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 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

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!
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

Diann O’Riordan     Sherry Salatto     Rita Olsen     Sandy Athenson
President         Vice President          Secretary                            Treasurer

Adele Schneider, Volunteer Administrative Director
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.

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 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 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

19th 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. I am planning on attending this one day seminar on April 27, 2002.

HELPFUL WEBSITES

American Foundation for the Blind  
www.afb.org
National Association for Parents of Children with Visual Impairments  
www.spedex.com/napvi
American Association of Pediatric Ophthalmology and Strabismus  
http://med-aapos.bu.edu
Micro and Anophthalnic Childrens Society  
www.macs.org.uk
Resource for the Blind, Visually Impaired, Disabled and Interested Parties  
www.hgea.org/~mota/resource.htm
Welcome to Blind Links  
http://seidata.com/~marriage/rblind.html
National Federation of the Blind  
www.nfb.org
American Printing House for the Blind  
www.aph.org
Social Security Administration, If you are Blind or Have Low Vision – How we Can Help  
www.ssa.gov/pubs/10052.html
Kolberg Custom Made Artificial Eyes  
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

WANTED:

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

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!

Vice President Sherry Salatto and son Colin.
Get Ready!
Our 3rd 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
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