THE MYOSITIS ASSOCIATION®

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It's Myositis Awareness Month!

At TMA, our mission is to support those living with myositis and their care partners through education, awareness, advocacy, and community. This May, we're coming together to amplify that mission and raise our collective voices to increase understanding of myositis around the world.

Throughout the month, you'll find Diagnosis Days, empowering in-person events, educational webinars and powerful resources to help you share your story and advocate for earlier diagnoses, better treatments, and stronger support.

Ready to raise awareness? Access all of TMA's Myositis Awareness Month content on our website.

Visit our Website

TMA member and medical advisors pivotal in patient reported outcomes research

TMA is excited to announce that The Journal of Rheumatology recently published a pivotal study titled "The Dermatomyositis Disease Symptom Questionnaire (DM-DSQ): A Measure to

Assess the Patient Experience of Dermatomyositis Symptoms."

This groundbreaking research was led by an international team of myositis experts, including TMA medical advisors Dr. Lisa Christopher-Stine, Dr. Namita Goyal, and Dr. Tahseen Mozaffar.

Above: Dr. Lisa Christopher-Stine

TMA member, advocate, and leader, Kaniah Gunter, was also part of the research team. As a co-leader of TMA's Women of Color Affinity Group, Kaniah has been instrumental in raising awareness about myositis among communities of color, a group that is disproportionately affected by myositis.

Diagnosed with dermatomyositis herself, Kaniah's insights and experiences have enriched the study, ensuring the DM-DSQ reflects the diverse experiences of all patients.

Above: Kaniah Gunter

Read More Today **See Published Research** **Watch Video Interview**

Announcing a new regional support group, TMA Cincinnati Tristate serving folks from Ohio, Indiana, and Kentucky (and whomever else wants to jump on)! Thank you to volunteer Tom Trevor for creating this new group! First meeting is May 17, 10:30 AM ET.

Learn More

Upcoming Myositis Awareness Month Events

Meditation Mondays

Every Monday in May | 9:00 AM ET | 6:00 AM PT

Join us for a peaceful start to your week with guided meditation sessions designed for people living with myositis and their care partners. All experience levels are welcome. Fill out the interest form to receive your session link.

Register Today

Living Well with Myositis Empowerment Clinic

Monday, May 5, 2025, 4 PM ET | 1 PM PT

Join us for an empowering panel discussion featuring individuals living with various forms of myositis and a care partner as they share real-life strategies for managing symptoms, navigating care, and maintaining quality of life. This insightful one-hour webinar offers practical advice and encouragement for patients, care partners, and anyone looking to better understand the myositis journey.

Register Today

MyoLive! TMA Open House

Friday, May 9, 2025, 11 AM - 2 PM ET

In celebration of Myositis Awareness Month, TMA is hosting an open house at our offices in Columbia, MD. If you happen to be in the area, come join us for this in-person event.

If you don't happen to be in Maryland, join us online for a special edition of TMA's popular "Ask the Expert" program with Dr. Myma Albayda. We will livestream from our TMA Facebook page from 1-2 PM ET | 10-11 AM PT. Submit questions online as you join the Facebook broadcast. No registration is required, simply open our TMA Facebook page at 1 PM ET.

We're grateful to our sponsors, AstraZeneca and Abcuro, for making this special event possible.

Register Today

Feel Good Friday: Jeopardy!

Friday, May 16, 2025, 7 PM ET - 4 PM PT

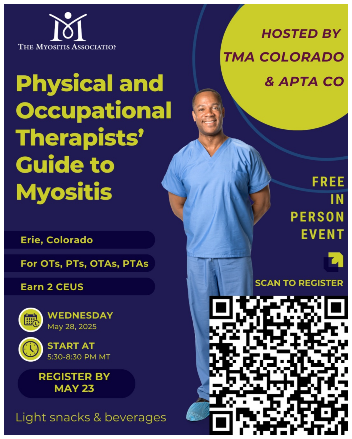
In honor of Myositis Awareness Month, we're bringing the whole community together for a virtual game night like no other. Test your trivia skills, cheer each other on, and celebrate the amazing strength of our myositis family.

