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ican/ 1-800-580-ican/ican@anophthalmia.org

Message from the President

Hello, I am Sherry Salatto **ican's** new President. At any time, if you have suggestions or comments that you feel would help **ican** please feel free to contact me. We are always looking for new ideas to make **ican** a great parent support organization.

I am looking forward to seeing more activity with the Parents. As a Parent support group I think it needs to be easier for Parents to connect. I would like to start a chat every month to get Parents together to discuss whatever is on their minds. We will have some guest speakers and Board members join the chat each month. We will be checking our message board regularly and encourage you to go and see if there are

any topics you can give some input on or you may have a topic you would like some information on yourselves. I would also like to compile a regional list of our members, so that when a new member calls **ican** we can put them in touch with other parents in their regional area who would be willing to share their information and experiences.

Our next conference will be held in Philadelphia in 2005. We will be working on putting that together. Let us know what ideas you have for making this our best conference yet. We will also need to do some fundraising to make our conference affordable for everyone. If anyone has any ideas for fundraising please contact us.

Meet the New Board

Executive Board

President- Sherry Salatto-Connecticut

Vice-President-Jodi Dennis-Ohio

Secretary-Lori Regan-Arizona

Treasurer-Sandy Athenson-Illinois

Members at Large

Spanish contact-Nelly Gamino-Illinois

Conformer contributor-Pat Renfranz-Utah

Hotline-Melissa Capps-Kansas

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.



The 2003 Conference: A Huge Success

The 3rd Annual **ican** Conference was held in April in St Louis MO this year. The conference was co-sponsored by **ican**, Delta Gamma Center for Children with Visual Impairments, Albert Einstein Medical Center, and the Washington State University.

The conference began Friday evening with a dessert hospitality at the Sheraton Clayton Plaza. This was time for the families to mingle, to catch up with old friends from the last conference and also time to meet new friends. It was really neat to see how much the kids had grown and changed in the last two years.

Saturday started with breakfast and registration at the St Louis Zoo. What a great place to have a Family Conference! Before the speakers began it was time for the children to connect with their Delta Gamma buddy. The kids really had a great time and it worked out great being paired with a caregiver for the day. Something funny that I noticed. It wasn't the micro/ano. kids having difficulty adjusting to the Delta Gamma caregivers, but rather the sighted siblings!

Dr. David Ng gave a wonderful presentation on genetics. His presentation was given in a manner that parents, not professionals, could fully understand. The panel of individuals with microphthalmia or anophthalmia was super. It really helps some families to envision how

well his or her child can do in life. Dr. Kim Martin spoke about "The Next Pregnancy". This was definitely a topic of interest for many.

We shared a catered lunch at the zoo, checked on the kids, and then back for more presentations. The afternoon session began with Terese Pawletko talking about autism. Informational handouts were given on this topic as well. Orientation and Mobility was discussed by the Delta Gamma staff. A parent advocate then spoke about Early Intervention and Laws. This seems to be a topic familiar to all. Following that was the oculoplastic/ocularist update. They brought pictures of their reconstructive work and talked about the preferred methods for the anophthalmic/microphthalmic socket.

The session wrapped up with relaxation techniques for parents—something all parents need!

The evening was concluded with a wonderful dinner buffet at the hotel and some fun karaoke entertainment.

The hotel prepared a nice brunch Sunday morning and then it was time for good byes.

ican Conference 2005: See You in Philadelphia

Plans are underway for the next **ican** conference. It will be held in Philadelphia in the Spring of **2005** in Philadelphia. We need volunteers to assist us in planning the conference. Please consider helping. Distance is not a factor. We are looking for suggestions for topics, speakers and activities as well as with conference logistics.

If you are willing to participate in any way, big or small you can contact:

Tanya Bardakjian
215-456-8726
bardakjiant@einstein.edu

Let's work together to make this conference a huge success!!!!

Feature Family- The Salatto's

When you have a baby your whole life changes instantly. You now have a little person who needs you and your love twenty-four hours a day. When our son Collin was born our whole life changed instantly, not only because he was in the world and needed us but because he needed our eyes to help him see the world. The day after Collin was born he was examined by a Doctor who came into my Hospital room and said "I don't think your son has any globes". Well, I had no idea what she was talking about. I have no idea what she said after that because about a thousand things were running through my head. I looked at her and said "are you telling me that my son has no eyes?" I didn't even understand the question I was asking. She told us that she thought he would be blind. When she left the room my Husband Ralph and I (Sherry) just sat there thinking now what? How do we do this? How will he play? How will he walk around? How will we teach him? What will other people think of him? Will he ever know what his Mommy and Daddy or his two brothers look like?

After a lot of testing and a great eye specialist, we found out that Collin was born with bilateral Microphthalmia with cysts. He would have no vision in his left eye and we were not sure how much vision he would have in his right. I bought every eye-stimulating toy on the market and we started doing everything we could think of to stimulate his vision. He got his first set of glasses and his first conformer when he was two months old. It was hard to deal with all the questions people would ask when we went out in public. We had good days when we would tell people he was

born with an eye condition that made him visually impaired and we had bad days when we would just say he failed the eye test so they gave him glasses. As Collin grew we waited for every milestone to be difficult for him because of his vision. Instead, Collin showed us that he could do everything any other child could do even though he could not see very well.

