

Summer 2007  
ican

International children's  
anophthalmia network

**Inside:**

- Message from the President
- Conference highlights
- Support Forum
- Future topics
- Feature Family
- Fundraising
- Visit iGive.com
- Request for donations letter to help with fundraising
- Donations
- A/M Research Update
- Membership Dues

# The Conformer

ican/ 1-800-580-ican / [ican@anophthalmia.org](mailto:ican@anophthalmia.org) / <http://www.anophthalmia.org/>

## Message from the President

Hello ican Families. I look forward to working with the new ican board to make this the best year ever for our family support group! We left the 5<sup>th</sup> ican conference with many new ideas and we are already hard at work. If you have any thoughts or suggestions for our group please feel free to email me at [JodiDennis@anophthalmia.org](mailto:JodiDennis@anophthalmia.org) and please remember that attending the conference is not a requirement to be involved with ican.

## 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.



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.



## 2007 ican Conference Highlights

What a wonderful conference! A sunny place, great speakers, seeing old friends and meeting new ones-it doesn't get any better.

A free medical clinic was held Friday afternoon at the Florida School for the Deaf and Blind. There were ophthalmologists, oculoplastic surgeons, and geneticists on hand to see the families. That evening everyone enjoyed the dessert and hospitality at the Hilton Historic Bayfront. The kids enjoyed the music, coloring, and story telling from the many volunteers.

The speakers were informative on Saturday. Adele Schneider MD and Tanya Bardakjian MS, CGC began with the genetics review and research updates. The **ican** meeting followed and we elected new board members.

President: Jodi Dennis  
Vice President: Nelly Gamino  
Secretary: Kelly Derezza  
Co Treasurer: Becky Pennington  
Members at Large  
Jody Hawkins, Sara Ault, Kelley Hoffman, and Elisa Rostkowski  
During the **ican** meeting we discussed ways to better **ican**, asked for more involvement, and also mentioned having

the 2009 conference on the West Coast.

Doctor Femida Kherani discussed the various treatments for anophthalmia and microphthalmia. She also showed some very good slides of her work-in-progress.

After lunch we had two very good speakers touch on the "every day" issues that many of us face. Deborah Eunpu, MS, CGC discussed Family and Marital Issues while Ann Usitalo Ph.D. spoke about Self-Esteem and Socialization.

A very nice dinner banquet was held at Trinity Hall Saturday evening. After the delicious meal, the kids had a great time with the karaoke machine.

Sunday morning was time to bid farewell. Lots of pictures being taken and email addresses exchanged. This year I noticed many of the siblings exchanging phone numbers and addresses with one another. The **ican** conference really is a benefit to the entire family! Hope to see you in 2009.

## 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!

## Future Topics in *The Conformer*

Remember, *The Conformer* exists for you, the families of **ican**. If you have any topics you would like to see in *The Conformer*, please email Jason Hawkins at [JasonHawkins@anophthalmia.org](mailto:JasonHawkins@anophthalmia.org) and subject: Future Topics or call 1-800-580-ican

## Hillary Welch , Featuring Madilyn Welch

I'm sure everyone reading this has gone through all the red tape and hassle of trying to get the best care, best medicine, and best food and nutrition for your child. Well so have I! And it can be the most frustrating, time consuming job a parent of a child with special needs has these days.

My name is Hillary Welch and I am the mother of Madilyn. We live in beautiful Northwest Arkansas. Madilyn was diagnosed with bilateral anophthalmia at birth. Because of various birth defects, she also has a Mic-key Button and a trach (which doctors are going to take out in June!). As many children with A/M, Madilyn has an adversity to textures in both her physical world and in what she eats. She also never learned to suck on a bottle. Due to this, it has been important that Madilyn get a very nutritious supplemental formula through her feeding tube.

