



THE MYOSITIS ASSOCIATION®

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## Help Us Raise \$5,000 for the International Annual Patient Conference Scholarship Fund During Rare Disease Week

Attending TMA's International Annual 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 24-28, our goal is to raise \$5,000 to provide scholarships that allow more myositis patients and their families to attend this life-changing conference.

Your donation, no matter the size, helps bring hope and connection to patients who need it most. Join us in making a difference—give today and help us reach our goal.

[Donate to the Scholarship Fund Today](#)



TMA is deeply committed to fostering a diverse and inclusive environment where all individuals feel valued, respected, and empowered. We believe that embracing diversity—whether in race and ethnicity, gender, background, or thought—strengthens our organization and enriches our ability to innovate and collaborate. Through ongoing education, support, and proactive 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 core values [here](#).

In honor of Black History Month, we're highlighting a 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](#)

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## TMA Proclamation 50

Do **YOU** live in one of these states?

- Alaska
- Idaho
- Indiana
- Kentucky
- Louisiana
- Maine
- Mississippi
- Montana
- Nevada
- North Dakota
- Oregon
- South Dakota
- Vermont
- West Virginia

Only 14  
left!

TMA NEEDS VOLUNTEERS FROM THE ABOVE STATES TO SUBMIT  
PROCLAMATIONS FOR MYOSITIS AWARENESS MONTH.

### Raise awareness in your state!

Proclamation 50 is TMA's goal to acquire proclamations in all 50 states in the US for Myositis Awareness Month in May! We are more than halfway there with just 14 states to go! If you live in any of these states, PLEASE consider making this small time commitment for a very vital cause! The volunteer does NOT have to be a patient or care partner so if you have family and friends in these states, please encourage them to join us! TMA Board Vice Chair Rich DeAugustinis will be available for coaching along the way. Watch the video as he shares about this important initiative and join today!

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Interested? Sign up to be a Proclamation 50 participant today!

[Join Proclamation 50](#)

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TMA Board Vice Chair Rich DeAugustinis shares TMA's Proclamation 50 initiative.

[Watch now](#)

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**Myositis families need you!**

**Become a**

**TMA Regional Myositis  
Support Group Leader**

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

## **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 coleader 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**



## Vance Robinson's Myositis Awareness First Pitch Campaign goes global!

TMA volunteer Vance Robinson has raised myositis awareness on behalf of TMA for nine years through his annual First Pitch Campaign. For the first time, the campaign has made it's global debut. On January 12, Drew Ponce, a friend of Vance's, threw the first pitch at the nonprofit organization Gloves for Cuba baseball game in Playa Largo, Cuba! TMA appreciates Vance and Drew for this incredible outreach!

You can pitch in to raise awareness of myositis, too!

[Learn More](#)

Did you know? Many of our support & affinity group meetings use breakout rooms for a highly interactive experience. For instructions on accessing and moving between breakout rooms, review [Accessing Zoom breakout rooms](#).



## TMA Meet & Greet Leadership Series: Advocacy Edition

Thursday, February 6, 12pm ET | 9am 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 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](#)



## Empowerment Clinic: 60 Seconds to Impact: Sharing Your Story with Purpose

Thursday, February 20, 12pm ET | 9am PT

Do you struggle with explaining your invisible illness to others? Do you wish there was a quick way to get the point across to family, friends and acquaintances? Or are you ready to become an advocate for myositis and want to enhance your elevator speech?

Join award-winning journalist, writer, and advocate Lindsay Guentzel for a powerful empowerment clinic that will help you harness the transformative power of storytelling. Diagnosed in 2023 with dermatomyositis associated with antisynthetase syndrome, Lindsay is now an active voice in the myositis community, using her expertise to raise awareness and inspire others.

In this session, Lindsay will teach you how to craft and deliver your personal story in 60 seconds or less—empowering you to connect, inspire, and make an impact. Learn how to channel your experiences and voice to advocate for yourself and others, and leave with the confidence to share your journey with purpose.

Whether the impact you want to make will be during Rare Disease Week advocacy on Capitol Hill with EveryLife Foundation at the end of February or simply being understood by those who know you in your every day life, this webinar is the perfect presentation.

[Register Today](#)

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## **2025 IgNS Patient 360 Virtual Conference: March 8-9**

The Immunoglobulin National Society (IgNS) offers this free, virtual education and support conference for those receiving immunoglobulin therapy and their care partners.

[Register Today](#)

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MAXIMILLIAN KONIG, MD



JANE MYLES  
TMA BOARD OF DIRECTORS

# CAR T-CELL THERAPY AND BISPECIFIC ANTIBODIES: NEW FRONTIERS FOR MYOSITIS TREATMENT



WEDNESDAY  
MARCH 12, 2025  
6 PM ET | 3 PM PT



## Chimeric Antigen Receptor (CAR) T-Cell Therapy and Bispecific Antibodies: New Frontiers for Myositis Treatment

Wednesday, March 12, 6pm ET | 3pm PT

CAR T-cell therapy is a revolutionary new treatment that is being tested for myositis. In this webinar, moderated by TMA Board Member Jane Myles, Dr. Max Konig of Johns Hopkins University will share how special cells in our body can be trained to fight autoimmunity. It's like sending superheroes into battle against bad guys! Learn how this therapy can help defeat myositis symptoms, possibly for good.

