



"Cheers to Research to Reality" IRSF Education and Awareness Conference, May 27-30, 2011 Boston, MA

Thank you for registering for IRSF's very important 27th Annual Conference. This year's conference is located in Boston, Massachusetts, May 27 - May 30, 2010 at the Boston Park Plaza Hotel. A full conference program can be downloaded from www.rettsyndrome.org/conference so that you can map your session attendance plan in advance. Though last minute changes may be made to our very full schedule, reviewing the program ahead of time will ensure you get to your priority lectures, workshops and panels. Also, be sure to read session descriptions carefully as some speakers have indicated materials that you should bring or complete in advance to enrich your session attendance.

Please note that registration fees do not include travel and hotel accommodations or all meals; these arrangements must be made separately. We have negotiated special room rates at the [Boston Park Plaza Hotel](#) and encourage you to reserve early while rooms are available, especially by our contract fulfillment date of May 13, 2011.

REGISTRATION

Full conference registration fees include:

- All registration and conference materials
- Access to all sessions, workshops, exhibitors, and IRSF Bookstore (Friday afternoon through Monday morning)
- Friday: Welcome reception and orientation, and Crackerbarrels
- Saturday: Continental breakfast; mid-morning and mid-afternoon refreshments; plus evening coffee and dessert Tribute Reception, entertainment and auction
- Sunday: Continental breakfast; lunch; and mid-morning and mid-afternoon refreshments
- Monday: Crackerbarrels and Bookstore

Single day conference registration fees include:

- Registration and conference materials
- All-session, workshop, exhibitor and IRSF Bookstore access for that day
- Continental breakfast and refreshments that day (Saturday single-day registration also includes the Tribute Reception, and Sunday single-day registration also includes lunch)

Webcast registration includes live webcast viewing of the Saturday sessions. Sunday sessions will be audio-recorded and made available after the conference. Webcast registration includes:

- (1) "virtual seat" to view live, in real-time, the conference sessions offered Saturday, May 28, 2011, between 7:30am and 5:30pm EASTERN time.
- PDF copies of Conference materials and the Helping Hands Keepsake Journal
- IRSF will email information for internet, computer and audio requirements 4-weeks prior, and the actual session link and password 2 days prior, to the email address specified at the time of registration. See website for program and session details.

TRIBUTE RECEPTION:

IRSF will host a coffee, dessert, and cash bar Tribute Reception, award ceremony, silent auction and entertainment on the evening of Saturday, May 28th at the Boston Park Plaza Hotel. Attendance is included with your paid full-conference attendance package. Our girls and women with Rett syndrome are welcome at no charge. Single-day conference attendees and non-conference friends and traveling companions are welcome to purchase tickets at \$15



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per person *while tickets are available*. Dress to impress, but formal attire is not expected. Live entertainment will be enjoyed at this year's Tribute and Awards ceremony.

BOSTON CONFERENCE RAFFLE

Donate an item for the Raffle - gifts for our girls and their caregivers, weekend vacation homes or getaway certificates, gift baskets, and fine wines are always desirable and the proceeds go to a good cause! Mail in advance to our local parent contact or bring your item to the registration desk upon your arrival. The Raffle items and ticket baskets be out near the Registration Desk and/or Bookstore all day Saturday, and close at the Tribute Reception Saturday evening. Email jgrammer@rettsyndrome.org or call 1.800.818.RETT (7388) with questions or for mailing address. Then get ready to buy your own Raffle tickets at the Registration Desk and try your luck at winning a desirable prize!

