

# IPVI INSIGHTS

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

**March  
2014**



## Seeing WHAT'S Possible

**Annual Dinner 2014**

**THURSDAY MAY 22, 2014**

**Benefit For The Chicago Lighthouse**



**Honorary Chairman** Congressman Danny Davis  
**Dinner Chairman** Anida Johnson "Cookie" Cohen  
**Guest Speaker** Rachel DeWoskin  
Prize-winning author of *Blind* and *Big Girl, Small Girl*  
who teaches fiction writing at The University of Chicago  
**Four Seasons Hotel Chicago**  
Business or cocktail attire recommended

**For information on tickets, sponsorship and underwriting opportunities**

visit: [www.chicagolighthouse.org](http://www.chicagolighthouse.org)

email: [events@chicagolighthouse.org](mailto:events@chicagolighthouse.org)

call: 312.997.3668

Jeffrey Hanson artwork (featured above) will be available on the live auction.

Funds support programs and services providing education, rehabilitation and employment services for people who are blind or visually impaired.

**Because there is still hope.™**

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# Tot Rock Family Concert

Saturday, March 22nd

An All Ages Show Plus So Much More!

Saturday March 22nd  
10:30 am to 12:00 pm

JCYS George W. Lutz Family Center  
800 Clavey Road  
Highland Park, IL

Featuring:

**Mr. Singer & The Sharp Cookies**

(named one of Chicago's 8 most influential kids' musicians by Time Out Chicago Magazine)

**Tickets:**

\$10/Child

\$5/ Parent or Grandparent

Children 1 and under are FREE

**Purchase tickets online** at

[http://store.chicagolighthouse.org/catalog/  
event-tickets](http://store.chicagolighthouse.org/catalog/event-tickets)

or at the door (cash or check only at the door)



**MS. VIC'S VOLLEYS**  
*Victoria Juskie, IPVI Treasurer*

**VOLLEY I**

Since our last publication, the following families, individuals, and/or organizations became members:

No new members have joined this month.

**VOLLEY II**

We are planning another bowling fundraiser for later this year. Anyone willing to help or secure a vendor to donate a prize basket would be greatly appreciated. More details will be forthcoming upon securing a date.

**VOLLEY III**

I write to you each month and wonder sometimes if I am just talking to myself or does someone read these thoughts and hear what I am trying to convey. I have many great notes of thanks for the columns over the years so I know there's a kinship that's grown. Thank you for that. It's a great lifeline. I want first of all to ask for more of your stories – the triumphs, the pitfalls, the "ah-ha moments," etc. I am certainly not the end all in experience or advice-giving but more of a channel on which our community can better connect, so your life experiences can enrich others.

I want to offer to listen to your or your child's story and help write a draft for publication, as well, for those who'd like a little assistance. Alternatively, you can dictate it from the telephone or send me a videotape of your thoughts via email. I will write the draft and send it to you. Then editing is easily done by email. Additionally, you could also videotape a snippet in your child's life that might be able to help us figure out how to assist our children. For example, how you taught your child to tie his shoe or your daughter to identi-

fy her hair care products if she has no vision. Also, please feel free to provide any overall laughable moment. Videos may be downloaded to the IPVI Facebook and/or website and accessed by others.

Our community's spectrum of vision is so vast. I've spoken to a number of people whose children were born with a problem or are totally blind and to others whose children have lost or are losing their vision now, either through disease or accident. The eye problems of the world are so diverse that it is hard to have all the right answers. That's why I need input from the rest of you. Let's help our kids in real time by using our phones and computers. We can communicate to try to help solve our children's issues together.

So my tip of the day is get creative with your camera and film success stories for us to hear about. It will make you feel so empowered and may help ease the frustration of some other family. Also, if you have a problem that you would like covered in an open topic forum, submit those also. You may send them to [vajuskie@aol.com](mailto:vajuskie@aol.com). Thanks for your help.

Have a great March.

Spring is coming! Yeah! God bless you.



## ASK M@



Hi, Everyone.

I hope you are getting through the winter as well as possible. If you don't know, I am not a huge fan of cold weather or snow. Give me the heat any day. However, we are going

to heat up this month of March with a fresh Ask M@.

We are going to discuss the lovely topic of college. I understand some may groan when reading that statement for many reasons; mainly because it is talking about school and we've talked about school so much in these articles. However, I don't want to be sassy because education is important, especially with the job market that we have today; but as long as you bear with me, we will get to a non-school subject afterwards.

So, looking for colleges that will fit you can be very overwhelming. Trust me I know, I was there back in the day... (okay, only a few months ago). There are just a few things that you really need to look at besides the available disability services. The first most important thing to do is to make an onsite college visit, not just a virtual tour, if you can afford to. Now while you're there, be sure to take a look at how the campus is laid out. Make sure that it suits your abilities. What I mean by this is, "Where are the dorms in comparison to classes? How long are the walks? How is the campus organized?", and other questions like that.

Secondly, how do the dorms themselves appeal to you? Is there enough room; and really, do you feel you can make it your home? Remember college will be your primary home

for the next four years in a lot of cases, so you have to make sure you like where you're sleeping.

