THE MYOSITIS ASSOCIATION®

# MyoNews February 2026 | Volume 6, Issue 2

## Black History Month

TMA is deeply committed to fostering a diverse and inclusive environment where all individuals feel valued, respected, and empowered. We believe that embracing diversity strengthens our organization and enriches our ability to innovate and collaborate. Through our ongoing initiatives, TMA works to ensure that every voice is heard, every perspective is valued, and every person has the opportunity to thrive. Our dedication to diversity and inclusion is not just a commitment, but a core value that shapes our culture and drives our success. **You can learn more about TMA's core values here.**

In honor of Black history Month, we're highlighting an archived TMA Women Of Color Affinity Group webinar "Impact of Social Connections on Patient Health and Resilience." It's good information, reminding us that we are all in this together!

Watch Now

## New BOD Officers Elected

TMA is pleased to announce our newly elected Board of Directors officers, whose leadership will guide TMA into its next chapter of growth and impact. **Rich DeAugustinis** will serve as Chair, bringing strategic vision and a deep commitment to the myositis community. **Jane Myles** steps into the role of Vice Chair, offering extensive experience in patient-focused innovation. **Laurie Boyer**, now Immediate Past Chair, continues to provide invaluable continuity and insight. **Frank Lipiecki** will serve as Secretary and **Richard (Chip) Galloway, Jr.** as Treasurer, each contributing strong organizational and financial stewardship. Together, this team strengthens TMA's mission and momentum.

**Meet the TMA Board of Directors**

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## Announcing New Board Members

TMA is proud to welcome an exceptional group of leaders to our Board of Directors. Each new member brings deep professional expertise, personal commitment, and lived experience that will strengthen TMA's mission and expand its impact across the myositis community. We welcome **Debbie Armstrong, Shagufa Hossain, Craig Miller, Lance Millington,** and **Alicia D. Polak.**

**Learn More About All of TMA's Board Members**

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## In Gratitude to Retiring Board Members

The leadership of TMA’s Board of Directors is one reason we are so successful in our mission to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy. **Howard Gerrin**, **Dave Mochel**, **Tahseen Mozaffar**, and **Nita Sharma** concluded their terms last month, and we celebrate their dedication, vision, and unwavering commitment to achieving a world without myositis.

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## Rare Disease Day 2026

### 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**

**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**

### TMA Women with IBM Affinity Group and NORD on February 17, 12 pm ET

Join the TMA Women with IBM Affinity Group on **February 17** for an engaging and empowering conversation on advocacy and policy affecting the rare disease community.

We're honored to welcome **Carolyn Sheridan, Associate Director of State Policy at NORD**, who will explain how state governments influence health policy and why state-level advocacy matters for people living with rare diseases like Inclusion Body Myositis. She'll be joined by **Jake Santonstol from NORD**, who will share practical advocacy opportunities, ways to get involved in community engagement, and how you can participate in **Rare Disease Day**.

Whether you're new to advocacy or already involved, this session will offer meaningful ways to stay informed, get engaged, and make your voice heard. **Open to all.**

**Register Today**

## NIH and FDA Observe Rare Disease Day 2026

**On Friday, February 27, 2026, from 9 AM to 5 PM ET,** the NIH will host Rare Disease Day 2026, both in-person at the NIH main campus (Natcher Conference Center) and virtually via NIH VideoCast. ***Be sure to stop by and say hello to the TMA team at our myositis exhibit table at the NIH.***

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

The FDA will host **"Moving Forward. Looking Ahead. An Event for Patients"** for Rare Disease Day. Join this virtual public meeting on **Monday, February 23, 2026**, in global observance of Rare Disease Week.

**Are you participating in a Rare Disease Day event?** Please email tma@myositis.org to let us know where 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 is now open!

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

**Learn More About Rare Disease Week**

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## 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!

TMA Volunteer Information Form 2026 Survey

**On February 11th at 6 pm ET, we will be hosting Proclamation50 Office Hours** where you can learn more about this initiative and ask any questions.

**Register Here for Office Hours**

MyoCon

TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

Save the Date!

THURSDAY, SEPT. 24 - SUNDAY, SEPT. 27, 2026

HYATT REGENCY • ST. LOUIS AT THE ARCH

Registration Opens April 1, 2026

Presented by The Myositis Assocation

MYOSITIS.ORG

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## Be More Involved in Shaping Myositis Research

OMERACT® Outcome Measures in Rheumatology Patient Research Partners Network

Do you want to be more involved in shaping myositis research? Here's one way you can make a difference.

OMERACT, a group of researchers dedicated to creating meaningful outcome measures for Rheumatology research, invites people with autoimmune conditions to become Patient Research Partners.

