



THE MYOSITIS ASSOCIATION®

## MYONews January 2025 | Volume 5, Issue 1

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Happy New Year! As we step into 2025, we want to take a moment to thank each of you for your strength, resilience, and unwavering support throughout the past year. Together, we continue to raise awareness, advocate for better care, and build a community where no one faces myositis alone.

As you think about your New Year's resolutions, we encourage you to consider goals that prioritize your well-being—whether it's focusing on self-care, setting realistic health goals, or connecting more with our supportive community.



This newsletter is filled with ideas and resources to help you on your journey in 2025.

Here's to a year filled with hope, progress, and good health. May 2025 bring you peace, joy, and the strength to keep moving forward.

Warmest wishes,  
The Myositis Association Team

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# PROCLAMATION50

SUBMIT A  
PROCLAMATION REQUEST  
IN YOUR STATE IN TIME FOR  
MYOSITIS AWARENESS MONTH!



SIGN UP TO RECEIVE TMA TOOLKIT



## New Year's resolution option 1: Raise awareness in your state!

In 2025, TMA is launching Proclamation50, 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!

Join Proclamation50



***Myositis families need you!***

***Become a  
TMA Regional Myositis  
Support Group Leader***

***No need to be an expert -  
training and support provided!***

## New Year's resolution option 2: Become a regional support group leader!

TMA's regional myositis support groups give those who live with myositis and their care partners the opportunity to connect and commiserate with others living near them. These intimate groups are vital to the myositis community, and TMA invites you to become a leader in your area.

Whether as a co-leader for an existing group or reactivating a group in need of leadership, TMA will provide training and support to help you along the way. This is a small time commitment of around three hours per month, and that's only if you choose to meet each month. How often you meet would be up to you!

To learn more, please fill out our [volunteer survey](#). Thank you for considering giving the gift of your time to the myositis community!

[Become a Support Group Leader](#)



## New Year's resolution option 3: Get involved with TMA affinity groups

TMA affinity groups are another way you can create supportive connections with others who live with myositis diseases and who also share your interests. Start your New Year by resolving to join one or more of these virtual communities from anywhere in the world! Find our full schedule of support and affinity group meetings on our [calendar](#).

- TMA Adelante! Grupo de afinidad - For Spanish speakers - Meets every other month, see calendar
- TMA Care Partner Affinity Group - For those who love someone with myositis - Meets in their own breakout room with TMA's Nationwide Support Group on first Saturday of the month at 1pm ET
- TMA Flying Solo Affinity Group - For those who do not have a live-in care partner - First Wednesday at 8pm ET
- TMA Men Managing Myositis - Fourth Tuesday at 7pm ET
- TMA Men of Color Affinity Group - Meets quarterly, see calendar
- TMA Military Veterans with Myositis Affinity Group - Second Saturday at noon ET
- TMA Rainbow Affinity Group - For members of the LGBTQ+ community - Fourth Sunday at 5pm ET



- TMA Women with IBM Affinity Group - Third Tuesday at noon ET

Join a TMA Affinity Group



TMA is honored to have a Medical Advisory Board made up of 26 of the world's most prominent myositis experts. We want to express our sincere thanks to five members who rotated off the MAB at the end of the year:

- Malin Regardt - Occupational therapist, MAB member since 2018
- Tae Chung - Rehab specialist, MAB member since 2018
- Sonye Danoff - Pulmonologist, MAB member since 2018
- Lindsay Alfano - Physical therapist, MAB member since 2020 and Research Committee Chair since 2022
- Louise Diedrichsen - Rheumatologist, MAB member since 2022



# Order the 2024 International Annual Patient Conference Recordings

The 2024 International Annual Patient Conference recordings are now available! Don't miss your chance—order now for only \$149 and enjoy access to 30 sessions, including keynote presentations, virtual talks, and the Heroes in the Fight Awards Ceremony. Secure your access today to watch these impactful sessions!