Lastly, hopefully you go there to visit the campus on a day where people are out and walking around. How is campus life there? Do the people that you're going to be going to school with seem like the people you would like to be going to school with? Some of these things may seem to be sort of obvious, but these are very important questions and some may overlook these things.

Now that we've gotten the college talk out of the way, let's get into the every-day life advice. I like that phrase. It rolls off the tongue nicely. Anyway, the one thing I have learned recently though is no matter what kind of friendship you are dealing with, it is in your best interests to be straightforward with your feelings and emotions. Here is an example that may clarify that a little bit for you. Let's say a friend -- no matter if it is a very close one or just a casual friend -- does something that kind of annoys you in some way. Obviously if it happens once, you may not do anything about it; however, if it is something repeatedly happening, you will probably get tired of it. What are you going to do, just keep letting it happen? NO! You need to be up front with your friend and let him/her know how you are feeling. This will keep the door open both ways in the friendship. I have learned this is important so you both know what each other is feeling. This can be applied in so many situations -- marriage, while dating, and even parents with their children -- so just keep that in mind while dealing with friendships and relationships.

So to recap, if you're visually impaired, there is more to the college search than just the disability services. There is also a very important rule for dealing with relationships with others -- you really have to be straightforward. Hope-



fully, this will help you until I talk to you next month. Until then have a good one!

M@



### FDA Approves Vanda Drug for Non-24 Disorder

January 31, 2014— Vanda Pharmaceuticals has been granted U.S. approval for the first drug to regulate the circadian rhythm of blind people to help them sleep.

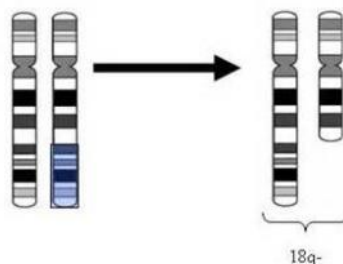
The Food and Drug Administration cleared the drug, Hetlioz, for non-24-hour disorder, a condition that affects roughly 80,000 people who are blind in the U.S.

"We have come to learn about the difficulties facing people with non-standard circadian cycles, and Vanda has responded with a thoughtful and effective treatment effort," said Paul Schroeder, Vice President of Programs and Policy at the American Foundation for the Blind. "We applaud Vanda for this effort, and we believe Hetlioz will be of great help to those who are blind and facing the challenges that come from sleep cycle problems."



**About 6 million kids in America receive special education**, according to the U.S. Department of Education. One out of every 10 children under the age of 14 has some type of special need, which includes any physical, cognitive, or medical disability, or chronic or life-threatening illness.

My 3-year-old son Jacob is one of them.



He has a disorder of the **18th Chromosome**. The 18th Chromosome has various named disorders, including Ring 18 and the more well-known

Trisomy 18 (which affects Rick Santorum's daughter, Bella). My son has the more rare 18q-. Only 1 in 40,000 Americans have Chromosome 18q-, which means that less than 7,800 Americans are affected by this disorder.

Because of this disorder, Jacob has had serious medical and developmental issues. He has had heart surgery, kidney tract surgery, bronchoscopies and endoscopies, slept with an oxygen tube, and has had dozens of medical tests and sees numerous specialists. We've been in and out of hospitals and doctors' offices since he was three months old. He also has severe developmental delays and receives speech therapy, occupational therapy, physical therapy and behavioral therapy.

Raising a child with any disorder, condition or special need, is both a blessing and a challenge. A challenge for the obvious reasons, and a blessing because you don't know the depths of victory and joy until you see your child overcoming some of those challenges (sometimes while smiling like a goofy bear).

Chances are that you know a special needs parent, or you may be one yourself. As a spe-

cial needs parent, I often don't share my feelings on this aspect of my life, even with my closest friends, so I decided to compile a list here with the goal of building understanding (I was largely inspired by [this beautiful post](#), authored by another parent to a child with a chromosomal disorder). I don't claim to speak for every special needs parent out there, but from the ones I know, some of these are pretty universal. If I've missed any, please leave a comment below.

