRESIDENT'S REPORT

Filiberto Almendarez III

Saturday, July 16, 2016. What a beautiful day for a Zoo Outing. Even the animals were happy. The Sun, the Sounds, the Joy. Our neon yellow T-shirts were seen all over the Zoo. It's beautiful to place a face, a person to our membership. It connects us. Plus, I truly enjoyed talking to parents, grandparents, family members and friends and meeting their child/children. The stories of where our children were and are now are amazing. I managed to make some children smile, while some ran away. That too was a joy to see. For the new parents that I spoke with, keep being your child's advocate, ask questions, have hope, read the IPVI Newsletter as a good sort for information and/or call a Board member. I once was not sure of the future, but always remained hopeful and thankful. What I say is look where we all are now.

Also, I want to express a gracious Thank You to the volunteers who assisted in making the event a success. From planning and tabulating order forms to greeting members as they arrived, to Zoo personal assisting with



Inside This Issue:

Zoo Picture/President's Report	1
Brookfield Zoo Pictures	3
Memories of Heidi Musser	4
...Blind Students Should Attend Oakton...	4
WonderBaby.org	6
8 Misconceptions About CVI	6
Tips & Ideas for Kids with CVI	6
20 Favorite iPad Apps/CVI	6
"Big 3 Tool Kit" for Children with CVI	6
Top 10 Light Toys Under \$10	7
Sorting Through the Grieving Process...	7
APH News	11
Orion TI-30XS Firmware & Learn Mode	11
APH Spring Fever Sale	12
APH InSights Art Calendar: 2017	12
FRCD	13
Inclusion of Child with Disabilities...	13
Stepping Stones of Transition	13
IPVI Board of Directors	14
Back To School Survivor Kit	14
IPVI Membership Dues	15
IPVI Calendar of Events	16

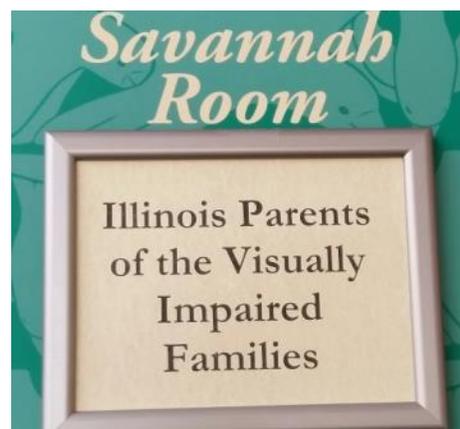


tickets and food. THANK YOU! In addition, a big Thank You to our Guest Speaker and fellow Board member Mary Zabelski who shared her experience on raising her daughter, striving for our children and allowing them to develop their independence.

Finally, I stated make sure to smile, you never know where the picture may end up. Well, it's page one of the Newsletter. As the cover shows, we had a wonderful turnout. This year we had the Dolphin Show and the Safari Tram ride. Hope you enjoyed them. I welcome all feedback. Please relate any ideas and/or comments. We strive to make our events a fun experience for all. It's OUR event.

Until next time, I will patiently wait to reunite again and share the life of our wonderful children.

OH, YEAH!!! It was Fun!



IPVI 2016 15th ZOO PICTURES



**ZOO
REGISTRATION**

**SAFARI
TRAM RIDE**



**DOLPHIN
SHOW**

MEMORIES OF
HEIDI MUSSER

Prepared for: IPVI Insights - Issue August 2016

MEMORIES OF
HEIDI MUSSER

For this month, I would like to share with you what my former student Akash Patel, who recently celebrated his 25th birthday, has to say about attending Oakton Community College. We are friends for 17 years.

When Akash was 8 years old, I was invited by his homeroom teacher and special education teacher to come to his school to help out with teaching him Braille. The first time I met him, he was hiding under the table. He seemed forlorn and "dispossessed."

Because we were assigned to meet in the music room, I generally started every lesson with me playing the piano and singing songs together. When I felt that he was ready, we sat down with the Braille. There were times when he pushed the Braille off the table and onto the floor, but after a few weeks, his enthusiasm for learning began to soar.

Everything seemed to change, when he became aware that I was totally blind like him. The teachers soon realized that for Akash knowing that he was not the only one in the world, who is blind, did the trick! Here are the exact words of a personal note to me by his second/third grade teacher:

"I knew that this young man had something special about him that was not being reached until his work with Heidi. You have put a spark in Akash that has given him the desire to learn and grow. You have

awakened him to a world of learning and experiences that only another blind person can share."

