

W I N T E R 2 0 1 3

The Conformer

ICAN Quarterly Newsletter

International Childrens Anophthalmia/Microphthalmia Network



www.anophthalmia.org

1-800-580-ICAN (4226)

ican@anophthalmia.org

Letter from Jodi Dennis

Hello ICAN friends and family,

As some of you know, we held elections at the most recent conference in Chicago. I am pleased to announce your new President, Ryan McGrady. Ryan comes fully equipped with a business background, but more importantly he and his wife, Leslie, are parents to wonderful Miss Noelle!! All of you know that it is our life experiences that bring us close to ICAN. Ryan and I live in the same state, making this an easy transition. I will still be an active ICAN volunteer. I love this group! I can't imagine NOT helping with the newsletter, 800 phone line, and most important of all- Fundraising! My email account with ICAN will remain active, don't hesitate to contact me.

It has been my pleasure to meet so many wonderful families throughout the years.

Best-

Jodi

jodidennis@anophthalmia.org

Table of Contents

Letter from Jodi Dennis

Letter From Ryan McGrady

ICAN 2013 Conference Review

Jennifer and Pete James

Alex Nobori

Q&A with Dr. David Rakofsky

Resources/Links

Officers and Contacts

Upcoming Issues

Fundraising Targets

Fundraising Ideas

ICAN Family Survey

Letter From Ryan McGrady

Hello,

As many of you that attended the conference this past July know, Noelle, Leslie and I are so excited to be a part of such a wonderful organization. I am truly honored to have the opportunity to continue to build upon all of the great work and successes that Jodi, Nelly, Tanya, Dr. Schneider and many others have achieved since the organization was first founded. Over the last 6 months, I've been working closely with Jodi, Tanya, Nelly and Dr. Schneider to make sure that we don't miss a beat.

Some of the pieces we have transitioned include ICAN email monitoring, web site administration, and updating of the contact list/database previously maintained at Einstein Medical. With the help of two generous volunteers we've transitioned the 800 line as well as the treasury/accounting responsibilities.



Noelle, Leslie & Ryan McGrady

Chau Berman, and I both took the opportunity to learn the call in line and Chau is now monitoring to make sure that we quickly reach out to new families who need assistance. Many of you may know Sandy Athenson and his family from previous conferences. Sandy has taken over the role of treasurer and has been working transition many of these tasks since the conference. I cannot thank Chau and Sandy enough for their willingness to donate their time as we move forward.

As of right now, we are planning to publish the newsletter on a quarterly basis. This issue is primarily dedicated to sharing experiences from the conference in Chicago. I hope it is informative for those of you who were not able to make the trip and sparks some great memories for families that were able attend. A very special thank you to everyone who contributed pieces to this newsletter (all of the names are listed in a section at the end). Without your help this issue would not have been possible.

In upcoming issues, we plan to have family spotlights/articles, additional perspective from the conference, medical updates, and information regarding fundraising to ensure we have the appropriate funds for the next conference. I am also very interested in understand what our readers would like to see, so please be sure to provide feedback on the newsletter. Thank you all again for this opportunity and I look forward to working with everyone over the next 2 years.

Sincerely,

Ryan McGrady

ICAN 2013 Conference – Chicago, IL

Conference Experience – The James Family

We got back from Chicago this past Monday. We had gone to Chicago for the 8th Annual ICAN conference. This was the second one that we have attended since Lily has been born. As most of you know Lily was born with a rare genetic eye condition called Bilateral Microphthalmia. She also has double colobomas and nystagmus. ICAN stands for International Children's Anophthalmia Network. www.anophthalmia.org I am beyond thankful for this conference though.

This year the conference was to be held in Chicago, July 12-14. We decided to fly up early and make a mini-vacation out of it. We spent some time at my in-laws lake house in Watervliet, Michigan. It was so beautiful and such a cute little lakeside community. The kids loved the environment and being able to see where Peter grew up. Pete has so many relatives there, so we got to meet a lot of them.

