THE MYOSITIS ASSOCIATION®

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Join us in Dallas, TX, for MyoCon 2025!

MyoCon, TMA's 2025 Global Myositis Patient Conference, takes place in Dallas, Texas, USA, on September 18–21. The conference ends on World Myositis Day – a celebration you don't want to miss! Secure your ticket today with special early bird pricing through July 1, 2025!

Register Today

Exciting Updates from TMA about MyoCon!

Click the video above to hear an important message from TMA's Executive Director, Paula Eichenbrenner about MyoCon 2025!

Questions about the 2025 Global Myositis Patient Conference? Visit our FAQ page for answers to the most commonly asked questions.

Visit our FAQ page

TMA represents patients at NIH meeting

Three TMA representatives were among the participants at a virtual Myositis Common Data Elements (CDEs) Consensus Conference from the NIH on May 5-6. The group of experts, including TMA patient experts, worked to identify the most important information that should be collected and how it should be collected across the broadest range of research. Standardizing these data elements will greatly support communication of findings across many different types of myositis research.

The NIH Office of Autoimmune Disease Research is also using this project as a model for creating CDEs in other autoimmune diseases. TMA is excited to be able to include the patient's voice in this important work.

TMA simply cannot do the work we do without the support of people like you. If you're enjoying this newsletter, if you've benefited from one of our educational programs or support groups, if you've taken advantage of some of our resources, or if you want to see more research devoted to myositis, please consider making a donation to help us continue providing these valuable services.

We’re trying to raise $70,000 during Myositis Awareness Month. It’s not too late to give.

Donate Today

Take Part in the INSPIRE-Flare Survey: Help Improve Autoimmune Flare Care

Adults 18 or older and living with an autoimmune disease are invited to join the INSPIRE-Flare study to help researchers better understand what triggers, prevents, and signals flares in autoimmune conditions. Your insights could lead to improved recognition and treatment of flares for patients everywhere.

☐ The online survey takes about 45 minutes.
☐ Participants can enter a prize draw to win one of four £50 Amazon vouchers.
☐ The survey closes in early June.

Take the Survey

From the blog: Your stories

Patient stories are among the most powerful and inspiring ways to help people understand and respond to the challenges of living with these rare, debilitating diseases. During Myositis Awareness Month, many of our members–both patients and care partners–shared their experiences with all forms of myositis.

Read Patient Stories Today

Your voice can inspire and empower. Share your myositis story with us, because every experience helps build a stronger, more connected community.

Share Your Story

Myositis Awareness Month on YouTube

TMA offers workshops, webinars, and more throughout the year—and you can catch every moment on our YouTube channel! Explore our Myositis Awareness Month playlist for powerful content, and don't forget to come back after June 15 for full access to all 2025 MAM recordings.

MAM Playlist

Upcoming Events

Meet & Greet: Special MyoCon 2025 Edition

June 18, 2025, 12:30 PM ET | 9:30 AM PT

Join us for a special *MyoCon 2025* edition of TMA's Meet & Greet Leadership Series! Connect with TMA leadership and special guests as we dive into all things *MyoCon*—from exciting sessions and speakers to travel tips and ways to make the most of your conference experience. Whether you're a first-time attendee or a seasoned MyoCon veteran, this is your chance to get the inside scoop and have your questions answered.

Don't miss this engaging and informative conversation as we gear up for the biggest Myositis event of the year!

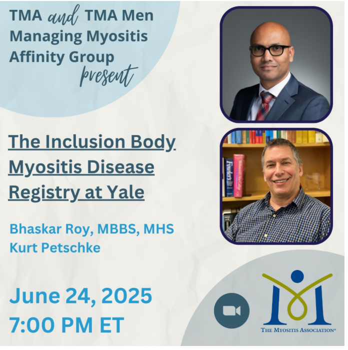
Register Today

Ask the Expert featuring Dr. Julie Paik

Tuesday, June 24 at 12:00 PM ET

This month's webinar features Dr. Julie Paik from the Johns Hopkins Myositis Center in Baltimore, Maryland, who also serves as Vice Chair of TMA's Medical Advisory Board. Join us on Tuesday, June 24 at 12:00 PM ET for the opportunity to ask your questions and learn from one of the leading voices in myositis care and research.