With the help of my mother, I typed up in Braille worksheets and little books at home. I always made sure that we had two copies: One for him and one for me. We read TOGETHER! He loved the *Toad and Frog* books by Arnold Loebel. We played roles; either he or I was Frog or vice versa. My mother was the narrator. Akash and I memorized practically all of Arnold Loebel's books. When we get together now, we sometimes still check our memories, if they are still anchored. Learning and reading became great fun for Akash.

Akash is presently a proud student at Oakton Community College at the Skokie Campus. I asked him to share with IPVI parents in his own words his experiences:

* * *

Please write me at: hmusser@msn.com

I welcome your comments.

**WHY MORE BLIND STUDENTS SHOULD
ATTEND OAKTON COMMUNITY COLLEGE
AND WHAT MAKES ME HAPPY TO BE A
STUDENT THERE.**

If you are searching for a positive college experience as a blind or visually impaired student, I would like to you to look no further and check out Oakton Community College. I serve as a Senator of the Student Government Association (SGA) and I would be happy to meet with you on the Skokie Campus, show you around and introduce you to numerous individuals to answer your questions.

Our first step on your visit would be the Access and Disability Resource Center to meet

Manager Teresa O'Sullivan. She and her staff are simply wonderful! She is an exceptionally dedicated educator. She has compassion and never uttered to me in a dogmatic way: "That's the way it is. We don't have the time or the money to cater to your personal preferences." She makes sure that all my required texts for my classes and all class hand-outs are transcribed into Braille.

The Office of Student Life has offered me the marvelous opportunity to join the Student Government Association (SGA), where I have a voice to speak up for students of a diverse background.

Oakton has great academic advisors that support me in how I want to move academically forward with my future endeavors and my desire to take it slow with my higher educational career. Also, I have great personal counselors, who really take pride in working with students like me; they understand my feelings.

I have great English tutors who help me with many assignments for my classes. I cannot forget English Professor Virginia Gibbons, who seems to always have her office door open to be ready to give advice.

On top of all that, I have great peers in my classes and in my extracurricular activities, who care about me, love me and have been very helpful to me in different capacities.

In short: (1) The Access and Disability Resource Center has come forth with compassion to understand my learning needs and what accommodations I would need to be successful in my classes. (2) Many professors are very accommodating to a diverse student body making sure that the learning objectives of the classes are met. (3) Oakton is the second cheapest community college statewide despite the State budget impasse.

As a Senator of the SGA, I feel very proud to have built a great relationship with college administrators on a professional level. I have personally met with President Dr. Joianne Smith and Dr. Karl Brooks, Vice President for Student Affairs. I work closely with Ms. Ann Marie Barry, Director of Student Life and Advisor to the Student Government Association.

Is it possible that Oakton Community College could emerge as a "model" serving blind college students nationwide? Yes, I strongly believe so. Come and join me.

* * *

Please contact me:
Akash Patel: 312-231-4444 (cell)



**Akash Patel and U.S. Senator Tom Harkin
at the 25-yr. ADA Celebration in Chicago -
July 2015**

Please contact IPVI to see if you are
up-to-date on your dues at
1-773-882-1331
Email: ipvi@ipvi.org
www.ipvi.org



8 Misconceptions About CVI

By Hillary Kleck

Cortical Visual Impairment is a visual impairment caused by the brain's inability to correctly process what is in front of the eye rather than a physical difference of the eye as in other visual impairments. For this reason, ophthalmologists often overlook the possibility of a CVI diagnosis and it is either misdiagnosed or goes completely undiagnosed until later in childhood. Learn more about the myths and truths of CVI in this post.



Little Bear Sees: Tips & Ideas for Kids with CVI

Shared by Amber Bobnar

From the creators of the first app for kids with CVI, Tap-n-See Now, comes the Little Bear Sees blog! Here you'll find all sorts of fun ideas for activities and toys for children and babies with CVI, from lights and switches to (my

favorite) a trip to the aquarium!



Our 20 Favorite iPad Apps for Kids with CVI

The iPad may not be as bright as a Lightbox, but it can be much more interactive and easily tailored to suit the needs of kids with CVI... if you have the right apps. There are more and more organizations recognizing the possibilities of the iPad and creating iPad apps designed specifically to help kids with CVI, but there are also other apps that might not have been created with CVI in mind yet still work great for our kiddos!



