

<u>WELCOME</u>

Every other year, this symposium is presented and hosted in a new country, and we are thrilled to welcome the global community to the United States. Though MPS and related diseases are rare, together we can make a difference. Each country works hard to provide resources for MPS patients and families, but as a global community, our impact is much more significant. This is an exclusive opportunity for us to learn, share and experience MPS and related diseases on a larger scale.

At the symposium, you can expect to see everything from workshops geared toward best practices in MPS care to the latest advances in research from around the globe. The symposium will feature scientific and family focused tracks to meet the needs of all attendees. We will also be treating our children and siblings to a full schedule of exciting activities and experiences to keep them happy and engaged throughout the conference.

This symposium is an opportunity for the MPS and related diseases community to share and exchange new information, learn about new breakthroughs in science and medicine, and develop strategies to keep us moving forward. As we look to an exciting future filled with opportunities on a global scale, we thank you for your hard work and dedication to eradicating these diseases and welcome you to the 15th International Symposium on MPS and Related Diseases.

REGISTRATION INFORMATION AND RATES

Rates:

Children and adults with MPS and ML are free.

Early Bird (before Apr. 21)

Adult (18+): \$275 Child (3-17): \$125

Regular (Apr. 21-July 18) Adult (18+): \$325 Child (3-17): \$175

On-site (After July 18)

Adult (18+): \$375 Child (3-17): \$225

<u>HOTEL</u>

Sheraton San Diego Hotel & Marina 1380 Harbor Island Drive San Diego, CA 92101, USA

Hotel rooms in the conference tower have been reserved for attendees. Check in: 3 p.m. Check out: Noon

How to reserve a room:

Book online or call 877-734-2726. Reference the MPS 2018 conference in order to receive the group rate. All reservations must be made by July 9 in order to receive the rate.

Rate and amenities:

\$214 per night, plus tax (currently at 12.7%) At the time of reservation, a deposit in the amount of one night's stay plus tax will be collected by credit card to confirm your booking.

Group rate includes:

Complimentary wireless internet in your guestroom, access to the fitness

<u>AIRPORT INFORMATION</u>

San Diego International Airport 3225 N Harbor Drive San Diego, CA 92101 Airport Code: SAN

Sheraton San Diego Hotel & Marina is located less than 1 mile from the San

<u>One-day</u>

Adult (18+): \$250 Child (3-17): \$125

Visit mps2018.

com to register for the conference, or scan the QR code above with your mobile device.

Included with full conference registrations:

Educational sessions

- Exhibit hall
- Breakfast and lunch Friday and Saturday
- Welcome reception (Thursday)
- Banquet dinner (Saturday)

Limitations:

Saturday one-day only registration does not include banquet dinner and awards. The Saturday banquet dinner needs to be purchased separately. The cost to attend the banquet dinner and awards is \$155.



center, complimentary shuttle to/ from SAN airport (ADA accessible)

Resort Fees:

The optional resort fee is \$26 (including applicable tax), and includes local and long-distance calls, access to tennis facilities and one-hour bicycle, kayak or stand-up paddleboard rental per day.

Cancellation Policy:

All hotel room cancellations must be made 72 hours prior to check in. If you do not cancel your reservation



72 hours prior, you will lose your deposit.

Hotel Parking:

Overnight self-parking is \$32 and overnight valet parking is \$37 per night.

Diego International Airport.

Ground Transportation from Airport

The Sheraton San Diego Hotel & Marina offers complimentary airport shuttle to/from the San Diego International Airport and runs daily from 4:45 a.m. to midnight.

The hotel shuttle is ADA accessible. Please be sure to contact the hotel at 619-291-2900 when you land to inform the hotel you have arrived and require an ADA accessible van.

15TH INTERNATIONAL SYMPOSIUM ON MPS AND RELATED DISEASES

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<u>AGENDA</u>

Agenda is subject to change. For the most up to date agenda, please visit mps2018.com.

