

Fall 2005

ican

International children's
anophthalmia network

Inside:

- Conference highlights
- Support Forum
- Future topics
- Feature Family
- Fundraising
- Visit iGive.com
- Request for donations letter

The Conformer

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

Message from the President

The conference in Philadelphia went very well. Everyone had a great time getting to know each other. It was so much fun to watch the kids sing and dance. We hope that if you could not make it to this conference then maybe you will be able to join us next time. More information on our next conference will be included in upcoming issues of The Conformer.

In order to make our next conference a success we need your help with fundraising. You can help by sending the request for donations letter found in this issue to anybody you feel could help. The money raised is used to fund our conference and to keep research going

It is important to all of us to keep **ican** growing. We are there for families in need of information and to share their experiences with others. Every family involved with **ican** is important to the growth of our organization. We need your help and input to make **ican** bigger and better for the next family that comes along and needs us.

Sherry Salatto
President

Meet the Board

Executive Board

President- Sherry Salatto-Connecticut

Vice-President-Jodi Dennis-Ohio

Secretary-Kelly DeRezza-Kentucky

Members at Large

Spanish contact-Nelly Gamino-Illinois

Conformer contributor-Pat Renfranz-Utah

Hotline-All the Board Members

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.

2005 **ican** Conference Highlights

The 4th biennial **ican** Conference was held in March 2005 at the Franklin Institute in Philadelphia PA. The conference ran from Friday to Sunday. It was a weekend packed full of information, and a great time to visit with friends from previous years and meet new families.

Friday was clinic day at the Children's Hospital of Philadelphia. On-hand for consultation were genetic specialists, oculoplastic surgeons, and ophthalmologists. After the clinic was a "Meet and Greet" dessert social for the families. This event was held at the hotel and included entertainment for the children.

On Saturday, conference sessions were held at the Franklin Institute, a wonderful science museum. What an awesome place to have a family conference! Tanya Bardakjian, Certified Genetic Counselor, gave a genetics update. Then, a group of blind and visually-impaired kids led a Q&A session. A peer-group session for sighted siblings was also offered, and seemed to be of real benefit to some of the brothers and sisters.



An interesting lecture was given by Dr. Holger Link At Oregon Health Sciences Center, who studies sleep and wake patterns of blind people. He discussed sleep patterns in blind children and how melatonin might be used to help them to regulate their body clocks. Finally, Dr. James Katowitz, a pediatric

oculoplastic surgeon at the Children's Hospital in Philadelphia discussed oculoplastics and compared current options regarding reconstruction of eye socket and lid.



Saturday evening included a wonderful dinner banquet, complete with music, karaoke, and dancing! Sunday morning served as a nice farewell. Those wishing to participate in a DNA study were able to sign up at that time.



The 2007 conference will be held in Florida

(Details will be available as the date approaches)

Hope to see you there!

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

The Gamino Family, Featuring Alexander Daniel Gamino

On October 28th 2001, our second child was born. Having had a perfectly smooth and healthy pregnancy we didn't expect any complications. We were ecstatic! We now had two perfect little boys. Oh, we could only imagine the endless hours of fun our boys would spend together. But the bad news came a day after Alex's birth when we noticed that our little Alex was still not opening one of his eyes. After having it checked by the pediatrician we were referred to a specialist. One of Alex's eyes was tiny; the opening so small that it was hard to even get a good look inside of it and it was not reacting to light. His other eye looked normal but it was not reacting to light either. The doctor's diagnosis: Microphthalmia (small eye) on the right and Coloboma (pupil not closing in a complete circle) on the left. But what did that really mean? As the specialist put it: His right eye had no hope. His left eye MIGHT have peripheral vision good enough to see the big E on the vision chart, but it was too early to tell (Alex was only 2 days old) and we should follow up in three months.

