



THE MYOSITIS ASSOCIATION®

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Thank You for Making MyoCon 2026 So Special

MyoCon 2026 brought the myositis community together for several unforgettable days of learning, connection, advocacy, and hope. We are deeply grateful to everyone who made this year's conference so meaningful, including our attendees, speakers, volunteers, sponsors, exhibitors, Support and Affinity Group leaders, Board members, Medical Advisors, and staff.

Thank you for showing up, sharing your stories, asking thoughtful questions, supporting one another, and helping create the kind of community that makes MyoCon so special. We left St. Louis feeling inspired by the strength of this community and more committed than ever to continuing our work in education, connection, advocacy, and awareness for all types of myositis.

**Rare Disease, Real Power:
Why Myositis Advocacy Matters More Than Ever**



As discussed in the MyoCon session, "Rare Disease, Real Power: Why Myositis Advocacy Matters More Than Ever" TMA is actively advancing important legislative priorities. Improving access to care and disability benefits is one of our most critical goals for our community. This includes efforts urging the VA to make IBM a presumptive diagnosis.

We urge you to write to your Representative and ask them to support presumptive status for veterans with IBM. If the Veterans Benefits Administration at the U.S. Department of Veterans Affairs approves this presumptive service connection for veterans with IBM, former service members with IBM would receive the help they need much more quickly.

Nearly two dozen Representatives have signed on to the "Dear Colleague" letter on this issue! Help us increase momentum! When you complete this quick action alert, you help keep myositis visible and remind lawmakers that patients, care partners, families, and advocates are working together to build awareness and support for all types of myositis.

Ask the VA to Make IBM Presumptive

MyoCon
TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

SEPTEMBER 24 - 27, 2026

HYATT REGENCY • ST. LOUIS AT THE ARCH

*Recordings
Available*

MyoCon 2026 Recordings

The 2026 MyoCon Recordings Package is now available for \$149 and includes access to the learning, expert insight, keynote presentations, breakout sessions, and community connection shared during MyoCon.

The package includes recordings from most of the conference agenda, including the opening and closing keynote addresses, the Heroes in the Fight Awards Ceremony, pre-conference virtual sessions, and audio-recorded breakout sessions synced with presentation slides.

For a limited time, when you purchase the 2026 MyoCon Recordings Package, you will also receive access to the 2025 MyoCon recordings at no additional cost.

Please note: **Registered MyoCon attendees will receive access to recordings automatically. No separate order is needed.** Recordings are expected to be available around October 31.

Secure Your Recordings Today



TMA Support Groups in NM, CA, FL, and KS were recognized at MyoCon 2026 for 15, 20, 25, and 30 years of service to the myositis community.

Find Connection Through TMA Support and Affinity Groups

You do not have to navigate myositis alone. TMA's Support and Affinity Groups give patients, care partners, and families a place to connect with others who understand the day-to-day realities of living with myositis.

Whether you are looking for diagnosis-specific support, regional connection, caregiver encouragement, or a community with shared experiences, there is a group that may be a good fit for you. Many groups meet virtually, making it easier to join from anywhere.

We encourage you to explore TMA's support and affinity groups and find a community that can offer connection, encouragement, and understanding throughout your myositis journey.



Board Service Opportunity

TMA is seeking passionate, committed individuals to be considered for service on the Board of Directors. Board service is a meaningful way to give back, help shape the future of TMA's mission, and ensure the voices of patients, care partners, and advocates are represented.

TMA is especially interested in engaged candidates from all myositis diagnoses, with a need for additional representation from the community outside of IBM. Support or affinity group leadership and advocacy experience are a plus.

Interested individuals should **complete the interest form by October 10**. New board members are expected to begin serving in early 2027.

Complete the Interest Form by October 10!

October Is Healthy Lung Month

October is Healthy Lung Month, a good time to learn more about myositis-associated interstitial lung disease, or ILD. TMA's ILD playlist includes educational conversations and resources to help patients, care partners, and families better understand lung involvement in myositis, questions to discuss with a care team, and ways to feel more informed and prepared.

Watch the ILD playlist and share it with someone who may find it helpful.



TMA New Member Orientation
October 9 @ 12:00 pm - 1:00 pm EDT

Open to all regardless how long ago you joined TMA! Living with myositis can be challenging, but you are not alone. Please join us virtually to learn more about education and resources to help you on your myositis journey and make new friends who know, understand, and share your new normal. Connect with people like you, connect with resources you need, connect with global myositis experts – connect with TMA!

Thank you to our sponsor Bristol Myers Squibb.

Register Today



Third Annual Meredith C. Thomas Trivia Night
Fundraiser (in-person event)
October 16 @ 6:00 pm - 9:00 pm CDT

In partnership with the Thomas family, TMA is honored to offer the Meredith C. Thomas Memorial Fellowship, funding grants for early-career researchers and clinicians focused on learning more about how best to treat antisynthetase syndrome and interstitial lung disease.

Meredith Thomas was diagnosed with antisynthetase syndrome and interstitial lung disease and passed away at age 33 in November 2023. In her honor, her family created Meredith's Legacy.

