

# MyoNews December 2025 I Volume 5, Issue 12



#### Greetings!

As we begin to wind down 2025, I find myself so grateful for the passion and perseverance of our TMA community.  $\Box$ 

We all know that rare disease journeys are never simple. The road is steep, and at times, overwhelming. But then, I look around and what I see is extraordinary: members sharing wisdom at MyoCon 2025, advocates raising their voices in every corner, and families turning pain into purpose.

This year, we lifted myositis awareness higher than ever before, wrapped stronger arms around one another through support networks, and kept momentum in the search for answers and treatments.

Behind every step forward are real people - patients, care partners, clinicians, researchers, and friends - showing up. Day after day.

Soon the days will lead us into 2026. Until then, I'm holding this gratitude, and this community, close.

Wishing you joy, rest, and light this season.

With appreciation,
Paula
Paula Eichenbrenner
Executive Director, The Myositis Association



For more than 30 years, TMA has been a lifeline for individuals and families affected by myositis. Through awareness building, education & support, and research funding, TMA empowers the myositis community and drives progress toward better outcomes.

This vital work is only possible because of generous donors like **you**. We are so grateful to the supporters for our GivingTuesday campaign. All gifts during this special season help TMA continue providing direct access to world-renowned medical experts, trustworthy information about diagnosis and care, and a supportive network where patients and care partners can thrive. Since 2002, TMA has invested more than \$8 million in groundbreaking research—and with your help, we'll keep pushing forward.

Please consider making a gift today. Your support fuels hope, connection, and discovery for everyone living with myositis. Let's finish the year strong—together.

**Give Your Gift Today** 





Myositis Research Insights featuring Dr. Erin Wilfong December 4 at 1:00 pm - 2:00 pm ET

Join TMA for our next Myositis Research Insights webinar, featuring Dr. Erin Wilfong, a leading expert in autoimmune muscle disease. Dr. Wilfong will share updates from her latest research and discuss how these findings may impact the understanding and treatment of myositis. Don't miss this opportunity to hear directly from one of the scientists advancing myositis research and to ask your questions during a live Q&A.



# The JASMINE Clinical Study: An Overview for the Myositis Community December 9 at 12 PM ET

Join us for a special webinar featuring Dr. Andrew Beaton as he provides a clear and accessible overview of the JASMINE Clinical Study. This session will help members of the myositis community better understand the study's goals, design, and potential impact, as well as what participation may entail. Whether you're a patient, care partner, or advocate, this webinar offers an opportunity to learn directly from an expert. Special thanks to AstraZeneca for sponsoring this webinar.

**Register Today** 



# Ask the Expert featuring Dr. Kendrea L. Garand Wednesday, December 11 at 12:00 PM ET

Join us for a special edition of *Ask the Expert* featuring Kendrea L. Garand, PhD, CScD, CCC-SLP, BCS-S, Associate Professor of Speech-Language Pathology at the University of Pittsburgh.

Dr. Garand is the Principal Investigator of the Swallowing Disorders Initiative (SDI) Research Laboratory and a board-certified specialist in swallowing and swallowing disorders. She will address swallowing issues commonly experienced by those living with myositis, including how to recognize signs of dysphagia, current diagnostic tools, and available interventions to improve safety and quality of life.

Bring your questions and gain valuable insights into this oftenoverlooked but critical aspect of myositis care.

**Register Today** 



TMA Adelante! Un grupo de apoyo sobre miositis para hispanohablantes

December 18 at 5:00 pm - 6:30 pm ET

Únete a TMA Adelante! – Una Comunidad de Habla Hispana Avanzando Juntos

iAdelante! es el primer grupo de afinidad de TMA diseñado para personas de habla hispana que viven con miositis y sus cuidadores. Fundado bajo la creencia de que, a pesar de los desafíos de la enfermedad crónica, todos podemos seguir avanzando, este grupo ofrece un espacio de apoyo para hispanohablantes de todo el mundo para conectarse, compartir experiencias y encontrar fortaleza en la comunidad.