The "Big 3 Tool Kit" for Children with CVI

By Amber Bobnar

There are some general rules of thumb for making vision easier for kids with CVI. Kids with CVI, for example, often prefer clear, crisp images with little background clutter. They respond well to high contrast, bright colors, movement and LIGHTS!

While anything dealing with the brain can be confusing, it's good to know there are some

great educational tools that you can use to help your child learn.



Top 10 Light Toys Under \$10

By Hillary Kleck

It may seem like \$10 won't get you much these days when it comes to toys and entertainment, and especially therapy aids, but we've done the work for you and list here the top 10 light toys under \$10 to incorporate light play around your home, during pretend play and even on your clothes!

For these articles, and many more, go to **WonderBaby.org**.

Sorting Through the Grieving Process After Receiving a Special Needs Diagnosis

By Mary McDonach

When you are first confronted by a diagnosis of any type of syndrome, disease, or congenital malformation in *your* child, a natural response is the **Grief Reaction**.

Because the grief reaction *is* a natural response, you are likely to go through at least some of the **Stages of Grief**. What can you do? You can either simply endure and hope that it eventually subsides or you can consider a few practical steps to process your thoughts and feelings a little quicker in order to

make things a little easier... on everyone.

Just understanding what is happening by looking for the signs and markers of your grieving will help you on your journey through the stages of grief. Everyone's experience of grief is unique; there is no right or wrong way to feel, and whatever you are feeling, it is valid.

Let's go through the stages of grief one by one...

Stage #1: Disbelief



What Other Parents are Saying:

While I was still in the hospital after Tony was born, the pediatrician told me that he was blind, but it didn't sink in. I really believed that all I had to do was to get him home and then he would be okay."

-From [Children with Visual Impairments](#)

You have an intellectual understanding of what you are being told but you also believe that someone has made a "Terrible Mistake" (in just this one case) and what is being said does not apply to you or your baby. Often, the paradox here is that you asked for this consultation; you felt at some fundamental maternal level that there *was* a problem with your child's sight!

This is not just a matter of believing the doctor; it is also about being able to feel at a visceral level that the information you are being given is correct. It can be helpful to consider where the doctor is in this situation—He does not want to be giving you this diagnosis any more than you want to be listening to it and he will have made triple sure of his facts before putting himself in a situation that makes him seem like the cause of your pain.

Health professionals do not lightly give distressing

information (although they may often seem cold or uncaring—this is quite possibly their own poorly thought out emotional response to the situation). They are well aware of the grief process, and the long-term consequences of living with and raising a blind baby. And, yes, very occasionally mistakes may happen, but you can be sure your doctor will have done all in his power to ensure the information he is presenting to you is accurate.

Your doctor will know that often, in the immediate aftermath of the diagnosis, you are unable to process any other information. I know from personal experience that after the initial few sentences from the pediatrician, all I could hear was a voice in my brain saying "She's got *what?*" repeatedly. It is difficult to assimilate more than the very basics at that first consultation and it happens to almost everyone. That's why the first contact with the physician is brief; it gives you an opportunity to go away, speak to your significant others, come, at least, to a first position of truce with the information you have been given, and sort through the questions you would have asked at the first consultation had you not been so traumatized.

During this stage, you may find that your emotional responses to things that would have made you cry, laugh, etc. are all more muted. You may feel a withdrawal from the world you usually inhabit and an inability to articulate how you feel. This can put a strain on your relationships, and if you have decided not to confide in anyone about the diagnosis you have been given they may feel confused, offended, or concerned about your apparently sudden personality change.

It is easy to see how logical, at this stage, it can be to simply ignore the issues surrounding your child's blindness: if you are not addressing things then they can't be happening because if they were happening you would be addressing things! There is a comfort in reassuring, circular logic, and it may work to relieve the pressure you feel, for a time, but for the sake of your child, the shorter the denial reaction the better.

Whilst all this is going on, though, your subconscious cannot ignore the feelings you are suppressing and tries to reach its own accommodation with things, so your sleep can be disturbed and provide little rest, which has further impact on how you feel during the day.

Stage #2: Anger



What Other Parents are Saying:

At first I was very angry and bitter, and I blamed God. I have since learned to adjust to my son's disabilities. Never will I accept them, but I will continually adjust."