Collin is now five years old and in Kindergarten. He wears a sclera shell in his left eye and he is beginning to learn Braille this year. He played on a Baseball team last spring called the Challengers (A league for kids with disabilities). His Brothers were volunteer "Buddies" for the team He took private golf lessons this summer with his Grandmother and he is now taking swimming lessons at our town pool. Needless to say he is a very energetic little boy who loves sports. He is always trying to keep up with his older brothers (Jason 14, and Brian 12) they are also very involved in sports so it was important for Collin to find a sport that he could play.

We have come a long way as you can see. It has not been an easy road but has certainly been interesting. Instead of us teaching Collin he has taught us. Collin is a very special little boy who has a way of touching everyone who spends any time with him. He adjusts to any situation and accomplishes things we never thought would be possible for him to do. I am so proud of him every day and now instead of wondering what things he will not be able to do we wait anxiously for him to show us everything he can do.

Research update

DNA The DNA research project is ongoing. Previously we were collecting buccal swabs (cheek cells) for DNA analysis. However, we now feel that blood is a better source of DNA. The blood will provide more DNA so that we can analyze the known genes completely and can actually keep DNA available for future studies as new developments arise. Therefore, we have changed our protocol and are waiting for funds in order to begin collecting DNA again.

There have been a few results of mutations reported. The families with these changes have been notified. If you have not heard anything yet it means results are not yet available. Once the funds are obtained to convert to blood analysis we will contact

everyone to offer participation.

The A/M Registry The Genetics Division at Albert Einstein Medical Center will be presenting four patients identified from the Registry at the Annual Genetics Conference. These children have a rare association of A/M with a birth defect, esophageal atresia. This association has only been seen in 9 children before. A rare association such as this can help us understand the timing of birth defects and may help DNA researchers focus their search in the gene map.

Please consider joining the Registry. All you need to do is fill out a detailed form describing your child. If you are willing please contact us for a Registry: Tanya Bardakjian 215-456-8726 or bardakjian@einstein.edu

"Please consider joining the A/M Registry"

ican website: New and Improved

"Visit the new and improved ican website at www.anophthalmia.org."

Visit the new and improved **ican** website at www.anophthalmia.org. There is a lot of information for new parents. You can also find old issues of The Conformer on the site. We will also be posting any upcoming events or research information on the site.

There is a support forum with a message board to help families connect. We encourage everyone to use this to make it a more successful tool to connect families. The more people who use this

service the more rewarding it can be.

If you have any ideas or suggestions for the website please contact us at ican@anophthalmia.org

We welcome comments that will help us better serve you!!!

Pre-Braille Experiences for Toddlers Part II

By Terri Connolly (Reprinted with permission from the VIPS newsletter, May/June 2001)

Number Concepts and Patterns

Important number concepts and patterns include: few/many; some/none; first/second/third; last and counting to ten. Play with objects in a six-muffin tin. Find and take out one or two. Guide the child's hand to learn how to use one hand as placeholder and the other hand to place an object in the hole. This reinforces one-to-one correspondence when one object is put in each hole. This will help the child imitate patterns later.

Large pegboard play is great for beginning number relationships. Let the child play creatively and later introduce number concepts. Older infants and young toddlers will enjoy positioning large pegs and blocks to create things. Older toddlers may be ready to initiate patterns of pegs on board or large shaped beads on a string. Create rows of tape or Velcro strips with blocks or shapes. Again, as with sorting and matching games, begin with two and increase to three or four.

Motor Skills

Practice doing movements with words to describe them. Also, talk to the child about what he/she is doing so the words have meaning at natural times of the day. Important movement concepts include: go; start/stop; fast/slow; push/pull; scribble; draw; trace; bend; open/close; side; roll; hold; insert/place/put; reach; sit; turn and follow.

1. Good head control and independent sitting are important to read Braille with ease. Reaching for an object based on sound or visual cues or on commands is also important.

2. Guide the child to develop a systematic

approach to searching for an object within reach to develop good skills for later exploration of pages and manipulation of books.

3. Fine motor skills that are important for eventual reading include: grasp/release; twist/turn; rotate and examine; open/close; stack; nest etc. Busy boxes and nesting stacking toys are good for developing these skills.

Dexterity

Further refinement in motor skills can be encouraged by putting objects into and taking them out of containers of all sizes and by playing with manipulatives such as; finger foods in containers, shape sorters; loop beads; linking chains; large pegs; form boards and simple puzzles and blocks. Important skills for dexterity include; pincer grasp; poke/probe; spreading/wiggling fingers; pointing; isolating each finger; relaxed curving of fingers; wrist flexibility; and tracking a raised line by touch.