15th ANNUAL INTERNATIONAL SYMPOSIUM

ON MPS AND RELATED DISEASES

August 1-4, 2018 · Sheraton San Diego Hotel & Marina · San Diego, CA

WEDNESDAY, AUGUST 1

5 p.m.-8 p.m. Registration

THURSDAY, AUGUST 2

7 a.m. – 7 p.m. Registration

7:30 a.m. – 2 p.m. Optional Event (\$50) San Diego Zoo (includes breakfast and lunch)

2:45 p.m. Camp Courage Opens

3 p.m. - 3:30 p.m. Break and Exhibitor Session

3:30 p.m. – 4 p.m. Opening Plenary and Welcoming Address: Known and Unknown Elements of MPS and other LSDs

4 p.m.–5 p.m. Keynote Speakers: Future for MPS Research and Drug Development

5 p.m. – 5:30 p.m. Break and Exhibitor Session

5:30 p.m. – 7 p.m. Key Insights into Disease Pathogenesis, Importance for MPS Societies Involvement, Patient Centered Care, Newborn Screening

7 p.m. Camp Courage Closes

7 p.m. – 9 p.m. Welcome Reception Dinner

FRIDAY, AUGUST 3

7 a.m. – 8 a.m. Breakfast

7 a.m. – 6 p.m. Registration

7:45 a.m. Camp Courage Opens

8 a.m. – 8:30 a.m. Opening Session: Clinical Management I

8:30 a.m. – 9:30 a.m. Neurological and Behavioral Manifestations of MPS

9 a.m. – 5 p.m. Exhibitor Hours

9:30 a.m. – 10 a.m. Break and Exhibitor Session

10 a.m.–12 p.m. Clinical Management II: Anesthesia, Bone Disease, Cardiac, Neurologic Conditions

12 p.m. Camp Courage Closes

12 p.m.-1 p.m. Lunch

12:45 p.m. Camp Courage Opens

1 p.m. – 2:30 p.m. Management II: Next Generation Treatments, Combination Therapies, and Advancing Clinical Trials

2:30 p.m. - 3:30 p.m. Break and Exhibitor Session

3 p.m. – 5 p.m. Management: Continued Gene Therapies, Transitioning to Adulthood

5:15 p.m. Camp Courage Closes

5:30 p.m. – 9 p.m. Boat Cruise for Adults with MPS and Related Diseases

SATURDAY, AUGUST 4

7 a.m. – 8 a.m. Breakfast

7 a.m. – 5 p.m. Registration

7:45 a.m. Camp Courage Opens

8 a.m. – 9:30 a.m. Opening Session: Importance of Research and Advocacy Group Collaboration

9:30 a.m. – 10 a.m. Break and Exhibitor Session

10 a.m.–12 p.m. Management and Research Updates: Pentosan Polysulfate/Genestein, Future for HSCT in MPS I, Managing Pain and Anxiety

12 p.m. Camp Courage Closes

12 p.m.-1 p.m. Lunch

12:45 p.m. Camp Courage Opens

1 p.m. – 3 p.m. Charting New Science in MPS Research Presentations

3 p.m. – 4 p.m. Writing our Future for MPS and Related Diseases and Ultimate Advocacy

4 p.m. – 5 p.m. Remembrance Ceremony

5:15 p.m. Camp Courage Closes

6:30 p.m. Banquet Dinner and Awards

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15TH INTERNATIONAL SYMPOSIUM ON MPS AND RELATED DISEASES



FAMILY AND ADULT EVENTS

Adult Cruise

On this adults only outing you will cruise San Diego Bay on the beautiful Admiral Hornblower. Enjoy dinner, entertainment and catching up with old friends and making new ones. This is your conference; this is your special night!

Admission is free for adults (18 years or older) with MPS or a related disease. Adults are welcome to bring a significant other or aide for no additional charge. However, please note that adults are limited to one guest for this event. The event is free, but you must register for the event in order to attend.



San Diego Zoo Outing

Located in Balboa Park, the San Diego Zoo is the largest and most progressive zoo in the world, with more than 4,000 animals and more than 800 species. It is also one of the few zoos in the world that houses the giant panda. On August 2 from 7:30 a.m. to 1:30 p.m., all MPS 2018 attendees can take a trip to the San Diego Zoo. Tickets are \$50 a person.

You must register and pay for the event in advance in order to attend. There will be an MPS representative on site for assistance with this outing.

Price includes:

- Transportation to/from the zoo from conference hotel
- Breakfast buffet at the San Diego Zoo
- Private animal presentation
- · Zoo admission
- Lunch voucher

<u>CAMP COURAGE</u>

Camp Courage is open to children, ages 3 to 17 years old attending the conference. This includes children with MPS and related diseases, as well as siblings or other family members. If you have a child over 17 and would like to include them in Camp Courage, please email debra@sswmeetings. com after registration is complete. Parent orientation will be held on August 2, from 2 to 3 p.m. to meet staff, answer questions and verify the accuracy of all registration information submitted by attendees. Rules and regulations for Camp Courage are coming soon. An agenda for Camp Courage will be

available in April.



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