-From *Children with Visual Impairments*

Anger is the next stage in the grief process and you may surprise yourself with your willingness to assign blame for your child's condition! Blaming yourself, your partner, your prenatal care, your post natal care, your housing conditions, your mother's "little drink problem," that spray you used on the cat, all allows you to indulge in a search for a reason that has little to do with informing yourself about your child's condition and lots to do with an atavistic need for a scapegoat.

The "why me" question can exhaust you looking for answers and more often than not the only answer you are ever likely to get is "why not you?" "Why did God forsake me?" you may ask, but God did not forsake you—**you had a baby with special needs!**

Does it really matter how your baby came by the condition? Will it help if you finally track down every last member of your husbands' family in order to prove to him that it must have "come from his side?"

Will your baby be blind regardless of *How's* and *Why's*? The distraction of the anger phase can give you useful time and motivation that you need to let others know what's happening with your child.

If you feel you have to say to your family or your neighbors or the postman "My baby is blind because my no-good-nik husband has a genetic weakness" then fine. When you remember saying that next year you may be embarrassed, but at least today the information is out there and you are starting to deal with it—*after a fashion!*

Blaming yourself can be the beginning of a lifelong relationship with guilt. This will not enhance your relationship with your child or with the rest of your family, so work through your feelings about blame with a view to getting rid of them. They will not help and in the long term these feelings will be damaging—to everyone—if they are left unchallenged.

Stage #3: Bargaining



What Other Parents are Saying:

"I know Jason has delays—I just keep expecting them to go away. I wonder what I have done wrong that he still has these delays."

-From [*Children with Visual Impairments*](#)

This is the fanciful part of grieving! You may not be sure who you are bargaining with but very often as parents we come to a position I think of as "negotiating with the cosmos." Are any of these statements familiar to you?:

- *We are hoping that she's not so badly affected (by whatever).*
- The doctors say it is a very mild case.
- Scientists are searching for a cure; they are very hopeful.
- He's affected to this degree; we couldn't have coped if it had been worse.

This can bring a subtle skewing of your ability to see the facts as they are. If you entrench yourself in the position that you can cope with, say, blindness but not blindness and deafness, are you truly open to seeing your child for who she is? Negotiating with an apparently silent deity or universe is a facet of bargaining that can leave you with a profound feeling of isolation, but being aware of what you are experiencing and knowing that it is finite often helps.

Bargaining can often, too, lead to a false perception of acceptance. One mother I know had found a way to protect her child with albinism: by not taking him out during daylight hours. Certainly, by treating her son, not as having albinism, but, more disturbingly to my mind, as though he had vampirism, she had come to a bargained accommodation with the facts. He could not be burned by the sun if he was never exposed to it and that was the current amount that this mother was able to accept. It is readily apparent though, that this was not a situation that could go unchallenged indefinitely, for anyone's sake.

Stage #4: Depression



What Other Parents are Saying:

"After a few tries of going to the store or to church, I just stopped. I couldn't stand how people looked at my baby (or at me)."

-From [*Children with Visual Impairments*](#)

Depression also can make an appearance whilst you are coming to terms with your grief. You will be aware that there is far more to dealing well with depression than I can write about here. So if you are currently suffering from the effects of depressive illness **GET MEDICAL HELP!** That you should deal with it is absolutely paramount.



You may feel that there is no reason for you to be depressed, you had a child; no-one *died*. It is reasonable to say, however, that you are grieving for the child you expected to have; no parent starts out thinking "I hope my child will be blind." That would be ludicrous, so when your child is diagnosed as blind (and *everyone* hopes fervently for another outcome) there is a kind of bereavement.

You have every right to grieve: for your hopes, for the trauma you have been through, and for your child and the limitations this condition gives him.

There is an unexpected positive to be seen in depression, paradoxically, because this is the immediate forerunner of acceptance and means that you have accepted the facts of your child's condition, at least to some extent (or why else would you be depressed?).

Stage #5: Acceptance



What Other Parents are Saying:

"From my child, I have learned to love unconditionally. My life has been opened up to include experiences I never would have considered."

-From [*Children with Visual Impairments*](#)

This will come. You will accept a new reality for yourself and your family. You will come to visualize a viable new way forward, embracing the new reality and accepting the burden of the work that lies ahead.

