INTERNATIONAL CHILDREN'S ANOPHTHALMIA NETWORK

ican 8th International Conference
July 12-14, 2013 • Chicago, IL
FROM THE PRESIDENT

Dear ican Families and Friends,

The Planning Committee of the ican Conference invites you to the 2013 International Children’s Anophthalmia Network conference in Chicago, located in the heart of this world class city. As you read through this registration packet, know that the Planning Committee is working hard on your behalf to make this an informative and rewarding conference. You will hear excellent speakers and attend workshops in which participants share experiences and learn not only from the experts leading the sessions, but also from one another. If you are unable to participate, but would like to help out in other ways, or if you know of anyone who may be willing to donate to this worthy cause, please email us at ican@anophthalmia.org. We will mail all necessary forms to you. Thank you in advance.

Jodi Dennis
President, ican
ican 8th INTERNATIONAL CONFERENCE AT-A-GLANCE

The conference will be held at the Illinois Eye and Ear Infirmary, Chicago’s first and largest ophthalmology center. The Eye Infirmary is located on the city’s near west side in the Illinois Medical District - 560 acres of medical research facilities, universities, labs, and more than 40 healthcare related facilities. Child care will be provided by an experienced paraprofessional team with The Chicago Lighthouse for People who are Blind or Visually Impaired. Accommodations at a special ican Conference Rate of $209/night are at the DoubleTree by Hilton, located on Chicago’s Magnificent Mile, renowned worldwide for its shopping, dining and entertainment. Bus transportation from the hotel to the campus will be provided.

FRIDAY, JULY 12

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>10:00 am–5:00 pm</td>
<td>A/M Clinic</td>
<td>Illinois Eye and Ear Infirmary Pediatric Ophthalmology and Adult Strabismus Service</td>
</tr>
<tr>
<td>7:30–10:00 pm</td>
<td>Coffee and Dessert Social</td>
<td>DoubleTree Hotel</td>
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</tbody>
</table>

SATURDAY, JULY 13

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00–8:30 am</td>
<td>Childcare Drop Off</td>
<td>The Chicago Lighthouse 1850 W. Roosevelt Rd., Chicago</td>
</tr>
<tr>
<td>7:30 am–5:00 pm</td>
<td>Conference</td>
<td>Illinois Eye and Ear Infirmary Auditorium</td>
</tr>
<tr>
<td>5:00–5:30 pm</td>
<td>Childcare Pick Up</td>
<td>The Chicago Lighthouse</td>
</tr>
<tr>
<td>6:30 pm</td>
<td>Banquet</td>
<td>DoubleTree Hotel</td>
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SUNDAY, JULY 14

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Location</th>
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</thead>
<tbody>
<tr>
<td>9:00–11:00 am</td>
<td>Brunch</td>
<td>DoubleTree Hotel</td>
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CONFERENCE REGISTRATION

Register before June 1, 2013 to take advantage of lower conference registration rates. The registration fee includes the Friday night mixer, breakfast, lunch, dinner and snacks on Saturday and brunch on Sunday, the facility for our sessions, printed materials, and speaker costs.

<table>
<thead>
<tr>
<th>Participant</th>
<th>REGISTRATION FEES BEFORE 6/1/2013</th>
<th>ON or AFTER 6/1/2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult(s)</td>
<td>$150.00</td>
<td>$200.00</td>
</tr>
<tr>
<td>Child(ren)</td>
<td>$50.00</td>
<td>$75.00</td>
</tr>
<tr>
<td>MD</td>
<td>$175.00</td>
<td>$225.00</td>
</tr>
<tr>
<td>Other Professional</td>
<td>$150.00</td>
<td>$200.00</td>
</tr>
</tbody>
</table>

REGISTRATION REFUND POLICY

Refund requests must be received in writing and postmarked no later than June 15, 2013. A $50 service fee will be charged for cancellations made under these terms.
TRAVEL INFORMATION

AIR TRANSPORTATION
Chicago O’Hare Airport
18 miles from hotel. Drive time about 30 minutes.
Approximate fees for transportation to and from airport:
- Limousine 85.00 USD
- Taxi 45.00 USD
- Super Shuttle 27.00 USD
- Subway/Rail: 2.25 USD

Chicago Midway Airport
15 miles from hotel. Drive time about 30 minutes.
Approximate fees for transportation to and from airport:
- Limousine 85.00 USD
- Taxi 45.00 USD
- Super Shuttle 22.00 USD
- Subway/Rail: 2.25 USD

ACCOMMODATIONS
DoubleTree Hotel by Hilton Chicago – Magnificent Mile
300 East Ohio Street
Located two blocks from Michigan Avenue and the famous Magnificent Mile, guests are in easy reach of Chicago’s best shopping, dining and entertainment. From the famous DoubleTree cookie upon arrival, to the welcoming staff and contemporary surroundings, this downtown Chicago hotel makes your trip hassle-free. Call (312) 787-6100 for reservations. Mention ican to receive the group rate of $209/night and discounted parking rate of $35/day.