1. **I am tired.** Parenting is already an exhausting endeavor. But parenting a special needs child takes things to another level of fatigue. Even if I've gotten a good night's sleep, or have had some time off, there is a level of emotional and physical tiredness that is always there, that simply comes from the weight of tending to those needs. Hospital and doctors' visits are not just a few times a year, they may be a few times a month. Therapies may be daily. Paperwork and bills stack up, spare time is spent researching new treatments, positioning him to sit a certain way, advocating for him in the medical and educational system. This is not to mention the emotional toll of raising a special needs child, since the peaks and valleys seem so much more extreme for us. I am always appreciative of any amount of grace or help from friends to make my life easier, no matter how small, from arranging plans around my schedule and location, to watching my son while I am eating.
2. **I am jealous.** It's a hard one for me to come out and say, but it's true. When I see a 1-year-old baby do what my son can't at 4 years-old (like walk), I feel a pang of jealousy. It hurts when I see my son struggling so hard to learn to do something that comes naturally to a typical kid, like chewing or pointing. It can be hard to hear about the accomplishments of my friend's kids. Sometimes, I just mourn inside for Jacob, "It's not fair." Weirdly enough, I can even feel jealous of other special needs kids who seem to have an easier time than Jacob, or who have certain disorders like Downs, or autism, which are more mainstream and understood by the public, and seem to offer more support and resources than Jacob's rare condition. It sounds petty, and it doesn't diminish all my joy and pride in my son's accomplishments. But often it's very hard for me to be around typical kids with him. Which leads me to the next point...
3. **I feel alone.** It's lonely parenting a special needs child. I can feel like an outsider around moms of typical kids. While I want to be happy for them, I feel terrible hearing them brag about how their 2-year-old has 100 words, or already knows their ABCs (or hey, even poops in the potty). Good for them, but it's so not what my world looks like (check out [Shut Up About Your Perfect Kid](#)). It's been a sanity saver to connect with other special needs moms, with whom it's not uncomfortable or shocking to swap stories about medications, feeding tubes, communication devices and therapies. Even within this community, though, there is such variation in how every child is affected. Only I understand Jacob's unique makeup and challenges. With this honor of caring for him comes the solitude of the role. I often feel really lonely in raising him.
4. **I am scared.** I worry that I'm not doing enough. What if I missed a treatment or a diagnosis and that window of optimal time to treat it has passed? I worry about Jacob's future, whether he will ever drive a car, or get married, or live independently. I am scared thinking of the hurts he will experience being "different" in what's often a harsh world (not to mention that I fear for the physical safety of the person who inflicts any hurt upon my son). I am scared about finances. Finally, I fear what will hap-

pen to Jacob if anything were to happen to me. In spite of this, my fears have subsided greatly over the years because of my faith, and because of exposure to other kids, teenagers, and adults affected with Jacob's disorder. When I met some of these amazing people at a conference last year, the sadness and despair that I was projecting onto Jacob's future life (because it was so unknown) melted away when I saw the love and thriving that was a reality in their lives. The fear of emotional pain (for both me and Jacob) is probably the one that remains the most.

5. **I wish you would stop saying, "retarded," "short bus," "as long as it's healthy..."** I know people usually don't mean to be rude by these comments, and I probably made them myself before Jacob. But now whenever I hear them, I feel a pang of hurt. Please stop saying these things. It's disrespectful and hurtful to those who love and raise the kids you're mocking (not to mention the kids themselves). As for the last comment, "as long as it's healthy," I hear a lot of pregnant women say this. Don't get me wrong, I understand and share their wishes for healthy babies in every birth, but it's become such a thoughtless mantra during pregnancy that it can feel like a wish against what my son is. "And what if it's not healthy?" I want to ask. (My response: you will be OK. You and your child will still have a great, great life.)
6. **I am human.** I have been challenged and pushed beyond my limits in raising my son. I've grown tremendously as a person, and developed a soft heart and empathy for others in a way I never would have without him. But I'm just like the next mom in some ways. Sometimes I get cranky, my son irritates me, and sometimes I just want to flee to the spa or go shopping (and, um, I often do). I still have dreams and aspirations of my own. I travel, dance, am work-

ing on a novel, love good food, talk about dating. I watch *Mad Men*, and like a good cashmere sweater. Sometimes it's nice to escape and talk about all these other things. And if it seems that the rest of my life is all I talk about sometimes, it's because it can be hard to talk about my son. Which leads me to the final point...

7. **I want to talk about my son/It's hard to talk about my son.** My son is the most awe-inspiring thing to happen to my life. Some days I want to shout from the top of the Empire State Building how funny and cute he is, or how he accomplished something in school (he was recently voted class president!). Sometimes, when I'm having a rough day, or have been made aware of yet another health or developmental issue, I might not say much. I don't often share with others, even close friends and family, the depths of what I go through when it comes to Jacob. But it doesn't mean that I don't want to learn how to share our life with others. One thing I always appreciate is whenever people ask me a more specific question about my son, like "How did Jacob like the zoo?" or "How's Jacob's sign language coming along?" rather than a more generalized "How's Jacob?" which can make me feel so overwhelmed that I usually just respond, "Good." Starting with the small things gives me a chance to start sharing. And if I'm not sharing, don't think that there isn't a lot going on underneath, or that I don't want to.

Raising a special needs child has changed my life. I was raised in a family that valued performance and perfection above all else, and unconsciously I'd come to judge myself and others through this lens. Nothing breaks this lens more than having a sweet, innocent child who is born with impairments that make ordinary living and ordinary "performance" difficult or even impossible.

It has helped me understand that true love is meeting someone (child or adult, special needs or not) exactly where he or she is -- no matter how they stack up against what "should be." Raising a special needs child shatters all the "should be's" that we idolize and build our lives around, and puts something else at the core: love and understanding. So maybe that leads me to the last thing you don't know about a special needs parent... I may have it tough, but in many ways I feel really blessed.

