



26th Annual National MPS Society Family Conference

July 26–28, 2012 • The Boston Park Plaza Hotel & Towers • Boston, MA

The National MPS Society invites you to attend the 26th Annual Family Conference, held at the Boston Park Plaza Hotel in Boston, MA. Many new features have been added to the conference, thanks to a special committee that creatively incorporated your suggestions and many more. The meeting begins Thursday evening with dinner and syndrome breakout sessions. Newly diagnosed families will join together Thursday evening with Dr. Joseph Muenzer and Dr. Kimberly Frye for an overview of the diseases and to share their experiences and strategies about coping.

On Friday morning and Saturday the latest medical knowledge, research updates and potential therapies will be presented, along with smaller workshops on specific topics. Lunch with the Experts will be held on Friday—an opportunity for a small number of parents to talk with a variety of MPS experts. Friday afternoon will be free to enjoy all that Boston has to offer. Be sure to stop back at the hotel for the ice cream social before heading out for the evening. The 2012 walk/run and fundraiser organizers are invited to attend a Society sponsored dinner on Friday. On Saturday afternoon, representatives from BioMarin, Genzyme and Shire will present information about treatments, natural history studies and clinical trials. Prior to the conference beginning, the board of

directors will meet at 8:00 a.m. on Thursday, July 26; Society members are welcome to attend.

As always, there is no registration fee for individuals with MPS and related diseases, and complimentary childcare will be provided Thursday evening for the syndrome breakout sessions and for the educational sessions Friday morning and all day Saturday.

Please consider attending the annual meeting of the National MPS Society and learn more about its activities. For more information, visit www.mppsociety.org. Call Laurie Turner

at 207.843.7040 with questions or send an e-mail to laurie@mpssociety.org.

Hotel and conference registration deadlines are June 25, 2012.

ACCOMMODATIONS

The Boston Park Plaza Hotel & Towers
50 Park Plaza at Arlington St.
Boston, MA 02116-3912
617.426.2000
800.225.2008
www.bostonparkplaza.com

Located just three miles from Logan International Airport, The Boston



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THURSDAY, JULY 26

5:00 p.m. – 9:00 p.m.	Registration
5:00 p.m. – 7:00 p.m.	Welcome buffet dinner
6:45 p.m.	Camp Courage opens
7:00 p.m. – 9:00 p.m.	Syndrome breakout sessions
9:15 p.m.	Camp Courage closes

For Newly Diagnosed Families

5:00 p.m. – 6:00 p.m.	Registration and dinner for newly diagnosed families
5:45 p.m.	Camp Courage opens for families attending the newly diagnosed session
6:00 p.m. – 7:30 p.m.	<i>Overview of MPS and Related Diseases</i> , Dr. Joseph Muenzer
7:30 p.m. – 9:00 p.m.	<i>Coping with MPS and Related Diseases</i> , Dr. Kimberly Frye and Nicole Shannon, LCSW

FRIDAY, JULY 27

7:30 a.m. – 9:00 a.m.	Continental breakfast
8:30 a.m.	Camp Courage opens
8:45 a.m. – 9:00 a.m.	Welcome
9:00 a.m. – 9:45 a.m.	<i>IEPs and Navigating the Educational System</i> , Lillian Wong, JD
9:45 a.m. – 10:00 a.m.	<i>One Family's Experience</i>
10:00 a.m. – 10:30 a.m.	Fundraising workshop
10:30 a.m. – 11:00 a.m.	Break
11:00 a.m. – 11:30 a.m.	<i>Ophthalmology issues in MPS</i> , Dr. Roberto Pineda
11:30 a.m. – 11:45 a.m.	<i>One Family's Experience</i>
11:45 a.m. – 12:00 p.m.	Legislative workshop
12:00 p.m. – 12:30 p.m.	<i>Taking Care of the Caregiver</i> , Dr. Kimberly Frye
12:30 p.m.	Remembrance ceremony
12:45 p.m.	Camp Courage closes
6:30 p.m. – 8:30 p.m.	Thank you dinner for fundraiser and walk/run hosts

Friday afternoon and evening are free to enjoy Boston.

