



the

conformer

Fall 2002

Newsletter of **ican** international children's anophthalmia network

Hello Everyone!

We hope you had a great summer!

I want to thank you for the feedback regarding the Conformer and I again, welcome any suggestions or comments. Please e-mail me at RVOLSEN001@aol.com and mark the subject as Conformer. Thank you.

From the Board! From the Board! From the Board!

The Board has been very busy planning the 3rd **ican** Conference to be held in St. Louis, Missouri. April 11-13, 2003

We are working with the Delta Gamma Center for Children With Visual Impairments. Established in 1951, the Delta Gamma Center provides early intervention services for children of any age with visual impairments. They also provide support services for family members of these children.

Each year, the Delta Gamma Center typically serves over 100 families within a 50-mile radius of the Center. They provide assessment services, individualized developmental/vision services, therapy, and family support. We welcome their help and input into our upcoming conference, and look forward to working with them! Registration for the Conference will be mailed out in January, so be on the lookout.

The Board is also working on establishing an **ican** website to assist us in our mission of providing resources to families of children with anophthalmia and microphthalmia. We hope to have a new website very soon.

We thank you for your continued support and hope to see you in April!

Sincerely,

ican board members

From Our Readers....



Claudia from Region 3 wrote us regarding her son Auggie. He is 12 and entering the crazy world of pre-adolescence. She would love to hear from parents of other children with A/M on this topic.

A couple wrote..."Our son Danny is turning 4, he is entering pre-K and doing great. But we worry all the time about the safety of his one seeing eye; he won't wear protective glasses at all. And is still bad when it comes to doctors and us touching or trying to remove his conformer. Any ideas?

A question from the west coast: My son is 5 years old, and wears his conformer only 1 to 2 days at a time. How long is the average time to keep a conformer in?

If you have any helpful comments or suggestions for any of the above readers or are willing to speak with them directly, please contact RVOLSEN001@aol.com subject: ican



**The 3rd ican Conference
for families and
professionals**

**April 11-13, 2003
St. Louis, MO**

THINGS TO DO AND SEE IN ST. LOUIS

One of the nice things about St. Louis is that there are numerous activities for families, which cost nothing or have a small admission fee (compared to other cities).

One of the top attractions is Forest Park, a large metropolitan park that was the site of the 1904 World's Fair. It is being completely overhauled for the 100th Anniversary of the World's Fair. The **ican** Conference and childcare will be held inside Forest Park at the St. Louis Zoo, the oldest and largest in the country. Admission to the zoo is free.

Within Forest Park, in addition to the wide open spaces and bike and jogging trails, one can find the St. Louis Art Museum, the History Museum, Science Center, and the Municipal Opera. The museums and Science Center are free as well. For smaller children, ages 2-8 years, the Science Center has a "Discovery Room" to provide a variety of fun activities for the youngest scientist! The Planetarium has a four-story screen Omnimax theatre with special showings most of the time.

For those who want to venture downtown, (only ten minutes from Forest Park) the City's best-known and most-visited sight is the 630-foot tall stainless steel Arch. Under the Arch is the Jefferson National Expansion Museum and families can take a tram up to the top of the Arch for views of the area. The price for a tram ride is \$6. While downtown, the City Museum, while not on the list of top ten attractions for St. Louis, is surely among the top ten for children. A children's museum with plenty of area to play, explore and create, is most unusual as everything in the building is made out of recycled materials.

Also downtown St. Louis, Union Station is a top attraction for families, and it might just be warm enough in April to enjoy a free concert by the lake under the train shed, or take a paddle boat ride in the lake. Union Station, the largest train station in the country, was restored as a shopping mall and hotel—with plenty of extra attractions for the family!

**For more information log onto
explorestlouis.com**

Pre-Braille Experiences for Infants and Toddlers, Part 1

By Terri Connolly, Early Intervention, VIPS-Louisville
Re-printed from VIP, a Quarterly newsletter Published by the Blind Children's Fund Mar/Apr 2001

Babies learn through movement and their senses. Play is the best way for babies to learn. Good pre-braille experiences for infants and toddlers include:

- Discovery through play
- Associating concepts of meaningful language
- Developing good fine motor skills; and
- Developing tactual awareness and discrimination skills.

Be patient! Infants and toddlers need to explore on their own for quite a while before we jump in and guide these discoveries. Caring adults can provide materials and language to support their play. Gradually guide their play by expanding it to include the skills and concepts below. Encourage little ones to use any vision they have as well as tactual cues.

Understanding Spatial Relationships

These are spatial concepts: *on/off, front/back, left/right, up/down, above/below, top/bottom/, in front of/behind, over/under, forward/backward, together/apart*. Others are *next to, beside, through, middle, center, between, here, there*.