*This was one of the stories on AOL. It comes from "The Blog" posted originally on 3/9/2012 and written by Maria Lin.*

### APH NEWS

#### 2014 Through the Looking Glass Scholarship Announcement

Through the Looking Glass and its National Center for Parents with Disabilities and their Families are pleased to announce new scholarships specifically for high school seniors or college students who have parents with disabilities. A total of fifteen \$1000 scholarships will be awarded in Fall 2014. Please go to their website, <http://www.lookingglass.org> for more information, including the application form, complete application directions and an FAQ page that answers many common questions as well as offers helpful suggestions. Deadline for submission is **March 17**.

#### NOAH Sponsored Scholarship

The **Michael J. McGowan Leadership Scholarship Award** was established on behalf of the National Organization for Albinism and Hypopigmentation (NOAH) to recognize leadership and empower young people with albi-

nism. NOAH will award one \$3,000 scholarship to a NOAH member with albinism residing in the U.S. or Canada who is enrolled in an undergraduate program at an institution of higher education in the U.S. or Canada. Please contact NOAH's Scholarship Committee with any questions at [scholarship@albinism.org](mailto:scholarship@albinism.org) or 800-473-2310 (U.S. and Canada).

### STAR NET REGION VI



We currently still have openings available for the two day Teaching Strategies GOLD workshop on March 7th and March 14th of 2014.

For a complete list of our upcoming workshops/webinars please go to our website at [www.swccase.org/starnet](http://www.swccase.org/starnet) and click on the "workshop" tab. If you are interested in attending any of the STAR NET workshops/webinars please register as quickly as possible to avoid cancellation due to low enrollment.

Thank You,

STAR NET Region VI  
6020 West 151st Street  
Oak Forest, Illinois 60452  
708-342-5370





**SAVE THE DATE!**  
**Early Childhood Today:**  
**Play, Learn and Grow Together**  
**for a Successful Tomorrow**

**STAR NET Region VI and the College of Education** will hold their seventh annual conference at the Romeoville Campus. This conference is for parents, caregivers and professionals who shape the lives of children ages birth to 5 years old. Workshops will address six themes of social/emotional, speech and language, accommodations, early literacy, health and wellness, and best practices.

Wednesday, March 5, 2014

**8:30 a.m. - 3:30 p.m.**

(sign in 8-8:30 a.m.)

**Lewis University - Romeoville Campus**

One University Parkway, Romeoville, IL 60446

LEWIS UNIVERSITY

**FEE:** \$35 (includes continental breakfast, lunch, and instruction and workshop materials). Conference is **free** for Presenters and Lewis Early Childhood students. **There will be no refunds given.** If paying by check make check payable to:

Lewis University  
Attn: Pat Levenda, Unit 224  
One University Parkway  
Romeoville IL 60446



For Invoice used to create a purchase order email Pat Levenda at [levendpa@lewisu.edu](mailto:levendpa@lewisu.edu).

**Registration:** Pre-registration is required and seats are limited. Registrations will be accepted based on a first-come, first-served basis. No on-site or phone registration allowed. When using a purchaser order, please fax a copy of the purchase order along with a completed registration form for each participant to (815) 588-7070. **Registration must be received by Friday, February 28.**

STAR NET provides training, consultation, and resources to the early childhood community. The STAR NET system assists the State Board of Education in meeting local needs by providing services to professionals and parents of young children with special needs throughout Illinois.

**Note:** Child care is not available at the conference. Parents of children with disabilities under age 6 can apply for a family fellowship for a reimbursement stipend through STAR NET at [www.swccase.org/starnet](http://www.swccase.org/starnet). Please click on **Fellowship info** to apply.

In the event of a weather related closing on March 5th please check Lewis University Website or contact STAR NET at 708-342-5370.

Co-Sponsored by STAR NET Region VI and Lewis University, in collaboration with SSAEYC, Early Intervention Training Program, Good Shepherd Center, and Child and Family Connections # 12.

# A NIGHT FOR THE AGES



The National Federation of the Blind of Illinois Chicago Chapter is sponsoring a once-in-a-lifetime fundraising experience. The place for this extravagance will be Dicks Last Resort located in Marina City, 300 North State Street, Chicago. The date for this not to be forgotten event is

**THURSDAY, MARCH 13**

and the cost for this event will be \$40 per person.

So, just what does this night entitle you to? Two hours of unlimited domestic beer, wine, or both beer and wine if you dare. Additionally, you are entitled to take advantage of a wide variety of hor d'oeuvres.

So, come one and all, and collectively experience a Night for the Ages.

Payment for this event must be received by David Meyer no later than March 8, the day of the March Chicago Chapter meeting. You may submit your payment at the February or March chapter meeting, or you may mail them to 814 Hannah Avenue, Forest Park, IL 60130. Payment may be made by cash or check. If you wish to make your payment by check, please make checks payable to the National Federation of the Blind of Illinois.





## The Chicago Lighthouse Scholarship Program

For students who are blind or visually impaired

The 2014-2015 Chicago Lighthouse Scholarship Application will be on our website and available for download by the end of this month.

