

**ican 7<sup>th</sup>**  
**International Conference**  
**July 15-17, 2011**  
**Boston, MA**



**Conference Location:**

Radisson Hotel Boston  
200 Stuart Street  
Boston, MA 02116  
1-617-482-1800

**Albert Einstein**  
**Medical Center**  
**Einstein**

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**ican**

Floating Hospital  
for Children  
at **Tufts** Medical Center

Dear Families and Friends,

The Planning Committee of the **ican** Conference invites you to our 2011 conference at the Radisson hotel Boston in Boston, MA, located in the heart of this historic city. 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. 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**

### **A Little about the Area:**

Boston Common, (T: Park Street or Boylston), founded in 1634, this is one of the oldest public parks in the United States. Over the years, many large gatherings have been held here, from British encampments in the revolutionary period to anti-war protests in the 1960s. A nice spot for walking around and people-watching at all times of year. The Frog Pond in the center of the Common has wading in the summer and ice skating in the winter. The Freedom Trail presents the opportunity for insight into Boston's rich history. The Freedom Trail is a 2.5-mile redbrick walking trail that makes its way to 16 of Boston's most historic sites. During this tour you will witness a unique collection of churches, museums, meetinghouses, burial grounds, historic ships as well as several other historical sites. Together these sites tell the story of the American Revolution as it unfolded in Boston during the 1700s.

### **Hotel Information:**

Situated in the center of the exciting Boston Theater District and just one block from Boston Common, the Radisson offers guests a prime location in the heart of downtown Boston, MA. Hotel amenities include a Fitness Center, parking garage, Business Center, two restaurants and an indoor, heated pool. Only three miles from Logan Airport, Fenway Park, the Children's Museum and within walking distance of some of the best attractions in Boston. The Radisson is one of the most convenient downtown Boston hotels for business and leisure travelers. **To make reservations call the hotel directly at 1-617-482-1800 and mention the ican group to receive the group rate of \$169/night and lowered parking rate of \$25/night.**

### **Nearby Airport:**

**Boston's Logan Airport** is located 3 miles from the hotel.

## **Conference Rates:**

Please register before June 1st 2011 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. 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 June 15, 2011. 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](mailto: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:**

ican

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 July 15

1:00pm - 5:00pm

TUFTS Medical Center

**Free Clinic (registration required)**

7:30pm - 10:00pm

The Radisson Hotel Boston

**Dessert and Social**

Saturday July 16

7:30am - 9:00am

The Perkins School for the Blind

**Breakfast and Registration**

9:00am - 5:00pm

Perkins School for the Blind (buses will be provided)

**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 Radisson Hotel Boston

**Dinner banquet and entertainment**

Sunday July 17

8:30am - 10:00am

The Radisson Hotel Boston

**Brunch**

*Conference Schedule*  
*Times are Tentative and Subject to Change*

Friday Night	The Radisson Hotel Boston
7:30pm - 10:00pm	Coffee and Dessert Social; Registration
Saturday	<u>Perkins School for the Blind</u>
7:30am - 8:45am	Breakfast and Registration
8:45am - 9:15am	Introductory Remarks
9:15am – 10: 30am	<u>Oculoplastic/Ocularist Treatment of the Child with A/M.</u> Speaker: Bill Katowitz, MD
10:30am – 12:00 pm	Keynote Speaker: Jennifer Bose, MA <u>Adult with bilateral microphthalmia</u>
12:00pm - 1:00pm	Lunch
1:00pm – 2:30pm	Orientation and Mobility Speaker: Mary Bernadette Dawson, M.Ed., COMS
2:30 pm- 2:45pm	BREAK
2:45pm -4:15pm	Family dynamics when a child has special needs Speaker: Angela Jones, PhD Open Discussion forum to follow
4:15pm - 5:15pm	Research Frontiers: Hope or hype? (Stem Cell Therapy, computer chip for vision) Speaker: TBA

# ican Conference Registration Form

## July 15-17, 2011

### 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 6/1/11	FEE AFTER 6/1/11	TOTAL
Adult(s)		\$150.00	\$200.00	
Child(ren)		\$50.00	\$75.00	
MD		\$175.00	\$225.00	
Other Professional		\$150.00	\$200.00	

**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 or formula for an infant.

**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  
Tufts Medical Center

On Friday, July 15, there will be an optional afternoon of free medical consultations with ocularists, 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