[Register Today](#)





## Ask the Expert Physiatry with Dr. Nicole Voet

Tuesday, March 18, 12pm ET | 9am PT

Nicole Voet, MD, PhD is a renowned rehabilitation physician and member of TMA's Medical Advisory Board, who will share insights on how physiatry can support individuals living with myositis.

Physiatry, also known as physical medicine and rehabilitation (PM&R), focuses on improving quality of life for patients with musculoskeletal conditions, pain, and functional impairments.

Dr. Voet will discuss the role of physiatrists in managing myositis, including rehabilitation strategies, muscle strength, and mobility enhancement, as well as the multidisciplinary approach to treatment. Don't miss this opportunity to learn how physiatric care can help you or a loved one manage myositis more effectively. Register now and get your questions answered by an expert in the field!

[Register Today](#)



Registration for the 2025 International Annual Patient Conference will open April 1, 2025. We can't wait to see you in Dallas, Texas!

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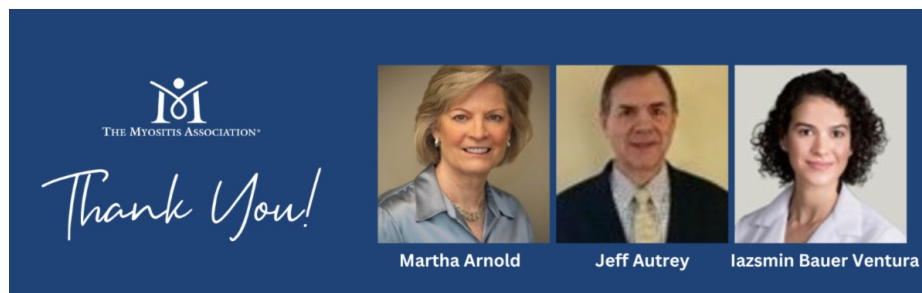


## From the Blog

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

- [TMA year in review: Reader favorites from the blog](#)
- [A treatment that's almost too good to be true](#)
- [Remembering Nori](#)
- [Tips for thinking about joining clinical trials](#)

[Read More on the TMA Blog](#)



## 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. We are grateful to three hard-working members who rotated off this year.

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## Shawna's Top Ten Tips for Newly Diagnosed

- Be patient with yourself
- Learn as much as you can from TMA, not Google
- Consider a second opinion at a specialty center
- Create a medical binder
- Keep records of abnormal tests
- Keep a list of medications
- Check the MyoTracker for symptoms
- Cut corners where you can, at home & work
- Ask for help
- Keep moving as much as you can

## Shawna's top ten tips for newly diagnosed

Shawna Nielsen is a registered nurse who has lived with DM for over 26 years. She is a tireless advocate for those who live with myositis, serving as coleader for TMA's Northern California myositis support group and managing two myositis Facebook support groups.

Do you have tips that have made your myositis journey easier? Share them with the community!

[Share Your Tips](#)



## FDA-NIH Rare Disease Day 2025

Sponsored by the **U.S. Food and Drug Administration (FDA)** and the **National Center for Advancing Translational Sciences (NCATS)**, **FDA-NIH Rare Disease Day 2025** will be held both in-person at the NIH main campus (Natcher Conference Center) and virtually on Thursday, February 27 and Friday, February 28, 2025 from 10am-4pm EST.

The event aims to provide the rare disease community with information relevant to



their lived experiences, including activities by FDA and NIH that promote research and product development for this underserved population.

TMA's own Lindsay Guentzel will present on Friday. Her talk is *Rare Story: The Full-Time Job of Living Rare—Advocacy, Resilience, and the Fight for Care*.

We want to know if you plan to attend. Please email [Rachel@myositis.org](mailto:Rachel@myositis.org) to coordinate schedules!

[Learn More & Register](#)



## FIND THE CARE YOU NEED

**MediFind**



THE MYOSITIS ASSOCIATION

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](#).

[TMA's YouTube channel](#) has been updated with links to all the most recent



## Mind your mental health: Social connection improves physical, mental, and emotional health

We all know how important things like diet, exercise, and sleep are to staying healthy. But did you know that calling a friend, spending time with your children or grandchildren, being part of a team, or joining a club are just as important for health and wellbeing?

Studies show that not having satisfying connections with others is worse for our health than obesity, smoking, and high blood pressure! Unfortunately, research also shows that loneliness is on the rise.

Don't let loneliness make you sick. Reach out to family, friends, neighbors, or coworkers, or start a conversation with the barista when you're ordering coffee. It doesn't take much effort to text someone and tell them you're thinking about them.

And don't be afraid to ask for help when you

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.

need it! Science also shows that asking not only makes *you* feel less stressed but also makes *the person who helps* feel happier too!

## TMA Nationwide Support Group

TMA provides monthly virtual myositis support by diagnosis with TMA Nationwide. Co-led by up to five trained and certified support or affinity group leaders from across the country, this group also welcomes our international members. Care partners have their own breakout room!

[To find additional groups, visit our list of all support & affinity groups.](#)



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



Connect with us!



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

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