Arkansas Medicaid will only readily pay for Nestle Pediasure and nothing else- even if the doctor prescribes it. After contacting several nutritionists and dietitians, a friend referred me to Compleat Pediatric formula from Novartis. It is actual pureed foods such as chicken, cranberries, and real juices from real food! It wasn't like all that other stuff made of chemicals where the first two ingredients are water and sugar. It just never made any sense to me to feed a newborn or toddler water and sugar even if it had a few good vitamins and minerals. Madilyn also had recurring problems with throwing up the Pediasure, especially if it was a flavor other than vanilla. I just knew there had to be something better!

Of course now I just had to figure out how to get the formula for Madilyn. Her doctor wrote a prescription and I took it to our local pharmacy. They could order it for us, but could not bill Medicaid because Novartis Compleat Pediatric was not on the Medicaid "list". Determined to get Madilyn started on this formula right away, I had the pharmacy order a case and we would just have to pay for it until I got the insurance straightened out. A case was 24 cans of 8.45 ounces and cost sixty dollars! This would only last Madilyn a little more than a couple weeks.

After contacting the Medicaid office, the feeding tube supply company, and even doctors and nurses all over Arkansas, I still have not got the insurance to pay for this wonderful formula! I wrote Senators and even the former Governor for help and advice. At first, everyone I contacted said they could get it for us. But after a couple weeks they would call back and say there was a mistake and Compleat Pediatric was not on the "list". By the third or fourth

time, I felt like if I heard anything about a "list" one more time I would scream! I wanted to know where this list came from and why this formula wasn't on it. Not to my surprise, a group of doctors made the list and it is to this point virtually impossible to get it changed. Staff at the Medicaid office told me that in order to add a product to the list the change would have to affect a lot of people. I am the only one I know that has even heard of this product, but many more should! Since Madilyn has been consuming it, she has gained weight and has had a better demeanor overall. She sleeps better and doesn't have problems with regurgitating after eating.

I am still working on getting Medicaid to pay for it, but I did find out I could get a partial supply from the Novartis Company. I am currently working with nutritionists and the supply company to change the infamous "list" so other parents will be offered this formula as another option to Pediasure. I encourage parents to stay strong and get information- demand it! Our children depend on us to get them the best care available!

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

*If you are willing to share  
your family's story or  
experience please contact  
us! E-mail us at*

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

*Or call  
1-800-580-ican*

## Fundraising

Happy Spring everyone.

It's been one month already since the **ican** conference. I would like to bring everyone up to date regarding fundraising efforts that have been ongoing.

First, we have our **ican** cookbooks. This cookbook is chock full of wonderful recipes from **ican** members. Hopefully by now most members have purchased one for themselves, if not, I encourage you to get your copy. Who needs the FoodNetwork when we have an **ican** Cookbook. We had many great ideas at the conference with regards to selling the remainder of the cookbooks, from bringing them to work with a short bio of your child and what **ican** has done for families. The main goal is to sell these cookbooks and get the revenue for **ican**. It doesn't make good sense for them to sit in boxes.

Second, and this is an easy one and it doesn't cost anything. We were introduced to the search engine Goodsearch.com. **ican** can earn a penny everytime you search the internet. Go to [www.goodsearch.com](http://www.goodsearch.com) and designate **ican** to be your charity. You can also download the Goodsearch icon to your desktop. I've instructed my kids to use Goodsearch instead of Google. So now as you begin to plan your summer activities you can help **ican**.

One more internet tool available to us and especially if you use the internet to shop, is the website iGive.com.

We will receive 26% of your purchase!! Now just for a second, think about all the chain-letters, jokes and prayers we get on a daily basis, these things get forwarded all the way around the world. If we simply pass these two websites onto our friends and family we can generate a decent amount of money for **ican**.

To the families that were unable to attend and to those of us who may have forgotten there are beautiful tee shirts that are embroidered with cute Braille sayings that are raised. E-mail Deb at [brailleawear@comcast.net](mailto:brailleawear@comcast.net) for details. Any purchase that you make **ican** again will receive a portion of the sale.

So, now that everyone has their summer homework assignments, enjoy cyberspace and help **ican** at the same time. It doesn't get much easier than that.

Have a wonderful summer!!

