

MYONews

SEPTEMBER 2023 | Issue Nine



One week until the 2023 Annual Patient Conference!

Today is the final day to purchase tickets for the 2023 Annual Patient Conference at the regular rate of \$289. Tomorrow prices are going up to the late registration rate of \$349! We're **Celebrating YOU Our Myositis Heroes** during this 4-day, in-person event in sunny San Diego!

We would love for you to join us September 7-10, 2023!

International Annual Patient Conference Sheraton San Diego Hotel and Marina

REGISTER TODAY!



If you're going to San Diego for TMA's Annual Patient Conference OR you'll be in San Diego on September 9, you won't want to miss our second annual Heroes in the Fight awards celebration.

Separate tickets are required for the Heroes in the Fight Award Ceremony.

Find all the details at the link below and secure your tickets today! Tickets are going fast and nearly sold out so don't delay!

GET YOUR TICKET



2023 Annual Patient Conference Recordings Available for Pre-Order with a Special Conference Bonus!

Are you unable to get to San Diego this year? Or are you attending the conference but unable to attend a session of interest? Never fear, we've got you covered!

TMA is thrilled to offer a complete set of recordings for nearly all presentations at our Annual Patient Conference 2023. This package includes:

- Eight video-recorded sessions, including opening and closing keynote addresses
- Thirty additional audio-recorded sessions synced with slides from the presentation
- Video of the Heroes in the Fight Awards Ceremony featuring Peter Frampton and other myositis heroes

All this will be delivered to you through a unique link where you can view the recordings at your leisure.

BONUS: For those who <u>preorder by September 8 at 4 PM PT</u>, you will also receive a Zoom link to participate in a live stream of the Medical Advisory Board's Town Hall Q&A session on Saturday.

Those attending the conference can also order the recordings at a reduced price, so you don't have to miss any sessions!

Registration Fees:

Preorder before October 24: \$149 Regular purchase after October 24: \$197

2023 Annual Conference attendees: \$99

ORDER NOW

*Please note - Annual Patient Conference recordings will not be available to access until October 24, 2023.

Thank you to all of our 2023 Annual Patient Conference Sponsors!



TMA thanks the above Exhibitors for their support in 2023!

TMA's Myositis Family Podcast will resume monthly episodes starting in January 2024



TMA's Myositis Family Podcast will resume monthly episodes starting in January 2024.

Are you curious about sharing your myositis journey as a guest on TMA's podcast? We have a new host and are preparing for 2024! The goal of our podcast is to share motivational stories that inspire and fortify listeners as they live their own myositis journey!

Your story reassures others that there is indeed life after diagnosis! You can participate anonymously if you wish.

An information session will be held to highlight how to participate as well as help you shape your story for the most impact! If you are interested but cannot attend this day, be sure to still register and we will send you the recording.

The information session will be held: October 6, 2023, at 1 pm ET | 11 am PT

REGISTER HERE

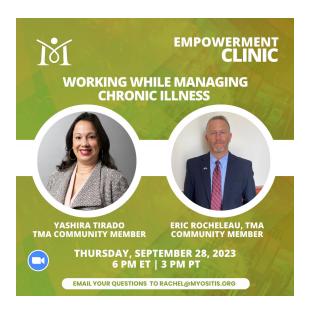


Ask the Doc with Dr. Helene Alexanderson, PT

September 21, 2023 12 PM ET | 11 AM CT | 10 AM MT | 9 AM PT

Helene Alexanderson, PhD, PT is an associate professor of physiotherapy at the Karolinska Institute in Stockholm, Sweden. She has 28 years of experience prescribing exercise for patients with myositis and focuses her research on the effects of exercise and development of clinical outcome measures in adult myositis. She is a member of TMA's Medical Advisory Board.

REGISTER TODAY



Empowerment Clinic: Working While Managing Chronic Illness

With Expert Guests and TMA Community Members Yashira Tirado and Eric Rocheleau

Thursday, September 28, 2023, 6 PM ET | 3 PM PT

Many people living with myositis are still employed, and that can be a challenge. In many cases, chronic illness limits how much you can get done in a day. You start with limited energy levels, and when you add in things like chronic pain and immune problems, everyday tasks can drain your batteries before you even get to work. Tune in as we discuss overcoming obstacles like handling your workload, communicating with your team about your illness, and finding support where you can.

