



33RD ANNUAL NATIONAL MPS SOCIETY  
**FAMILY CONFERENCE**

DEC. 19–21, 2019 • ORLANDO, FL

**45<sup>th</sup>**  
ANNIVERSARY  
1974–2019



# WELCOME

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Our Disney Conference planning starts now! I am excited to announce that registration is open for the 33rd Annual Family Conference in Orlando, Florida. Traditions are cherished at the National MPS Society and every fifth year we celebrate at Disney. Our conferences provide key opportunities to engage with families, physicians, and researchers. I am confident you will go home with new resources and meaningful support that will sustain you in your daily life.

You will have time to relax with meals provided, claim a spot at the Destination Disney 5K Run and memorial walk, enjoy Camp Courage with the return of Coach Jerry, and celebrate the 45th anniversary of the National MPS Society during our Friday family banquet. Also, you can participate in these important initiatives: blood spot collection, the ConnectMPS Registry, and actively sign up to volunteer with committees that need your help!

We take our members' feedback seriously and have included sessions this year based on your requests. Conference sessions include: clinical trials, gene therapy updates, scientific panel discussions, syndrome breakouts, management of late onset MPS symptoms, holistic therapies, and more. This two-day conference will cover many topics that will heighten your experience.

In 2011, when our son Jack was diagnosed with this devastating disease, we found both comfort and priceless education at our first conference. We learned valuable information on how to navigate the MPS II environment with access to ERT and how to identify Jack's future critical care needs. We made lifelong friends and gained a support system like nothing else. If this will be your first time attending, I know your family will experience this, too. If your family has attended our conferences in the past, we hope to see you again! The National MPS Society's Disney conference draws more than 700 families, researchers, and physicians. We hope you join us for this exceptional event and for the chance to grow your "family" exponentially overnight!

I look forward to our time together, sharing all the wonderful news about innovations and research at the conference, and helping empower your family to become the strongest advocates you can be in the MPS and ML community. Science is changing the future for those living with these rare diseases. As we explore all these new opportunities, let us walk this journey together. I can't wait to see you this December in Orlando!



Lisa P. Todd  
*Chairman, Board of Directors*



## REGISTRATION & FEES

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Register online at [www.etches.com/mps2019](http://www.etches.com/mps2019)

### NATIONAL MPS SOCIETY MEMBERS

**Adult (age 13+)** \$250  
**Child (age 3-12)** \$100  
**Child (age 0-2)** no charge  
**Individual with MPS or ML** no charge  
**Professional** \$350

### NON-MEMBERS

**Adult (age 13+)** \$300  
**Child (age 3-12)** \$150  
**Child (age 0-2)** no charge  
**Individual with MPS or ML** no charge  
**Professional** \$450

# ACCOMMODATIONS



## HILTON ORLANDO LAKE BUENA VISTA

1751 Hotel Plaza Blvd.  
Lake Buena Vista, FL 32830  
407.827.4000

Hilton Orlando Lake Buena Vista is set on 23 beautifully landscaped acres in the Walt Disney World® Resort. Just across from the new pedestrian sky bridge sits beautiful Disney Springs™ with all new shopping, entertainment, and dining experiences. The hotel is a quick walk to Disney Springs™ (with access to ADA elevators taking you to the sky bridge), and only a 10-minute bus or car ride to Epcot Center and 20 minutes to the Magic Kingdom. This location is also close to Universal Studios and SeaWorld.

The hotel will provide transportation to Walt Disney World Parks via Disney Lines Bus Transportation. Loading for the buses is every 20 minutes from the side doors of the hotel lobby. There are some ADA tie-down buses every hour. In addition, the Hilton is located 20 minutes from Orlando International Airport (MCO).

## ROOM FEATURES

Guest rooms are fully renovated and feature refrigerators, dual-line phones, PURE allergy friendly air filtration, coffeemaker, shower chairs on request, and WiFi access (free standard WiFi for Hilton Honors members). Handicap accessible rooms are available.

## PARKING

**Self parking—conference event days (Thursday and Friday)**  
\$10/day (24 hours)

**Self parking—nonconference event days**  
\$18/day (24 hours)

**Valet parking**  
\$24/day (24 hours)

## TO BOOK YOUR ROOM

To book your room by phone, call 407.827.4000 and reference the group code “MPS.” To book online, visit <https://book.passkey.com/go/NationalMPSSociety>.