Optional Friday events: *require signup*

1:00 p.m. – 2:30 p.m.	Lunch with the Experts
4:00 p.m. – 5:00 p.m.	Ice cream social

SATURDAY, JULY 28

7:30 a.m. – 9:00 a.m.	Continental breakfast
8:30 a.m.	Camp Courage opens
9:00 a.m. – 9:45 a.m.	<i>Management of MPS and Related Diseases</i> , Dr. Joseph Muenzer
9:45 a.m. – 10:15 a.m.	<i>Orthopaedic Issues</i> , Dr. William Mackenzie
10:15 a.m. – 10:30 a.m.	<i>One Family's Experience</i>
10:30 a.m. – 11:00 a.m.	Break
11:00 a.m. – 11:15 a.m.	<i>Coping in Fathers of Children with MPS</i>
11:15 a.m. – 11:30 a.m.	<i>Treatment of Bone Disease</i> , Dr. Calogera Simonaro
11:30 a.m. – 12:00 p.m.	<i>Research Update</i> , Dr. Steven Walkley
12:15 p.m.	Camp Courage closes
12:30 p.m. – 1:30 p.m.	Box lunch and annual general membership meeting of the National MPS Society
1:45 p.m.	Camp Courage opens
2:00 p.m. – 4:00 p.m.	Sibling Working I, ages 7–11 Sibling Workshop II, ages 12–17
2:00 p.m. – 4:00 p.m.	Concurrent Sessions <ul style="list-style-type: none">• Ancillary Therapies• Behavioral Management• Marriage and Family• IEPs• Telling Your Story & Asking for What You Want
4:00 p.m. – 5:00 p.m.	Treatment and Clinical Trial Updates <ul style="list-style-type: none">• BioMarin• Genzyme• Shire
5:15 p.m.	Camp Courage closes
5:30 p.m. – 6:30 p.m.	Social hour
6:30 p.m. – 9:00 p.m.	Awards banquet

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Park Plaza Hotel & Towers is steps away from the nation's first public parks, the beautiful Boston Common & the Public Garden. The hotel is easily accessible to shopping along world-renowned Newbury Street, Faneuil Hall Marketplace, the theatre and financial districts, and Boston's historic landmarks. Boston Park Plaza Hotel is the city's premier dining destination.

Room features:

- In-room dining
- 100 percent non-smoking hotel
- Pet friendly
- 24-hour valet parking
- In-room safes; can accommodate most laptop computers
- Iron and ironing boards
- Electronic key system; guest rooms equipped with additional locks
- New Simmons Beautyrest pillowtop mattresses
- Coffee maker
- Desk, sizable work space and ergonomic chair
- Hair dryer
- Voicemail
- Wireless high-speed Internet (for additional cost)
- State-of-the-art climate control system

To book your room: Call The Boston Park Plaza Hotel & Towers at 617.426.2000 (local) or 800.225.2008 (toll-free) and reference the National MPS Society. A major credit card is required at the time of making a reservation to guarantee the reservation. The guaranteed room rate of \$159 per night, single or double occupancy, will be honored **until June 25, 2012, or until the Society's room block is filled.** The total amount per night with tax is \$182. After June 25, room rates will increase. You may reserve rooms at the \$159 per night group rate for three days before June 25 and three days after June 28, *based upon availability.*



We encourage you to book hotel rooms for your complete stay as soon as possible to ensure you will be guaranteed a room at The Boston Park Plaza Hotel & Towers at the special rate.

DINING

Across the street from the hotel is a food court with multiple fast food choices, and The Boston Park Plaza Hotel offers eight restaurants and lounges on site, including:

- McCormick and Schmick's—seafood.
- Smith & Wollensky—steakhouse located in a historic stone and brick "castle" built in 1891.
- Au Bon Pain—fresh salads and sandwiches for dine-in or takeout.
- The Melting Pot—fondue restaurant.
- Statler's Lounge—classic piano bar setting featuring vintage cocktails and casual fare.
- Finale—sensational desserts.
- MJ O'Connor's—eclectic Irish food and spirits.
- Pairings—contemporary American Cuisine designed for sampling and sharing with an extensive list of wines and creative cocktails.

GETTING TO THE BOSTON PARK PLAZA HOTEL & TOWERS

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 fifth set of lights and turn left for The Boston Park Plaza Hotel.

From the North: Take Route I-93 South into 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



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Beacon St., then make an immediate right onto Arlington St. The Boston Park Plaza Hotel is the second building on the left after the park.

From the South: Follow I-93 North toward 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 make an immediate right onto Arlington St. The Boston Park Plaza Hotel is the second 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 make an immediate right onto Arlington St. The Boston Park Plaza Hotel is the second building on the left after the park.

AIRPORT TRANSPORTATION

From Logan Airport:

- Airport cab service (meter rate); estimated one-way fare is \$25–\$30.
- Boston's subway (The "T")—The Boston Park Plaza Hotel is located on Arlington Stop (Green Line) and Back Bay Stop (Orange Line). The hotel is one block from the Arlington T Stop off of the Green Line and three blocks from the Back Bay T Stop off of the Orange Line.
- Ultimate Shuttle (888.437.4379, www.ultimateshuttle.com)—\$17 each way per person.

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