Register Today



Ask the Expert Speech and Swallowing Edition October 15 @ 6:00 pm - 7:00 pm EDT

Join us for a live Ask the Expert webinar focused on speech and swallowing difficulties (dysphagia) in myositis, featuring Dr. Georgia Malandraki, a member of The Myositis Association's Medical Advisory Board and an expert in swallowing disorders. Dysphagia is one of the most challenging and under-discussed symptoms of myositis, affecting communication, nutrition, and quality of life.

[Register Today](#)



MyoCon Reunion & Staying Acquainted (Virtual Session) October 23 @ 12:00 pm - 1:00 pm EDT

MyoCon may be over, but the connections don't have to end there! Join us for this virtual reunion to reflect on the conference and keep the momentum going with the friends you made in St. Louis.

We'll kick off with a 30-minute recap presentation looking back at MyoCon 2026 — highlights, key takeaways, and a chance to relive some of the best moments from the conference together.

Then, we'll break into small group rooms by diagnosis type for 30 minutes of "staying acquainted" time. Reconnect with the folks in your diagnosis-specific breakout from Conference Orientation, share how you're feeling post-conference, and keep building the friendships and support networks you started at MyoCon.

Whether you attended in person, joined virtually, or are just looking to stay connected with your myositis community, come reminisce, reconnect, and keep the MyoCon spirit alive!

To join this session, **register for MyoCon 2026** in person or **order the recordings** and you will receive the invitation to join all virtual pre-and post-conference content!

[Register Today](#)



Myositis Collaborative Groups Summit (in-person) November 6 @ 12:00 pm - 6:30 pm CST

Please join TMA and Cure JM for the in-person Myositis Collaborative Groups Summit to learn about recent initiatives of IMACS, iMyoS, MCTC, CARRA, PReS JDM, and MIHRA. Our aim is to allow members to share information, learn more about research opportunities, and enhance national and international collaborations.

Register Today



TMA's blog is a great source of myositis information and community. Check out these recent blog posts.

Latest post highlights:

[Let's Talk About Pain](#)
[Clinical Trials Move Forward One Careful Step at a Time](#)

World Myositis Day Blogs:

[Recognizing World Myositis Day: Natalia Chmielewska](#)
[Recognizing World Myositis Day: Joan Reid](#)
[Recognizing World Myositis Day: Brogan Greenbough](#)
[Recognizing World Myositis Day: Lachy Beckett](#)

Read More



Meet Our 2026 Heroes in the Fight Awardees

Get to know the inspiring individuals and organizations recognized during MyoCon 2026 as this year's Heroes in the Fight awardees. These new blogs highlight their stories, service, leadership, and lasting impact on the myositis community. Read their

stories and join us in celebrating the people helping move awareness, care, research, and support forward for all types of myositis.

- [Dr. Chris Weihl Receives TMA's 2026 Heroes in Research Award](#)
 - [Catherine "Kitty" Trejo Celebrated as TMA's 2026 Marianne Moyer Myositis Leader Award Recipient](#)
 - [Hospital for Special Surgery Receives TMA's 2026 Heroes in Healthcare Award](#)
 - [Father Stuart Long Honored with TMA's 2026 Patient Ambassador Award](#)
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Help Shape International Recommendations for Juvenile-Onset Myositis

Patients, care partners, and health care professionals with experience in juvenile-onset myositis are invited to participate in an online consensus meeting this October. The goal of this effort is to help define recommendations for juvenile-onset myositis that can be applied internationally.

The first meeting options are October 8 at 11 a.m. GMT or October 13 at 8 p.m. GMT. This opportunity is intended for those connected to juvenile-onset myositis and is not applicable to adult-onset myositis only.

Space is still available, and interested participants are encouraged to register soon. Questions may be directed to [Jess Fitzgerald](#) or [Liza McCann](#).

Learn More & Register

*This is shared on behalf of the **IMACS Scientific Interest Group (SIG)** - Developing international recommendations for the management of juvenile idiopathic inflammatory myopathies (JIIM), a cross-party initiative: IMACS, PReS, CARRA JDM working groups facilitated by an IMACS Scientific Interest Group (SIG), supported by Cure JM.*

FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

Finding a healthcare practitioner who knows how to care for someone with myositis is often a challenge.

While we can't guarantee you'll find an elite physician, **TMA's Find a Doctor** tool can at least provide options.

Check out our [**suggestions for using the tool here.**](#)

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options**

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to learn
about an
FDA-approved
treatment option for
DERMATOMYOSITIS
and **POLYMYOSITIS.**



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TMA's Top 10 Travel Tips for 2026



Community Tips

Travel can bring extra challenges for people living with myositis, from fatigue and muscle weakness to mobility needs and unpredictable symptoms.

TMA's latest blog shares 10 practical travel tips to help make trips more comfortable and less stressful, including planning rest, requesting assistance, keeping medications close, using mobility aids, and giving yourself permission to adjust the plan when needed.

TMA's Top 10 Travel Tips for 2026

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially.

Please **make a gift** to TMA to support our impact today!

Donate Today



TMA provides monthly virtual myositis support by diagnosis with TMA Worldwide.

Co-led by up to five trained and certified support or affinity group leaders from across the country, this group also welcomes our international members. Care partners have their own breakout room!

To find additional groups, visit our list of all support & affinity groups **here**.

RSVP Today



Connect with us!



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