THE MYOSITIS ASSOCIATION®

MyoNews January 2026 | Volume 6, Issue 1

Happy New Year!

As we welcome the start of 2026, we pause with heartfelt gratitude for each of you—our members, supporters, and friends. Your dedication, resilience, and generosity make our mission possible, and we are deeply thankful for the strength of this community.

Together, we have built a network of hope, support, and advocacy that uplifts everyone affected by myositis. We are especially grateful to our 2025 donors whose generosity helped make this work possible and strengthened the impact of our shared mission.

Looking ahead, we are excited to continue working side by side with you to advance research, raise awareness, and provide resources that empower lives. May this year bring you renewed energy, good health, and moments of joy. We wish you peace, connection, and the courage to embrace new opportunities.

Warmest wishes,
The Myositis Association Team

NIH Rare Disease Day 2026

NIH Rare Disease Day 2026 will be held both in-person at the NIH main campus (Natcher Conference Center) and virtually via NIH VideoCast on **Friday, February 27, 2026, from 9 a.m. to 5 p.m. EST**.

Don't miss TMA Support Group Leader Lindsay Guentzel, Multimedia Journalist, Storyteller, Advocate who will share her dermatomyositis journey in the 11:10 a.m. **"Rare Story: The Full-Time Job of Living Rare — Advocacy, Resilience and the Fight for Care."** The event agenda features panel discussions, in-person exhibitors and scientific posters, and an art exhibit. The event is free and open to the public.

For more information and to register: **Rare Disease Day at NIH | National Center for Advancing Translational Sciences**.

Please email tma@myositis.org to let us know you are participating.

EveryLife Foundation Rare Disease Week

The EveryLife Foundation for Rare Diseases is hosting their **Rare Disease Week on Capitol Hill February 24 – 26, 2026 in Washington, DC.** Registration opens on January 7.

Please email tma@myositis.org to let us know you are participating.

Learn More About Rare Disease Week

Raise Awareness in Your State!

TMA has launched Proclamation50 for 2026, our aspiration to spur proclamations in all 50 states in the US for Myositis Awareness Month in May! You can use this handy guide to drafting and requesting this official designation of Myositis Awareness Month from your city, county, or state. This is a small-time commitment for a very vital cause! Please sign up to be one of our Proclamation50 participants!

Take the TMA Volunteer Information Form 2026 Survey!

Additionally, we are going to be hosting a **Proclamation50 informational Zoom session on Thursday, January 8, at 4 pm PT/7 pm ET,** where TMA volunteer Jamie Batiste will share more about this opportunity and be able to answer any questions.

RSVP to the Proclamation50 Info Session

TMA Partners with MDA to Fund IBM Research

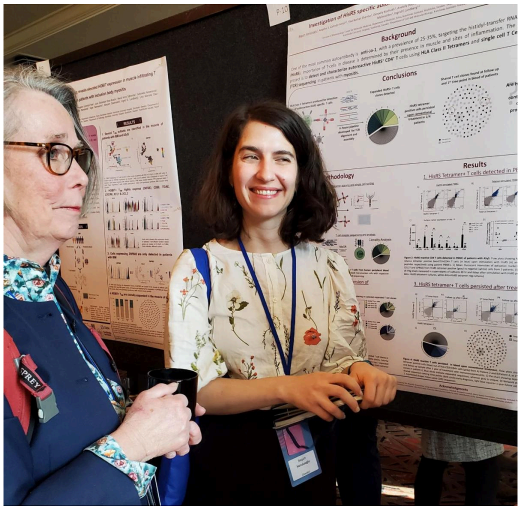
TMA is proud to announce a new research partnership with the Muscular Dystrophy Association (MDA) to co-fund a groundbreaking study aimed at advancing the understanding of inclusion body myositis (IBM).