FREE CHILD CARE
Child Care will be provided by paraprofessional staff at The Chicago Lighthouse at no cost to conference participants. Child care will include a variety of activities to keep children busy and happy. Parents will have the opportunity to meet Lighthouse staff at drop off. To discuss any concerns prior to the meeting, please contact Mary Zabelski, President/Educational Services, The Chicago Lighthouse, at (312) 997-3675 or mary.zabelski@chicagolighthouse.org. We know personally that if parents see that their children are happy, they can get the most out of the meetings.

CONFERENCE SCHOLARSHIPS
A special Conference Scholarship Fund for those who need financial assistance has been established to fully or partially cover registration fees and other travel costs. Do not hesitate to ask for help. If you would like to apply to receive one of these scholarships, please e-mail bardakjiant@einstein.edu or send your requests to the ican Conference Scholarship Fund at the address below.

SPONSORS NEEDED FOR THE CONFERENCE SCHOLARSHIP FUND
Some of ican members wish to attend the educational conference but due to financial constraints may not be able to do so. We are looking for people to donate to the Conference Scholarship Fund to help those who cannot afford to come. If you are interested in fully or partially sponsoring those in need, send a check to the address below. Your donation is tax-deductible and a great way to help others touched by A/M. Anyone contributing to this fund will be acknowledged in ican’s newsletter, The Conformer.

ican
Conference Scholarship Fund
c/o Albert Einstein Medical Center
Genetics, Levy 2 West
5501 Old York Road
Philadelphia, PA 19141
FRIDAY, JULY 12
10:00 am—5:00 pm  A/M CLINIC: Illinois Eye and Ear Infirmary
Free medical consultations with ocularists, an oculoplastic surgeon, ophthalmologist, geneticists and genetic counselors
7:30 pm—10:00 pm  Coffee and Dessert Social
DoubleTree Hotel

SATURDAY, JULY 13
CONFERENCE: Illinois Eye and Ear Infirmary
Childcare: The Chicago Lighthouse
7:00 am—8:30 am  Childcare Drop Off
The Chicago Lighthouse
7:30 am—8:45 am  Breakfast and Registration
Illinois Eye and Ear Infirmary
8:45 am—9:00 am  Introductory Remarks
9:00 am—10:15 am  Ophthalmology issues in microphthalmia/anophthalmia
Nathalie Azar, MD
Director, Pediatric Ophthalmology & Adult Strabismus Service, Illinois Eye and Ear Infirmary
10:15 am—11:00 am  The Genetics Revolution
Tanya Bardakjian, MS, CGC
Coordinator of the Anophthalmia/Microphthalmia Research Project at Einstein Medical Center
11:00 am—12:00 pm  KEYNOTE SPEAKER: Ronit Ovida, MS, CGC
Helping Your Child Succeed: Tips from a Blind Adult
12:00 pm—1:00 pm  Lunch
1:00 pm—2:00 pm  Low Vision Technology
Janet Szlyk, PhD
Executive Director, The Chicago Lighthouse
2:00 pm—5:00 pm  Emotional and Psychological Impact of Parenting a Child with A/M
David Rakofsky, PsyD,
Associate Director of Psychological Services, The Chicago Lighthouse

There will be sessions for siblings of children with A/M facilitated by a Child Psychologist. These sessions will run concurrently with the parents’ workshop. To register your child, please contact Tanya at bardakjian@einstein.edu
FREE A/M CLINIC

FRIDAY, JULY 12
Sponsored by Albert Einstein Medical Center and Illinois Eye and Ear Infirmary

The Pediatric Ophthalmology and Adult Strabismus Service of the Illinois Eye and Ear Infirmary will host a Free Anophthalmia/Microphthalmia Clinic on Friday, July 12. Participants will have the opportunity to consult with pediatric ophthalmologists, ocularists, an oculoplastic surgeon, geneticists and genetic counselors. If you would like to have your child evaluated by any of the specialists please answer the following questions and mail this form back with your registration form. We invite anyone interested to request an evaluation. We will contact you to let you know if your child is eligible for these consultations.