Fast forward to Thursday, July 11... We head into Chicago for the ICAN conference. We check into our hotel the DoubleTree on the Magnificent Mile in downtown www.doubletreemagmile.com/ and head out to check out the Navy Pier. Lily was excited that our room on the 9th floor overlooked the pool down on the 5th floor! We told her we would swim after we went on an adventure. Navy Pier was just a short walk from our hotel and had so many things to do. We let Lily ride the little Thomas the Train ride (a few times), then we did the Carousel and Giant Ferris Wheel. We made our way back to our room after getting her a \$7 Happy Meal for McD's on the pier (yikes) and got ourselves some Chipotle (Pete's First Time). Lily insisted that we were going to go swimming, so swim we did!

The night came and went and we had an early appointment during the ICAN free medical clinic day held at Illinois Eye and Ear Infirmary. We arrived at the clinic and then were seen by a series of specialists and doctors from UIC Department of Ophthalmology and Visual Sciences, as well as the Einstein Medical Center-Genetics Division. First up was the Ophthalmologist, she tested Lily's vision and they were amazed at how wonderful Lily did! Then we had a talk with Oculoplastics and an Ocularist. This is what we had wondered and struggled with the most...whether or not to have Lily's right eye fitted with a shell to enhance her facial growth on her right side. Our current pediatric ophthalmologist at All Children's told us she didn't need it. We were told at conference, that she really should have it. It will help her now and is harder to do later on in life. We went on to the next specialist where Lily had an ultrasound done on her eyes. It was a bit hard to get Lily on board for that at first, but she finally gave in and did great. Genetics was up next. We had given blood at the last conference in order to have genetic testing done. Lily never got blood drawn, they couldn't get her veins.

So this time was VERY interesting...she HATED every minute of it and they had to stick her in each arm. Did I tell you Lily HATED IT? She is super strong too! After that we had to go and have her eyes dilated so they could get a look at the insides of her eyes. Pete went back and had his done too. He has never had an eye exam so they did one on him also. It was a very good thing, because it helps us to understand a bit more about why Lily has the eye conditions she does. Pete checked out a okay, just a bit near-sighted. When they took Lily back to see about a prescription for her glasses (another thing that our pedi ophthalmologist at All Children's said she DIDN'T need) , they were really shocked that her eyes weren't as far-sighted as they "should" be. Most often with the shape and condition of her eyes, her script would be much stronger...but it wasn't the case. They kept coming in and checking her eyes. Then two doctors came in and started scratching their heads...baffled. Lastly, we had our overview and we were sent on our way. We had been there since 10:45am and now it is 3:15pm..

We walked over to the Lighthouse of Chicago and toured their facilities. It was like Disney compared to our local Lighthouse. It was huge! They do such wonderful things there. Check out their website and see www.chicagolighthouse.org

We headed back to our hotel rooms for some dinner and to relax before our Meet and Greet at 7pm. Then we plug-in our phones to charge and see that the doctors have been calling us. URGENT -Please call ASAP! Oh No!! What could it be?? I listened to the voicemail, they wanted us to come back to the Eye and Ear Infirmary now. That was 2 hours prior to us getting the messages. Dr. Azar, Director of Pediatric Ophthalmology at the Illinois Eye and Ear Infirmary wants us to meet up with Dr. Felix Chau tonight. They had reviewed our case after we had left the clinic, and talked about Lily and how unusual it was. They saw "something strange" in her ultrasounds of her left eye. Her "good eye" with vision. It was imperative that we get Dr. Chau to do another evaluation on her. At this point we will have to wait for the Retinal Specialist to get out of surgery. Dr Azar told us that it appeared that her retina was detaching. What?!! What does this mean? She explained that this was not okay, it was very devastating if her retina would detach. It would mean Lily would go blind.

I hung up the phone and just looked at Peter. In THAT moment, my heart sank. There were no words..none. How? Why? What do we do now? Help! This was such a blow. Lily has always been our special little girl with special eyes. We had always been worried about her, but as time has gone on... we have been reassured that she is a "mild" case and that she is doing so well. Almost "better" than expected. Dr. Hess at All Children's in St. Pete. has been our pediatric ophthalmologist. He's beenvery underwhelming to say the least. Always feels like a waste when we leave those appointments. We have gotten second opinions here in our area and they said the same thing... "It is what it is, and Lily is doing fine." Well, now we find out she IS NOT FINE! Had they not caught this, Dr. Hess wasn't going to even be seeing Lily for at least another year. She could've been blind by then!!