Through this collaboration, **Bhaskar Roy, MBBS, MHS**, of Yale University has been awarded a **$299,992 research grant** spanning three years for his project titled *"In-depth characterization of immune dysfunction in inclusion body myositis."*

Dr. Roy's research will explore how immune cells contribute to muscle degeneration in IBM. Using cutting-edge single-cell analysis, his team will examine B and T cell interactions in both muscle tissue and blood samples. The goal is to uncover novel therapeutic targets and deepen scientific understanding of the disease's underlying mechanisms.

Learn More

TMA Research Grants Fuel Discovery



Ten years ago, the treatment landscape for myositis diseases was, let’s be honest, bleak. We had no FDA-approved treatments for myositis. Only one or two clinical trials were available to test new treatments for this community, and those trials failed. Today, that landscape is much more hopeful, and TMA’s Research Grants Program has been part of the progress.

Read About TMA Research Successes

Research Grants Program Report

TMA Men of Color Affinity Group Meeting
January 7, 2026, at 7:00 pm - 8:30 pm ET

This new group now meets quarterly on the first Wednesday as a way for men of color who are living with myositis to connect, share their stories, and learn more about myositis and how they can navigate the challenges of chronic disease.

[Find our other affinity groups here.]

Register Today

TMA New Member Orientation
January 16, 2026, at 12:00 pm - 1:00 pm ET

You don’t have to be new to TMA to join our **New Member Orientation**! This virtual event is open to all members, no matter how long ago you joined!

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!

Register Today

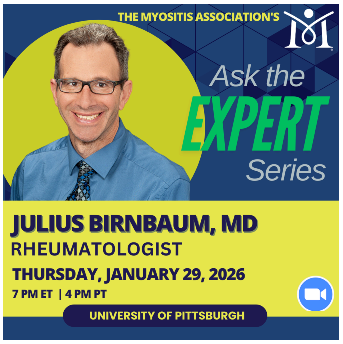
Empowerment Clinic: Mindfulness and Self-Compassion for Chronic Illness and Pain
January 22, 2026, at 12:00 pm - 1:00 pm ET

In this 60-minute session, we will define and explore what Mindfulness and Self-Compassion are and how they can reduce pain and discomfort, reduce stress, and enhance our ability to live a life beyond simply struggling with our illness and pain. The workshop will include an overview of the subject matter, guided meditation, and time for Q&A.

By the end of the time, participants will be able to:
1. Define what Mindfulness is and what Self-Compassion is
2. Describe and engage in practices to grow these qualities
3. Be able to apply these skills to daily life

This event is in a Zoom meeting-style format, with the camera optional.

Register Today



Ask the Expert featuring Dr. Julius Birnbaum
January 29, 2026,at 7:00 pm - 8:00 pm ET

TMA's Ask the Expert series is our most popular webinar series. It provides an opportunity for our community to get answers to their burning questions from an expert who likely has more knowledge than their doctor. This is also a chance for the community to meet a member of TMA's expert Medical Advisory Board or another distinguished member of the myositis medical community.

Register Today

Partnering for Success: Understanding the Role of Your Clinical Trial Representative
February 10, 2026, at 12:00 pm - 1:00 pm ET

When you join a clinical trial, you're paired with a clinical trial representative who becomes your primary guide throughout the study. But what exactly does this role include—and how can you build a strong, effective partnership?

In this webinar, Mercedes Herrera, an experienced Clinical Research Coordinator with the UCI Center for Clinical Research, will walk participants through the key responsibilities of a clinical trial representative, what communication and support you can expect, and how to work together to ensure a smooth and informed trial experience.

Register Today

2026 TMA & KUMC Regional Myositis Conference
March 7, 2026, at 10:00 am - 2:00 pm ET

Join The Myositis Association and the University of Kansas Medical Center for a free virtual regional conference designed for individuals living with myositis—including inclusion body myositis, immune-mediated necrotizing myopathy, dermatomyositis, polymyositis, anti-synthetase syndrome, and overlap syndromes. Patients, care partners, family members, and friends are all welcome to attend. Don't miss this opportunity to connect with experts and the myositis community.