Conference attendees have been sent a link to access the recordings free of charge. Email [IAPC@myositis.org](mailto:IAPC@myositis.org) if you did not receive a message describing how to access the virtual content.

**Order Your Recordings Today**



## New Member Orientation!

January 17, 2025 12 PM ET | 11 AM CT | 10 AM MT | 9 AM PT

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 Session: Finding Peace: Easing Anxiety in the Face of Myositis

January 22, 2025 12 PM ET | 11 AM CT | 10 AM MT | 9 AM PT

Do you struggle with anxiety like so many do? Anxiety can feel incredibly scary because it triggers both physical and emotional responses, leaving us feeling out of control or unable to cope with everyday situations. Knowing that anxiety doesn't have to dominate one's life—and that there are ways to reduce its intensity—can go a long way in alleviating the fear that comes with it. Join The Myositis Association on Wednesday, January 22, 2025, at noon ET for a special webinar, "Finding Peace: Easing Anxiety in the Face of Myositis," featuring Sanchita Sharma, PsyD from the Maryland CBT Center.

In this empowering session, Dr. Sharma will guide you through proven Cognitive Behavioral Therapy (CBT) techniques that help reduce anxiety, stress, and emotional distress—tools you can start using right away. Whether you're managing the uncertainties of living with myositis or supporting a loved one, this webinar will equip you with practical strategies to find emotional balance, improve resilience, and cultivate peace of mind.

Don't let anxiety control your life—take the first step toward emotional well-being and reclaim your peace of mind. Register today and discover how CBT can help you navigate the emotional challenges of myositis with greater confidence and calm.

[Register Today](#)



The banner features a dark blue background with a geometric pattern. At the top left is the logo for The Myositis Association, consisting of a stylized figure with arms raised. To its right, the text "THE MYOSITIS ASSOCIATION'S" is written in white. Below this, the words "Ask the" are in white, "EXPERT" is in large green letters, and "Series" is in white. On the right side is a circular portrait of Dr. Namita Goyal, a woman with dark hair, smiling. Below the portrait, the text "DR. NAMITA GOYAL" is in large white letters, followed by "NEUROLOGIST" in smaller white letters. Below that is "JANUARY 23, 2025" in white, and then the times "4 PM ET | 3 PM CT | 2 PM MT | 1 PM PT" in white. At the bottom, a dark blue bar contains the text "UNIVERSITY OF CALIFORNIA IRVINE" in white. A small blue circular icon with a white video camera symbol is located on the right side of the banner.

**THE MYOSITIS ASSOCIATION'S**

Ask the  
**EXPERT**  
Series

**DR. NAMITA GOYAL**  
**NEUROLOGIST**  
**JANUARY 23, 2025**  
4 PM ET | 3 PM CT | 2 PM MT | 1 PM PT

**UNIVERSITY OF CALIFORNIA IRVINE**

## Ask the Expert: Neurology

January 23, 2025 4 PM ET | 3 PM CT | | 2 PM MT | 1 PM PT

Do you have burning questions that can't wait until your next appointment? Are you newly diagnosed and learning all you can? Please join this Ask the Expert webinar. Dr. Namita Goyal is a Professor of Neurology at University of California, Irvine and co-Director of the Neuromuscular Center at UC Irvine. She is a lead site investigator in several myositis clinical trials. Dr. Goyal serves as chair of TMA's Medical Advisory Board.

[Register Today](#)

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**UNLOCKING THE  
POTENTIAL OF CAR T  
IN MYOSITIS:**  
**ADVANCES  
& INSIGHTS**

*Iazsmin Bauer*  
*Ventura, MD, MSc*  
*University of  
Chicago*

**TUESDAY, JANUARY 28, 2025**  
**5:30 PM ET | 2:30 PM PT**



## Unlocking the potential of CAR T therapy in myositis

January 28, 2025 5:30 PM ET | 4:30 PM CT | 3:30 PM MT | 2:30 PM PT

Join us for an exciting and informative webinar exploring the groundbreaking role of CAR T (Chimeric Antigen Receptor T cell) therapy in the treatment of myositis.