KEEPSAKE PROGRAM JOURNAL, TRIBUTE VIDEO, PHOTO BUTTONS

- Place a special message in the IRSF 27th Anniversary Helping Hands Keepsake Program Journal in honor of the Rett angel that has touched your life. The Helping Hands Journal will be distributed at Conference, and will be downloadable from our website after conference. Tell grandparents, family members, friends, co-workers, doctors, teachers and therapists about this opportunity to write a poem, share a loving thought, a message of hope, feature a scanned picture or piece of school/artwork, and/or advertise a business - ideas are endless! Visit the website www.rettsyndrome.org/conference or contact Jenni Grammer at jgrammer@rettsyndrome.org or 1.800.818.RETT (7388) for ad rates and details. **Ads MUST be finalized by Monday, May 9, 2011.**
- Include your child in the much-anticipated Tribute Video. Email a .jpeg picture or short movie file attachment to lhayden@rettsyndrome.org with "Conference Tribute Video" in the subject line **by Monday, April 25, 2011.**
- Proudly wear a **photo button** of your child throughout the conference! Mail a 3" photo of your child to IRSF, Attn. Lisa Hayden at 4600 Devitt Drive, Cincinnati, OH 45246 or email a .jpeg to lhayden@rettsyndrome.org with "photo button" in the subject line **before Monday, May 9, 2011.** Buttons will be ready for pickup at the onsite registration desk.

DRESS

We encourage you to dress comfortably for the day sessions, and wear something a little nicer for the Saturday Tribute Reception. The weather in Boston can still be cool in the month of May, and conference room temperatures can fluctuate, so wear layers. Wear comfortable shoes - you can log miles on your feet at a busy conference. There are many historic and fun activities plus great restaurants within easy reach of the Boston Park Plaza Hotel so pack to explore the city.

SPECIAL THOUGHTS ON CHILDCARE/RESPITE

On a tender note, we must remind you that the conference sessions are for paid registered attendees only; and no children under 12 will be permitted at all in the sessions. This weekend is a fast-paced event intended to educate all attendees, provide you with an opportunity to interact with other members of the RTT community and provide some respite time away from the daily challenges of caregiving. This is hard to do if you are juggling family demands. However, we also want you to feel welcome to bring your family members to the great city of Boston. If you choose to do so, please arrange childcare in advance so you will be free to attend sessions and network with other attendees. Many couples trade off these responsibilities throughout the weekend.



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IRSF is pleased to offer limited Respite at this year's annual conference. It is sure to be something your daughters will enjoy. This will allow you to fully participate in the sessions while feeling at ease knowing your daughter is not only being well taken care of but also enjoying herself. So if you plan to attend the conference and your daughter will accompany you, consider signing her up—but be sure to act fast as space is limited.

Respite Hours:

Saturday

Block #1: 7:15 am to 12:30 pm

Block #2: 1:30 pm to 5:45 pm

Sunday

Block #1: 7:45 am to 12:30 pm

Block #2: 1:30 pm to 6:00 pm

Cost:

\$25 per block

Happenings at Respite:

The girls and women signed up for Respite will take part in several fun activities such as art activities, a visit from service dogs, story time, current and popular movie viewings, music, snacks and more! You can feel confident your daughter will receive the proper care you are looking for as IRSF has contracted with a professional agency to offer these services to you. You can feel free to stop in the Respite rooms at anytime to check on your daughter. Special diet, health and medical issues will be closely monitored.

How to Register:

Space is limited so contact Lisa Hayden today at lhayden@rettsyndrome.org or by calling 513-870-4375 during east coast business hours; you will fill out a form which will allow you to share the important information about your daughter.

Deadline is Friday, May 20 at 3:00 pm.

HOTEL/RESORT INFORMATION

The IRSF 27th Annual Conference will be held in the heart of historic Back Bay at the landmark **Boston Park Plaza Hotel**, 50 Park Plaza at Arlington Street, Boston, MA 02116. We have negotiated an incredible room rate of \$135 per night for up to 2 adults. No additional charge for children, and only \$20 additional per adult over 2 adults per room for all conference registrants, subject to availability. There is a fee for parking at the hotel, or less expensive at a few nearby garages noted below. You will find a link to resort reservations off of our website www.rettsyndrome.org/conference. ** Please note: this is a downtown historic urban area, the sleeping rooms may be smaller than what you are accustomed to, but will offer a memorable experience ** The Boston Park Plaza is a unique location that offers many special amenities, and easy access to restaurants and local historic sights. We hope you can come a little early, or stay a few extra days, to relax and explore. The Boston Park Plaza Hotel is also offering a special rate immediately before and after our conference to registered attendees only, subject to availability. Fees available on our [custom IRSF conference room reservation link](#).



