



THE MYOSITIS ASSOCIATION®

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We Care for Rare Summit

Rare Disease Week was a great success for TMA, raising awareness of myositis and other rare diseases across the nation and the world. Stay tuned for a special recap of Rare Disease Week coming to your email soon!

Until then, check out the recording of our Rare Disease Day summit, now available.

[Watch the We Care for Rare Summit Replay](#)



TMA Awards Nearly Half a Million Dollars in Myositis Research Grants

TMA's vision is a world without myositis. We know the only way to achieve this ideal is through scientific research. That's why investing directly in innovative research is at the heart of our mission.

Since 2002, TMA's annual research grants program has approved 68 projects totaling nearly \$8.2 million to study the underlying causes and natural progression of myositis, develop

better treatments and more effective therapies, and ultimately create a cure for this collection of rare, disabling conditions.

We are pleased to announce that in 2024, three of these research projects, totaling nearly half a million dollars, were completed.

[Read About These Projects](#)



Myositis Research Awards Bring Hope to those with Rare Diseases

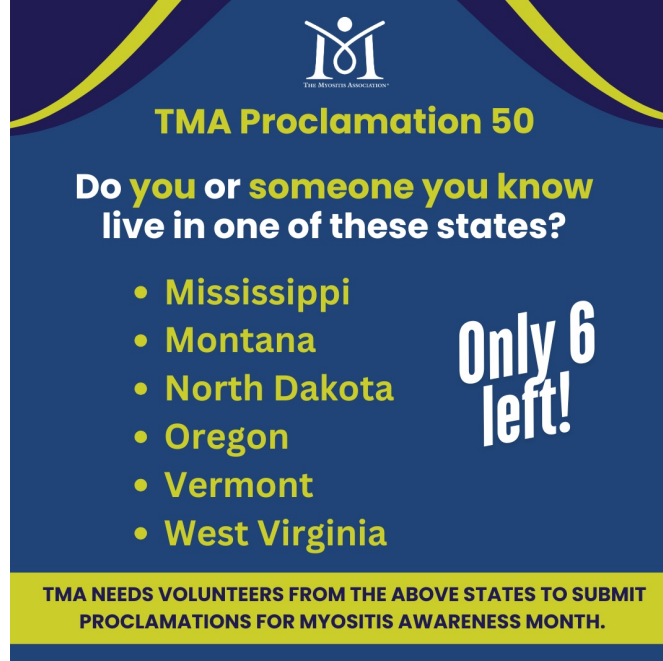
Every year since 2002, TMA has awarded research funding to exceptional scientists working to understand, treat, and cure myositis diseases. TMA invites projects from across the spectrum of myositis diseases and specialties.

Our most recent grant cycle targeted projects related to two specific forms of myositis: inclusion body myositis (IBM) and juvenile myositis (JM).

We are pleased to announce a grant of \$80,000 was awarded to Thomas Lloyd, MD, PhD, Chief of Neurology at Baylor College of Medicine, Houston, TX, for his project "Senolytic therapies in a novel patient-derived myoblast model of inclusion body myositis (IBM)."

Our second grant of \$45,000 was awarded to Christian Lood, PhD, Associate Professor of Medicine at the University of Washington School of Medicine, Seattle, WA, for his efforts to identify "Mitochondrial contribution to juvenile dermatomyositis (JDM)."

[Read About These Grants](#)



Only 6 states left!

Do you or someone you know live in the following states? TMA only has 6 states left to reach its goal to acquire proclamations in all 50 states in the US for Myositis Awareness Month in May! This volunteer role has a small time commitment and as project lead, TMA Board Vice Chair Rich DeAugustinis will be available for coaching along the way.

Interested? Email proclamations@myositis.org today!



Myositis Awareness Month 2025

May is Myositis Awareness Month! It's a time for the myositis community to raise our collective voices and let the world know what this rare disease is all about. It's TMA's mission to support those who live with myositis and their care partners by bringing awareness, sharing resources, educating patients and the public about myositis diseases, sharing strategies for advocacy, and building a stronger and more connected myositis community.

