

Frequently Asked Questions

REGISTRATION IS NOW OPEN AT: www.cureim.org/conference

General Information

- Location: Hyatt Lodge at McDonald's Campus, 2815 Jorie Blvd, Oak Brook, IL 60523
- Dates: Friday, June 27 Sunday, June 29, 2025

Schedule Summary:

- Friday: Registration opens at 9am and breakout sessions kick-off at 1PM, followed by a meet-and-greet reception in the evening.
- Saturday: Educational sessions, general session with JM experts, Q&A, small group sessions, and an evening recognition dinner.
- *Sunday*: National Walk Strong to Cure JM family fundraising event with games, activities, and a walk.

Who can attend?

Anyone affected by juvenile dermatomyositis (JM) or juvenile polymyositis (PM) is welcome, including patients, families, extended family, and medical professionals.

We understand that family schedules can be busy and challenging to coordinate, so we encourage you to bring whichever family members work best for your plans. At the conference, you might see:

- one parent attending on their own
- one parent, with one or more children
- multiple parents, with or without children
- entire families
- extended families, including any mix of grandparents, parents, children, teens, and young adults
- any combination of family members that fits your unique needs

We're here to support you and have intentionally made the event flexible and family-friendly. If you aren't sure who can attend from your family, register one adult now to secure your family's spot and then you can add or subtract attendees later. We look forward to welcoming your family!

If you have any questions or need additional information, feel free to contact James Tealy at james.tealy@curejm.org.

What to expect:

- Educational sessions on the latest JM research and treatments
- Social time and networking opportunities with other families
- Activities for children, teens, young adults, grandparents, and caregivers
- A recognition dinner and auction on Saturday evening
- Walk Strong to Cure JM family fundraising event on Sunday

Dress Code:

The conference is family-friendly and casual. For the Saturday celebration banquet we suggest business casual attire but this is completely optional. On Sunday, wear the **Walk Strong to Cure JM** T-shirt we give you or your team's shirt.

Registration:

- Opens in January 2025 at www.curejm.org/conference
- Three steps:
 - register for the conference
 - book your hotel room
 - RSVP for the Walk Strong to Cure JM event by emailing nicole.ryba@curejm.org

How much is the registration fee?

\$140 per adult. This covers all activities, conference events and meals Friday evening – all day Saturday. Children 17 and under are free and childcare for ages 3-12 is provided with additional special activities & sessions for teens.

 A \$20 (15%) early bird discount will be available until February 28th, 2025 using the code "strongertogether". After that, the price returns to \$140 per adult.

This cost includes: All conference events, Friday afternoon snack, Friday dinner, Saturday 3 meals and 2 snack breaks.

How do I book my hotel room?

Families are responsible for booking their own hotel accommodations. All conference activities will be hosted at The Hyatt Lodge in Oak Brook, IL and there is a discounted block of rooms available at www.curejm.org/conference. Please use the link provided there to book your hotel, as the Cure JM Foundation needs to utilize all the rooms in our block.

You are not required to stay at the Hyatt Lodge to attend the conference but all conference activities will be hosted there.

Expected Cost Summary:

- Event Registration. \$140 per adult. This covers all activities, conference events and meals Friday evening all day Saturday. Children 17 and under are free and childcare for ages 3-12 is provided with additional special activities & sessions for teens.
 - A \$20 (15%) early bird discount will be available until February 28th, 2025 using the code "strongertogether". After that the price returns to \$140 per adult.
- Hotel Rooms. \$184 + taxes x 2 nights. Hotel room Friday and Saturday night.
 This is a discounted rate for conference attendees. Follow the hotel booking link at curejm.org/conference.
- Parking Free. For those driving to the conference, the hotel offers free self-parking.
- Airfare Expect \$300-\$500 per person. O'Hare airport (ORD) is approximately 15 miles from the conference hotel and Midway (MDW) is approximately 18 miles away.

- **Uber/Lyft from Airport. Expect \$40-\$60 one way**. You can use the conference app (WHOVA) to ride-share with other conference attendees.
- Additional food/snacks. Expect \$20-\$40. While all meals and coffee breaks
 during the conference are included, you might choose to budget a little extra for
 kids snacks, waters, or the cash bars that will be available during cocktail hours.
- Expected total for 1 adult + 1 child driving to the conference? Average \$500-\$600 plus gas.
- Expected total for 2 adults + 2 kids flying to the conference? Average \$2000-\$2200 depending on airfare.

Is this a family-friendly event?

Absolutely! The conference is designed to support families affected by JM and is a celebration of our children and families of all ages, with flexibility to make everyone feel comfortable. Activities are planned for all ages, and caregivers can manage their schedules as needed. Special programming is scheduled for kids (3-9), tweens (10-12), and teens (13-17). Children are welcome to come in and out of sessions as needed, and children under age 3 are welcome to stay with their parents throughout the weekend.