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MEALS

The Continental breakfasts and Sunday lunch included with your conference registration fee will be onsite at the Boston Park Plaza. Local parents and the hotel concierge have helped us compile a list of wonderful restaurants within walking distance of the hotel from the casual and affordable to more elegant dinner dining. We would like mealtimes to be a comfortable opportunity for you to spend time with your family as well as new friends made at the conference. Please visit our website for more information www.rettysyndrome.org/conference.

TRAVEL AGENT

Maryann Sabo, a Rett syndrome parent and seasoned travel agent with Sato Travel, has attended numerous IRSF conferences. She is well-equipped to answer all of your travel questions, and we encourage you to utilize her expertise to plan your travel. She can be reached via telephone at 1-800-872-7286 or 703-931-4290 or email her at MSabo@CWTSatoTravel.com. She has access to special rates with all airline carriers and is able to customize your itinerary based upon your individual travel needs.

LOCATION

Located in the heart of the historic Back Bay district of Boston, the hotel is only 3 miles from Logan Intl airport.

DRIVING DIRECTIONS

From the West

Take the Massachusetts Turnpike (Rte. 90 East) into the city. Exit at Copley Square (22) and follow straight onto Stuart St. Follow to the 5th set of lights and turn left for the hotel.

From the North

Take Rte. I-93 South into the city. Take the Storrow Drive exit (26) off of I-93. Follow Storrow Drive and exit left at the Back Bay/Copley Exit. At lights, take left onto Beacon St, and then take an immediate right onto Arlington St. The hotel is the 2nd building on the left after the park.

From the South

Follow I-93 North towards Boston. Take the Storrow Drive Exit (26) off of I-93. Follow Storrow Drive and exit left at the Back Bay/Copley Exit. At lights, take left onto Beacon St., and then take an immediate right onto Arlington St. The hotel is the 2nd building on the left after the park.

From Logan Airport

Follow signs to Sumner Tunnel/Boston. Take the ramp onto RT-1A S/William F McClellan Hwy. Merge north onto Interstate 93 and take the Storrow Drive Exit (26). Follow Storrow Drive and exit left at Back Bay/Copley Exit. At lights, take left onto Beacon St, and then take an immediate right onto Arlington St. The hotel is the 2nd building on the left after the park.

[VIEW MAP/ MAPQUEST](#)

TRANSPORTATION OPTIONS TO/FROM LOGAN AIRPORT:

You have three options when arriving at or departing for Logan International Airport:

- **Airport Cab Service** (approx \$35-\$40 one-way) and 24-hour taxi service available at the hotel's Main Entrance



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- [Boston 's Subway: The "T"](#) - (only \$2 one-way) Hotel is literally located at the Arlington Stop (Green Line) and only 3 blocks from the Back Bay Stop (Orange Line) -a free shuttle ride from the airport to the "T", and one train transfer from Blue Line to the Green Line. Total transit time approx 30 min, easy if you are traveling light to negotiate escalators/stairs
- **Ultimate Shuttle** - (\$14+\$3 service charge, total \$17 per person) Make a reservation by calling 1.888.437.4379, or at the hotel Concierge desk. Reserve online at www.ultimateshuttle.com and enter discount code "7777" for 10% off of the \$14 fee.

PARKING

Valet Parking

The Boston Park Plaza Hotel & Towers offers valet parking for \$26 for up to 8 hours and \$44.00 per night. Valet is located at the Columbus Avenue Entrance of the hotel (between McCormick & Schmick's and Melting Pot) . For more information please visit www.ultimateparking.com

Self Parking - Motor Mart Garage

The Motor Mart Garage is located directly across the street from The Boston Park Plaza Hotel & Towers. Offering 24-hour access, visible security and a clean friendly environment. www.motormartgarage.com

Up to 1 Hour	\$8
Up to 2 Hours	\$12
2 to 3 Hours	\$16
3 to 12 Hours	\$20
12 to 24 Hours	\$31

Self Parking - Boston Common Parking Garage

Charles Street between Boston Common and Public Garden, .4 miles from Boston Park Plaza
(617) 954-2098

Email: bcbg@massconvention.com

<http://www.mccahome.com>

Weekdays

1 hr -	\$8
2 hr -	\$12
3 hr -	\$16
10 hr -	\$22
24 hr -	\$27

Enter 4pm-6am & exit by 8am - \$11

Weekends

6am-8am -	\$11
6am Sat - 8am Mon -	\$22

LOCAL ATTRACTIONS

Our wonderful Massachusetts families have suggested these fun activities for a real Boston experience. More details coming soon!

