

# The Conformer

Spring 2008

ican

International children's  
anophthalmia network

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## **Meet the Board**

### **Executive Board**

**President-** Jodi Dennis-Ohio

**Vice-President-** Nelly Gamino-Illinois

**Secretary-** Kelly Derezza-Kentucky

**Treasurer-** Becky Pennington-California

**Head of Fundraising-** Margaret Cote-Massachusetts

### **Members at Large**

Jody Hawkins-Minnesota

Sara Ault-Michigan

Kelley Hoffman-Georgia

Elisa Rostkowski-New York

**Spanish contact-**Nelly Gamino-Illinois

**Conformer contributor-**Jason Hawkins-Minnesota

**Hotline-**Jodi Dennis-Ohio

Please get involved. We welcome any ideas, suggestions or assistance. You can contact us at any time. To contact a Board member e-mail them at [ican@anophthalmia.org](mailto:ican@anophthalmia.org) and put their name in the subject.

## Helpful Hints for Daily Living Skills

### READING TO LITTLE ONES WITH VISUAL IMPAIRMENTS

Parents often ask when they should begin reading to their baby who has a visual impairment. Literacy begins in infancy so you should begin reading right away. The same as you would with a baby with sight. Babies get comfort from sitting in their parent's lap and feeling the resonance of their voice as they read a favorite story over and over again. Babies like repetition so even when you feel like you could recite "Goodnight Moon" in your sleep, don't assume that your little one is tired of the book.

Reading to your baby helps develop awareness of representational reference whether it is in print or braille. Letting your baby feel the words in braille establishes this pre-reading readiness skill. We realize sighted babies can't read the words in a book but they are getting information visually by seeing the letters as a representation of what you are reading. The same is true for the child with a visual impairment. We don't expect the baby to read braille but the braille is a tactile representation of what you are reading.

Seedlings Braille Books for Children is a non-profit, tax exempt organization dedicated to literature in braille. They have wonderful books that you find in your local bookstore with braille overlay. The print-braille and picture books for the pre-readers are called twin vision books because the parent reads the print while the child feels the braille. Some of my favorite twin vision books are:

1. **Razzle Dazzle Numbers and Shapes** – These two board books by Chuck Murphy have cut outs with mylar inside to provide a visual spectacle. They are great to work on shift of gaze by shining a flashlight on the pages from left to right. The cut-outs allow the child to feel the numbers and shapes on each page. \$5.00 each.
2. **Scratch and Sniff Books and Touch and Feel Books** – Each board book from DK Publishing has delightful bright pictures, wonderfully realistic textures or smells to explore. The words are in print and Braille of course! \$7.00 each.
3. **Goodnight Moon** – This board book is a favorite of mine by Margaret Wise Brown. It is perfect to share with a child at bedtime! \$7.00

If those peaked your interest, call toll free for a catalog: 800-777-8552. E-mail address is [seedlink@aol.com](mailto:seedlink@aol.com). The web page is: <http://www.seeklings.org>.

Happy Reading!  
Jo Russell-Brown, M.Ed.  
Parent – Infant Teacher/Vision Consultant  
E-mail: [jorussell@dgckids.org](mailto:jorussell@dgckids.org)

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*Please consider joining the A/M Registry, and help scientists investigate the causes of anophthalmia and microphthalmia. Contact [ican@anophthalmia.org](mailto:ican@anophthalmia.org) or call 1-800-580-ican for more information.*

## Sharing Stories

The Florida Times-Union

March 16, 2008

### BOLD JOURNEY

By DIANA MIDDLETON,  
The Times-Union

The scrape of a ski pole on rock, the woolly textured rugs hanging in a textile market, the frenetic chatter of Spanish-speaking villagers: These will be Michelle Lamm's memories - mental postcards in a slideshow without images.

The blind teenager will be hiking on a remote trail to the once-lost hidden Incan city of Machu Picchu this summer, traversing rocky terrain, rivers and hundreds of uneven, stony stairs. At an altitude of 7,710 feet - almost 15 times the height of the Modis Building - the air is thin, causing the insides to coil in nausea. Plenty of sighted people can't make it. "Did you know I was born without any eyes?" she says with all the drama of a typical teenage girl. "It's very rare." Steely blue glass eyes peer from beneath her eyelids. Many of Lamm's classmates at the Florida School for the Deaf and the Blind in St. Augustine have progressively lost their sight by their teens. Lamm has been blind since birth, born with bilateral anophthalmia. The condition, caused by a gene mutation, occurs in one out of every 100,000 children.