The emotions came hard and fast. But we were so numb that we just sat there. Looking at each other. Holding Lily tight and silence filled the room. We had promised Lily that she could ride Thomas the Train again, because she was soooooo good during the blood draw and all of the poking and prodding they had done during the medical clinic. The clock was ticking for the meet and greet and now we have to go and see another doctor this evening.... We jumped up and put on a "fake" happy face and RAN down to Navy Pier to let Lily have some fun! She was so excited about the train. We were just in shock. How do you even start to comprehend all of the information you have just been given and still function? It was it just was...

We run back to the hotel and freshen up for our Meet and Greet. There are so many wonderful families there. Again, we are just unsure of what the night is going to bring us. we don't really get to enjoy it.

We go back to our room. The phone call comes in at 10pm. Dr. Chau wants to meet with us tonight..in a half hour. Now we jump up and head out the door. Dr. Chau meets us on the curb and walks us into his empty office. It's so dark and quiet. He begins to talk to Lily and reassure her that it won't hurt and that he just wants to take pictures of her eyes. She is absolutely still and so calm. I am holding Lily in my lap while the dr. is performing the ultrasound, Peter is watching the screen. I can see him tense up and starts to ask the Dr. if he sees something. They talk for a moment about the images on the screen. Yes, he sees something. A retinal tear. A horseshoe-shaped tear in the bottom portion of her left eye, by her coloboma. He proceeds to explain what that means. He describes the retina like "wet tissue" paper. It is along the back of our eye. The eye is filled with fluid, viscous fluid. When the retina tears, the viscous fluid enters the tear and begins to pull at the retina and will eventually detach the retina, leading to blindness. The only way to fix the tear is to laser around the tear to keep the fluid from entering in. WHOA! So what did he think we needed to do? We need to preserve the eye that has vision. He wanted to schedule an immediate EUA (exam under anesthesia) Monday morning at 6am and to be prepared to also do the laser surgery. He called down to the UIC surgicenter to see what was available as far exam rooms go. They were all booked. Our other options was to take our original flight home from South Bend, IN at 6pm and then drive straight to Bascom Palmer in Miami, FL. to have the EUA done there. IMMEDIATELY....this has to be done now. Her retina was extremely vulnerable at this point and this is her only eye that has vision. We really didn't know what to do. But we went ahead and filled out the papers to be registered and ready for the EUA and possible surgery to correct the tear. All being on standby for an exam room on Monday. How were we going to make our flight?...

Now as silly as this sounds... we were very unsure if we even wanted to go thru with the EUA/surgery at this point. We got back to our hotel room around 2am. We sat down on the bed and looked at each other. Still totally numb. We barely said a word to each other. Only to look and mutter out small sentences...

Is this happening? What do we do? Is this something that has to be done now? Can we wait til we get home? Is it really this bad? How are you feeling? Are you okay? Is Lily going to be okay? Are we doing the right thing? How did Dr. Hess not know that this could happen? Can we survive this? What if she goes completely blind?

These were just some of our thoughts. I know I was holding in the tears, trying to be strong. It was late and we had to be up in a few hours to go to our all day ICAN event. Gam was going to come fast enough and the day would be long with speakers going until 5pm.

It was a very informative day on Saturday and all of the speakers were so amazing. What stuck out the most was at the very end. They had a psychologist who is known for his expertise in low-vision psychology. He talked about the "grieving process" for the child that we "expected" to have and the child that we did have. I felt that..it resonated with me. Then he went on to talk about how it not only affects the parents of the visually impaired child, but the ENTIRE family..everyone. He talked about the parents needing "alone" time and also to be honest with how we feel. I felt like he knew exactly what I had been feeling and had actually been at my house, seeing how Pete and I had been interacting, or the lack of communication that had been going on. Then he made us break out into groups, women in 2 groups and men in another. We all talked thru our feelings and realized that we are all going thru the exact same trials and tribulations. We all have struggles with how people react to our children. We all struggle with the "am I doing the right thing?" or the "am I doing enough for my child?" I enjoyed this alot.