Register Today

Cultivating Calm: Community Resilience Model Skills for Daily Life
March 10 @ 12:00 pm - 1:00 pm ET

Living with myositis—or caring for someone who does—can place ongoing stress on both the mind and body. The Community Resilience Model (CRM) offers simple, practical skills to help regulate the nervous system, build resilience, and restore a sense of balance in daily life.

In this webinar, Kelly Purcell, a certified CRM trainer with the Trauma Resource Institute, will introduce the core principles of CRM and guide participants through its accessible, body-based techniques. You'll learn how to recognize your own nervous system patterns, shift toward a steadier state, and use CRM tools to respond more effectively to stress, uncertainty, and overwhelm.

Register Today

The TMA blog is filled with patient stories, research updates, and simple, helpful tips to support your life with myositis.

Latest post highlight:

[TMA Funding Supports Early Career Researcher]

[If You're on Rituximab, Timing is Everything]

[New Hope for Those with Myositis]

Read More

TMA's Scholarship Fund

Donate now to help us reach our goal!

How to Help

TMA has set a goal of $5,000 for the MyoCon 2026 Scholarship.

How It Works

All funds donated go directly to the TMA MyoCon Scholarship to help offset the cost of attending for scholarship recipients.

Where to Donate

myositis.org/scholarships

Help Us Raise $5,000 for TMA's Patient Conference Scholarship Fund

Attending MyoCon: TMA's Global Myositis Patient Conference is a life-changing experience for those living with myositis and their families, providing education, support, and a sense of community. This year, for Rare Disease Week, February 23-27, 2026, our goal is to bring together 50 donors and raise $5,000 to provide conference scholarships. Your donation, no matter the size, helps bring hope and connection to patients who need it most. **Give today and help us reach our goal.**

Give Your Gift Today

Mind Your Mental Health: Volunteer

Volunteering isn’t just about giving back—it’s also a powerful way to nurture your own mental well-being. Studies show that helping others can reduce stress, combat feelings of loneliness, and even lower symptoms of depression. When you volunteer, your brain releases endorphins, often called the “helper’s high,” which boosts mood and creates a sense of fulfillment.

One of the greatest benefits of volunteering is the connection it fosters. Whether you’re serving meals, mentoring youth, or giving of your time to TMA, you’re building relationships and strengthening your sense of community. These social bonds are vital for mental health, offering support, belonging, and shared purpose.

Volunteering also provides structure and meaning. Having a role where your efforts make a tangible difference can increase self-esteem and resilience. It shifts focus away from personal worries and toward collective goals, helping you gain perspective and gratitude.

Additionally, volunteering encourages mindfulness. By being present in acts of service—listening, helping, caring—you cultivate awareness and compassion, both of which reduce anxiety and promote inner calm.

TMA has lots of ways you can offer your services to the myositis community. If you’re interested, please complete our **Volunteer Information Form 2026**.

Volunteer with TMA

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.**

Community Tips: Keep it Positive

Living with myositis brings challenges, but cultivating positivity can make each day brighter. Remember: positivity isn't about ignoring difficulties—it's about finding light even in the midst of them.

1. Celebrate small wins – Acknowledge progress, no matter how modest. Each step forward is worth celebrating.
2. Stay connected – Lean on friends, family, or support groups. Sharing experiences helps reduce isolation and builds encouragement.
3. Practice mindfulness – Simple breathing exercises or meditation can ease stress and bring calm to daily routines.
4. Focus on what you can control – Shift energy toward activities that bring joy—whether it's reading, music, or creative hobbies.
5. Seek inspiration daily – Surround yourself with uplifting stories, affirmations, or nature. A positive environment nurtures a positive mindset.

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

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!

TMA Worldwide continues 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

Rare Disease Journeys Community Survey

For Rare Disease Day on February 28th, 2026, TMA wants to hear from you! **Share your tips for navigating a rare medical journey** in myositis and what you and your family do to overcome isolation, connect with others, and make your rare experience easier.

Share Your Rare

The Myositis Association®

Connect with us!

The Myositis Association | 6950 Columbia Gateway Drive Suite 370 | Columbia, MD 21046 US