



36TH ANNUAL FAMILY CONFERENCE  
**Nashville, TN**  
AUGUST 4-6, 2022



# WELCOME

**We invite you to join us in Music City!** I am excited to announce that registration is open for the National MPS Society's 36th Annual Family Conference in Nashville, Tennessee. We will join in person once again, for unique opportunities to celebrate and learn together. 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 carry you in your journey.

The conference provides countless opportunities to meet families in various breakout sessions, engage with physicians and researchers from around the world, and participate in educational conference sessions. You will have time to relax with conference meals provided, run or walk at our Rock and Roll 5K event, enjoy Camp Courage for children, and celebrate coming together at the family banquet. Throughout the conference, there will be opportunities to engage with others, participate in critical initiatives, visit booths, and more. We will also have key educational opportunities regarding clinical trials, including updates on gene therapy and other clinical trials. We are in a new age of scientific discovery and clinical options for our families, and our conference is a great way to remain up to date on these breakthroughs.

In 2011, when our son Jack was diagnosed with this devastating disease, we found both comfort and priceless education at our first conference. Our first conference provided us with critical resources for Jack's continued care and therapy. We learned valuable information on how to navigate the MPS II environment, access treatment options, and how to assist Jack in receiving needed care. We made lifetime 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! Your "family" will grow exponentially overnight, and we welcome you.

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 MPS and ML. As we explore all these new opportunities, let us walk together on our journey. I can't wait to see you this August in Nashville.



Lisa P. Todd  
Chairman, Board of Directors



## REGISTRATION & FEES

Register online at [na.eventscloud.com/ehome/mps2022](https://na.eventscloud.com/ehome/mps2022)

### National MPS Society Members

**Adult (age 13+)** \$200

**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



### COVID-19 Protocols

The National MPS Society will adhere to recommendations by the Centers for Disease Control (CDC), state and local health authorities, and the Sheraton Music City Hotel at the time of the conference. Conference attendees will be informed of specific protocols (as applicable) prior to the event.

# ACCOMMODATIONS



## Sheraton Music City Hotel

777 McGavock Pike, Nashville, TN 37214  
615.885.2200



Sheraton Music City Hotel provides an authentic southern experience with elegant mansion-style décor nestled on 25 beautifully landscaped acres and just minutes from downtown Nashville. From the Grand Ole Opry, museums, and the natural beauty of the Cumberland Plateau, there are many sites to visit. The area is teeming with fun and exciting locations to share with friends and family.

The hotel also features both an indoor and beautiful outdoor expansive pool and patio area, fitness center, comfortable oversized guest rooms, and private balcony or patio for leisure. The Nashville International Airport (BNA) is only five minutes away via a complimentary shuttle service, roundtrip to the hotel.

## Room Features

Guest rooms and expansive lobby have been renovated and feature dual-line phones; high speed wired and wireless internet; access to private balcony or patio in all guestrooms; in-room coffee and tea; sweet sleeper bedding; hypoallergenic feather-down pillows; same day cleaning, dry cleaning, and laundry service; ironing board; TV; and deluxe bath amenities. Handicap accessible rooms are available. Refrigerators upon request.

## Parking

**Hotel stay—Free Parking** for those who stay at Sheraton Music City Hotel on conference days (Thursday, Friday, and Saturday)

**Non-Hotel Stay Self-parking—conference event days (Thursday, Friday, and Saturday)**

Valet only \$20/day

## Onsite Dining

**Old Hickory Grill**—Great upscale southern cooking is served, with deli options to choose from as well. Kick back with your favorite beverage on the veranda outdoors.

## To Book Your Room

The National MPS Society is excited to share that **ONE NIGHT** of your conference experience will be on us! Eligible days are **August 4–6**; simply reserve your room and register for the conference by **July 1st** to receive your complimentary night!

To receive your complimentary night:

- To qualify, registrant must be a parent, legal guardian, or adult with MPS or ML.
- Registration to the conference must be completed prior to or on July 1.
- Hotel reservations must be completed prior to or on July 1.
- Complimentary night applies to one room only.
- Complimentary night may only be applied to stays at Sheraton Music City Nashville August 4–6.
- This offer is limited and will be granted on a first-come, first-served basis.
- The maximum value of this offer is \$185.75 per registrant's room.