If you have specific questions about accommodations for your family, please reach out to James Tealy at james.tealy@curejm.org We look forward to seeing you there!

Why attend?

- Gain valuable knowledge from world-renowned JM researchers.
- Connect with other families facing similar challenges.
- Find hope and inspiration from JM patients and families.
- Participate in fun activities and build lasting friendships.
- Contribute to JM research by participating in the Walk Strong to Cure JM event.

Activities for Children:

• Kids Fun Camp (ages 3-9): Supervised activities, games, arts & crafts, and music time. Supervised by local teachers.

Activities for Tweens and Teens:

 Tweens (ages 10-12): Fun camp and tween activities. Supervised by local teachers. • Teens (ages 13-17): Age-appropriate sessions, teen lounge, activities, and workshops including a social "ice breaker" event.

Activities for Young Adults:

 Sessions of interest, Q&A with JM experts, Young Adult coffee social and a meeting of Cure JM's Young Adult Advocates' Council (suggested age 18-30 but all patients who wish can attend)

Activities for Grandparents:

- Special session on resources and support for grandparents of JM patients.
- Educational sessions and opportunities to network with other grandparents.

Walk Strong to Cure JM:

- Cure JM's signature fundraising event.
- Families walk in honor of their loved ones with JM.
- Raise funds for JM research.

Research Participation Opportunity:

 Participate in research right at the conference! Specific opportunities will be published on the conference app (WHOVA) will goes live 90 days before the conference begins.

For more information:

 Visit <u>www.curejm.org/conference</u> or reply to james.tealy@curejm.org with any questions.

Grandparent FAQ

Reach out to Randy Putt, Grandparent Chair, at puttsr@yahoo.com with questions or for more information.

Q: What is the Cure JM Family Conference?

A: The Cure JM Family Conference is a weekend-long event bringing together families affected by Juvenile Myositis (JM), medical professionals, and researchers. It offers education, support, and opportunities to connect with others in the JM community.

Grandparents should plan to arrive Thursday, June 26 in the afternoon and should plan to depart Sunday, June 29. Families will depart from the hotel around noon.

Q: When and where is the conference?

A: The 2025 Cure Jm Family Conference is scheduled for June 27-29, 2025. Details are at www.curejm.org/conference.

Q: Who can attend the conference?

A: Anyone affected by JM is welcome, including grandparents, parents, siblings, patients, and clinicians.

Q: What kind of support is available for grandparents at the conference?

A: The conference offers dedicated sessions for grandparents, providing information, resources, and opportunities to connect with other grandparents of children with JM.

You'll also have the chance to attend general sessions and meet with medical professionals.

Q: What if my children and grandchildren cannot attend?

No problem! Many grandparents come alone or with a spouse or friend.

Q: Will there be opportunities to learn more about JM?

A: Absolutely! The conference features educational sessions led by leading JM experts, covering the latest research, treatment options, and coping strategies.

Q: How can I support my grandchild and their family?

A: The conference will provide valuable information and resources to help you support your grandchild and their family. You'll also have the opportunity to connect with other grandparents who understand your challenges and experiences.

Q: Will there be time for socializing and networking?

A: Yes, the conference includes ample time for socializing and networking with other families. You'll have the opportunity to connect with other grandparents and share experiences.

Q: What should I expect from the conference?

A: Expect a supportive and informative environment where you can learn, connect, and find strength. The conference offers a balance of educational sessions, social activities, and opportunities to connect with other families.

Q: How can I register for the conference?

A: Registration is now open at cureim.org/conference

Q: How much does the conference cost?

A: The conference fee is \$140 per adult. Register before February 28, 2025 using the code "strongertogether" for a \$20 early-bird discount. Children 17 and under attend free of charge.

This cost includes: All conference events, Friday afternoon snack, Friday dinner, Saturday 3 meals and 2 snack breaks.

Q: How do I book my hotel room?

A: Families are responsible for booking their own hotel accommodations. All conference activities will be hosted at The Hyatt Lodge in Oak Brook, IL and there is a discounted block of rooms available at www.curejm.org/conference. Please use the link provided there to book your hotel, as the Cure JM Foundation needs to utilize all the rooms in our block.

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Q: Is the conference accessible for people with disabilities?

A: Yes, we strive to make the conference accessible to all attendees. The conference venue will be wheelchair accessible, and we will provide accommodations as needed. Please inform us of any specific requirements when registering.

Q: Is Childcare provided during the conference?

A: Yes! Childcare is provided for children age 3-12. Activities are provided for children ages 12-17.

Young adult patients and siblings between the ages of 18-30 will have their own activities as well.

In summary:

By attending the Cure JM Family Conference, you'll gain valuable knowledge, support, and connections within the JM community. We encourage you to participate and be part of the journey towards a brighter future for children with JM.