Communication Skills

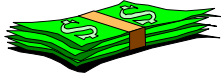
Babies are like sponges-they absorb information. Use words to name and request-eventually the baby will, too. Guide infants and toddlers to use words to name and request and to follow simple directions.

Braille in everyday Life

Encourage "scribbling". It's fun and important. Allow toddlers to "scribble" with a Braille writer or stylus (with supervision)-plastic sheets from bacon packages, when thoroughly washed, work great for braille.

Share with your toddler what you are writing-grocery lists, notes to friends, etc. Braille notes for toddlers to take to family members and have them read aloud. (cont page 6)

Membership Dues and Fundraising



In December be on the lookout for an invoice from **ican** asking for the Membership dues. The fee is \$25.00 per family. This covers expenses for newsletters, mailings, the 1-800 number and the website. In the past we have not been billing regularly for the annual dues. However, due to increasing services and the costs associated with them we must be diligent about dues collections. We will be sending an invoice at the end of every year. Please help us continue to provide support to you and other families by paying your dues. Please note that if you cannot afford the dues simply contact us and we will make every effort



to provide you with member privileges

Contact us by calling
1-800-580-ican or e-mail
ican@anophthalmia.org

Fundraising is also essential to the continued efforts of **ican**. We need ideas for fundraising activities. All money is used for the day to day operations of **ican** or for the research on A/M. If you have any suggestions or can help in any way please contact Sherry Salatto at Shersalatto@cox.net

First Research Conference on Anophthalmia/Microphthalmia

In January 2003 Dr. Adele Schneider was approached by the Office of Rare Diseases, a branch of the National Institutes of Health (NIH) to apply for a grant to plan a conference for researchers. The topic was to discuss the diagnosis and classification of anophthalmia/microphthalmia. The goal of the conference was to develop a tool to assist doctors and researchers to better describe and classify the different eye abnormalities. This was the first conference, which brought together numerous experts from the field. Premiere researchers from the US and England joined in the two day conference held simultaneous to the parent conference in St. Louis. The attendees were from various specialties including, genetics, ophthalmology and developmental biology. Each attendee

gave a brief presentation regarding their area of work and expertise with A/M. They discussed the challenges of research on such a rare birth defect and the difficulty in describing the condition accurately because there are no specific or universal guidelines. The goal is to develop universal guidelines to help clinicians diagnose and describe the eye findings accurately. This will in turn help lab researchers by pointing out the difference and similarities between cases. A written report from the conference will be published in the medical literature. This is a huge step in the research awareness for anophthalmia and microphthalmia. Thank you Dr. Schneider for your continued efforts and for keeping us on the research radar screen. We hope research will continue to develop!

"This is a huge step in the research awareness of anophthalmia/microphthalmia."

ican

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children's
anophthalmia
network

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We're on the Web!
See us at:
www.anophthalmia.org

Pre-Braille *Continued from page 4*

Leave Braille "love notes" under the toddler's pillow or in her lunch box; include print so anyone can help the child read it.

Take the toddler's hand to experience Braille in the community on signs, elevators and Braille menus. Remember, sighted infants have been seeing print in their world from a very early age.

Get a Braille labeler or a slate with slits for dymo tape for labeling. Label the child's belonging with his name (diaper, cup, lunch box, snacks, etc) Label areas of the home, familiar objects and toys.

Literature Rich Experiences

Create a box or bag with items associated with a familiar routine. Write a story on an index card about taking a bath, visiting Grandma or going to a restaurant and include objects associated with that experience-a story in a box or bag! Clap and bounce with rhymes, finger plays and songs; pause before the last word of a familiar rhyme to let the child anticipate and fill it in. Keep textured books, cloth and cardboard books, Braille books and sound books available on a low shelf where your child can find them herself.

*Go to the library for story hour

*Practice turning pages together.

Reinforce this by slipping treats, leaves or pieces of fabric to find between the pages.

*Adapt print books by placing Braille above or below the lines of print.

Reading from Left to Right

*Play at making rows of large pegs in a pegboard from left to right

*Roll a car or rolling toy on a table from left to right

*Play at following the track with wooden sticks, sandpaper strips, lines of glue and brailed materials

*Glue objects to a strip and have the child move from left to right to discover and talk about each object.

*Place objects in a 12-muffin tin and have the child identify objects from left to right across each row

Concrete to Abstract

Braille is a system of symbolic representation of real objects and experiences, just as print for a sighted reader. Infants and toddlers learn best at a concrete, hands-on level. Touching and experienced with objects are critical. Begin by talking out loud to the baby when he is playing with a toy: Describe what he is doing or what you are doing.

The next step is to use an object as a reminder or to prepare for a transition in activity, such as a key to go for a car ride. For example, let the baby hold the keys before you go out (and only at that time).

Then make a book with object symbols to tell a pretend story about someone else. At this time, add a raised drawing to represent the object and match it, as well as a Braille label next to it. Then the connection can be made between the real object and the Braille word. Match the real objects to things that go together or outlines of them. Trace familiar objects to make puzzles out of them.

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