Register Today



IBM Disease Registry at Yale

June 24, 2025 at 7pm ET | 4pm PT

TMA invites everyone to attend a special speaker presentation hosted by TMA Men Managing Myositis Affinity Group on The Inclusion Body Myositis Disease Registry at Yale.

The Inclusion Body Myositis (IBM) Disease Registry at Yale houses one of the world's largest systematic categorizations of IBM: its origins, its biological markers, its risk profile, its natural history, and its clinical management.

Register Today

Global Conference on Myositis 2026

The 6th biannual GCOM will take place in Lisbon, Portugal on March 23-26, 2026. This international scientific meeting brings together the world's leading researchers and clinicians from all the different myositis specialties to share their unique perspectives on the science of myositis diseases.

Representatives from patient support organizations from around the world—including TMA—will also be there to network and collaborate and to emphasize the role and importance of patients in the work of the scientific community.

We'd love to have a group of TMA members join us for this amazing opportunity to show these international myositis experts how this disease affects your life. It's not too soon to start planning to be part of this exciting conference in an exciting city. **Please let us know if you'd like to join TMA for GCOM 2026!**

GCOM 2026

Community Tips

"I learned to understand that this sickness comes with a grieving process that occurs every day. You realize that every day you need to overcome the loss of your past self and what you "were supposed" to be able to do. This helped me understand that it will be normal to have breakdowns in mental and body health. I prioritize my health and comfort because the price of not doing so due to external opinions will be very high and painful.

I track small wins or progress that I make so I don't fall into desperation. I make a realistic list of things I need to do to survive the day and things I would like to do, even if they are small. In the morning, I select the tasks I can do with the energy I have. I always include my resting times, so I make them mandatory."

-Melissa R, *lives with polymyositis*

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.

TMA's YouTube channel has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's webinars are published on the first of the following month.

Mind Your Mental Health

Mindfulness is the practice of intentionally focusing your attention on the present moment—without judgment. It involves being fully aware of your thoughts, emotions, bodily sensations, and surroundings, and accepting them as they are.

When we asked TMA members to tell us how they manage mental health challenges, many shared ideas about mindfulness practices that helped them cope. **Here are a few daily practices:**

- Enjoy the little things, like a good book or coffee with a friend.
- Sit quietly and focus on your breathing for a few minutes.
- Listen to your body. Notice its sensations. Eat when you're hungry. Sleep when you're tired.
- Walk outside and notice the feel of the air, the sound of the birds, the green of the trees, the beauty of the flowers.
- Keep a gratitude journal where you write down what you're thankful for.

We know that myositis can take a toll on your emotional wellbeing. **Help others navigate these challenges by sending us your insights on mental health and myositis.**

Take the Survey


Tap into the power of peer support!

1:00-2:30 PM ET | 10:00-11:30 AM PT
FIRST SATURDAY OF EVERY MONTH

TMA WORLDWIDE
Myositis Support Group

Find encouragement and motivation to persevere through tough times. Connect and learn. Breakout rooms grouped by diagnosis and led by trained, certified peer leaders from across the nation!

Register Now!

In honor of the international members who have consistently attended our TMA Nationwide myositis support group since its inception in 2022, we have updated the name to more realistically represent the population it serves.

TMA Worldwide will continue the group’s commitment to monthly virtual myositis support by diagnosis. Co-led by up to five trained and certified support and/or affinity group leaders from various regions, we also provide a safe space for our TMA Care Partner Affinity Group to meet in their own breakout room!

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

RSVP Today

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

THE MYOSITIS ASSOCIATION®

Connect with us!