



THE MYOSITIS ASSOCIATION®

MyoNews August 2025 | Volume 5, Issue 8

MyoCon[™]
TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

SEPTEMBER 18-21, 2025

Register Now

SHERATON DALLAS HOTEL | DALLAS, TEXAS

MyoCon 2025: Find Your Myositis Community

Join hundreds of fellow patients, care partners, and experts at MyoCon: TMA's 30th Global Myositis Patient Conference in Dallas, TX from September 18-21, 2025. From cutting-edge science to meaningful connection, MyoCon is where you'll find the knowledge, support, and friendships that last long after the conference ends.

Rates increase after September 4. Lock in the lowest rate today with code **ROLLBACK** at checkout!

Register Today

MyoCon[™]
TMA'S GLOBAL MYOSITIS PATIENT CONFERENCE

Speakers

DALLAS, TEXAS
SEPTEMBER 18-21, 2025
SHERATON DALLAS HOTEL



DR. TOM LLOYD
NEUROLOGIST



DR. LISA CHRISTOPHER-STINE
RHEUMATOLOGIST



DR. JANINE LAMB
GENETICIST



LINDSAY GUENTZEL
MYOSITIS ADVOCATE

Do you have questions about MyoCon 2025?

Visit TMA's MyoCon FAQ page for answers to the most commonly asked questions.

[MyoCon FAQ's](#)



Rare Across America with EveryLife Foundation

Rare Across America is the opportunity to meet with your Members of Congress at their in-district offices and educate them on the issues that are most important to the rare community by sharing your story. All Senate meetings will be scheduled virtually and House meetings will be in-person at your Member's in-state, in-district office.

[Learn More](#)

We're partnering with Pampered Chef to raise funds for The Myositis Association!



- TMA will earn up to 30% of all sales! (Plus my commission)
- For every party booked through this fundraiser, \$10 will be donated!
- The shopping link will be available through 8/15/25
- Order anytime through the link provided or this QR code.

PC Consultant: Kristin Hicks
pcckhicks@gmail.com

Email me with any questions
or to book an online party!



New TMA Board Officer

Richard (Chip) Galloway, Jr. has stepped into the role of Treasurer of TMA's Board of Directors, effective April 1, 2025.

Chip was diagnosed in 2020 with inclusion body myositis. Since then, he has been tireless in his efforts to raise awareness of this rare disease in everything he does and in every place he goes. He brings professional experience as an auditor and nonprofit board leader to the role, as well as indomitable energy and passion for serving his fellow myositis warriors.

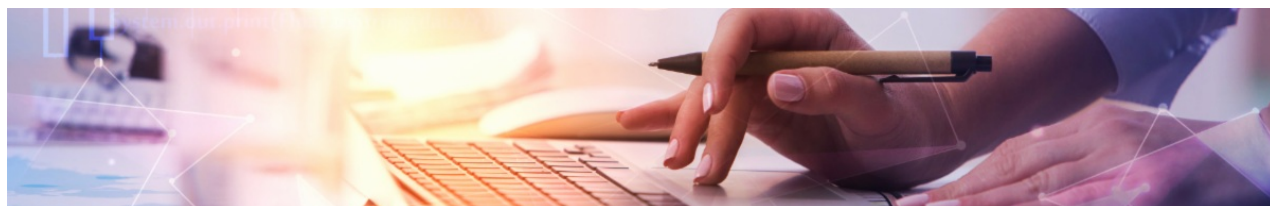


The Board wishes to thank Howard Gerrin for serving as Treasurer prior to Chip. His expertise in finance and investments served him well in his role overseeing TMA's finances.

Howard's leadership and involvement will continue to benefit TMA's mission driven work as he remains on the Board and Finance Committee. An IBM patient, Howard is well known for inventing the "I've Been Motivated" T-shirts. Learn more about



TMA's Board [on our website](#).



From the Blog

Looking for expert advice or a dose of encouragement? The TMA blog is filled with patient stories, research updates, and simple, helpful tips to support your life with myositis.

Latest post highlight:

[Seeing the other side: On being a clinical trial participant](#)

[MyoCon 2025: Melissa's List](#)

[Rare disease research depends on you](#)

[Living in the Present](#)

[Read More](#)



Patients Help Shape the Future of Myositis Research♥

People living with myositis (& *their loved ones*) MUST have a say in how future research is selected.

MIHRA Patient Advisory and *MIHRA Board of Directors* are launching a global project to define research priorities from the patient perspective. Your input will guide future funding and where researchers should put their focus.

We ask people living with myositis (& *their loved ones*) to [use this survey link](#) to voice what areas of research are most important to you.

(translate the survey into your language by 'right-clicking' and choosing 'translate') No science background needed - speak from your heart & experience.

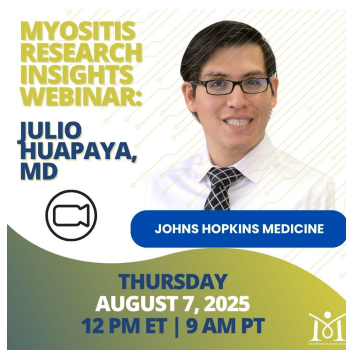
This survey will remain open until Monday, August 18, 2025. Please pass this message on to others in the myositis community.