Ya sea que busques orientación, apoyo o simplemente un lugar para conectarte con otros que entienden tu camino, TMA Adelante! está aquí para ayudarte. Las reuniones se realizan cada dos meses, brindando una oportunidad constante para interactuar con otros que comparten el mismo idioma y experiencia.

**Register Today** 



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

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!

**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** 



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

### Latest post highlight:

Nobel Prize for Autoimmunity Advances Brings Hope to Those with Myositis

My First MyoCon

A Story of Discovery and Success...So Far

Long-time Friends Find Humor and Purpose in Difficult Journey

Read More

# MDA Offers Grants for Durable Medical Equipment

Those with IBM may benefit from a new program through the Muscular Dystrophy Association that provides up to \$1,000 towards durable medical equipment. This is not based on finances, only need.

**More Information** 

**Apply Here** 



Celebrating the holidays with a chronic condition like myositis can be joyful and fulfilling but may require a little planning and a lot of compassion. Here are some practical tips to help you and your loved ones enjoy the season together:

- Plan ahead: Share schedules so everyone knows what to expect.
- Focus on connection: Presence matters more than perfection.
- Communicate openly: Share your needs and limitations without guilt.
- Pace the festivities: Schedule rest breaks and avoid overexertion.
- Adapt meals: Offer soft, easy-to-swallow foods if dysphagia is a concern.
- Simplify traditions: Focus on meaningful, low-effort activities.
- Share the cooking: Invite others to help or bring dishes.
- Virtual visits: Consider video calls to connect if travel is not possible.





# MyoCon Session Recordings Available!

Order your copy of the 2025 MyoCon conference recordings to gain access to most of the educational sessions, as well as select other key events.

#### The recordings package includes:

- Video recordings of pre-conference virtual sessions
- Video recordings of the opening and closing keynote addresses
- Video recording of the Heroes in the Fight Awards Ceremony, featuring our myositis heroes
- Audio-recorded breakout sessions synced with slides from the presentation.

### For only \$149!

Recordings are only sold as a package. Individual sessions are not available for purchase.

When you sign up for these digital resources, they will be delivered to you in an email with a unique link where you can view the recordings at your leisure. Recordings are coming soon!

Thank you to MyoCon recordings sponsor, Pfizer MyOPath.

**Order Your Conference Recordings Today** 

\*MyoCon Attendees - do you want to revisit some of the sessions after your Dallas trip? Registered attendees automatically receive the recordings as an extra benefit of their conference registration! No need to order separately.





Presented by The Myositis Assocation
MYOSITIS.ORG

HYATT REGENCY • ST. LOUIS AT THE ARCH
Registration Opens April 1, 2026

# FIND THE CARE YOU NEED

**MediFind** 



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 <u>suggestions</u> <u>for using the tool here.</u>

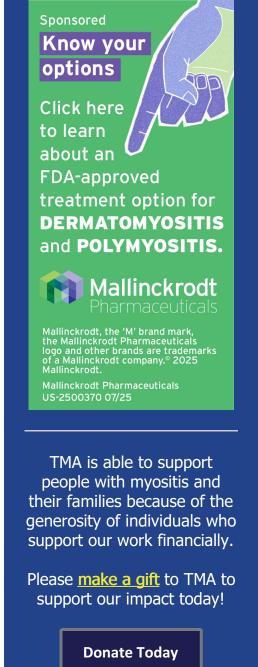


## Mind Your Mental Health

The holiday season is upon us! It's a time to celebrate with family and friends, enjoy home-cooked meals, and give thanks for all the blessings in our lives. We all look forward to this time of year, but none of us look forward to the stress it brings.

Dorothy Vetrano shares her journey with making this season more enjoyable and less stressful.

**Read More Today!** 





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



Connect with us!













Try email marketing for free today!