To book your room by phone, call 615.885.2200 and reference the group code “National MPS Society.”

To book online, visit <https://book.passkey.com/go/MPSSociety>.

The guaranteed room rate is \$159 per night at the single/double/triple/quad occupancy. The total amount per night, with tax and fees is \$185.75.

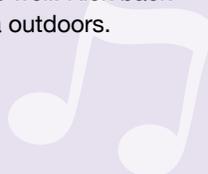
These rates will be honored until July 1, 2022, or until the National MPS Society's room block is filled. After July 1, the room rate will increase or may not be available. Attendees may book up to three days prior to the conference and up to three days following the conference for the same rate, subject to availability. We encourage you to book your hotel room as soon as possible to ensure you will be guaranteed a room at the Sheraton Music City Hotel Nashville.

## Getting to the Hotel

The Nashville International Airport (BNA) is located 3.5 miles from the Sheraton Music City Hotel. There is a free shuttle to and from the airport. Private transportation services (taxis, Uber, Lyft, and wheelchair-accessible ride services) are available to arrange. A bus station and Music City Circuit stop are located nearby. On-site parking is complimentary for registered conference attendees staying at the hotel.

### From the airport

- Get on Donelson Pike from Terminal Drive (1.0 miles)
- Follow Donelson Pike to Royal Parkway (0.8 miles)
- Continue on Royal Parkway (1.7 miles)
- Turn onto McGavock Pike



# SCHEDULE

## Thursday, Aug. 4

- 7:00am – 2:00pm** **Board of Directors Meeting—open to visitors**
- 2:00pm – 8:00pm** **Registration Opens**
- 3:00pm – 3:30pm Opening Keynote
- 3:30pm – 4:00pm Science Overview
- 4:00pm – 5:00pm Newborn Screening and Advocacy
- 5:00pm – 6:00 pm Foundations Roundtable
- 6:00pm – 7:30pm** **Welcome Buffet Dinner**
- 7:30pm – 9:30pm All Syndrome Breakouts/  
Family Breakouts

## Friday, Aug. 5

**7:00am – 8:00am** **Breakfast Buffet**

### **SESSION I—MPS and ML Management and Care**

- 8:00am – 8:30am Overview of MPS & ML
- 8:30am – 9:30am Orthopedics
- 9:30am – 10:00am Airway and Anesthesia
- 10:00am – 10:30am Pulmonology
- 10:30am – 11:00am Fundraising
- 11:00am – 12:00pm Neurocognitive Considerations

**Noon – 1:00pm** **Lunch Buffet**

### **SESSION II—Patient and Family Warriors**

- 1:00pm – 1:45pm Adult Panel Discussion
- 1:45pm – 2:30pm Sibling Panel Discussion

### **SESSION III—Translational Dialog with Key Stakeholders**

- 2:30pm – 3:15pm FDA Presentation
- 3:15pm – 5:30pm Industry and Clinical Trial Updates

**6:30pm** **Nashville Night on Your Own—  
(Buses travel back and forth  
until 11pm)**

## Saturday, Aug. 6

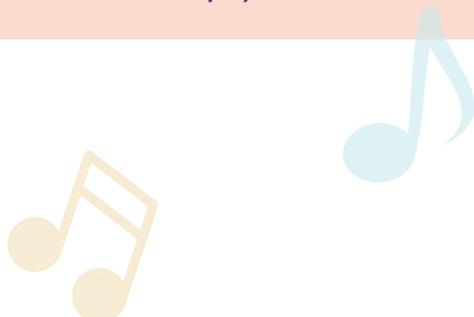
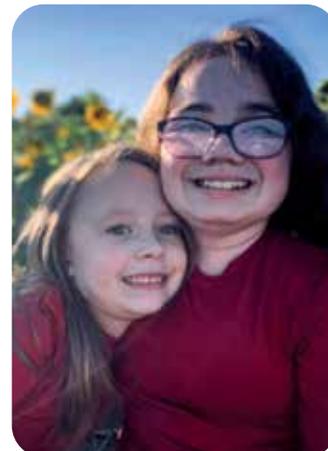
*(Science Sessions/Research Presentations will run concurrently after 12pm)*

- 7:00am – 7:45am** **Grab-n-Go Breakfast, Board Buses to Nashville MPS 5K Run**
- 8:30am – 11:00am** **Nashville MPS 5K Run, Memorial Walk, Celebration Lunch & Entertainment**
- 11:00 – 11:30am** **Board Buses back to Sheraton, Return to Conference sessions**