The guaranteed room rate is \$149 per night at the single/double/triple/quad occupancy. The total amount per night, with tax, is \$167.63.

These rates will be honored until Nov. 27, 2019, or until the National MPS Society’s room block is filled. After Nov. 27, the room rate will increase or may not be available. For those arriving early or staying later, group rates start as early as Dec. 16 and extend until Dec. 23, based on availability. We encourage you to book your hotel room as soon as possible to ensure you will be guaranteed a room at the Hilton Orlando Lake Buena Vista.

## ONSITE DINING

**24-hour Mainstreet Marketplace**—a variety of options for breakfast, lunch, dinner, snacks, and Starbucks Coffee

**Andiamo Italian Bistro & Grille**—authentic Italian specialties with a variety of steak, seafood, and homemade pasta selections

**Benihana**—Japanese cuisine, sushi

**Covington Mill**—meet your favorite Disney characters on Sunday during breakfast

**John T’s**—TV and refreshments

## GETTING TO THE HILTON ORLANDO LAKE BUENA VISTA

### From the Airport (Orlando International Airport—MCO)

Take Highway FL-528 W/FI-528 Toll W to Exit 68, Highway I-4W. Take Highway I-4W to Hotel Plaza Blvd. Follow signs to Disney Springs™. The Hilton Orlando Lake Buena Vista is located across the street from Disney Springs™.

Available transportation to and from the airport (located near baggage claim):

- The Hilton Orlando Lake Buena Vista does **NOT** have a shuttle.
- Taxi service—approximately \$40–\$45/one way
- Uber service—price to be determined
- Mears Transportation: \$23/passenger one way; \$37/passenger round-trip. Reservations for round-trip can be made at baggage claim. Mears Transportation is a ride-share transportation and requires one hour to take your family to the Hilton Orlando Lake Buena Vista. For more information, contact Mears Transportation at [www.mearstransportation.com](http://www.mearstransportation.com).

# SCHEDULE

## THURSDAY, DEC. 19

8:00 am – 12:30 pm	Board of directors meeting
11:00 am – 1:00 pm	Adults with MPS and ML meet and greet
12:00 pm – 5:00 pm	Registration open
<b>12:30 pm – 4:30 pm</b>	<b>Camp Courage open</b>
1:00 pm – 2:00 pm	<i>Opening Plenary Session—MPS &amp; ML</i>
2:00 pm – 2:30 pm	<i>Science Today—Emerging Therapies</i>
2:30 pm – 3:00 pm	<i>Gene Therapy and Gene Editing Overview</i>
3:00 pm – 3:30 pm	Research update
3:30 pm – 4:15 pm	Scientific panel
4:15 pm – 4:30 pm	Research grant awardee presentation
<b>4:30 pm</b>	<b>Camp Courage closes</b>
4:30 pm – 6:00 pm	Welcome buffet dinner
4:30 pm – 6:00 pm	Newly diagnosed family dinner (diagnosed in the last 12 months) <i>Overview and Coping with MPS and Related Diseases</i>
6:00 pm – 6:15 pm	Remembrance ceremony—outdoor garden
<b>6:15 pm – 9:40 pm</b>	<b>Camp Courage open</b>
6:30 pm – 8:00 pm	Syndrome breakout sessions
8:15 pm – 9:30 pm	Targeted breakout sessions (moms, dads, siblings [7:00 – 8:00 pm ages 6-11; 8:00 – 9:00 pm ages 12-18], grandparents)
8:15 pm	Adults with MPS and ML networking
<b>9:40 pm</b>	<b>Camp Courage closes</b>

## FRIDAY, DEC. 20

6:30 am – 7:45 am	Grab-and-go breakfast, board buses to Destination Disney 5K Run/Walk
8:00 am – 11:00 am	Destination Disney 5K Run/Walk, Memorial Walk, Celebration Lunch, entertainment
10:00 am	Awards and sponsor recognition
11:10 am	Board buses back to Hilton; return to conference sessions
<b>11:45 am – 5:35 pm</b>	<b>Camp Courage open</b>
12:15 pm – 12:45 pm	<i>Advocacy and Newborn Screening—How to Unravel the Message</i>
12:45 pm – 1:30 pm	<i>Orthopedics for MPS and ML</i>