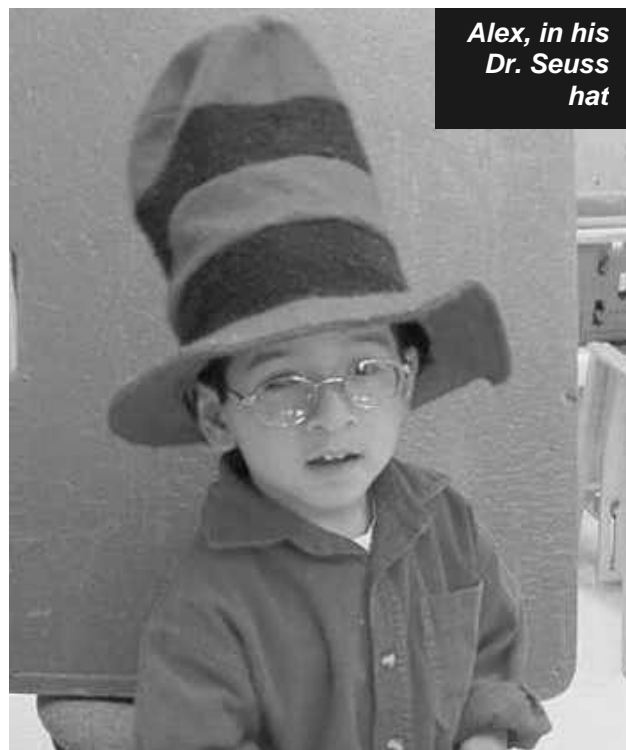
The news of our baby's condition was devastating to our family, our friends and us. The next couple of months were very difficult, to say the least. We hoped and prayed and looked for any sign that would show us that our baby's eyes were seeing something. We filled our days with appointments seeking second opinions and trying to find a way to help our son. At his three-month appointment with the ophthalmologist, I asked what else I should be doing, how we could help our child and we even asked about the early intervention program; the ophthalmologist said it was too soon for that. Luckily we found **ican's** website. I called the 800 number and they sent me a list of exams that should be done and steps that needed to be taken. And we also called the state's early intervention program as a friend of ours had recommended.

Alex was behind in a lot of his milestones. He was six months old when he received his first therapy session. At this age he was not yet rolling over, lifting his head, much less sitting up. He did have a great smile though and he flashed it often. Thanks to his therapists' wonderful job Alex began to roll, sit and crawl very quickly. He walked at 16 months and had us with our holding our breath all the time as he would never sit down and try to imitate his older brother's actions.

Alex is an explorer and he has definitely gotten the concept of "practice makes perfect" as he will go in and out a door, up and down a step, on and off the carpet until he feels confident enough to run and play in the area without having to think twice about it. He

keeps his older brother busy all day long, as he never gets tired of running and hopping from one end of the house to the other. Alex has grown to be a very independent and confident toddler with tons of energy. He does not let his visual impairment get in the way of anything he wants to do and as if to prove that he can get around without our help, he will sometimes throw a towel over his head and walk all around the house without a problem.

Alex never ceases to amaze all those who meet him. At the age of 2 years he had an extensive vocabulary, a full repertoire of songs (both in English and Spanish) and an incredible hunger for learning. If we didn't challenge him enough he would come up to us and say "ask me, ask me" wanting us to ask him the colors, numbers or ABC's. He mastered the ABC's without a problem and now at the age of 3 he has even started saying them backwards. He falls asleep and wakes up wanting to spell words, identifying shapes and counting. He absolutely loves books and although his vision on the one eye is very weak he has started to read large print and has excellent memory. Alex is now attending a school for the visually impaired in Elmhurst, Illinois. It is hard to know if we will keep him in that type of school or if we will bring him back to his district school. I guess we will have to wait and see what the best options are for him in terms of challenge and ensuring that he is not bored. --- Nelly Gamino



*Alex, in his
Dr. Seuss
hat*

Fundraising

*ican:
Sharing
hopes,
joys,
and
challenges*

ican continues to thrive! At the conference in Philadelphia, PA this past May, families gathered to share ideas, learn about genetic updates, and confront issues on partial - total blindness. Some discussion at the conference looked at the funding necessary to keep **ican** going. It was clear that fundraising in the near future is important to keep family services and research running. One idea shared was a fundraising letter that folks could copy and send out to friends (neighbors, daycare, co-workers, etc.), family, and organizations (Lions Club, Knights of Columbus, Elks, etc.) in an effort to solicit donations to **ican**. A copy of that letter is included on page 5 of this issue of The Conformer. PLEASE take the opportunity to make copies of this letter and send them to people who you feel could help to make a difference for our organization. Our involvement and the generosity of ourselves, friends, family, and organizations are critical in keeping **ican** alive! THANK YOU for your time and dedication.

Jane and John Allen

Fundraising Chairparents!

Membership Dues

*Be on the lookout in December for your Membership dues invoice from **ican**. The fee is \$25.00 per family and 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.*

Support **ican** while you shop online!



ican is a registered cause at the E-philanthropy shopping mall iGive.com. With your free membership (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.

Autumn 2005

Dear friend,

Many of us had the opportunity to attend the ICAN (International Children's Anophthalmia/Microphthalmia Network) conference in Philadelphia 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

Join in the Discussion: Visit the ican Support Forum at www.anophthalmia.org

As well as offering a wealth of information about anophthalmia and 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*

Future topics include a genetics update, discussion of a recent scientific publication concerning viral infection rates and a possible association with the rates of A/M in Great Britain, and tear duct obstruction.

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 Pat Renfranz, care of ican@anophthalmia.org or call 1-800-580-ican

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

