

The Conformer

Fall 2008

ican

International children's
anophthalmia network

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ican/ 1-800-580-ican / ican@anophthalmia.org / <http://www.anophthalmia.org/>



We are trying to update the mailing/e-mail list in order to make contacting everyone more efficient. We want to ensure that everyone receives newsletter and updates in a timely manner, especially with the conference coming up. Please take the time to e-mail your name and e-mail address as soon as possible to ican@anophthalmia.org so that you can be added to the e-blast list. Thank you!!!!

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 and put their name in the subject.

SAVE THE DATE



**ican's 6th international
conference**

June 19-21

in

Los Angeles, California

*Bringing Families and Individuals with
anophthalmia and microphthalmia together*

Conference Hotel:
Beverly Garland Holiday Inn
Universal Studios

www.beverlygarland.com

Topics to include: Treatment updates, genetics update, panel discussion including individuals with A/M and parents, question and answer forums to answer questions from parents. There will also be a licensed psychologist to facilitate group sessions for the kids (both those with A/M and their siblings). Look for Registration packets in the fall.

To make suggestions or volunteer any help please contact

Jodi Dennis

740-361-5672

jodidennis@anophthalmia.org

Tanya Bardakjian

215-456-8726

bardakjiant@einstein.edu

Sharing Stories

"Life is either a daring adventure or nothing." Helen Keller, 1941

My Trip to Machu Picchu

By Michelle Lamm
Bilateral anophthalmia



Hi every body,
I just came back from my adventure. I am extremely happy that I made it.

I left Jacksonville on June 23. I arrived in Miami airport to meet my team, and everyone was so excited about this whole trip. When we arrived at the Miami airport, our next flight was delayed one hour, but we finally made it to Lima. Then we took an early morning flight from Lima to Cusco where we stayed for three days at the hotel to get used to the high altitude.

While we were in Cusco, we took a one day bus trip to the ruins of Pacchar and I felt lots of stones. We also saw llamas and fed them weeds. They were pretty big and soft. They sounded like sheep. After we fed llamas, we went shopping at a market called Pisac where I bought two stone objects; one is shaped like a pyramid and the other one is shaped like a perfect hart. And I bought a pair of turquoise ear rings and a hat. Many people make a living by selling local handy crafts in Peru. I wished I could speak more Spanish. I tried to teach myself some Spanish with the Spanish language CD before I left. I was able to speak some Spanish, but it was so hard to communicate with Peruvian kids. On another day, we checked out the church near by after we hiked for a while.

On the fourth day, we bused to Huarcoondo where we started hiking. We hiked up for five hours, had lunch, and hiked some more. I had to take a horse some of the way, because of altitude sickness. I wanted to hike all the way to the camp site, but we hiked till past dark, and there were safety issues involved in it. Then we camped out that night. It was very cold at night and every body was so exhausted we all went to bed after dinner.



The second day of hiking was a rest day so whoever felt good participated in community service near the village. Some of us did



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

not get to participate, because we did not feel well. They cleaned and painted the reservoir where Peruvian people treat their water.

The third day was the hardest, since we woke up at four fifty in the morning and climbed to our highest point of 14,850 ft. I took a horse for a while that day too, because I felt dizzy and out of breath. It was so cold, but the air was clean and fresh. Then after we had our lunch, we started hiking down.



The fourth day of hiking, we hiked some more, and were still going down hill. On that day, I was more consistent about hiking than I was the past few days we hiked. I was so consistent that some of us were ahead of the group, and I was one of them. Then when we finished taking the last break of that day, two of my teammates, and I were way ahead of the group and when we got really close to our next camp site, we saw a giant bull. It was so big and was about to eat us, so my friend decided to put me on her back and carried me past the bull. Then we continued our way to our camp site. When we were taking our next break alone, our instructor caught up with us before the rest of the group did and found out that two of our other teammates had to ride the horse on the way to the next camp site. After the rest of our group caught up with us, we hiked to our camp site after our instructor told us that we were not supposed to leave by ourselves. We arrived at the camp site, had some nice hot tea, and I rested afterwards. Our dinner was delicious that day. After dinner, we did some activities relating to our everyday life. Finally, we brushed our teeth and went to bed.

The fifth day, we hiked some more downhill. It was very cold at night, but the weather was nice during day. Nothing pretty much happened. We were close to Machu Picchu.

The sixth day, we finally rode a train to Machu Picchu, and checked out the ruins of that area. There were many tourists and I heard many languages such as Japanese, English, and Spanish. We also spent another day in Machu Picchu before we went back to Cusco. That day, we checked out the walls that have not been finished.

Friday was the day we left Peru and were coming back to United States. I came back to Florida on Saturday.

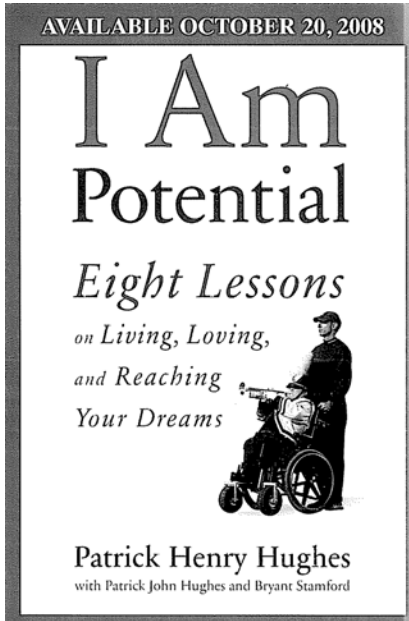
The most fun part was hiking. Most of the time, I used only one trekking pole and held my partner's shoulder while my partner told me where to turn and what was in front and beside me. I really appreciated my sighted partners. I wouldn't have made it without my teammates.