Postsecondary students of all ages who are blind or visually impaired are welcome to apply for Lighthouse scholarships, including those pursuing two-year, undergraduate, graduate and advanced degrees as either full-time or part-time students. Although applicants from anywhere in the U.S. are encouraged to apply, priority will now be given to local applicants, that is, those who are from or are attending school in Illinois.

When submitting application materials, students should be sure to include:

- ✓ A completed application
- ✓ A personal essay
- ✓ Personal statement of financial need
- ✓ A completed vision report
- ✓ Official transcripts from the most recent academic year
- ✓ Two (2) letters of recommendation



Each of these items is discussed in more detail on the Scholarship Application. **The application deadline for the 2014-2015 school year is March 28, 2014 by 5pm.**

Please don't hesitate to contact me if you have any questions or concerns.

**Araceli Heredia, M.A., CRC, LPC**

**Vocational Evaluator, Customer Service Trainer, Youth and Scholarship Coordinator | Employment Services**

Phone: 312.666.1331 ext 3548

[araceli.heredia@chicagolighthouse.org](mailto:araceli.heredia@chicagolighthouse.org)

**[www.thechicagolighthouse.org](http://www.thechicagolighthouse.org)**

**The Chicago Lighthouse for People Who Are Blind or Visually Impaired**

1850 West Roosevelt Road | Chicago, IL 60608

STAR NET REGION V

*Welcome to Illinois  
STARNET Region V  
(City of Chicago)*

**Now Available**

**January - June 2014  
Calendar of Events!**

**STARNET Events**

STARNET workshops and events emphasize evidence-based, family-centered practices. STARNET does not endorse specific treatments or methods for children with disabilities. Our events present a variety of current research-based practices currently used with young children. Parents, family members and Chicago residents are given priority for workshop and event registration. STARNET activities are provided free-of-charge, with the exception of some collaborative events.

Online registration is available at [www.StarnetChicago.org](http://www.StarnetChicago.org).



STARNET Region V  
Chicago Public Schools  
125 S. Clark - 8th Floor  
Chicago, IL 60603



**2014 NFB Writers'  
Division Writing  
Contest**

The annual youth and adult writing contests sponsored by the NFB Writers' Division will open January 1st and will close April 1st.

Adult contests, poetry, fiction, non-fiction, and stories for youth are open to all entrants eighteen years and over.

The Youth Writing Contest, poetry and fiction, is to promote Braille literacy and excellence in creative writing. Entries will be judged on creativity and quality of Braille. The contest is divided into three groups, determined by grade level – elementary, middle, and high school.

Prizes for contest winners range up to \$100 for adult categories and up to \$30 for youth.

All contest winners will be announced the first week in July, at the Writers' Division business meeting during the NFB national convention, held in Orlando, Florida. In addition, shortly after convention, a list of winners will appear on the Writers' Division's Website,

<http://writers.nfb.org>

First, second, and third place winners in each category will be considered for publication in the Writers' Division magazine, "Slate & Style."

For additional contest details and submission guidelines, go to our website,  
<http://writers.nfb.org>

Chelsea Cook [astrochem119@gmail.com](mailto:astrochem119@gmail.com)

Nfbnet-members-list mailing list

[Nfbnet-members-list@nfbnet.org](mailto:Nfbnet-members-list@nfbnet.org)

List archives: [http://www.nfbnet.org/pipermail/nfbnet-members-list\\_nfbnet.org](http://www.nfbnet.org/pipermail/nfbnet-members-list_nfbnet.org)

Patti Gregory Chang  
NFB President  
NFB Scholarship Committee Chair





# IPVI's Matthew Benedict Juskie Scholarship Fund

For students who are blind or visually impaired

Any individual intending to continue his/her education at a college, university or trade school and is interested in being considered for the MBSF, must meet the following criteria: Illinois resident, blind or visually impaired, undergraduate or graduate student, and an IPVI member.

The candidate's application is processed free of charge. The student must mail or fax a written request to receive a copy of the application from IPVI. Then the student must complete the MBSF Application Form, provide 3 completed Reference Forms, submit medical records or a letter from the vision specialist confirming the condition, and mail them to IPVI. The applicant may attach a 1-page resume of clubs, offices held, or any other pertinent information concerning his/her activity record.

The IPVI Board of Directors will review all scholarship applications and select the winners. IPVI reserves the right to announce such awards in its newsletters and marketing materials.

The MBSF is funded completely from tax-deductible donations from individuals, companies and corporations who support IPVI's goals. Any individuals or groups wishing to donate to this fund, please forward your tax-deductible donations to IPVI. Thank you for your continued support of IPVI.



**To request a scholarship application, please contact the Scholarship Program Coordinator, Vicki Juskie at: 815-464-6162 or [vajuskie@aol.com](mailto:vajuskie@aol.com)**



## National Federation of the Blind 2014 Scholarship Program

To recognize achievement by blind scholars, the National Federation of the Blind annually offers blind college students in the United States and Puerto Rico the opportunity to win one of thirty merit-based, national-level scholarships worth from \$3,000 to \$12,000. All scholarships awarded are based on academic excellence, community service, and leadership.

