

The Conformer

Summer/Fall 2000

Letter from **ican** President

Diann O'Riordan

President, ican

Fall is a busy time for all,
I hope everyone is having a great time!

We have started the planning for the 2001 **ican** Conference in Chicago.

We have had several conference calls to discuss
fundraising, and other various ideas and projects for the conference.

A special Thank You to those that took the time to attend and who
continue to work hard towards making our conference a success!

There is still a lot to do and plan. If you have any suggestions that may help,
or if you are interested in volunteering some time, please let us know!

Please contact me at run4@earthlink.net or call me at 918-341-8791.

Look for the latest details about the conference in this issue of *The Conformer*.

Have a Safe and Happy Fall and Winter!!

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ican Conference Details

Conference Dates

Friday, April 20 through Sunday, April 22, 2001
Chicago, Illinois

Preliminary Conference Topics/Agenda

The **ican** conference planning committee is preparing to have: a parent panel and professional panel, which will include an ophthalmologist, ophthalmologist, oculoplastic surgeon, and several others. In addition there will be speakers discussing topics such as encouraging self-esteem, sibling issues, fostering peer relationships, technology for the low vision and visually impaired, concerns about recreational activities, an update on the genetic research of A/M and several other topics.

Friday evening, April 20, 2001, early registration will be at the hotel over coffee and a snack. The conference will start at 8:00 AM on Saturday April 21st, with breakfast and registration. The speakers will present from 9:00 AM- 5:00 PM. Saturday night we will have a dinner for the conference participants to mingle and relax. Entertainment will be provided for the children after dinner. The conference will conclude on Sunday with a brunch and other activities, such as DNA collection, ending at approximately 2:00 PM.

Conference Costs

- The **ican** conference planning committee has held a block of rooms at the Congress Plaza Hotel located at 520 S Michigan Ave., Chicago, IL. Call 1-800-635-1666 for reservations. Be sure to say that you are part of the **ican** conference. The cost will be \$109 for a single room and \$119 for a double occupancy. The reservation will need to be made by March 20, 2001 to ensure these room rates.
- **American Airlines** is the official carrier for the **ican** 2001 conference. The special fare being offered is a 10% discount if reservations are made at least 60 days before departure and a 5% discount if reservations are made within 60 days of departure. Discounts are valid for travel between April 16-25, 2001. This offer is not valid with any other discounted fare (i.e., Senior, child, military/government).

Call American Airlines Meeting Services at (800) 433-1790 and be sure to refer to Star # S 4941AK for the **ican** conference airline discount.

Conference Costs Continued

- We expect registration will be \$100 for **ican** members and \$125 for **ican** non-members. The full conference registration will include all meals on Saturday and brunch on Sunday, entertainment for the children Saturday night, shuttle from the hotel to the conference center and the conference program. Free childcare will be provided on Saturday only.
- One-day registration will be available on Saturday for professionals only. The registration fee will be \$100 for MD's and \$75 for other professionals. This fee will allow for admittance to all education sessions as well as breakfast and lunch.
- Conference Scholarships will be available to help fully or partially sponsor the registration fee for those needing help with finances. Applications will be requested. Look for details in a future newsletter.

We will be mailing the Conference registration forms in January. We hope to see you in Chicago!!!!

Medical Consultations

The Genetics Division of Albert Einstein Medical Center and The Eye and Ear Infirmary at the University of Illinois at Chicago will be having another afternoon of free medical consultations on Friday, April 20, 2001 in Chicago. The free evaluations would be with a clinical geneticist, genetic counselor, oculoplastic surgeon, and ophthalmologist. We have a limited number of spaces available for evaluations and they will be granted based on need. Please do not register if you live near a major medical center and have access to specialists. Some of our families live in rural areas and travel hundreds of miles to receive care for their child. If you are interested in signing up, please answer the following questions and mail this section back. We will contact you to let you know if your child is eligible for these consultations.

Name of child: _____ Parent's Name: _____

Daytime Phone Number: _____

Address: _____

Child's date of birth: _____

Circle one

Unilateral

Bilateral

Circle one

Anophthalmia

Microphthalmia

Nearest Medical Center: _____

Distance from your home: _____

Name of Medical Specialist who care for your child: Ocularist _____

Ophthalmologist _____

Oculoplastic surgeon _____

Genetics _____

Donate American Airline Miles or Help Sponsor a Family

If you are willing to donate your American Airline frequent flyer miles or make a donation for a family to attend the **ican** conference, please contact Diann O'Riordan at run4@earthlink.net or call her at 918-341-8791 for details. Or you may send a check made payable to **ican**, designating it for this purpose and mail it to Mary Dwyer at Albert Einstein Medical Center, 5501 Old York Rd., Genetics, Levy 2 West, Philadelphia, PA 19141. This donation is tax deductible.

A Message from the Secretary

I am really excited about the upcoming **ican** Conference 2001. I just got back from spending two great evenings with my local Lions Club. I just cannot believe all the great help they give and work they do. There are Lions Clubs all over the world waiting and willing to give assistance to any family in need, whether it is transportation, funding for a conformer or sending a child to a camp for the visual and hearing impaired. They want to help. They have also agreed to take part in our **ican** Conference 2001. They will assist with food service, child care and helping all the attendees around the town. We are also working to set up a booth with information you will be able to take home about a Lions Club near you.

Another exciting part of my visit was meeting a man in charge of the Lions Club research division. My personal goal of being involved in **ican** is to know why this happened to my son and to have the answers for him before he reaches childbearing age. Research is something all of us are interested in but of course this takes money and interest. By getting involved with fund-raisers and attending the **ican** conference we will be putting A/M on the map; this will benefit all of our children. We all need to start talking and promoting our cause. If we don't who will? Some suggestions I have for everyone are: call your local Lions Club and educate them about this condition, call or write an article for your neighborhood newspaper and look for ways to start a fundraiser. I would gladly help! Please attend the **ican** conference. We will be trying to get as much attention to A/M as possible. We need to get people interested and to start studying this eye condition!!

I also have been asked to attend a low vision conference held in Chicago to work with families affected with A/M. This is a great way to learn and to meet new families. This conference will be held in September of this year. I will update you on that and the progress I make with the Lion's research department in the next Conformer.

Until then,
Rita Olsen
ican,

secretary

ican Feature Family
ican Feature Family

We hope to see you in Chicago!!!



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ADDRESS CORRECTION REQUESTED