REGISTER TODAY



Myositis Research Webinar featuring Dr. Mazen Dimachkie

Thursday, October 12, 2023, 12 PM ET | 9 AM PT

Mazen M. Dimachkie, MD is a tenured professor of Neurology and Director of Neuromuscular Division at the University of Kansas Medical Center (KUMC). Dr. Dimachkie is ABPN board-certified in Neurology, Clinical Neurophysiology, and Neuromuscular Medicine and holds a UCNS certificate in Clinical Neuromuscular Pathology. He is Executive Vice Chairman and Vice Chairman for Research Program, Department of Neurology. He is the Associate Director of the Institute for Neurologic Discoveries at KUMC. Dr. Dimachkie has national and international reputation as a clinician, educator, and researcher.

REGISTER TODAY



My Myositis Tracker: Improving Communication in Your Care

The My Myositis Tracker is a tool for keeping track of your symptoms and changes in your health that may have happened over the last several months. It gives you a record of changes in how you feel, medications you've started or stopped, vaccinations you've received, illnesses and hospitalizations, mental health challenges, and more. Plus, you can jot down the questions and issues you want to discuss with your doctor at the next visit so you don't forget anything.

The My Myositis Tracker can be downloaded from our website. We suggest you tape it to your refrigerator door so it's always handy.

DOWNLOAD TODAY

2023 UPCOMING EVENTS

Visit the

TMA Events Calendar

to see upcoming support and affinity group meetings, webinars, and more.





Is exercise more effective than medication for depression and anxiety?

A recent study shows that getting physically active is one-and-a-half times more effective at reducing mild-to-moderate symptoms of depression, psychological stress, and anxiety than either medication or cognitive behavior therapy.

While the value of physical activity-any type of physical activity-is widely recognized, it is usually not considered in a treatment plan for people with depression and anxiety.



Myositis Interstitial Lung Disease Nintedanib Trial - MINT

If you have been diagnosed with ILD and you also have myositis you may be eligible to take part in this research study led by former TMA medical advisor Dr. Rohit Aggarwal. The goal of this study is to gain a better understanding of whether a drug called nintedanib (Ofev) can help treat ILD associated with myositis.

The exciting part is that this clinical trial is unique because you won't need to visit a study center. You can participate in the study from the comfort of your own home. No need to worry about traveling long distances or spending time away from your familiar surroundings.

CHECK YOUR ELIGIBILITY

Or scan the QR code with your phone.





Community Tips

TMA members can be very resourceful when it comes to dealing with the challenges of muscle weakness. Here on some of our favorite hacks:

- Use food service gloves in the kitchen or when cleaning the bathroom. They protect your hands and add some traction for a better grip.
- Wear shirts that button up the front instead of t-shirts that you have to pull over your head.
- A yoga mat keeps your feet from slipping when standing up out of a chair or rollator.
- Use a light-weight terrycloth robe instead of heavy towels when you shower.
- Use long kitchen tongs with silicone tips to pick things up.
- Install a portable bidet on your toilet instead of using toilet paper. It cleans better and saves money on toilet paper.

Did you miss one of our previously aired webinars?

FIND THE CARE YOU NEED



Please check out TMA's Find A Doctor tool (through a new partnership with MediFind)! If you are looking for a clinician or specialist with documented experience treating the different types of myositis (or to add to your current care team), this could be a great place to start!

We are working out some things in the partnership to better feature some of the docs known to TMA, but we are so excited about the availability of this new feature for our patients! If you have any trouble navigating, please reach out to us at tma@myositis.org.

FIND A DOCTOR



In honor of our 30th anniversary this year, TMA would like you

Click here to view all of our past videos!



Special Program Speaker: TMA Military Veterans with Myositis Affinity Group Meeting

Do you need help obtaining approval for your VA disability claim? Join TMA's Military Veterans with Myositis Affinity Group with special guest speaker, Kerry Baker, Attorney-At-Law.

Mr. Baker has been successful in obtaining 100% service-connected disability with IBM veterans and is happy to share what he has learned with our veteran community, as well as answer any questions you may have.

This virtual event is scheduled for Saturday, September 9, 2023, at 12pm ET.

REGISTER HERE

to please let us know how we are doing! You can help us shape future programming by taking this very brief survey. We look forward to receiving your response by September 15, 2023.

TAKE THE SURVEY

AFFINITY GROUP MEETINGS



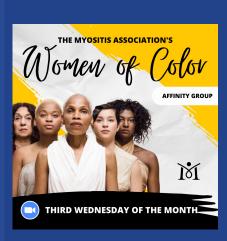




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Connect with us!









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

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