### **SESSION IV—Scientific Conference**

*Open Syndrome Conversation Rooms available from 12–1pm and 4–5pm*

- 12:00pm – 5:00pm Scientific Conference
- Society-Sponsored Research Reports
  - Navigating Therapies and Clinical Trials
  - Science on the Horizon
- 1:00pm – 3:00pm Concurrent Sessions
- Medical Trauma in Patients and Families
  - Genetic Testing/Family Planning
  - Navigating IEPs and Educational Needs
- 4:00pm – 5:00pm Mental health, wellness, and coping strategies
- 5:00pm – 5:30pm Remembrance Ceremony
- 6:30pm – 8:30pm** **National MPS Society Banquet and Awards**
- 8:30pm – 10:30pm** **Nashville Party, onsite music, beverages**



# SCHOLARSHIPS

## Dear Friends,

The National MPS Society is pleased to offer scholarships to our 36th Annual Family Conference, August 4–6, 2022, at Sheraton Music City Hotel in Nashville, Tennessee. Scholarships will be awarded to a parent or legal guardian of a child with a diagnosis of MPS or ML or an adult with a diagnosis of MPS or ML. 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 applicant.

### Family conference scholarships can be allocated to:

**Registration:** one adult conference registration (valued at \$200)

**Travel reimbursement:** maximum of \$500

**Hotel:** maximum of 2 nights (valued at \$185.75/night). *The National MPS Society is covering one hotel night for conference attendees at the hotel. This will be in addition to the nights offered through the scholarship. Scholarship recipients can have up to three nights paid.*

### Criteria for applying:

- Member of the National MPS Society, with membership renewed and updated for 2022
- Parent or legal guardian of a child with MPS or ML or adult with MPS or ML
- Application must be completed electronically using our online application program

Go to [mps.onlineapplications.net/applications](https://mps.onlineapplications.net/applications). If you are a first-time user, click on “Register Now” to set up your account. Once you are logged in, open the 2022 Family Conference Scholarship Application. If you are returning user, simply log in on the left-hand side and apply. Scholarship awards will be announced in late May.

The application deadline is April 30, 2022. If you are a newly diagnosed family after this date, please contact Leslie at [leslie@mpsociety.org](mailto:leslie@mpsociety.org) for additional information.

Leslie Urdaneta

*Director of Family Support & Communication*



The application must be submitted electronically no later than April 30, 2022, at 11:59pm EDT.

# NASHVILLE ROCK AND ROLL

## Nashville Rock and Roll 5K Run and 1 Mile Walk

Join us in beautiful Centennial Park in Nashville! The Nashville Rock and Roll 5K Run/One Mile Walk will be held Saturday, Aug. 6, at 8:00am. There will be a chip-timed 5K run, a one mile walk, awards in various categories, all followed by a family luncheon. Buses will be available to and from the park from 7:00am to 12:00pm. Race packet pickup is available Thursday, Aug. 4, from 5:00 to 8:00pm at the conference registration area. The packets will also be available for onsite pickup at the park.

### Schedule

7:00am	Registration opens, onsite packet pickup
8:00am	5K chip-timed run
8:10am	One-mile family walk
9:30am	Awards Ceremony
10:00am – 11:30am	Family Picnic, Centennial Park Events Shelter

### Register, Build a Team, and Raise Funds Online

Register online at [bit.ly/mpsnashvillerun](https://bit.ly/mpsnashvillerun)

\$25 Early bird individual chipped and timed 5K run

\$15 Early bird one mile walk

\$80 Early bird family of four 5K run

\$30 Day of individual chipped and timed 5K run

\$20 Day of one mile walk

\$90 Day of family of four 5K run



### Contact

Tracy Kirby

[tracy@mpssociety.org](mailto:tracy@mpssociety.org)

Madeline Schehl

[madeline@mpssociety.org](mailto:madeline@mpssociety.org)



### Centennial Park

One of the most beloved parks in town, this gorgeous natural setting occupies 132 acres. The site has served as a fairground, a racetrack, and the location for the 1897 Tennessee Centennial and International Exposition. The park is located 15 minutes from the Sheraton Music City Hotel.