For my part, I spent a short time in a mini-phase of **Trying it on for Size**, also known as **Inappropriate Disclosure**. I have a vivid recollection of telling the manager of my local *Gecko!* Shop that I would be unable to buy one of his fine animals because my baby had been born blind!!!

Neither then nor now have I ever had any desire to

own a reptile so exactly what I was thinking escapes me (not to mention the fact that I'm sure a blind child could handle a lizard just as well as a sighted one), but I will give myself credit for imaginative thinking when it comes down to identifying those people who comprise my community!

Moving Forward for Yourself and Your Family



What Other Parents are Saying:

"I don't think my husband and I have been on the same wavelength since our daughter was born. It seems like one of us is always up, while the other is down. Sometimes I think he's being unrealistically optimistic, and sometimes he thinks the same of me."

-From [*Children with Visual Impairments*](#)

Not everyone goes through the grieving process, and not everyone who does go through it goes through it in the order I have described nor even always has each part of the process. It is an entirely individual experience and is as valid in its differences as it is in its similarities.

This can be particularly difficult for married couples who find themselves on opposite ends of the grieving process. The incidence of divorce in families with disabled children is exceptionally high, partly due to the obvious stressors and pressures of having a disabled child, but also partly because both parents may be experiencing the grieving process in unique and individual ways and unable to offer each other the love and support they need. Dealing with the grieving process head on will not only benefit yourself and your child, but also your marriage!

The reason for this article's title is to help you look at

where you are in the process and how you are behaving towards yourself. Get a coffee in a quiet moment and *think*—When did you last show yourself any tenderness, any charity? Try to be more gentle with yourself; there is no "blinding catharsis," but acceptance will come. Just when you least expect it, you'll get what you least expect!

Please search “Stages of Grief” and click on [Sorting Through the Grieving Process After Receiving a Special Needs Diagnosis](#).

Reprinted with permission from Amber Bobnar who began this site in 2006.



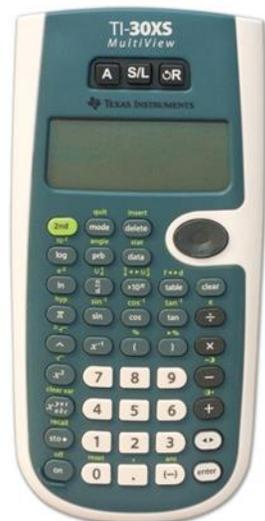
Finding this article on WonderBaby.org, I knew that it would be one of the most important information for new parents to know. Why? When my daughter was born I was going through the same stages. Luckily I had a neighbor who had a handicapped child and she gave me a book to read that explained it all. I was stuck on “what did I do during the pregnancy to cause this” and “how could I have prevented it”? Knowing these stages helped me to move on and begin to enjoy my child rather than feeling sorry for myself.

APH NEWS

Orion TI-30XS Firmware and Learn Mode Update

Great news! The most recent production of Orion TI-30XS calculators has a new firmware version and updated Learn mode recordings that improve functionality. So that all custom-

ers who have purchased the Orion TI-30XS have the same improved functionality, we have created a method to update the older units to the newer version. Changes in the new release include:



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1. Changes in recordings for learn mode announcements on many keys to match what is shown on the key. For example, the previous learn mode announcement for the fraction key was "Fraction;" now, it is "N over D." This allows a user to find the key when it is described by a teacher.
2. Fix made to lists of numbers that now announces negative numbers. Previously, there was a bug where negative numbers did not show up in some cases.
3. New Upgrade utility

Before you perform the upgrade, check your version of the calculator by pressing the Access key followed by the Memory Variable key (two rows up from the On key). If the version announced is something other than 1.00.12, we suggest you perform the upgrade.

To get the new update, follow the instructions at the **Orion TI-30XS 1.00.12 Update** website.

We would also like to invite users of the Orion TI-30XS to join our low-traffic email list, where

we answer questions, announce updates, and receive input from you, the user. To subscribe to the email list, send a blank email to: Xs-subscribe@tech.aph.org.