We have both state and national scholarships to award. The applications are due by 3/31. So far, Illinois has only two applicants for our national scholarships which award \$122,000 in cash awards annually. Don't forget our state scholarships which award, \$8,500 annually.

Please direct any additional questions to the chairperson. Email is preferred.

Chairperson Patti Chang, Esq.  
Email: [scholarships@nfb.org](mailto:scholarships@nfb.org)

Office: (410) 659-9314, extension 2415

NFB Scholarship Program  
NATIONAL FEDERATION OF THE BLIND  
200 East Wells Street at Jernigan Place  
Baltimore, Maryland 21230



## MAKING SENSE

### Important Information About Microsoft XP:

Effective April 1, 2014, Microsoft will no longer support Windows XP. This means that no more Windows updates will be available to protect your computer against viruses and hackers. In our Tech Times email newsletter, David Flament offers some suggestions you might want to consider. If your computer is less than three or four years old, it may be able to be upgraded to Windows 7, but it may require backing up all your data and doing a clean install. Your best bet may be to buy a new computer. Prices on laptops have come down considerably and will be protected for at least a few more years. The most important thing to remember: you have made a decision even if you do nothing! If you'd like to receive our quarterly Tech Times newsletter with tips and commentary on adaptive technology, call David Flament or email [david.flament@second-sense.org](mailto:david.flament@second-sense.org). Tech Times is also available on our website and on NFB Newline on the Second Sense channel.

**More College Scholarships!:** Locally, Blind Service Association and nationally, Microsoft, are offering scholarships to students who are attending colleges this coming fall. Blind Service Association awards legally blind students scholarships up to \$3,000 for those who live in the Chicago area. Awards can be used for tuition, books, equipment or other expenses related to their education. Scholarships are based on academic record, community service, and financial need. Deadline for submission is April 1, 2014. Contact BSA at 312-236-0808 to learn more and for an application. The Microsoft Disability Scholarship is a new initiative with the Seattle Foundation and is intended to help college students with disabilities who are pursuing a career in the technology field.

(Continued on page 15)



## REGISTER FOR YOUR FREE PARENT WORKSHOP TODAY!

Space is limited; registration is mandatory. Please visit [www.frcd.org](http://www.frcd.org) or call 312-939-3513 for registration and workshop location.

**Six Principles of IDEA: Special Education  
What you Need to Know**  
Saturday, March 1, 10am-1pm

**IEP Individualized Assistance  
(By appointment only)**  
Friday, March 7, 10am-5pm  
Monday, March 10, 9am-4pm  
Friday, March 14, 9am-4pm

**Skills for Effective Parent Advocacy**  
Saturday, March 8, 10am-1pm

**Destrezas Para una Abogacía Eficaz de  
Parte de Los Padres**  
Tuesday, March 11, 12:30pm-2pm  
Monday, March 17, 10:30am-12pm  
Tuesday, March 25, 12:30pm-2pm

**Navigating the IEP Process**  
Saturday, March 15, 10am-1pm

**Transition Series: Self Advocacy and  
Supports: Keys to Independence**  
Saturday, March 22, 10am-1pm

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**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](mailto:info@frcd.org) |  
[www.frcd.org](http://www.frcd.org)  
20 East Jackson Blvd., Room 300  
Chicago, IL 60604**

*(Continued from page 14) - Making Sense*

gy industry. This is a \$5,000 nonrenewable award paid to the financial aid office of the student's chosen institution. High school students are eligible to apply if they have a declared major from an approved list, carry a 3.0 GPA, demonstrate financial need, and have a passion for technology. Deadline for applications is March 15, 2014. To learn more, visit [www.microsoft.com](http://www.microsoft.com) and type "Disability Scholarship" in the search field.

**Laws and Statutes Protecting Guide Dogs:** Pilot Dogs Alumni Association has a comprehensive listing of state laws and statutes regarding the use, protection, and penalties regarding guide dogs. While the use of a guide dog for a person with vision loss is protected, there are still many nuances and differences in each state. For instance, in Kentucky the guide dog must be specially trained by a recognized guide dog school. To familiarize yourself with a specific state statute, go to [www.pilotdogsalumni.org](http://www.pilotdogsalumni.org) and click on access laws.

**March is Eye Health and Safety Month:** Despite vision loss, it is still important to protect your eyes and your remaining sight. Prevent Blindness America provides tips to help prevent injury and preserve vision. Wear sunglasses, even in the winter time, as sun reflecting off of snow can cause damage to your eyes. The added glare can also be uncomfortable and cause you not to use your vision to its maximum potential. Purchase sunglasses that block 99% to 100% of UVA and UVB rays. Many eye injuries occur in the home, so if do-

ing home repairs, using household chemicals or performing other tasks around the home, wear safety glasses. Wearing your eyeglasses can help protect your eyes from dust particles or other airborne particles when you are outdoors. Eyeglasses can also help protect against objects that might poke you around the sensitive eye area. For more tips on preventing eye injury and preserving eye health, visit [www.preventblindness.org](http://www.preventblindness.org).