Begin with experiences with objects relating to child's body, i.e. Find the teddy bear behind you (next to you, under you). Gradually expand experiences to include toys and objects related to each other. For example: Talk about the block on top of the cup next to the plate. Later talk about and play with objects around a room in relationship to furniture, i.e. "The ball rolled under the couch." Mark spots in paper or surfaces with crayons, stickers, or magnets (top, under in the raised line box, etc.)

Other Important Cognitive Concepts

Discrimination skills begin with just touching and playing with an object. Let babies hold, drop, bang and mouth toys in safe ways to discover concepts. When a baby begins to recognize familiar objects and explore new ones, they are ready to build on cognitive concepts. Provide toys that help them develop these concepts: *big/little, open/close, thick/thin, wide/narrow, long/short, same/different*.

Introduce basic shapes to your child. Include shapes such as : ball, circle, round, square, box, cube, rectangle, triangle, cylinder, oval, diamond, heart, cross, dotted line, curvy line, When the toddler is ready to play sorting and matching games, begin with two and then increase to three or four objects at a time.

Tactile Discrimination

Introduce a variety of textures in a playful, systematic way with words to describe as the baby plays. Tactual concepts include: *smooth, rough, hard, soft, sticky, furry, bumpy, fuzzy and slick*.

Encourage two-handed play and exploration of details. Give the baby names for things until he or she can recognize familiar objects by touch and name them too. Name for the baby what the object is made of: *paper, cloth, wood, plastic, metal, leather, vinyl*. Talk about the edges, corners and pieces of toys, books and objects.

Try presenting several pieces of the same tactile objects and one that is different. Have your child find the one that is "different" and the ones that are the same. Again with sorting or matching games, start out presenting two objects, and then increase to three or four. Tactual awareness and strength can be refined by playing with whipping cream and play dough, opening jar lids and playing with keyboards and the many musical toys with buttons and knobs



Genetics Update



The Genetics Division at Albert Einstein Medical Center is pleased to announce that Tanya Bardakjian, MS is back. She will be coordinator of the A/M Registry and DNA research project. She will also be assisting **ican** with activities such as the newsletter, the conference and parent contact. Her position, which will focus only on A/M activities is being funded for one year by a grant from the Knights Templar Foundation. Please contact her at 215-456-8722 or bardakjiant@einstein.edu if you have any questions.

As always, we are looking for funding to allow us to continue our research efforts by supporting this coordinator position. If you know of any funding sources please let us know!!!

Microphthalmia Research at the National institutes of Health

Dr. David Ng is conducting research at the Human Genome Research Institute in Washington D.C. to find the gene that cause Lenz microphthalmia. Lenz microphthalmia is an inherited condition that leads to small eyes or absence of eyes at birth. In addition to the eyes being affected, a child may also have small head size, mental retardation, abnormal looking ears, fingers, teeth, narrow appearing chest, curving of the spine, and abnormally formed genitalia or kidneys. The presence of these features are variable. Each patient may have some of these findings in varying degrees of severity, but rarely does one individual show all the features.

Lenz syndrome is a sex linked condition. Most individuals carry 46 chromosomes. 23 chromosomes are inherited from one's mother and the other 23 from the father. The sex chromosome are called X and Y. Males are typically XY while females are XX. Sex linked means that the causative gene is located on the X chromosome. In large families with Lenz syndrome, unaffected carrier females transmit the syndrome to affected males. Males manifest the symptoms because they have one X chromosome. Females carry the gene and do not show symptoms as they have one abnormal copy and one normal copy on the other X chromosome. In families where there is only one affected male, it is difficult to know if the individual actually has Lenz syndrome as there are other forms of inherited microphthalmia that are not sex linked.

If you have a child that fits some of the afore mentioned features and are interested in participating in this research study, please contact Tanya at # 215-456-8722 and she will have Dr. Ng contact you to go over the details of participating in a research project.

CONFERENCE HOTEL-SHERATON CLAYTON PLAZA

Step out to dozens of neighborhood bars , restaurants and sidewalk cafes when you stay here. Located in the heart of St. Louis' financial and judicial center. Complimentary van service both to and from Lambert International Airport and immediate shopping areas makes a personal automobile unnecessary. A full-service restaurant, lounge, health club and pool enhance each guest's experience. **Also, FREE shuttle service will be available to and from the ican Conference site.**

ican Board elections

We are planning on having an **ican** meeting and Board elections at the Conference this year. Please consider volunteering for the board to help make a difference in the lives of many families!!! Come prepared to put your name on a ballot.

Conference Registration

We expect to have the Conference Registration Forms with full information about the conference mailed in early January. If you have not received one by February, please contact Tanya Bardakjian at Albert Einstein Medical Center 215-456-8722.

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