As autoimmune diseases like myositis continue to challenge traditional treatment approaches, CAR T cell therapy offers new hope by harnessing the power of the immune system to target and destroy disease-causing cells. This session will dive deep into the latest advancements, clinical trial results, and the potential impact of CAR T on myositis care. Don't miss the chance to learn more about this rapidly evolving field!

Dr. Bauer Ventura is leading Cabaletta Bio's CAR T clinical trial at the University of Chicago. She is an expert in inflammatory myopathies and directs the Myositis Program at the University of Chicago. Dr. Bauer Ventura is also an immediate past member of TMA's board of directors.

*Thank you to our webinar sponsor, Cabaletta Bio.*

[Register Today](#)

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## 2025 TMA & KUMC Regional Myositis Conference

February 1, 2025, 10 AM - 3 PM ET | 7 AM - 12 PM PT

The Myositis Association (TMA) and the University of Kansas Myositis Center (KUMC) are proud to host the 2025 Regional Myositis Conference on Saturday, February 1st from 10:00 AM to 3:00 PM Eastern. This *virtual* event is completely free for individuals living with myositis and their care partners, offering an invaluable opportunity to connect, learn, and gain support.

Whether you're newly diagnosed or have been living with myositis for years, this conference is designed to provide critical information on managing the condition, understanding the latest research, and improving quality of life. Sessions will feature expert speakers in myositis care, including top doctors, researchers, and specialists from the University of Kansas Myositis Center.

Register now to secure your spot!

[Register Today](#)



## TMA Meet & Greet Leadership Series: Advocacy Edition

February 6, 2025, 12 PM ET | 11 AM CT | 10 AM MT | 9 AM PT

Join us for an exclusive virtual Meet & Greet: Advocacy Edition! This exciting event features guest Deborah A. Armstrong, former New Mexico Legislature Representative and TMA member, who will share her invaluable insights on advocacy in the myositis community.

During this interactive session, you will learn about the critical role of advocacy in advancing myositis awareness, research, and policy change. Deborah will discuss her personal journey in advocating for rare disease communities and offer practical tips on how you can become an effective advocate.

TMA Board Chair Laurie Boyer and TMA Executive Director Paula Eichenbrenner will also be on hand to facilitate the conversation. Don't miss this unique opportunity to connect with others, gain inspiration, and learn how you can make a difference in the fight for myositis awareness and research.

[Register Today](#)



## Check out what other TMA members found compelling on our blog. Read our top five recent posts:

### How to qualify for Social Security Disability benefits with myositis

<https://www.myositis.org/blog/how-to-qualify-for-social-security-disability-benefits-with-myositis/>

### Immune boosting supplements can make autoimmunity worse

<https://www.myositis.org/blog/immune-boosting-supplements-can-make-autoimmunity-worse/>

### CAR T-cell therapy: A viable option for myositis treatment?

<https://www.myositis.org/blog/car-t-cell-therapy-a-viable-option-for-myositis-treatment/>

### Dermatomyositis: Not my whole life

<https://www.myositis.org/blog/dermatomyositis-not-my-whole-story/>

### Celebrating World Myositis Day: Myositis Africa

<https://www.myositis.org/blog/celebrating-world-myositis-day-myositis-africa/>

[Read More on the TMA Blog](#)

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## Mind Your Mental Health: Diet?

Can what you eat really affect your mental health? Many research studies have shown that, yes, diet definitely influences mood and brain function. Here are some ways you can use food to help you feel better.