Myositis Awareness Month 2025

PATIENT 360 IgNS

MARCH 8-9, 2025 VIRTUAL CONFERENCE


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](#)


**MYOSITIS
RESEARCH
INSIGHTS
WEBINAR:**

**CHEILONDA
JOHNSON,
MD, MHS**



 UNIVERSITY OF PENNSYLVANIA

**TUESDAY
MARCH 11, 2025
12 PM ET | 9 AM PT**



Myositis Research Insights Webinar Featuring Dr. Cheilonda Johnson

March 11, 2025, 4 pm ET | 1 pm PT

Don't miss an exclusive opportunity to hear from Dr. Cheilonda Johnson, a pulmonologist and expert in autoimmune-related interstitial lung disease (ILD) at the University of Pennsylvania and member of TMA's Medical Advisory Board. Dr. Johnson's groundbreaking research focuses on understanding the clinical and genetic factors behind autoimmune-ILD, a serious condition often associated with myositis.

In this webinar, Dr. Johnson will share insights from her recent pilot project funded by TMA, which identified key genetic markers linked to ILD in myositis patients. This work, which includes a unique lung tissue sample database, reveals critical information on how myositis genes can predict not only who is at risk for ILD, but also the severity of the disease. Dr. Johnson will discuss these and other findings of her research and what they mean for advancing treatments and improving outcomes for myositis patients.

[Register Today](#)

The graphic features two circular headshots of speakers: Maximillian Konig, MD, and Jane Myles, TMA Board of Directors. The title 'CAR T-CELL THERAPY AND BISPECIFIC ANTIBODIES: NEW FRONTIERS FOR MYOSITIS TREATMENT' is displayed in large, bold, yellow and blue text. The date and time 'WEDNESDAY MARCH 12, 2025 6 PM ET | 3 PM PT' are shown in white text on a green background. A small video camera icon is also present. The TMA logo is in the bottom left corner.

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**

 The Myositis Association

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

Friday, March 28, 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](#)



New Member Orientation

Friday, April 11, 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](#)



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



From the Blog

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

- [CAR T: A promising new frontier for myositis treatment](#)
- [Rare diseases need more research, not less](#)
- [TMA board vice chair testifies in support of Georgia's Hope for Patients Act](#)
- [Finding strength in the shadows](#)
- [How to qualify for Social Security Disability benefits with a rare disease](#)

[Read More on the TMA Blog](#)

March is Autoimmune Disease Awareness Month. Each year, TMA partners with the Autoimmune Association and their National Coalition of Autoimmune Patient Groups (NCAPG) to increase understanding and awareness of autoimmune diseases.



[Learn More](#)



Welcome to Meditation Mondays A Space for Mindfulness & Healing - pilot starting in May!

When: Every Monday starting May 5 (except holidays), 9-9:30am ET | 8-8:30am CT | 7-7:30am MT | 6-6:30am PT

Who's it for: People living with myositis and their care partners.

What we'll do: We'll come together for a guided meditation session that includes brief exercises, followed by reflections. These exercises will be led either by a special guest, a member of the group, or through a pre-recorded exercise. Each week, we'll explore different types of guided mindfulness exercises, and people of all levels of experience are welcome.

Whether you're just starting your mindfulness journey or have been practicing for years, you're welcome here. To join us, please fill out the interest form to receive the link for the session. First session is May 5!

[Learn More](#)



Representatives of ten companies who support TMA's mission through our Corporate Advisory Council met with Board Chair Laurie Boyer and Paula. Physical therapist Jim Milani was also there as a special guest, sharing about Myositis Awareness Month, Proclamation 50, and an upcoming webinar with panelists who are health care providers living with myositis. Jim is TMA's Colorado Support Group leader, and he lives with IBM. Corporate advisors were impressed with the data!