Whether you're playing to win or just there for the good vibes,

everyone's welcome. Bring your best guesses, your biggest smiles, and let's make it a night to remember!

Special thanks to TMA's Women of Color Affinity Group for bringing this community event to life!

Register Today



PT/OT Myositis Symposium

Wednesday, May 28, 2025, 5:30–8:30 PM MT | Erie, CO

Are you a physical or occupational therapist caring for people with myositis? Join TMA's Colorado Support Group and APTA Colorado for an in-person symposium designed for PTs, OTs, assistants, and students interested in expanding their knowledge of myositis care. Attendees will earn 2 CEUs while gaining valuable insights into treating this rare and complex condition.

Please note this event if for healthcare professionals only.

Register Today

Confident & Comfortable

Saturday, May 31, 2025, 12 PM ET | 9 AM PT

Have you always loved fashion? Do you still like to look sharp while choosing clothing that's easy to wear and makes you feel good? Having a chronic illness can mean wardrobe changes, but not all is lost! We invite you to share photos and stories about how fashion—whether adaptive clothing, sun-protective hats, or favorite outfits—helps you feel like *you*. Submissions will be included in our May webinar, "Confident & Comfortable: Embracing Fashion as Self-Care."

Email Minerva

Registration is now open for TMA's 2025 Global Myositis Patient Conference. This years conference takes place in Dallas, Texas, USA on September 18–21, 2025 featuring workshops, research-based presentations, tips for care partners, information about clinical trials, and so much more!

While the value of these educational sessions is tremendous, for many attendees the chance to meet and make friends with others who have their disease has been life-changing. Make plans now to join us for the conference as well as our popular Heroes in the Fight awards gala.The conference ends on World Myositis Day with a celebration you don’t want to miss!

Thanks to generous donations from members of the myositis community, TMA is able to provide a limited number of scholarships for members in need. Conference scholarships are available for TMA members only. If you are not a member, please join TMA before applying. Applications are due by May 15, 2025.

Register for the Conference Today

Apply for a Conference Scholarship

Community Tips

In a recent blog story, Tesse Muldoon says that her most useful daily hacks for managing myositis focus on conserving her energy and moving strategically to reduce muscle fatigue and inflammation.

Here are some specific tips:

- The 80/20 rule for energy: Try to use only 80% of your energy and save 20% to prevent overexertion. Pushing too hard can trigger a flare.
- Adaptive tools and mobility aids: Don't hesitate to use assistive devices like grabbers, shower chairs, or walking aids to reduce strain on weak muscles.
- Hydration and electrolytes: Staying well-hydrated, especially with electrolytes like Liquid IV or Pedialyte, can help reduce muscle cramping and fatigue.
- Compression and heat therapy: Compression gloves, braces, or heating pads can help with pain and circulation, especially in the morning when stiffness is worst.
- Gentle movement and stretching: Low-impact exercises like water therapy, resistance bands, or even simple stretching can maintain mobility without overexertion.
- Meal and task prep on good days: Batch cooking, using adaptive kitchen tools, or setting up essentials in easy-to-reach places can make tough days easier.
- Voice-to-text and smart home devices: If muscle weakness makes writing or

gripping difficult, use voice-to-text or smart home tech to reduce physical strain.

Read Tesse's Whole Story

From the Blog

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

Unshakeable optimism
My medical binder
A tribute to Marianne Moyer

Read More on the TMA Blog

We Care for Rare Summit

For those who weren’t able to attend our virtual Rare Disease Day Summit, we’ve put together a couple of articles to recap the day’s events.

- We Care for Rare Summit: Celebrating myositis science and patient stories on Rare Disease Day
- The full-time job of living rare
- We’ve also got a YouTube playlist so you can watch each segment or the whole session!

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

Staying positive can be challenging, especially during tough times, but it's essential for maintaining mental and emotional well-being. Here are some tips to help you stay positive:

1. Start the day by acknowledging the things you're grateful for.
2. Spend time with people who uplift and support you.
3. Exercise to reduce stress and improve your mood.
4. Mindfulness and meditation can help you stay present and reduce anxiety.
5. Limit exposure to negative news and social media that can contribute to stress and negativity.
6. Make time for hobbies and activities that bring you joy.

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!

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!