

The Conformer

Fall 2011

ICAN

International children's
anophthalmia network

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



Meet the Board

Executive Board

President- Jodi Dennis-Ohio

Vice-President- Nelly Gamino-Illinois

Secretary- Open

Treasurer- Open

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.

WHAT THE CONFERENCE MEANT TO US

We were so grateful for the opportunity to attend our first ican conference this past July in Boston, MA! It was so great to meet so many incredible families who are along the same journey as us. For an entire weekend, everyone understood and shared our world of raising a child with A/M. We also benefited from the medical clinic in which Faith was evaluated by a geneticist, oculoplastic surgeon, ophthalmologist, and physiatrist. We gathered recommendations from each of the specialists and now have some next steps to work on. We cannot imagine going through this without the help and support of ican. We are so thankful for this organization and all it has done for our family.

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 Wildschuetz Family (Mike, Bridget, & Faith)



BOSTON! Our 6th ICAN Conference – An educational experience for the entire family. Rob, Jodi, Blake and Wyatt Dennis

. I'm just writing to thank you for including me in the conference on July 16th. I enjoyed presenting and also learned a great deal. I've joined ICAN and look forward to keeping in touch. I'm also interested in sharing any more resources and information from the Institute for Community Inclusion that might be helpful to professionals and parents.

Regards,

Jennifer Bose
Research Data Coordinator
Institute for Community Inclusion
University of Massachusetts, Boston

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Sharing Stories

ican summary By April Archibald

We attended the ICAN conference in Boston in July. We had a great time! The conference was good with intriguing speakers and conversations. The speakers included doctors talking about conformers, genetics, and stem cell research. From those speakers, we learned this...we probably did the right thing putting Mason in conformers to expand his eye sockets. However, we do wonder now that Mason wears glasses and no conformers if there is too much space. This might be causing his lids to be droopier and cover his eyes some. We also learned that our "ace in the hole" (stem cell research) is a long way off from helping Mason. People ask if transplants would help our boys and the only real transplant would be a retinal transplant (or implant). Being that retina is brain tissue and so fragile, it's not able to be removed from someone and re-implanted in someone else. Stem cell research has already proved that a retina can be grown in a dish from stem cells.

However, there are a lot of problems that remain. The biggest issue we learned is... how do they control the growth? How do they know if they implant a growing retina that it will stop growing? We learned some stem cells are unpredictable and won't stop growing. This could lead to tumors and many other issues. As you know, there are also ethical issues with stem cell research...where the stem cells come from, the procedures they use and the animals they test the research on. The only thing I have to say about that is.... someone might have a problem with it UNTIL one of their loved ones could benefit from it. Suddenly, it seems like a great idea...at least we think so.

The other speakers included other visually impaired and blind people talking about their experiences growing up and their lives as adults. It helps to talk to others to help answer all the questions we have about the boys' futures.... Will they have girlfriends, will they have children, how

will they care for their children, what can we do to prepare them for life, what can we do to give them confidence? One woman (completely blind) has a toddler and shared her funny stories about raising her. Another mom (visually impaired) has a blind daughter and 3 other sighted children- wow! The inspiration out of those women was profound!

There was also a speaker that was an O&M (orientation and mobility) instructor. This is a topic interesting to us now as Mason is starting training and will have a cane soon. We've learned it IS a cane, not a walking stick (which I preferred to call it). Mason will soon name his cane and we will soon need to get over the fact that people will be staring and feeling sorry for him again. So please talk about the cane when you see it in an upbeat "that cane is cool" kind of manner. Please don't avoid its presence as it might be the elephant in the room and we want to get over that! The cane will HELP Mason be "normal". He will learn to run and play safely with the other kids without an adult always next to him in order to prevent him from tripping and/or falling. It will give him independence and freedom...something we all need!



Sharing Stories



Alex: The ICAN conference gives me a chance to see other children with the same eye problem as me. Some are old friends, but I meet many new ones too.



Nick: The ICAN conference is FUN. We meet many people from other states and sometimes other countries. And I know that that my brother is not the only one who is blind.

Parton's Imagination Library Partnership Launched!

As Dolly herself might phrase it, "The Little Engine That Could" ...*did!* This past June, the American Printing House for the Blind (APH) and the Dollywood Foundation announced an exciting partnership to expand Dolly Parton's Imagination Library (DPIL) to provide young blind and visually impaired children with accessible books.

Today, we are pleased to announce that the [APH/DPIL Partnership](#) has launched!

The first DPIL audio book files are now available at the site as free downloads to registered National Library Service (NLS) members. Audio books will be added each month until most of the 75 titles in the DPIL collection are available to children and their families.

Beginning in 2012, the Partnership will make available an annual selection of print/braille Imagination Library books free to eligible families and for purchase at low cost to all others (regular funds or Federal Quota funds can be used).

In addition to the audio book files, website visitors will find links to: National Library Service to help them register and receive an NLS digital playback device necessary for listening to the APH/DPIL encrypted audio book files

- *Louis* Database of Accessible Materials
- APH shopping site to see related APH products
- Other national and international sources for tactile, print/braille, and braille books for children
- Downloadable PDFs with information about emergent literacy and sharing books with a young child with a visual impairment

We're very excited that APH's partnership with DPIL not only expands the number of accessible books for young children, but also connects families to a wide range of resources that will enable them to locate and bring more accessible books into their home.

For more information about our partner, Dolly Parton's Imagination Library, visit <http://www.imaginationlibrary.com/> or the official [Facebook](#) page.



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Keep Searching

MEDICAL RESEARCH UPDATES

The Genetics Division at Albert Einstein medical Center(AEMC) in Philadelphia is offering several new programs.

- 1) Does your child exhibit behaviors consistent with a diagnosis of autism? AEMC has initiated a new multidisciplinary clinic to evaluate children who are blind and may have autism. The goal is to ensure that individuals are correctly diagnosed with autism and to prevent those that are not autistic from receiving the diagnosis. If you are interested in learning more about this program please contact Tanya Bardakjian at 215-456-8726 or bardakjiant@einstein.edu**

- 2) SOX2 Natural History Study**
Has your child been diagnosed with SOX2 syndrome? We would like to better understand the long-term effects of this syndrome to provide better information to families and medical professionals. We are collecting clinical data and other medical history information on individuals with SOX2. If you are interested and have not been in touch with Tanya already, please contact her using the information from above.

Firstgiving

Please consider creating a Firstgiving webpage. It is simple and a great way to raise funds for ican. We would like to raise more money to be able to provide financial assistance to families and children who may need it. We would like to help with purchases of technology or other assistive devices, conformers or other treatment if not covered by insurance etc. With your help we can really take the support ican offers to the next level.

It is really simple go to www.igive.com and click create a page. In the search box look up anophthalmia and once international childrens anophthalmia network comes up click on that. Follow the instructions to write a story then e-mail out to your friends. It is a safe way to raise money for a great cause!

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!