Reprinted from MAKING SENSE, March 2014, *Second Sense, Beyond vision loss*, 65 East Wacker Place, Suite 1010, Chicago, IL 60601, 312-236-8569, [www.second-sense.org](http://www.second-sense.org).



The National Federation of the Blind of Illinois Presents a  
Seminar for Parents and Teachers

### **“Making it Happen”**

**Saturday April 5, 2014**

8:30 a.m. to 5:00 p.m. -- Holiday Inn  
Express Hotel and Suites Chicago O'Hare

On Saturday, April 5, 2014, the National Federation of the Blind of Illinois will hold concurrent annual Spring Seminars for Students and Parents at the Holiday Inn Express Hotel and Suites, Chicago O'Hare, 6600 Mannheim Road, Rosemont, IL 60018. These seminars will be a day-long event consisting of meetings for visually impaired students, teachers and parents of children with visual impairment or blindness. Topics will include socialization, education, assistive technology, development of requisite blindness skills, and much more.

Our keynote speaker is Edward Bell. Dr. Bell serves as Director of the Professional Development and Research Institute on Blindness at Louisiana Tech University. He has an extensive background in rehabilitation and educational psychology. His focus for our seminar will be on orientation and mobility.

Children ages three to twelve are invited to participate in Kids Camp. This all-day program will provide children with the chance to try new activities and to meet other young people who are also visually impaired or blind. Siblings of your visually impaired child are very welcome.

The student seminar is appropriate for anyone age 13 and older who is a student or interested in student issues. This seminar is run by our Illinois Association of Blind Students. We will have demonstrations of adaptive sports opportunities such as Judo, Beep-Baseball, and Goalball.

Cost: \$30 for parents' seminar; \$15 for our student seminar; and \$10 for ages 3 to 12, including box lunches. Overnight accommodations are available for \$109 at the Holiday Inn Express and Suites by calling (877) 786-9480. Indicate that you are asking for the National Federation of the Blind rate. For those traveling from outside the Chicago-metro area, financial assistance may be available. Please apply through the Chappell Memorial Awards at [www.nfbfillinois.org](http://www.nfbfillinois.org) on or before March 15, 2014

The National Federation of the Blind (NFB) is a 50,000-member organization that works to insure the full participation of blind people in all aspects of society. The National Organization of Parents of Blind Children (NOPBC) is a division of NFB that has been helping to spread a positive message about vision loss to parents for more than twenty-five years.

If you would like to attend the seminar, please **submit the registration form by March 24, 2014**. For more information, please contact Debbie Kent Stein at (773) 203-1394 or [dkent5817@att.net](mailto:dkent5817@att.net). Vision impairment can be reduced to a nuisance with proper training. Please come and learn how.



## EFFECTS ON THE FAMILY OF A VISUALLY IMPAIRED CHILD

As early as 1944, researchers were examining how parents of visually impaired babies respond to the news about their child's disability. They concluded that parents needed ongoing support during the early years, as they learned to live with a visually impaired child. Although "stages" of adjustment are often mentioned in discussions about parental reactions to having a disabled child, this philosophy implies a progression, or developing levels of feelings. This is not necessarily the case with parents of visually impaired children. There is no endpoint resolution of the problem - no "complete" time-frame. Instead of a progression of emotional stages, moving from shock towards acceptance, there is actually an ongoing mourning process, typified by both recurring bargaining ("If I just do\_\_\_\_, everything will be okay") and depression (crying, feeling lost and alone). What is sometimes viewed as "acceptance by professionals may actually be learning to live with the hurt; "accepting " parents usually avoid comparing their visually impaired child with normally sighted peers, and are able to release themselves from guilt; they are able to place "blame" for their situation onto the real cause (e.g., disease). When parents can accept that "it's not my fault," it appears to be easier to live with the hurt. The pain never completely goes away, and surfaces at times of stress (transition periods, situations of uncertainty). When the sorrow reappears, it is hard for parents to "hear" helpful suggestions, and the wise professional waits until the crisis has passed.

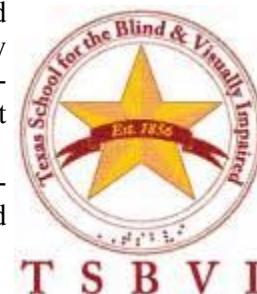
Problems in parental attitude may arise if parents deny that a problem exists, or overprotect their visually impaired child (i.e., do not allow him/her to achieve independence appropriate to his/her age). Denial closes off parents from positive suggestions, and may interfere with intervention strategies. Over protectiveness insulates the visually impaired child from the very world he/she needs to discover on his/her own. There is no clear method of helping parents to resolve these problems. Ongoing support (a strong shoulder and a ready ear) may be the best that the professional can offer; teachers should not attempt to provide "therapy" for parents, since more harm than good can be done by even the most well-intentioned educator who has had no training in counseling (and most have not). If severe emotional problems seem to exist (e.g., the family seems to be in danger of "falling apart"), professional help (and, possibly, respite care) should be recommended.