The conference came to an end and we all went back to the hotel to get ready for our 7pm dinner. Everyone was curious to what was going on with Lily. It was overwhelming and at the same time comforting to know how many people cared. Some of the families have already been thru this same procedure and were so wonderful to help ease our minds and to help us with any questions we may have forgot to ask the dr. The dinner was great. They had karaoke for the kids and Lily had a blast using a microphone. The children got to meet other children with the same conditions and just had fun!

Sunday came quick as well. Breakfast was at 9am and check out was at noon. We all came together for one last time. Time to exchange names, email addresses and phone numbers so we can stay in touch. We agreed that we need to come up with some more fundraising ideas and ways to get more money into ICAN. Reality is starting to really sink in...We have an early appointment for Lily to have a EUA and possible surgery tomorrow. Everyone is asking how we are doing...we reply.."We are okay". Hugs and goodbyes are always hard, especially when we won't all be together for another 2 years.

Back to the hotel room to pack. We decided we wanted to go to Grant Park and see the giant bean. We walk the mile to Grant Park. It's so hot and Taste of Chicago is going on. ...It's so HOT... We decide we can't even begin to think about eating. Lily wants to bubbles so I picked up some from the Walgreens. We sit in Millennium Park and blow some bubbles and just let her run around...Let her enjoy the day, the grass and chase some bubbles. She begins to tire, as are we. We head back to the hotel and get ready to change and meet up with our friends for one last dip in the pool. It was so nice to get to hang out for a little longer with one of our favorite families. Time to head to the new hotel by the hospital across town.

Once in our new hotel room, the silence begins again. Lily cannot have anything to eat or drink after midnight. She is passed out and not wanting to wake up to eat. As the time keeps ticking away, we ask each other again. "Are we doing the right thing?" We decide we are doing what is best for her at this time. We cuddle her a little tighter tonight. She is our angel.

4am and we are up and packed. We take the shuttle to the hospital and walk into a packed waiting room at the UIC SurgiCenter. Oh Boy.. we don't even really have a scheduled appointment time...this could turn into a really long day. They take her back around 7am and it seems to move really fast. Lily is starting to get hungry. UH OH... The nurses were amazing and found a little car for Lily to ride around the pre-op area. Everyone was calling her "Dr. Lily" She was a hit. Time seemed to go really quick now. She was going to go into surgery at 845am. Here we go. I feel so sick to my stomach, yet telling myself the whole time that everything is going to be fine. They will start the evaluation and that they will find nothing. Hoping surgery won't be needed the entire time.

Back she goes and Peter and I just hold each other for a moment. This is a BIG DEAL. She is our baby and our little angel. What happens if she loses her sight? What if they make a mistake? Will she wake up the same happy little girl with the sparkle in her eyes?

We go down to the cafeteria and try to eat.. just as we sit down, we get the call. It is a retinal tear in her left eye, her good eye. We are asked if we want to go ahead with the surgery. We were struggling over the last few days, but in the actual moment... we said go ahead. Do the laser surgery. Now we are flooded with even more sadness and heartache. How was this missed? This was MAJOR. We wouldn't even be back at her doctor for another year.... She could've been blind by then.. maybe not..but maybe .

We sit for what seems like forever and ever. They come down to get us and want us to have a talk with Dr. Chau. He says everything went well. We are to follow-up in Miami at Bascom Palmer. Lily will need to be monitored every 2 months from now on. She also needs to always wear her protective lenses. The nurses lead us over to Lily. She is still groggy, but looks so cute and peaceful. About an hour later she comes out of anesthesia fighting, kicking and punching.. and crying about her eyes. They are swollen and will be sore for a few days. She finally calms down and we are ready to be discharged.

Reality is beginning to sink in again. We have to make our flight!!!! We have to race to South Bend, IN from Downtown Chicago...now! We are leaving the hospital at around 230pm and we have at least a 2 hour drive ahead of us. Our flight is to leave at 6pm! And we lose an hour in Michigan... We literally haven't stopped in days! We managed to make our flight by mere minutes. Lily was amazing thru the whole process.

