

# The CONFORMER



Spring 2002

## Happy Spring!

As the new editor of "The Conformer", I hope to make the newsletter something special.

Our plan is to publish four issues per year, in conjunction with each season.

**ican** is a parent run support group for families affected with anophthalmia / microphthalmia. It truly helps to know you are not alone and there are others that can answer questions or lend an ear.

We are hoping to get more people involved. Maybe it is researching a topic for the next issue, suggesting fund raising ideas or answering the 1-800 line. Whatever your hidden talent may be, we need you!

Please get involved...

Throughout this issue you will see many things meant for you to cut out and save. Please take advantage of that. You may not need the information but maybe someone you know will.

If there is something new in your neighborhood or something you want to share, (I would love pictures!) or if you would like to be a Feature Family in the next issue, you can e-mail it to me at [rvolsen001@aol.com](mailto:rvolsen001@aol.com) or U.S. mail at the address below. All I ask is that you mark it CONFORMER or **ican**.

Looking forward to a fun year!

Rita Olsen  
9058 S. Meade  
Oak Lawn, IL 60453

[rvolsen001@aol.com](mailto:rvolsen001@aol.com)



*Editor Rita Olsen and her sons Bobby (on left) 7, and TJ (on right) 4, during a recent trip to Coco Beach, Florida.*

## Get Growing!

Gardening is a terrific way to help children who are visually impaired or blind to use their senses of touch, taste, smell, and hearing.

For example:

Digging, weeding and watering helps youngsters improve their development by increasing their attention span and relaying a productive feeling which can help to increase self esteem.

Smells of the garden are many. Some herbs to try are dill, basil and rosemary; flowers include lily-of-the-valley and roses (be careful!)

A fountain provides soothing sounds together with chirping birds. And lastly, the taste of fresh vegetables surpasses anything frozen or canned.

So get up and get growing!

# DNA RESEARCH

A new researcher from the NIH has recently joined our group. David Ng, MD, is looking both at families with multiple affected males and those with single affected males.

Our other researchers are continuing to collect DNA samples to examine genes known to be involved in eye development. DNA samples are collected from affected individuals with A/M, their parents, any other relevant family members and are obtained by collecting buccal mucosa (cheek cells) and/or blood. We will also require families to participate in our Registry and in the collection of medical records in order to increase the value of the results from the DNA study. Please complete the form below to receive a DNA collection kit.

I wish to receive the following DNA collection kits. *Please put a check in front of the kit(s) you wish to receive. Indicate the number of kits that you will need.*

Buccal Mucosa Kits     Blood Drawing Kit

Number of Participants in the study for which kits are needed

Send kits to:

Name \_\_\_\_\_

Address \_\_\_\_\_

Day Phone Number \_\_\_\_\_

This research is grant funded and the funds are running low. If you wish to have a kit sent to you, we hope that you will return it within a reasonable amount of time, so our investment in you is not lost.

If you wish to participate in the DNA study or have any questions, please call 215-456-8722 or mail this form to:

**Mary Dwyer, MS**  
**Albert Einstein Medical Center**  
**5501 Old York Road**  
**Genetics, Levy 2 West**  
**Philadelphia, PA 19141**

**ican Executive Board**  
**1-800-560-ican**

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# Regional Reps

We are looking for volunteers in different regions of the United States to help parents gain easier access to information in their own communities. Our goal is to see people getting together to share information and support in their own area of the U.S.

If you think you might be interested, contact Sherry Salatto at [shersalatto@aol.com](mailto:shersalatto@aol.com).

We would appreciate any comments or suggestions you may have.

There will be at least 7 regions:

Region 1  
ME, NH, VT, NY, CT, MA

Region 2  
NJ, PA, MD, OH, KY, VA, WV, DE, DC

Region 3  
MN, IA, MO, WI, IL, IN, MI

Region 4  
TN, SC, NC, GA, FL, AL, AR, LA, MS

Region 5  
KS, OK, NM, TX

Region 6  
WA, AK, HI, OR, CA, NV, UT, AZ, ID

Region 7  
CO, MT, ND, SD, WY, NE

**A special thanks**

**to Jodi Dennis**

**for**

**answering the**

**800 line!**



# Vision Dynamics

Vision Dynamics is a superstore for people who are blind, visually impaired and learning disabled. The store is run by people who are visually impaired and they can tell you first hand how the equipment works. They have everything from Braille equipment, games, kitchen products, video magnifiers, mobility aids and all kinds of computer aids. You can reach them through their website address at:

[www.visiondynamics.com](http://www.visiondynamics.com)

or by telephone at  
**203-271-1944**



## Finger Plays

### My Body

Here are my eyes

Here is my nose

Here are my fingers

And here are my toes

Here are my eyes opened wide

Here is my mouth with my teeth inside

Here is my tongue for me to speak

Here is my chin, and here are my cheeks

Here are my hands that help me to play,

And here are my feet that run all day!