- **Eat regularly.** Low blood can make you feel tired and grumpy.
  - **Stay hydrated.** Even mild dehydration can affect your mood, energy level, and ability to concentrate.
  - **Don't avoid healthy fats.** Your brain needs healthy fats to function well. Focus on health fats, such as olive oil, canola oil, nuts, seeds, oily fish, avocados, milk, and eggs. Trans fats, however, should be avoided. These unhealthy fats include vegetable shortening and margarine and are often found in processed or packaged foods.
  - **Eat protein at every meal.** It contains helpful compounds that the brain relies on to help regulate mood.
  - **Maintain good gut health.** The digestive tract is an important factor in autoimmune diseases like myositis and responds readily to stress. Healthy food for your gut includes fruit, vegetables, beans, and probiotics.
  - **Check your caffeine.** Coffee, tea, chocolate, cola, and energy drinks can make you anxious and cause sleep problems.
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## Spotlight on Giving: There's Still Time to Make an Impact

As we step into 2025, there's still time to support The Myositis Association and help us provide vital education, advocacy, and research funding for those living with myositis. Your generosity can create brighter tomorrows for individuals and families impacted by this rare disease. Donate today and start the new year by making a lasting impact!

[Donate Today](#)

## FMLA leave can be used for clinical trial participation

In an opinion letter dated November 8, the US Department of Labor (DOL) clarified that FMLA leave can also be used for participation in clinical trials. This is a significant development for employees facing serious health conditions like myositis.



[Read More](#)

**Do you have an autoimmune or rheumatic disease?**

Complete our online survey on the impact of the weather on these diseases!

Scan the QR code to take our survey now!



Or use this link:  
[https://uchicago.co1.qualtrics.com/jfe/form/SV\\_6D82NPNto0W034](https://uchicago.co1.qualtrics.com/jfe/form/SV_6D82NPNto0W034)

If questions/concerns, please email the PI, Iazmin Bauer Ventura MD, MSc, at [iventura@uchicago.edu](mailto:iventura@uchicago.edu).

For more information, visit <https://reactrheum.org/>

Does climate change affect autoimmune disease? A [group of concerned rheumatologists](#) and the Autoimmune Association need your help to answer this question.

[Take the survey now](#) or [take the survey in Spanish](#).

[Read the Autoimmune Association's Message](#)



## How satisfied are you with your Medicare Part D drug coverage?

The Autoimmune Association is evaluating how well Medicare Part D drug policies cover the cost of the medications used by those with autoimmune diseases. If you are a Medicare beneficiary with a Part D policy, please complete this easy, 5-minute survey. We'll let you know the results in a few months.

[Take the Survey Now](#)



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.

We've worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our [suggestions for using the tool here.](#)



### Community Tips: Infection Prevention

If you're living with myositis, it's likely that you are immunocompromised. That means, because of your disease or treatment (steroids and other immune suppressant medications), your immune system isn't doing a great job fighting infections and diseases. This is the time of year when we are all especially vulnerable to colds, flu, and COVID.

Following are some things to think about to help you avoid infections:

- **Wash your hands often**, especially before eating or preparing food, after changing diapers or using the bathroom, after gardening, or after touching pets or farm animals.
- **Carry hand sanitizer** and use it whenever soap and water are not available.
- **Wear a mask when you're in a crowded indoor space** like the grocery store or movie theater, especially during times when COVID and flu are on



## CLINICAL TRIALS CORNER

- the rise in your community.
- **Avoid contact with others who are sick.**
- **Avoid touching your eyes, mouth, or nose** without washing your hands first with soap and water.
- **Clean surfaces you touch frequently** like counters, doorknobs, handrails, and grocery cart handles.

**Should you get the jab?** If it's a live vaccine—one that uses a weakened form of the disease-causing organism like chicken pox, MMR, and rotavirus—the answer is probably no. Inactivated vaccines, however, like the flu, pneumonia, and COVID shots, are generally safe for immunocompromised individuals. Be sure to talk to your doctor about which vaccinations are right for you.

Pfizer is proud to support the Ig community

Pfizer

We're committed to supporting your DM treatment experience by providing patients and caregivers with:

- Support
- Treatment options
- Resources

Scan to learn about Pfizer's treatment option for adults with DM

DM=dermatomyositis; Ig=immunoglobulin.  
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[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.

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**



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