Lily has proven she is a trooper! I believe that she is truly an angel on Earth. I don't know how she does what she does and how she is so happy. Of course she is 2 1/2 and she has her moments ofsassiness and crabbiness. But she has shown me what true strength is. I love her with all of my heart. As I reflect back on the events of the last several days, I can't help to think (again)...Am I doing enough? What do I need to do to make sure she "sees" all she needs to see in this world? How do I protect her?

I thank God for allowing us to make it to this conference even though I felt like the universe doing everything in its power to make us miss it. I am also very thankful for the thoughts and prayers that everyone sent to us during this extremely difficult time.

The ICAN conference was truly a "Blessing In Chicago"!

Jennifer, Pete, and Lily James

Conference Experience – The Future Medical Leaders – Alex Nobori

I would like to thank you for the opportunity to meet you and your children. I felt welcomed to the group, and it was very nice to meet new families as well as see ones I met two years ago at the last meeting. At the conference, I found it tremendously informative to listen to the lectures and learn from the ophthalmologists, geneticists, and ocularists. But the part I will remember the most was the chance to hear some of your individual stories, and getting a glimpse of the daily life of raising a child with A/M.

Much of medical school is spent reading books and learning the mechanism of different diseases, instead of spending time directly with patients. Even in a busy clinic, I have learned it can be difficult to find time to discuss a parent's deepest worries, concerns, and hopes for their child. But attending the ican conference was an eye-opening experience. I was surprised to learn some of the challenges parents commonly face, including the feeling of isolation given the rarity of A/M, but I was glad to see the conference lift some of those feelings. I loved meeting the children and seeing their energy and enthusiasm, and I felt moved to witness the deep caring you show them.

I will be spending the next year conducting research on A/M treatments. Attending the conference has been inspiring and reminded me of the purpose of my work. During the conference, one parent remarked that even though there are challenges ahead for his child, he felt comforted knowing there were compassionate people who were looking out for him, including many of the health professionals he had met over the weekend. As I continue my research and training, I hope to be such a person, and I will certainly remember your stories for the rest of my life.

Alex Nobori, MSIV
David Geffen School of Medicine at UCLA, Jules Stein Eye Institute

Conference Experience – Q&A with Dr. David Rakofsky – Low Vision Psychologist

1. What made you interested in participating in the ICAN conference?

I had no idea about ICAN before I was approached about the Chicago conference by Dr. Janet Szlyk, who is the executive director of the Chicago Lighthouse for People Who are Blind and Visually Impaired. I was nearing the end of a 5-year tenure as the founder of a psychological support clinic there when she asked if I would be interested in running a session during the ICAN weekend conference related to helping families cope with microphthalmia/anophthalmia, and I gladly accepted. My interest partly comes from the awareness that microphthalmia/anophthalmia was simply not the everyday, bread-and-butter of my work with people in the visually impaired community, and I wanted to learn a lot more. Preparing my lecture and the activities we facilitated for the conference added to my body of knowledge and comfort with another subgroup in the visually impaired world, and my colleagues and I were better for having taken this on.

2. After visiting with the ICAN families, can you talk about how this group compared to other groups that you have provided support for in the past?

In some ways, ICAN families are like all families: They want what's best for their kids and want them to thrive wherever possible. They aspire to raise children who have peers, friendships, productive lives and interests that sustain them after their parents are gone. Where ICAN families stand out for me—even among parents of other visually impaired children—is the frustrating and sometimes demoralizing public interactions they reported enduring. I learned a lot about the futility of trying to educate well-meaning strangers in the grocery aisles one-at-a-time, to the point of feeling extremely raw and on edge when encountering inquisitive people at large. I noticed a feeling of self-blame that some unnecessarily contend with, as well as the suspicion—sometimes even confirmed!—that people in the community mistakenly assume that these parents abused illicit drugs or alcohol, causing their children to exhibit these abnormalities in their physical traits. But, aside from this, I was so impressed to see how ICAN families showed an interest in one another and the experiences they could share. After all, anything that helps them to feel less isolated is a win, since incidences of microphthalmia/anophthalmia are so diffuse within the general population.