[Take the Survey](#)

Upcoming Events

Myositis Research Insights Webinar

July 7, 2025 at 12 PM ET | 9 AM PT



Join us for an insightful session with Julio Huapaya, MD, a critical care and pulmonary specialist affiliated with Johns Hopkins Medicine and the NIH Clinical Center.

Dr. Huapaya's talk will dive into his cutting-edge research on myositis-associated interstitial lung disease (M-ILD).

[Register Today](#)

From Diagnosis to Determined: Grace, Grit, and Getting Back Up

Wednesday, August 13, 2025 at 12:00 PM ET



Join TEDx speaker and founder of The disABLED Company™, Alicia Polak, for a powerful and uplifting Empowerment Clinic as she shares her personal journey with inclusion body myositis. In "From Diagnosis to Determined: Grace, Grit, and Getting Back Up," Alicia offers an honest, heartfelt perspective on living fully and joyfully with a disABILITY™.

[Register Today](#)

Ask the Expert: Cell Therapy Edition featuring Dr. Iazsmin Bauer Ventura and Dr. Satyajit Kosuri

August 19, 2025 at 12 PM ET | 9 AM PT

August's Ask the Expert webinar features Iazsmin Bauer Ventura, MD, a clinician and researcher specializing in neuromuscular disorders and regenerative medicine. In addition to her academic and clinical expertise, Dr. Ventura is currently



leading Cabaletta Bio's CAR-T clinical trial at the University of Chicago. Her work is helping to pave the way for new, innovative treatment options for those living with myositis.

Join us for an in-depth conversation on cell therapy for myositis, including current clinical trials, therapeutic potential, and what patients should know about emerging treatments.

[Register Today](#)



ILD Day is September 10

[TMA recognizes ILD Day](#) as a way to spread awareness of this devastating condition that causes scarring in the lungs, making it difficult to breathe. Myositis is one of the known causes of ILD. There is no known cure.

We encourage those who develop symptoms such as shortness of breath, dry cough, fatigue and weakness, chest discomfort, "clubbing" of the fingertips, loss of appetite, and unexplained weight loss to speak with their doctor about the possibility of ILD and educate themselves on the symptoms and treatment of ILD.

Save the date for The Pulmonary Fibrosis Foundation's ILD Day webinar, "Genetics and beyond: Exploring interstitial lung disease in families and individuals."

[Learn More about ILD Day](#)

Community Tips: Managing Pain with Myositis

Pain in myositis is real and affects your quality of life. Here are some tips from TMA members on how they deal with this distressing symptom.

1. Magnesium malate helps ease my muscle cramps and supports muscle function. Always consult your doctor before starting supplements.
2. A hand-held massager can provide deep relief, especially for my calf pain and tight muscles.
3. A battery-operated T.E.N.S. machine can stimulate aching muscles and reduce my pain.
4. Peppermint oil applied to my feet to cool and soothe pain.

5. Ice packs wrapped in a dish towel and secured with thick Velcro Ace bandages reduce inflammation.
6. I wear an *AlignMed* posture support bra to improve alignment and reduce strain. It's been life-changing!
7. A memory foam neck support pillow eases neck tension and helps me sleep better.

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.

Check out our [**suggestions for using the tool here.**](#)



Mind Your Mental Health - Exercise

For people living with myositis, gentle, regular exercise can be a powerful ally for mental health. Movement—adapted to your abilities—can help reduce anxiety, lift mood, and improve sleep.

Activities like stretching, aquatic therapy, or short walks can boost endorphins and provide a sense of control and accomplishment. Exercise also supports social connection and combats the isolation that can come with chronic illness.

Always consult your healthcare team to find safe, personalized ways to stay active. Even small steps can make a big difference for both body and mind.

We want to know how you manage the mental health challenges of having a chronic disease.

[**Take the Survey**](#)

LiftSeat®
Power Toilet Lifts
SIT • CLEAN • STAND



Made in the USA!

Save \$100
with code
MASAVINGS

Regain independence in the bathroom with the award-winning LiftSeat Power Toilet Lift! Take advantage of our 15-day, 100% satisfaction guarantee, plus \$100 off any model with coupon code MASAVINGS. (Sponsored)

[Visit LiftSeat](#)



Tap into the power of peer support!

1:00-2:30 PM ET | 10:00-11:30 AM PT
FIRST SATURDAY OF EVERY MONTH

TMA WORLDWIDE

Myositis Support Group

Find encouragement and motivation to persevere through tough times. Connect and learn. Breakout rooms grouped by diagnosis and led by trained, certified peer leaders from across the nation!

[Register Now!](#)



In honor of the international members who have consistently attended our TMA Nationwide Myositis Support Group since its inception in 2022, we have updated the name to more realistically represent the population it serves.

TMA Worldwide will continue 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](#)

Sponsored

**Know your
options**

Click here
to learn
about an
FDA-approved
treatment option for
DERMATOMYOSITIS
and **POLYMYOSITIS**.



Mallinckrodt
Pharmaceuticals

Mallinckrodt, the 'M' brand mark,
the Mallinckrodt Pharmaceuticals
logo and other brands are trademarks
of a Mallinckrodt company. © 2025
Mallinckrodt.

Mallinckrodt Pharmaceuticals
US-2500370 07/25

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!



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

[Unsubscribe](#) | [Update Profile](#) | [Constant Contact Data Notice](#)



Try email marketing for free today!