Author Unknown

# *Taking Care of Our Children ...Taking Care of Ourselves*

## **19<sup>th</sup> Annual New England Regional Seminar**

The Perkins School for the Blind will be holding their seminar on April 27, 2002. This is a New England Regional seminar for families of Children with Visual Impairments. It is held at The Perkins School for the Blind in Boston, Massachusetts. This year's topics will include:

1. Sensory Integration and its Impact on Development
2. A panel of professionals who provide services to young children will describe their roles in working with young children, their families and educational teams
3. Activities with Low Vision Simulations
4. Encouraging Functional Vision Use During Play and Daily Activities
5. Orientation and Mobility for Infants and Toddlers
6. Beginning Braille for Parents
7. Everything you Always Wanted to Know about Adaptive Technology
8. Enhancing Communication Skills for Children with Visual and Communication Impairment
9. Providing Early Literacy Experiences for Children with Visual Impairments

There will be a presentation with a music therapist and a speech and language pathologist and support groups for all members of the family, including grandparents and siblings.

Anybody wanting more information on this seminar can contact Sherry Salatto at [shersalatto@aol.com](mailto:shersalatto@aol.com). I am planning on attending this one day seminar on April 27, 2002.



*Sandy Athenson, treasurer of ican with Adele Schneider at the last conference.*

### **HELPFUL WEBSITES**

**American Foundation for the Blind**

[www.afb.org](http://www.afb.org)

**National Association for Parents of Children with Visual Impairments**

[www.spedex.com/napvi](http://www.spedex.com/napvi)

**American Association of Pediatric Ophthalmology and Strabismus**

<http://med-aapos.bu.edu>

**Micro and Anophthalmic Childrens Society**

[www.macs.org.uk](http://www.macs.org.uk)

**Resource for the Blind, Visually Impaired, Disabled and Interested Parties**

[www.hgea.org/~mota/resource.htm](http://www.hgea.org/~mota/resource.htm)

**Welcome to Blind Links**

<http://seidata.com/~marriage/rblind.html>

**National Federation of the Blind**

[www.nfb.org](http://www.nfb.org)

**American Printing House for the Blind**

[www.aph.org](http://www.aph.org)

**Social Security Administration,**

**If you are Blind or Have Low Vision – How we Can Help**

[www.ssa.gov/pubs/10052.html](http://www.ssa.gov/pubs/10052.html)

**Kolberg Custom Made Artificial Eyes**

[www.artificialeye.net](http://www.artificialeye.net)



*"Argue for your limitations,  
and sure enough they're yours."*

*- Richard Bach*



# Speaking about People with Disabilities

## *Alternatives to Outdated Expressions*

Afflicted with .....has  
Birth defect.....born with  
Blind person..... person who is blind  
Cerebral palsied.....has cerebral palsy  
Confined to a wheelchair.....uses a wheelchair  
Deaf and dumb .....hearing and speech impaired  
Emotionally disturbed..... behavior disordered  
Epileptic .....has epilepsy  
Handicapped .....disabled  
Handicapped accessible..... accessible to people with  
disabilities  
Insane ..... mentally impaired  
Lame ..... uses crutches; walks with a limp  
Midget, dwarf..... short-statured  
Mongoloid ..... Down Syndrome  
Normal ..... non-disabled  
Paralytic ..... is paralyzed  
Retarded..... developmentally delayed  
Wheelchair-bound .....uses a wheelchair  
Victim of .....has



*Vice President Sherry Salatto and son Colin.*

# WANTED: FUNDRAISING

Help, ideas or suggestions.

*If you have any connections, know of any successful strategies, have a new idea or ANYTHING, drop us a line.*

[rvolsen001@aol.com](mailto:rvolsen001@aol.com)

*Coming in the next issue.....*

***Genetics Report, Treasurer's Report,  
A Feature Family, Conference Update,  
Your Responses***

***Fundraising Ideas – Do you have any?***

***We want to hear your good times,  
ideas, tips, gripes and pics.***

***Drop us a line!***

**Get Ready!**  
**Our 3<sup>rd</sup> ican**  
**Conference is**  
**coming in APRIL 2003!**

**We're headin' to St. Louis, MO**

We are looking for ideas on what **YOU** would like to see at the conference.

**TOPICS? SEMINARS? WHAT TYPE OF PROFESSIONALS? WHAT ARE YOUR CONCERNS?**

**LET'S ANSWER YOUR QUESTIONS!**

Send your E-Mail: [aemcgenetics2@hotmail.com](mailto:aemcgenetics2@hotmail.com)

U.S. Postal mail: ican,  
c/o Albert Einstein Medical Center,  
5501 Old York Road  
Genetics, Levy 2 West  
Philadelphia, PA 19141  
Attn: Mary Dwyer

Phone: 1-800-580-ican or 215-456-8722

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ADDRESS CORRECTION REQUESTED