<table>
<thead>
<tr>
<th>Name of Child</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent’s Name</td>
<td>Phone #</td>
</tr>
<tr>
<td>Address</td>
<td></td>
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<td></td>
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</tbody>
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Unilateral or Bilateral (circle one)     Anophthalmia or Microphthalmia (circle one)

Other medical problems, birth defects, or developmental delay? Yes _____ No _____
If yes, please describe

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Nearest Medical Center __________________________ Distance from your home __________________________

Name of Medical specialists who care for your child:
Ocularist __________________________
Ophthalmologist __________________________
Oculoplastic Surgeon __________________________
Genetics __________________________
ican 8th INTERNATIONAL CONFERENCE  | JULY 12-14, 2013

REGISTRATION FORM

Name of Attendees _______________________________________________________________

Address _______________________________________________________________________
______________________________________________________________________________

City                                                                                     State                                                Zip Code
   _______________________________        _________________________________

E-mail ____________________________________________________________________________

Telephone (day) __________________________________________________________________
Cell ____________________________________________________________________________

INFORMATION ABOUT THE PERSON WITH A/M IN YOUR LIFE

Name ___________________________ Age ___________________________

Name ___________________________ Age ___________________________

SPECIAL REQUESTS

Any hotel-related special requests (i.e. cribs, refrigerators, or roll away cots) should be taken up with the hotel staff.

What is your primary language? English _____ Spanish _____ Other __________________________

Would you like to be included in our Conference Directory of Attendees? Yes _____ No _____

CONFERENCE REGISTRATION FEES AND PAYMENT METHODS

<table>
<thead>
<tr>
<th>Conference Attendee</th>
<th># of people</th>
<th>Fee BEFORE 6/1/13</th>
<th>Fee AFTER 6/1/13</th>
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<td></td>
<td>GRAND TOTAL</td>
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TO REGISTER

Please mail your completed form with check payable to ican to:
ican, c/o Albert Einstein Medical Center, Genetics
Levy 2 West
5501 Old York Rd
Philadelphia, PA 19141

Each family is responsible for their hotel room or lodging; it is not a part of registration. The registration fee includes the Friday night mixer, breakfast, lunch, dinner and snacks on Saturday and brunch on Sunday, the facility for our sessions, printed materials, and speaker costs.
CHILD CARE REGISTRATION (FREE)

_____ Yes, I will need child-care.

Please reserve for # __________ children.

Name ____________________________________________ Age
Name ____________________________________________ Age
Name ____________________________________________ Age
Name ____________________________________________ Age

INFORMATION ABOUT THE PERSON WITH A/M

Name ____________________________________________ Birth date __/__/____
Name of Parent/Guardian ____________________________________________

Child’s primary means of communication?
Speech ___ Sign Language ___ Gestures ___ Other __________________

Does your child speak English? Yes ___ No ___
Does your child understand English? Yes ___ No ___

Additional information you want us to know:
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________
_____________________________________________________________________________

PLEASE NOTE THE FOLLOWING

• Please remember to provide diapers, a change of clothes and any other essential items or equipment for the childcare room. All items (strollers, infant seats, clothing, diaper bags, etc.) should be clearly labeled with child’s full name.
• Toys and cribs will be provided.
• Childcare participants must wear a name tag. Name tags will be provided in your registration packet.
• You must provide food if your child has any dietary restrictions or formula for an infant.

I understand and agree that neither ican nor any cosponsoring organization, nor their respective chapters, officers, directors, employees, agents, members or volunteers shall assume or have any responsibility or liability for expenses or medical treatment or for compensation for injury I or my child may suffer during or resulting from our participation in this program.

Parent Signature ___________________________________________ Date ____________________
MEET THE FACULTY

EINSTEIN

Tanya Bardakjian, Certified Genetic Counselor
Adele Schneider, MD, Director Clinical Genetics

ILLINOIS EYE AND EAR INFIRMARY

Nathalie Azar, MD, Director, Pediatric Ophthalmology and Adult Strabismus
Marilyn Miller, MD, Pediatric Ophthalmologist

Irene Maumenee, MD, Director, Ophthalmic Genetics
Pete Setabutr, MD, Director, Oculoplastic & Reconstructive Surgery Service

Aisha Traish, MD, Director, Pediatric Cornea Clinic
Vinay Aakalu, MD, Surgeon, Oculoplastic & Reconstructive Surgery Service

Javaneh Abbasian, MD, Pediatric Ophthalmologist
Julie Lenth-Carver, CO, BS, Orthoptist

Genie Bang, MD, Pediatric Ophthalmologist
Lisa Hartemayer, CO, COMT, MBA, Orthoptist

Iris Kassem, MD, PhD, Pediatric Ophthalmologist
Robert J. Brown, BCO, Board Certified Oculist, UIC Craniofacial Center, Maxillofacial Prosthetics Clinic

THE CHICAGO LIGHTHOUSE

Janet P. Szlyk, PhD, President & Executive Director
Mary Zabelski, Senior Vice President/Educational Services

David Rakofsky, PsyD, Associate Director of Psychological Services