- Afternoon Tea at the Boston Park Plaza <http://www.bostonparkplaza.com/?t=s&id=2993&lang=212>



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*Tea is the new wine when it comes to Afternoon Tea at The Boston Park Plaza Hotel & Towers. The hotel is home to Tea Sommelier, Cynthia Gold, one of the few tea sommeliers in the world. Gold not only creates her own exclusive tea blends but she uses her tea as an ingredient in exclusive cocktails and recipes. Enjoy one of our special tea experiences and relax with an assortment of savory and sweet delicacies that are unique to The Boston Park Plaza Hotel & Towers. The Boston Park Plaza has turned tea into a culinary art. **Be sure to make your reservations in advance!***

- Museum of Science www.mos.org/
- Boston Duck Tours <http://bostonducktours.com>
- Samuel Adams Brewery www.samueladams.com
- John F. Kennedy Museum and Library www.jfklibrary.org
- Museum of Fine Arts www.mfa.org
- USS Constitution Museum www.ussconstitutionmuseum.org
- Boston Common, Public Garden and Swan Boats <http://www.boston-discovery-guide.com/boston-public-garden.html>
- Faneuil Hall Marketplace www.faneuilhallmarketplace.com/
- Holocaust Memorial <http://nehm.org>
- North End <http://northendboston.com>
- New England Aquarium www.neaq.org
- Children's Museum <http://bostonchildrensmuseum.org>
- Harvard Square www.harvardsquare.com
- Freedom Trail <http://thefreedomtrail.org>
- Boston Harbor Cruise www.bostonharborcruises.com
- Tour the State House <http://www.sec.state.ma.us/trs/trsbok/trstour.htm>
- Tour Fenway Park <http://boston.redsox.mlb.com/bos/ballpark/tour.jsp>
- Boston Red Sox vs Chicago White Sox Game - several families are attending the Monday night baseball game at Fenway Park on May 30. If interested, look to buy tickets in Section 160 or a nearby section to meet up with conference friends! You can purchase tickets through the Red Sox website link <http://www.ticketnetwork.com/tix/boston-red-sox-vs-chicago-white-sox-05-30-2011-tickets-1467896.aspx> or thru Ace Tickets http://www.aceticket.com/boston_red_sox_vs_chicago_white_sox_5-30/event/1021771/ (sometimes cheaper). Tickets will not be available thru IRSF but we suggest you make plans with your Rett friends, and meet beforehand.
- Out of town: Head to Salem , MA , or Rockport , MA

WEBCAST - SATURDAY SESSIONS



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For those who cannot attend the conference in Boston, or who wish to re-visit the talks after conference, **SATURDAY sessions ONLY** will be broadcast via LIVE webcast. You must register for the live streaming Saturday sessions at least 48-hours in advance, and a discount is offered for registrations before MAY 9, 2011. You may also purchase access to the on-demand replay after conference.

IRSF will email information for internet, computer and audio requirements 2-weeks prior, and the actual session link and password 2 days prior, to the email address specified at the time of registration. See website for program and session details.

Webcast Registration includes:

- (1) "virtual seat" to view live, in real-time, the conference sessions offered Saturday, May 28, 2010, between 7:30am and 6pm EASTERN time.
- Online on-demand replay of the sessions for 90 days after the conference, beginning about one week after conference
- PDF copies of Conference materials and the Helping Hands Keepsake Journal

AUDIO RECORDINGS - SUNDAY SESSIONS

Don't want be distracted by taking notes during the Sunday sessions? Want to share the full material with those back home? IRSF will audio record all Sunday sessions. Zip files of the MP3 audio recordings paired with the speaker slides (when permissible) will be available for sale through the IRSF website Store within a few weeks after conference. Sessions will be available for a per-session rate, or a discounted package for the full set.

A special bundled rate for the Saturday on-demand webcast plus Sunday audio recordings will also be available. Visit www.rettsyndrome.org/conference for more details.

QUESTIONS

If you have additional questions, please feel free to call the IRSF office at 1-800-818-RETT (7388).