3. Did you have a particular experience that stood out as particularly unique or moving during the conference and why?

Yes, more than I expected, I was moved by this group of parents. For one thing, ours was the final lecture or presentation of the weekend, so we were coming in at the tail end of a few days that had already been filled with bonding, relating, support and learning, and many Facebook-friendings. The final 45 minutes of our presentation to the group consisted of breakout sessions for the parents (who were split up by gender) to vent off some pretty painful and also affirming thoughts, feelings and war stories, in some cases. As a psychologist, working with men is one of my specialties and passions, and as such, I had all the dads with me in that final portion of the program. I sat with men who were suddenly shedding tears—tears of despair, joy, or of being moved by someone else's story. Some of these were men who talked about coming from places where men simply don't cry, places where the value system is such that a man is seen as "weak," or "lesser" for letting his feelings out in such a visible way.

It struck me that, just *being there*, among other men who were going through similar parenting experiences (though, some were further along than others and had older children) was an engine for their own successful transformation into fathers who could handle what they were being asked to handle. Incidentally, I believe that the act of mourning *with* others is actually an important step toward getting on with things and really rising to the occasion of parenting a special needs child. For some, this may have been the first time they felt authorized in some way to let these feelings out, believing that the people in their lives “needed” them to “be the strong one,” for their family. I was moved by the possibility that some dads came away with a new ability to challenge that idea, maybe for the first time.

4. Do you have some advice as to how families can continue to practice some of the techniques throughout the course of the year that you discussed?

I feel like I presented enough ideas that at least some of them are going to work for each couple, but that certainly some other ideas will not. I have to believe that, with some customization to their own family rhythms and situations, families will adopt the ideas into their lives and stick with the ones that feel helpful. But, above all, self-care and care of the couple (the parents’ bond to one another) must be attended to if the children are to be given the best chance for normalcy in their own lives. Adjusting to this “new normal” is an ongoing and ever-shifting proposition, and eternally “sucking it up” will eventually lead to fatigue without taking care to see to one’s own mental, spiritual and physical health and that of one’s partner.

5. When do you think it is appropriate to have your children involved in a support group (do you feel this is always necessary)?

I suspect that being in a support group is probably most helpful to the *siblings* of ICAN-involved children, actually. One of the aspects of being a brother or sister in such a family is the tendency to be shuttled around from appointment to appointment with their affected sibling, leaving less room and attention for the unaffected child to express interests of their own. Even the best “troopers” among these kids may eventually wear down or feel that they do not get to have something special about them or about their relationship to their parents. A support group can help to normalize these feelings before they can fester and transform into outward emotional problems.

6. If you had one piece of support related advice for parents of children with visual impairments, what would that advice be?

The one item I know I repeated several times was about the importance of staying active in your network of families and parents of affected children. No matter the distance, families who are going through a similar experience, or have been there before you, can help you more than any doctor or therapist with the big picture of helping your kids—affected and unaffected—to thrive in a world such as ours. I wish them all luck, perseverance and wisdom as they do just that.



A Very Special Thank You!!!

Jennifer James – ICAN Conference Family Contributor

Dr. David Rakofsky – Q&A from the ICAN Conference

Alex Nobori – Future Medical Leader Perspective

Chau Berman – Our new Hotline Administrator

Blake Dennis – Our new Sibling contact Coordinator

Hanna Mason & Kelly Cucé – Newsletter Design

Be on the Lookout for the Next Edition of The Conformer, which will be published
in March 2014!!!!



ICAN Board Members

President – Ryan McGrady (Ohio) – rpmcgrady@yahoo.com

Vice President – Deb Brezgel (Wisconsin)

Treasurer – Sandy Athenson (Georgia)

Hotline – Chau Berman (California)

Sibling Contact – Blake Dennis (Ohio)

Immediate Past President – Jodi Dennis (Ohio)

Immediate Past Vice President – Nelly Gamino (Illinois)