At last! The Voice of the Patient Report has been released for last year's Externally Led Patient Focused Drug Development meeting with the FDA in which TMA partnered with MSU. Many TMA members participated as panelists and commenters and completed the survey, telling their stories and experiences of living with DM. And TMA medical advisors presented medical background on DM. Thanks to everyone involved with this important and enlightening presentation to those responsible for approving new treatments for DM.



Engage, Educate, Empower

[Read the Report](#)

**Coping for Inclusion Body Myositis (IBM)
Caregivers Survey**

This study was conceived by Myositis Support and Understanding (MSU) and led by
Marlene Jansen, PhD a person with Inclusion Body Myositis (IBM) and VP of Myositis
Canada. Marlene Jansen has a degree in Health Psychology, and is a passionate advocate
for caregivers and living well with IBM.

The purpose of this study is to gain a deeper understanding of the challenges that IBM
caregivers may face and the results will be used to help MSU and Myositis Canada
provide proper resources, knowledge and help to IBM families.

The survey will take approximately 10 - 15 minutes to complete, and your time and honest
feedback will be greatly appreciated.

This study understands MSU's commitment to research led by myositis patient advocates.

Are you an IBM Care Partner? Take the Coping for
Inclusion Body Myositis (IBM) Caregivers Survey today!

Take the Survey

TMA's Scholarship Fund
Donate now to help us reach our goal!

How to Help
TMA needs 50 donors to the scholarship fund to reach our goal during **Rare Disease Week!**

How It Works
All funds donated go directly to the TMA International Annual Patient Conference Scholarship to help offset the cost of attending for scholarship recipients.

Where to Donate
myositis.org/scholarships

The graphic features a large thermometer on the right side, with a yellow liquid level reaching the 50 mark. The thermometer has the TMA logo at the bottom. The background is light blue with white stars and wavy lines.

Spotlight on Giving

Thank you to everyone who donated to the TMA 2025 International Annual Patient Conference Scholarship Fund! With your help we were able to raise over \$5400 during Rare Disease Week! All funds go directly to help send myositis patients and their care partners to the conference. Want to learn more? Visit our website today!

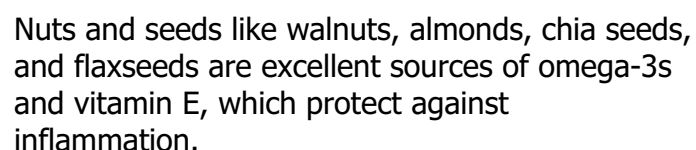
Learn more and support TMA Scholarships



Advocacy Updates: Medicaid

Medicaid cuts are still a hot topic on Capitol Hill, as the House Energy and Commerce Committee has been tasked with slashing \$880 billion. Medicaid coverage is a lifeline to health and long-term care for 83 million adults and children in the United States. Work

With TMA advocates from seven states in Washington, DC, for Rare Disease Week Feb. 24-26, myositis was more visible than ever in the nation's capital. Let's keep the momentum going! From the comfort of home, you can follow up on the key issues we discussed with Congressional offices. View action alerts about federal research funding, pediatric Priority Review Vouchers, and more on the [Every Life Foundation and Rare Disease Legislative Advocates website](#).



[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.

Whole grains and legumes, including brown rice, quinoa, oats, beans, and lentils, are high in fiber. Fiber supports gut health by feeding good bacteria in your gut microbiome (more on this later) and reducing overall inflammation.

Spices and herbs like turmeric (curcumin), ginger, cinnamon, garlic, and rosemary all have natural anti-inflammatory properties.

Probiotic foods like yogurt, kefir, kimchi, sauerkraut, miso, and kombucha help balance gut bacteria-an important factor in controlling inflammation.

Green tea contains EGCG (epigallocatechin-3-gallate), a compound known for its strong anti-inflammatory effects.

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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