Socioeconomic status seems to be a factor in parental reactions to having a visually impaired child. As the socioeconomic situation improves (e.g., there is at least one wage earner in the family, and the bills get paid), the ability to deal with the stress also seems to improve. Conversely, if there are few resources to address the basic needs of food, shelter, clothing, and medical care, the ability of parents to manage their emotional reactions to a visually impaired child may be stretched to the breaking point. Financial assistance can go a long way towards balancing the emotional levels of the family.

It is important to the visually impaired child that he/she feel "accepted" within the family. Being treated "like the other kids" can help build this feeling of security. The child's self-image and self-esteem are closely related to how he/she perceives his/her value within the family. Nurturing parents, regardless of socioeconomic status, are good for all children, but crucial to visually impaired children. Pride in the child's achievements, no matter how small, and praise for effort, can build a sense of accomplishment: "I did it myself!"

Since services for visually impaired children in the B-3 year old range focus on the family (the child is in the family), every effort should be made to assess each family's specific and unique needs. Because timing for intervention is so critical for visually impaired children in this age group, the VI teacher should be an active member of the IFSP team, to provide both strategies and suggestions for cooperative service provision. This is especially critical in the early years, when parent - child bonding is taking place. Blindness

or visual impairments can interfere with the bonding process (the child may not make eye contact, may startle when touched, or may turn his/her head away). Moreover, the child with early medical problems may have had either extended hospital time, with separation from caregivers, or have had uncomfortable experiences with physical contact (shots, intensive care procedures, etc.). These children may require special handling (soothing, calming, stroking), and caregivers may need extra support and counseling. On-going family support can help resolve miscommunication issues, and ensure the necessary bonding between child and parents.





Are you a teenager who could use a week of fun, outdoor activity and friendship this summer? Would you enjoy the challenge of developing new travel skills and stretching your independence? If so, the Leader Dog Summer Experience was designed with you in mind.

Our Summer Experience combines outdoor camp activities such as kayaking, rock wall climbing and tandem biking with things exclusively Leader Dog—GPS training and the opportunity to try-out the guide dog lifestyle. The combination will help you increase the skills you need to live independently!

The Leader Dog Summer Experience is for boys and girls ages 16 and 17 who are legally blind. The program is completely free including airfare—and everyone receives a free Kapten PLUS audible pedestrian GPS device to keep.

The **Summer Experience is scheduled for June 21—June 28, 2013** and **applications are due May 1**, so time is of the essence. For more information and to start the application process, go to **[www.leaderdog.org/programs/youth](http://www.leaderdog.org/programs/youth)** or call our client services department at 888-777-5332.

Regards,

**Rachelle Kniffen**  
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Leader Dogs for the Blind  
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Rochester Hills, MI 48307-3115  
Direct (248) 659-5013  
Toll Free (888) 777-5332  
**[leaderdog.org](http://leaderdog.org)**



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**THIS PUBLICATION IS SUPPORTED  
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HILTON/PERKINS  
PROGRAM AND (IN PART) FROM A  
GRANT FROM THE FAMILY RE-  
SOURCE CENTER ON DISABILITIES**



## 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 2947 • Naperville, IL 60567-2947

**Have questions or need  
more information?**

**Call us at  
1-815-355-2098**



**Illinois Association for Parents of  
Children with Visual Impairments**  
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Naperville, IL 60567-2947

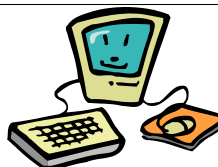
**Please contact IPVI to see if you are  
up-to-date on your dues at the  
address on the left or  
1-815-355-2098  
Email: [ipvi@ipvi.org](mailto:ipvi@ipvi.org)  
[www.ipvi.org](http://www.ipvi.org)**

## **IPVI CALENDAR**

- |           |   |                   |
|-----------|---|-------------------|
| ▶ 3/5     | <b>STAR NET VI &amp; the College of Education 7th Annual Conference</b> | <b>Romeoville</b> |
| ▶ 3/18    | <b>Lighthouse North Parents' Night</b>                                  | <b>Glenview</b>   |
| ▶ 3/13    | <b>A Night for the Ages (NFB of IL Chicago Chapter) Fundraiser</b>      | <b>Chicago</b>    |
| ▶ 3/28    | <b>The Chicago Lighthouse Scholarship Program Deadline</b>              |                   |
| ▶ 4/1     | <b>2014 NFB Writers' Division Writing Contest Deadline</b>              |                   |
| ▶ 3/31    | <b>NFB 2014 Scholarship Program Deadline</b>                            |                   |
| ▶ 4/5     | <b>NFB "Making it Happen" Spring Seminars</b>                           | <b>Chicago</b>    |
| ▶ 6/21-28 | <b>LeaderDogs Summer Experience</b>                                     | <b>Michigan</b>   |

Please call  
**1-815-355-2098**  
for any questions, concerns,  
or comments that IPVI can  
help you with.

**Newsletter Deadline for  
APRIL 2014 is MARCH 15<sup>th</sup>**



**Check Out  
[www.ipvi.org](http://www.ipvi.org)**

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