**Applications for OMERACT 2027 Patient Research Partners (PRPs) will open in early 2026.**

**PRP application window:** March 1 to March 31, 2026

Patient Research Partners interested in applying will be asked to complete an online application. As part of the application process, PRPs are expected to have:

- **Reviewed the OMER-ED learning modules**
- **Familiarized themselves with the OMERACT PRP Toolkit**

These resources support meaningful and informed participation in OMERACT Working Groups and conference activities. Additional details and application links will be shared closer to the opening date.

These resources can also be beneficial for serving as a PRP in other organizations like TMA as well.
👉 Find the OMERACT PRP Network Website Here

Learn More

## 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**

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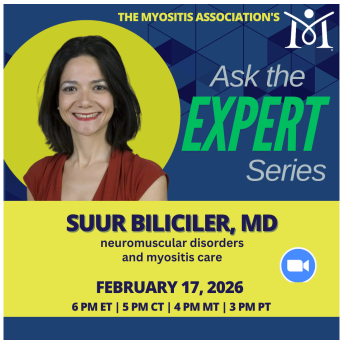

## Ask the Expert featuring Dr. Suur Biliciler
## February 17, 2026, at 6:00 pm - 7:00 pm ET

**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**

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## 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

### GCOM 2026: Global Conference on Myositis
### March 23-26, 2026 in Lisbon, Portugal

The 6th Global Conference on Myositis is the premier international forum dedicated to clinical care and research in myositis. Clinicians, researchers, healthcare professionals, patients, and industry partners from around the world are invited to be part of a global community shaping the future of myositis care and research! GCOM 2026 takes place in Lisbon, Portugal from March 23-26.

Learn More

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

**Latest post highlight:**

[TMA Researcher Examines Autoantibody Testing](#)
[The New Dietary Guidelines: What are they really saying?](#)
[Turning Grief into Advocacy](#)
[The Biopsy Question](#)

**Read More**

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MDA® | Muscular Dystrophy Association

## Care partners: MDA wants to hear from you!

As part of its efforts to support caregivers, the Muscular Dystrophy Association advocates for addressing the common challenges that caregivers face through public policy change.They invite you to share your experiences with caregiving to help them better understand the realities and challenges of providing care. Your insights will continue to inform their advocacy work around supporting caregivers in the neuromuscular disease community and beyond.

**Take the Survey Today**

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## TMA x Steroids and Me

TMA has partnered with Steroids and Me to provide additional support for myositis patients navigating corticosteroid treatment. Through the wealth of information on their site and **Sam's Journey Tracker**, you can better monitor symptom changes, prepare for doctors visits, and feel more in control of your health during treatment.

**Steroids and Me**
/steroidsandme

**Learn More about the TMA Partnership with SAM**

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## Register Now for the Patient 360 Virtual Conference!

**Saturday, March 7–Sunday, March 8, 2026**

Join us for a two-day online event made just for patients on Ig therapy and biologics! Get answers to your most important questions about:

- Managing treatment and daily life
- Diagnoses and conditions
- Side effects and safety
- Building your care team
- Family, parenting, and relationships
- Insurance and access
- And more!

This event is filled with support, practical tips, and tools to help you, your family, and your caregivers feel more confident and informed.

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**Registration is FREE for all patients, families, and caregivers!**

**Register Today**

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## Chip Galloway’s IBM WARRIOR! Campaign

I am a 1991 Graduate of The Citadel in Charleston South Carolina. I was diagnosed with Inclusion Body Myositis in January 2020. My hope is to help raise funds to find a CURE in my lifetime. Myositis is a cure worth fighting for! There are many ways to bring awareness to Myositis.

My prayer is to bring as much awareness as possible to help make this world a place without myositis. Psalm 139:14 God says we are fearfully and wonderfully made, and He says we are MARVELOUS!

**Help Chip Raise $4,316**

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.

## Mind Your Mental Health: Connection

Staying connected with others can be a powerful buffer against stress and loneliness. Strong social ties support emotional resilience, boost mood, and help people feel grounded during challenging moments. A few simple habits can make a meaningful difference.

**1. Schedule regular check-ins:** Short calls or messages help maintain steady connection.
**2. Join interest-based groups like TMA’s Support and Affinity Groups:** Shared interests make conversation easier and more fulfilling.
**3. Take walks with a friend:** Movement plus company strengthens both body and mind.

**Did you know?**

TMA provides support for each myositis diagnosis in one convenient format through TMA Worldwide breakout sessions.

Care partners also have their own breakout room! Each breakout room is led by a trained and TMA-certified group leader. Come see what all the hub-bub is about on the first Saturday of each month!

Email leader Dave Volk at Volk@myositis.org with any questions!

**RSVP Today**

**4. Volunteer locally:** Helping others naturally builds community.
**5. Start small social rituals:** Weekly coffee chats or game nights create dependable touchpoints.

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!