#### Mastering an unpredictable terrain

She will join three other teens - all are either blind or visually impaired - and make the trek alongside six sighted guides. Prior to the June trip, Lamm will train in Colorado, where the altitude is similar to Peru, to master the unpredictable terrain, according to David Shurna, the executive director of Global Explorers, organizers of the expedition. "The hiking can range from a steady, uphill travel to hundreds of rock stairs," Shurna said. "In an eight-hour hiking day, you could encounter five different terrains, and the adjustment is what's difficult." The trip will start slowly - so the students can acclimate to the high elevation - with a four-day exploration of Cuzco's colorful markets and archaeological sites. Later, during the five-day hike on a remote trail, the students will visit with villagers and perform community service, such as painting a school. Negotiating the trail together is the great equalizer between the blind and sighted students, Shurna said. "All of the students complete the same curriculum and are taught the same principles of volunteerism and conservationism," he said. "Being blind is just one aspect of some of these students, but all of them love the adventure."

#### Eagerly anticipating the trip

Lamm's bedroom is cluttered with the usual teenage trappings: A shelf piled with teddy bears, a closet spilling with clothes and a computer surrounded by manila file folders (these are puckered with Braille labeling). She doesn't even turn on the television (it just makes her go to sleep), but she loves to listen to books. The nightstand in her bedroom is piled high with audiobooks, including one titled *High School Isn't Forever*. When asked if she's looking forward to being away from home, her voice tightens in excitement. "I am so ready to be independent," she said. "I can't wait to have my own job, get married and have a family. I'm an adult." To prepare for the physical vigors of the Peru trip, Lamm jumps on her backyard trampoline and swims laps. She touches her muscles, a kind of body Braille, to feel if they're getting larger. She rides a tandem bicycle with her



<http://www.globalexplorers.org/leadingtheway/>  
For Cost and Applications

father, a Jacksonville firefighter - although he is currently away and serving in Iraq. Her athleticism is one of her greatest strengths, according to Peter Sandberg, who specializes in mobility at the Florida School for the Deaf and the Blind. "Often, blind people don't have a lot of social experience, but a trip like this changes people," he said. "To hike a trail that you can't even see - well, it takes a very determined and strong-willed person to undertake."

#### Sound as a compass

Like a bat uses echolocation to navigate through the night, Lamm will learn to use noise as a compass in the mountains: The guides will give verbal instructions and ring hand bells to indicate curves in the trail. Lamm will use two poles, similar to ski poles, to scan for rocks and poke for crevices. Having always operated in darkness, Lamm sometimes has difficulty articulating her expectations of Peru. "I am not sure what it will be like," she said. "Maybe there will be people playing in a field." But the air will feel different. She won't be able to understand Spanish. She'll hear the trees rustle in the breeze. She will sense the sheer drop of a cliff. And when she finally reaches the remote temples of Machu Picchu, her guide may take her hand and trace the mountains' outline in the air. Lamm won't see the ancient city carved in the mountain. But she will be able to feel it.



*ican:*  
*Sharing hopes,*  
*joys,*  
*and challenges*

**A tip to share from Nelly Gamino.**

I would say definitely be involved with the City, State, and National organizations. You never know what resources you might find. The story I'm sharing came out of a picnic I attended with the NFB. At the picnic they had a chance to meet Alex and not only did the story come out to it but also a brailier. Yes, one of the members had a brailier that she no longer used and decided to give it to Alex. Alex was so excited when he got it in the mail he couldn't sleep.

**MEET A FEDERATIONIST: ALL ABOUT ALEX**

By Carmen Dennis

How much can one say about a five-year-old child? Well, let me get started!

Young Alex Gamino will be six years old on October 28 and is starting kindergarten on August 29. This isn't his first year of school. He already has two years of pre-school behind him. He can read and write in both Braille and print. He reads English and Spanish. He uses a computer and sends e-mail.

Alex was born with a rare eye condition called microphthalmia, along with another condition called coloboma. He has some vision in one eye. He knows that a CCTV makes reading print a bit easier, but he is also learning that he can sit and read for longer periods of time when using Braille. He is already learning Braille contractions. Now he says that he is ready to start learning French. There is no stopping this young man!



(pictured Carmen Dennis, Alex and Noelia Gamino.)

Those of us who attended the first annual Chicago Chapter picnic had the pleasure of meeting Alex. He was an absolute joy to talk to. We also met his mom, Noelia, and his seven-year-old brother, Nicky.