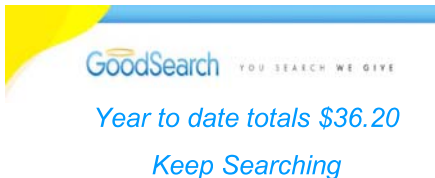
Margaret Cote

## Cookbooks Update:

Thanks to Nelly Gamino and everyone who helped for all the hard work on the cookbooks. As of June 20<sup>th</sup> the cookbooks have made \$3,300 for **ican**. There are still 29 left so email **ican** if you would like to sell anymore.

## Support ican help you while you shop online!

**ican** is a registered cause at the E-philanthropy shopping mall iGive.com. With your free membership ([www.igive.com](http://www.igive.com)), you can make purchases at over 600 stores, including popular web vendors like Barnes & Noble, LandsEnd, and Constructive Playthings, and up to 25% of your transaction will be donated to **ican**. Just sign on to iGive.com before beginning your Internet shopping — you'll be helping our organization.



\$82.96 has been raised so far

Summer 2007

Dear friend,

Many of us had the opportunity to attend the ican (International Children's Anophthalmia/Microphthalmia Network) conference in St. Augustine, Florida this spring. It was wonderful to gather with other families who share our walk in life! We shared our stories with each other. We spoke of our hopes, joys and challenges and learned from each other. Conference speakers brought us up to date on their genetic research and shared potential surgical interventions that may aid in giving our children more balanced facial features. We also learned strategies to guide our children through school, friendships and other social situations. The opportunity for our children to meet others like themselves was fantastic! New friendships were started and others rekindled. Whole families attended, which allowed siblings to meet others who have a brother or sister with special needs. It was truly a time for everyone!

Like any organization, ican survives on generous donations made by its members and friends. As our friend, we are asking you to consider making a donation to this organization so that research may continue, that new families may find hope with their diagnosis, and that additional conferences may be held in the future. There is a saying: "It takes a village to raise a child". We believe that is true. Please join our village and help our children. We truly appreciate your support and generosity. Donations may be made to:

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

Thank you in advance for your generosity!

Sincerely,

ican Member

*Donations made to ican are tax-deductible to the fullest extent allowed by law and receipts will be provided to any donor.*

**ican**

international children's  
anophthalmia network

PHONE:  
1-800-580-ican

E-MAIL:  
ican@anophthalmia.org

## Donations

**We would like to thank the following for their donations:**

Mr. and Mrs. Fisher  
Audrey M.T. Jones  
John J Kelley

Merle Santerian  
Mr. Henry Fine

We want to recognize those of you who have donated and thank you for your generosity. If I left your name out, please email me at [KellyDeRezza@anophthalmia.org](mailto:KellyDeRezza@anophthalmia.org) and we will put it in the next newsletter. We appreciate your donations tremendously and with your help we can continue to keep **ican** alive and strong.

Kelly DeRezza  
**ican** secretary

## A/M Research Update

Adele Schneider, MD and Tanya Bardakjian, MS are excited to announce that we have received grants totaling \$160,000 for the A/M Research project. Albert B. Millett Memorial Fund, a Mellon Mid-Atlantic Charitable Trust (\$50,000)

Rae S. Uber Trust, a Mellon Mid-Atlantic Charitable Trust. We also received \$60,000 from the Pfeiffer foundation.

These funds will allow us to continue to collect and analyze clinical data on individuals with A/M. This will hopefully provide more guidance and information to parents of children with A/M. In addition, we will continue to collect blood samples for gene screening. Our plan is to ensure that all ocularists, oculoplastic surgeons, pediatric ophthalmologists and genetics professionals are aware of **ican** and the A/M research project.

We will be creating a new handbook (booklet) for parents. This will be shared with the above professionals to hand out to new families. In this way, we hope that all families are aware of the support available to them through **ican** and the availability of research, should they be interested.

We are very excited that we can continue the research . We will keep you all informed through the Conformer of any progress made.

## Membership Dues

Be on the lookout in December for your Membership dues invoice from **ican**. 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.

**ican**  
C/o Albert Einstein Medical Center  
5501 Old York Road  
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