APH Spring Fever Sale

Load up a world of savings on selected APH products with APH's Spring Fever Sale 2016,

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APH Spring Fever Sale



Load up a world of savings on selected APH products with APH's Spring Fever Sale 2016, April 1—June 30. As always, first come, first

served. www.aph.org/sale/

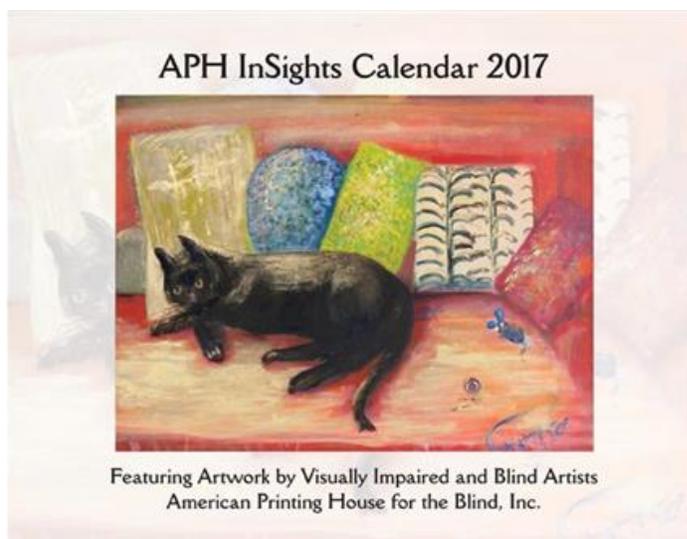
NEW! APH InSights Art Calendar: 2017

5-18971-17 — \$7.00

Note: The APH InSights Calendar may be purchased with Federal Quota funds; however, quantity purchases of this calendar for fundraising purposes MAY NOT be made with Quota funds.

This beautiful full-color calendar features the artwork of visually impaired artists. This calendar is suitable for low vision or blind students and adults or anyone who enjoys unique artwork.

Months, days, holidays, and moon phases appear in both braille and large print. This calendar can be used at a desk or hung on a wall and is ring bound to allow pages to be folded over easily.



**FREE SPECIAL EDUCATION
TRAINING FOR PARENTS**

FRCD



FRCD's workshops, training sessions, and hour long Lunch and Learn Webinars focus on specific aspects of the special education system in Illinois. All webinars are free.

Lunch and Learn: Seizure Recognition and First Aid Presentation:
Wednesday, August 3, 12-1pm

Six Principles of IDEA: Special Education Rights Training for Parents
Saturday, August 6, 10:30am-12:30pm

Lunch and Learn Webinar: Inclusion of Children with Disabilities in Early Childhood Programs
Wednesday, August 10, 12-1pm

Navigating the IEP Process
Saturday, August 13, 10:30am-12:30pm

Transition to Post Secondary Education
10:30am-12:30pm
Saturday, August 20, 10:30am-12:30pm

The Family Resource Center on Disabilities (FRCD) offers parents of children with disabilities birth to 21 years old, their helpers, relatives, professionals, and interested community members no-cost training and workshops, telephone and e-mail assistance, and resources to help claim their role as the child's most effective and significant advocate.

You are invited to contact FRCD for information, resources, support and training.

1-312-939-3513 | info@frcd.org |
www.frcd.org
20 East Jackson Blvd., Room 300
Chicago, IL 60604

**INCLUSION OF CHILD WITH
DISABILITIES IN EARLY CHILDHOOD
PROGRAMS**



Early CHOICES is a Preschool Least Restrictive Environment (LRE) Initiative of the Illinois State Board of Education. This organization promotes increasing high quality inclusive education for each and every preschool aged child by providing technical assistance and professional development to early childhood professionals and families in Illinois. In September, 2015, the US Departments of Education and Health and Human Services jointly released a Policy Statement on Inclusion of Children with Disabilities in Early Childhood Programs, which states that all young children with disabilities should have access to inclusive high-quality early childhood programs, where they are provided with individualized and appropriate support in meeting high expectations. This webinar will share how this policy can be used this to support access to inclusive options.

August 10, 2016 | 12-1pm
www.frcd.org

STEPPING STONES OF TRANSITION

Illinois Statewide Transition Conference
Thelma Keller Hotel & Convention Center
Effingham, IL from October 27-28 2016

The conference, titled "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.

This year's Annual Transition Conference is for transition aged youth and young adults with disabilities, their family members and teachers, vocational professionals, caregivers, health care professionals, and college students pursuing careers in special education and community advocates

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SPANISH TRANSLATOR

Noelia Gamino





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: (_____) - _____

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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
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
September is August 15**



**Check Out
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Calendar of Events!
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And more...