The Peruvians were happy even though they did not have as much money as we do in America. I missed America very much, and I am happy to be home. I really recommend the other visually impaired students to apply for this program. It was very hard, but I had a great time and it was worth it. I would like to thank every body for their support. I have achieved my goal and I feel more confident.

Our Visit with Patrick Henry Hughes

Last month I sent an email to Patrick Hughes. I knew he and his father usually had a full agenda – speaking engagements, playing piano for weddings, and so on – but I thought just maybe we could see them at one of the events as we'd be traveling through the Bluegrass State, Kentucky. To my pleasant surprise, Patrick said, "Why don't you stop by, meet our family, and see the Extreme Home Makeover". Oh, my, I couldn't believe what the email said?!?! We were so excited! The house was spectacular. The technology in the house is such a benefit to Patrick. As I was talking to him about how "awesome" he is, he said to me, "I'm just a guy living my life". I still think differently. He is an extremely talented young man. And I love his saying that he has "Abilities not Disabilities". Patrick has his first book coming out this Fall. It will be on the shelves October 20 and I am definitely going to the bookstore that day. Here's the link to his book www.iampotentialbook.com. Patrick also has a website if you want to take a look. www.patrickhenryhughes.com.

The Dennis Family



Empowerment Funds

Time is flying by and soon we will be making our plans to attend the ican conference. To be held in Los Angeles, California. Now is the time to start finding ways to help alleviate some of the expenses for our families. In the past I have been able to access grant money from my state. I can only speak for what is available for Massachusetts residents.

The grant is from the Massachusetts Developmental Disabilities Council/Consumer Empowerment Funds. This is available to an individual with a developmental disability, a family member or guardian of an individual with a developmental disability.

Plan to apply for such grants prior to the event. In this case you must fill out an application form and write a short paragraph and send along the brochure with info on the event. The maximum amount that is available per family is \$500.00. Once you receive an award letter detailing the amount. Following the event you will be reimbursed for the expenses that have been approved.

Keep all of your receipts from the event, including gas, food, registration fees for the event.

I encourage our families to check with their state on the possibility of these funds being available to you under a different title. The application process is very simple and is available online and very well worth it.

Feel free to contact me through the ican website ican@anophthalmia.org and put my name in the subject.

Margaret Cote

"The best and most beautiful things in the world cannot be seen nor even touched, but just felt in the heart."

Helen Keller, 1891

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international children's
anophthalmia network

PHONE:
1-800-580-ican

E-MAIL:
ican@anophthalmia.org



Amount Raised
\$140.53

Keep Searching

Fundraising

Funding – it's out there!

In this edition of the Conformer you'll see that we've set a date for the 2009 Conference. With today's economy I don't want any ican family to feel that they cannot afford to attend the conference. There is funding available – it's just a matter of finding it.

One resource that my family utilized was our local Lions Club. We simply contacted a member, explained the benefits of attending the conference, and gave them a copy of the ican registration newsletter. They paid the fees for our entire family to attend.

I was recently talking to a family in Minnesota. The mother told me she contacted their county social worker who informed them of a program to pay for conferences. The family's hotel, ican fees, and airfare are completely covered. The only expense they incur is meals and their typical son's airfare. If your child does not have a social worker, I would start by looking in the yellow pages and finding one. If your child is older, you could begin with the birth to three program that most of us utilized at one time or another. They may be able to connect you with the right place. It may seem like a lot of calls in the beginning, but persistence does pay off.

I stumbled upon a website that might be of help. It's the Administration on Developmental Disabilities. www.acf.hhs.gov Some of the states have an "empowerment fund" that will pay for families to attend conferences. Once you enter the website, go to DD Programs/Partners. State Councils on Development Disabilities. Then click on your state and go to their site.

I hope I've given you a head start on some valuable resources. If you cannot find any grants or would like me to help you locate some resources, please email me jodidennis@anophthalmia.org I will do my best to find a grant for your family. I also wrote a donation request letter for your use.

Good luck!

Jodi Dennis, ican President

All occasion greeting cards with artwork done by our own ican children!

Interested in having your children participate? We'll send you a sheet of paper with a black border, either drawn in regular or raised print. If the artwork is kept within this space it will be in the correct proportions when we shrink it down for the cards. The kids can use markers, paint, whatever they like – the deeper and more brilliant the colors that are used the better the designs will look once they are scanned.

We're planning to choose the top 10 drawings and make them into a box of all occasion greeting cards. We would like to have the cards ready by June so that we can show them off (and sell them) at our next conference! ☺

This will only work if families participate so please encourage those little artists! Siblings are welcome to participate as well. Just contact me and I will send out the "blank canvases" to you ASAP.

Rosanne Keep
rbkeep@gmail.com
306 Aqueduct Dr., North Wales, PA 19454

Conference Donation Template

Dear Friend,

On June 19-21, 2009, the International Children's Anophthalmia Network, a family support group for individuals and families affected by anophthalmia, microphthalmia, and coloboma, will host the 6th ican Conference. This is a great opportunity for my family to meet others affected by anophthalmia, microphthalmia, or coloboma. We will learn about the latest research and treatment news.

I am raising money to attend the conference and I need your help. The conference fees are \$100 for each adult and \$ 40 for each child that attends. The conference hotel has agreed to give us a rate of \$159 per night. This is a great price for the Los Angeles area. My family will also need funds for travel and some meals. My goal is to raise \$_____ for our family to attend the conference.

If you would like to learn more about anophthalmia, microphthalmia, or coloboma, please visit our website. www.anophthalmia.org or call 1-800-580-4226.

Thank you in advance for your kindness.

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

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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