For kindergarten Alex will be attending Salt Creek School in Elmhurst, where he went for pre-school. The school has resource classes for the blind, but he will be mainstreamed as he has been for the last two years. He went to school three full days a week his first year and five his second, so he's ready for a full-day program this fall.

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PHONE:  
1-800-580-ican

E-MAIL:  
ican@anophthalmia.org



## Fundraising



Amount Raised  
\$115.53

[Keep Searching](#)

Please continue to use Goodsearch.com as ican does receive a small donation from each search. Remember to pass this onto everyone in your address book and encourage others to use Goodsearch.com. It can really add up for ican.

For our online shoppers don't forget the website [www.iGive.com](http://www.iGive.com)

Make sure you also check out the website [www.braille-a-wear.com](http://www.braille-a-wear.com) you can find very cute tee shirts, bibs, sweatshirts, hats, canvas totes each has tactile Braille and print sayings. They were a hit at my son's school. Be sure when you order you tell them you are from ican. We will receive a portion from your purchase.

If you have any thoughts or suggestions on fundraisers or you are looking to head a local fundraiser, you can contact Margaret Cote at [margaretcote@anophthalmia.org](mailto:margaretcote@anophthalmia.org).

### Hello ican Members and Happy Spring!!

I hope you find this edition of the Conformer helpful and enjoyable to read. I want to thank all of the ican families that created this newsletter. It really is a group effort.

I recently stumbled upon a great fundraiser for ican. Anyone, from any state, can be involved; and you can invite your family and friends to participate as well. Just log onto <http://www.magfundraising.com/anophthalmia> and check it out. Each renewal or subscription will profit ican. So far, Mickey McLaughlin-mom to Daniel, has earned the most for ican. She invited everyone on her email list and sold 11 magazines! Currently 17 magazines have been sold, totaling \$145.20 profit. That's a large amount for such a small effort. Thank you Mickey for being so involved with ican, maybe your effort will be "catching" to other ican members!

Jodi Dennis, ican President  
[jodidennis@anophthalmia.org](mailto:jodidennis@anophthalmia.org)

## Website Update

Many of us still remember our need to find answers to our child's condition, our need to find pictures, stories, definitions, and literally a translator for all of those medical terms that were being thrown our way. Well, we still have many new parents visiting ican's webpage looking for those same answers. In an effort to give parents a more visual picture we are asking parents to allow us to publish close-up pictures of their child's face. The idea is a picture before any conformers or shells were used (maybe where child is a few weeks old) and then one more recent where the child is wearing their prosthetics (or not) depending on the situation. We are working with an ophthalmologist to provide pictures of different sizes of shells, conformers, and painted eyes so that parents have an idea of what they are being told and of the different stages of this journey. If you would like to help us in this effort please email your pictures to us at [ican@anophthalmia.org](mailto:ican@anophthalmia.org) and include "child picture" in the subject line.

Thank you,

Nelly Gamino, ican VP

[NellyGamino@anophthalmia.org](mailto:NellyGamino@anophthalmia.org)

## Membership Dues

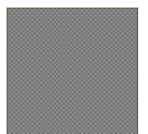
The fee is \$25.00 per family. **This is very important** as it covers expenses for newsletters, mailings, the 1-800 number and the website. Please help us continue to provide support to you and other families by paying your dues. If you cannot afford the dues, simply contact us and we will make every effort to provide you with member privileges.

## Join in the Discussion: Visit the ican Support Forum at [www.anophthalmia.org](http://www.anophthalmia.org)

As well as offering a wealth of information about anophthalmia/microphthalmia, the **ican** website also hosts a Support Forum, where interested individuals can share their questions, fears, hopes, and ideas with others. Topics recently discussed include finding doctors, surgery options, managing prostheses, autism, and genetics. Many posts are from families newly affected by A/M, who express a great desire for help and information and who could surely benefit from the insight of others. Please take the time to visit the Support Forum with your questions and comments!

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ican  
C/o Albert Einstein Medical Center  
5501 Old York Road  
Genetics, Levy 2 West  
Philadelphia, PA 19141



## 2008 ican dues

Dues are used for **ican** operations such as printing and mailing the newsletter, maintaining the website and 1-800 line. The funds may also be used to help in conference planning. Thank you for your payment!

Checks can be made payable to **ican and mailed to:**

**ican**  
**c/o Albert Einstein Medical Center**  
**5501 Old York Rd**  
**Genetics, Levy 2 West**  
**Philadelphia, PA 19141**

( ) Family membership \$25.00

( ) Professional Membership \$50.00

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