1:30 pm – 2:15 pm	<i>Neurocognitive Function in MPS/ Neurobehavioral Symptom Management</i>
2:15 pm – 2:45 pm	<i>Corneal Transplants—Issues of the Eye</i>
2:30 pm – 2:45 pm	<i>Health Break</i> (runs concurrently)
2:45 pm – 3:45 pm	<i>Treatment and Clinical Trial Updates—Industry</i> (six 10-minute sessions)
4:00 pm – 5:30 pm	Concurrent Sessions (45-minute rotating sessions) <ul style="list-style-type: none"><li>• <i>Navigating Complexities of Clinical Trials</i></li><li>• <i>Habits of Emotionally Resilient People</i></li><li>• <i>Navigating SSI and Medicaid</i></li><li>• <i>Genetic Testing/Family Planning</i></li><li>• <i>Holistic Care for Your Family</i></li></ul>
<b>5:35 pm</b>	<b>Camp Courage closes</b>
6:30 pm	45th anniversary banquet celebration and awards
8:30 pm	Sibling outing to Disney Springs

## SATURDAY, DEC. 21 (SPIRIT ATTENDEES ONLY)

8:30 am – 3:00 pm	SPIRIT conference for adults with MPS and ML <i>Strength-Purpose-Independence-Resilience and Initiative Together</i>
8:30 am – 9:30 am	Breakfast (SPIRIT only)
9:30 am – 12:00 pm	Meeting ( <i>Optimal Living; Breaking Psychosocial Barriers; Navigating SSI, Medicaid, and Health Insurance</i> )
12:00 pm – 1:00 pm	Lunch (SPIRIT only)
1:00 pm – 3:00 pm	Meeting ( <i>Adult Transitions; Being Your Best Personal Advocate</i> )



# SCHOLARSHIPS

The National MPS Society is pleased to offer scholarships to its 33rd Annual Family Conference. Scholarships will be awarded to a parent or legal guardian of a child with MPS or ML.

Adults with MPS or ML ages 18 and up, please refer to the SPIRIT scholarship program for this conference at [www.etches.com/2019spirit](http://www.etches.com/2019spirit).

Scholarships will help enable families to attend the conference who are otherwise not financially able to do so. Preference is given to families attending a conference for the first time. The exact number of scholarships offered will be determined by the requests received and the financial needs of the applicants.

Family Conference Scholarships can be allocated to one adult conference registration (valued at \$250), hotel (maximum of two nights, valued at \$335.26), and travel reimbursements (maximum of \$500).

## APPLICATION CRITERIA

- Member of the National MPS Society, with membership updated for 2019.
- Parent or legal guardian of a child with MPS or ML.
- Application must be completed electronically using online application program.
- Applicant must provide a statement indicating why they want to attend the conference and how they or their family may benefit.
- Application must be completed and submitted electronically **no later than July 20, 2019**.

To apply for a scholarship, go to <https://mps.onlineapplications.net/applications/>. If you are a first-time user, click on "Register Now" to set up an account. Once you are logged in, open the 2019 Conference Scholarship Application. If you are a returning user, simply log in and apply.

*Scholarship awards will be announced in late August.*



# DESTINATION DISNEY

## MPS 5K RUN/WALK

Join us for a day of fun in Orlando! The Destination Disney MPS 5K Run/Walk & Memorial Walk will be held Friday, Dec. 20 at 8:30 am. The event will feature a special one-mile memorial walk, chip-timed 5k run, and awards for several categories with lunch to follow. Buses will be available to and from the venue from 7 am to 12 pm. Race packet pickup is available Dec. 19 from 3 to 7 pm at the conference registration area. Packets will also be available on race day.

### SCHEDULE

- 7:30 am Registration opens
- 8:30 am 5K chip-timed run
- 8:45 am One-mile memorial walk
- 10:00 am Race and Courage Awards



**2019 National MPS Society 5K Run/Walk**



### REGISTER, BUILD A TEAM AND RAISE FUNDS ONLINE

Register online at:

<http://support.mpssociety.org/orlando5k>

\$20 early bird individual 5k run registration

\$60 early bird family of four 5k run registration

\$10 registration one-mile memorial walk

\$25 day of event 5K individual registration

\$80 day of event family of four 5K registration

### SPONSORS

BioMarin, Sangamo Therapeutics, Sanofi Genzyme and Takeda

### CONTACT

Brian Buechler, Race Director  
[brian@mpssociety.org](mailto:brian@mpssociety.org)