

**ican 6th
International Conference
June 19-21, 2009
Los Angeles, CA**



Conference Location:

Beverly Garland Holiday Inn
4222 Vineland Ave.
North Hollywood, CA 91602
1-818-255-7491
or
1-800-238-3759

**Albert Einstein
Medical Center**
Einstein



Dear Families and Friends,

The Planning Committee of the **ican** Conference invites you to our 2009 conference at the Beverly Garland Holiday Inn in North Hollywood, CA, located right outside Universal Studios. As you read through this registration packet, know that the committee is working hard on your behalf to make this an exciting, informative, and rewarding conference. You will hear excellent speakers, attend workshops designed for participants to share experiences and learn not only from the experts leading the sessions, but also from one another. 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. Another exciting part of the **ican** Conference this year will be the 1st ever **ican** walk! A walk to benefit Anophthalmia, Microphthalmia, and Coloboma. We hope all of our families will remain with us after brunch on Sunday to take part in the walk. If you are unable to participate, but would like to help out in other ways or know of anyone who may be willing to donate to this worthy cause please email us and we will mail all necessary forms to you. Thank you in advance.

Jodi Dennis
President, **ican**

SPECIAL GUESTS!

We are so excited that POSITIVE EXPOSURE will be part of the Conference! Positive Exposure, founded in 1997 by former fashion photographer, Rick Guidotti, and Diane McLean, MD, PhD, MPH, is a highly innovative arts organization working with individuals living with genetic differences. Their programs support and promote human dignity through the Spirit of Difference photographic image data bank and through video interviews of people, particularly children, living with genetic conditions. Visit www.positiveexposure.org to learn more!

A Little about the Area:

The Beverly Garland Holiday Inn Hotel is conveniently located in North Hollywood, blocks away from Universal Studios, which includes the theme park, as well as the famous "City Walk." Also nearby are NBC studios, where you can catch a taping of the Tonight Show. A short mile from the hotel is the famous shopping district of Ventura Blvd. And if the Arts are more your scene, North Hollywood is the theatre and arts section of Los Angeles, home to contemporary theaters, art galleries, cafes, and interesting shops. The area features more than 20 professional theatres producing new work and classics, diverse art galleries, public art and professional dance studios. The district also features the largest concentration of music recording venues west of the Mississippi.

Hotel Information:

The Beverly Garland Hotel is a beautiful and charming facility with many amenities including a free shuttle to Universal Studios, an exercise room, lighted tennis courts, heated swimming pools, and a full service restaurant and bar.

The Hotel is offering a rate of \$159/room/night plus applicable tax. Please mention the **ican** conference when making reservations. These rates are also available for 2 days before and 2 days after the conference.

Nearby Airports:

Burbank/Bob Hope Airport (BUR) is located 4.5 miles from the hotel. (This is the closest but please compare prices as this airport tends to be more expensive).

Los Angeles International Airport (LAX) is located 25 miles from the hotel.

Santa Ana/John Wayne (SNA) is located 50 miles from the hotel.

Conference Rates:

Please register before May 15th 2009 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.

Child Care:

Child Care will be provided, at no cost, by Kid's Nite Out which is a special corporation that specializes in conference childcare. We anticipate a program that the children will enjoy with many activities to keep them busy and happy. We know personally that if parents see that their children are happy, they can get the most out of the meetings.

Registration Refund Policy:

Refund requests must be received in writing and postmarked no later than May 15, 2009. A \$50 service fee will be charged for cancellations made under these terms.

Scholarships

A Special Conference Scholarship Fund has been established to help fully or partially sponsor the registration fee and other travel costs for those who need financial assistance. 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:

ican
Conference Scholarship Fund
c/o Albert Einstein Medical Center
Genetics, Levy 2 West
5501 Old York Road
Philadelphia, PA 19141

Sponsors Needed!!!!

Some of our members would like 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:

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Conference Scholarship Fund
c/o Albert Einstein Medical Center
Genetics, Levy 2 West
5501 Old York Road
Philadelphia, PA 19141

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.

CONFERENCE OVERVIEW

Friday June 19

1:00pm - 5:00pm

University of California Los Angeles, Jules Stein Eye Institute
Free Clinic (registration required)

7:30pm - 10:00pm

The Beverly Garland Holiday Inn
Dessert and Social

Saturday June 20

7:30am - 9:00am

The Beverly Garland Holiday Inn
Breakfast and Registration

9:00am - 5:00pm

The Beverly Garland Holiday
Workshops and discussions all day. Please see detailed schedule on page 4 for information on sessions and speakers. 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. Registration is required.

12:00pm

Lunch

6:30pm

The Beverly Garland Holiday
Dinner banquet and entertainment

Sunday June 21

8:30am - 10:00am

Beverly Garland Hotel
Brunch

10am

Fun Walk for **ican**

Conference Schedule
Times are Tentative and Subject to Change

Friday Night	The Beverly Garland Hotel
7:30pm - 10:00pm	Coffee and Dessert Social; Registration
Saturday	<u>The Beverly Garland Hotel</u>
7:30am - 8:45am	Breakfast and Registration
8:45am - 9:15am	Introductory Remarks/ Genetics Update
9:15am – 10: 30am	<u>Oculoplastic/Ocularist Treatment of the Child with A/M.</u> Speaker: Bill Katowitz, MD and Stephen Haddad, BCO
10:30am – 12:0 pm	Keynote Speaker: Ronit Ovidia, MS: <u>Genetic Counselor with bilateral microphthalmia</u> and PANEL: Children with A/M and their parents with A/M
12:00pm - 1:00pm	Lunch
1:00pm – 2:30pm	Break Out Sessions (Please Select One) Session A: Educating Visually Impaired Children with Multiple Handicaps Session B: Promoting Self-Confidence in a Child with Craniofacial Differences
2:30 pm- 2:45pm	BREAK
2:45pm -4:15pm	Break Out Sessions (Please Select One) Session A: Orientation and Mobility for 0-3 years Session B: Orientation and Mobility for Older Children
4:15pm - 5:15pm	Technology for the Visually Impaired

ican Conference Registration Form

June 19-21 2009

GENERAL INFORMATION

Name of Attendees: _____

Address: _____

City: _____ State: _____ Zip Code: _____

E-mail: _____ Telephone (day): _____

Telephone (evening): _____ Cell: _____

INFORMATION ABOUT THE PERSON WITH A/M IN YOUR LIFE

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

CONFERENCE ATTENDEE	# OF PEOPLE	FEE BEFORE 5/15/09	FEE AFTER 5/15/09	TOTAL
Adult(s)		\$125.00	\$150.00	
Child(ren)		\$50.00	\$60.00	
MD		\$100.00	\$120.00	
Other Professional		\$75.00	\$95.00	

GRAND TOTAL: _____

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.

I understand and agree that neither I 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: _____

MEDICAL CONSULTATIONS

Sponsored by Albert Einstein Medical Center
and
University of California Los Angeles

On Friday, June 19, there will be an optional afternoon of free medical consultations with ophthalmologists, an oculoplastic surgeon, ophthalmologist, 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.

Name of Child: _____ Date of Birth: _____

Parent's Name: _____ Phone #: _____

Address: _____

Unilateral or Bilateral 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 Conference Registration Form

Tanya Bardakjian
Division of Genetics, Levy 2 West
5501 Old York Road
Philadelphia, PA 19141