



# MYONews

October 2023 | Issue Ten



## 2023 Annual Patient Conference Recordings Available!

**Were you unable to get to San Diego for this year's Annual Patient Conference? Or if you attended the conference, are there sessions you want to view again?**

***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 including 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.

Those attending the conference can also order the recordings at a reduced price, so

you don't have to miss a single session!

### 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.



This year's Annual Patient Conference brought together the myositis community for an amazing four days of learning and sharing! If you missed this year's conference or you just can't wait to do it again, here's the scoop you've been waiting for:

**TMA's 2024 Annual Patient Conference will take place on September 6-8, 2024 at the Hilton Baltimore Inner Harbor!**

If you want to get all the latest information as soon as it's available, be sure you are signed up as a TMA member. It's FREE!

**BECOME A MEMBER**

## Have you ever thought about taking on a leadership role for TMA?

The Board of Directors is currently looking for new members. If you're interested, please [access this link](#) or scan the QR code with your phone to complete a questionnaire. After you do, a member of the Board of Directors will be in touch.





## Share your myositis journey on TMA's Myositis Family Podcast

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

We have a new host and are preparing for 2024 now with the goal of sharing motivational stories that inspire and fortify listeners as they live their own myositis journey!

Are you curious about sharing your myositis journey as a guest on TMA's podcast? Your story can reassure 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**

---



## 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](#)



## Overcoming Caregiver/Care Partner

# Stress Syndrome

With Expert Guest **Natasha D'Arcangelo** and  
TMA Community Member **Meriel Parker**

October 26, 2023 6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

Caregiver stress syndrome is a condition characterized by physical, mental, and emotional exhaustion. It typically results from a person neglecting their own physical and emotional health because they are focused on caring for an ill, injured, or disabled loved one.

Join this TMA empowerment clinic to learn how to recover from and prevent caregiver stress syndrome. Our expert will discuss signs and symptoms to look for, as well as developing a robust plan that is more than self-care. Also joining us will be a care partner and TMA community member to talk about what caregiving looked like for her whole family.

**REGISTER TODAY**

---

## 2023 UPCOMING EVENTS

### Find YOUR Community

TMA has support groups around the country and many affinity groups for those with shared interests beyond myositis. Most meet virtually, so you can attend from wherever you are. You might want to check out [TMA's Nationwide Myositis Support Group Meeting](#) on Saturday, October 7, 2023 | 1:01 pm - 2:30 pm ET

Visit the [TMA Events Calendar](#) to see and register for upcoming support and affinity group meetings, webinars, and more.

---



## Attention Adult Dermatomyositis Patients

MSU and TMA Announce

Externally-Led  
Patient-Focused Drug  
Development  
Virtual Town Hall



ENGAGE, EDUCATE, EMPOWER

## SAVE THE DATE

Friday, June 7, 2024

**What is it?** This unique community event is designed for you and your care partner to share your experience with the FDA and other government agencies, doctors, scientists, and medical product developers to help them gain a better understanding of how Adult DM affects lives.

**Why participate?** This is your opportunity to affect the decisions made in developing and approving drugs for your condition and highlight what is most important to you! The meeting on June 7, 2024 is hosted by MSU in partnership with TMA. We hope to recruit as many participants as possible to maximize our impact.

**How do I engage?** Look for our new community website launching in January 2024, where you can learn more, provide testimonials, and take surveys. If you are a member, or join TMA or MSU, we will provide notifications to keep you up to date as the process develops.

For information contact Lynn Wilson, [lynn@understandingmyositis.org](mailto:lynn@understandingmyositis.org)

For email updates <https://form.jotform.com/232623765075055>



For information contact Lynn Wilson: [lynn@understandingmyositis.org](mailto:lynn@understandingmyositis.org)

## FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

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

## ARTICLE OF THE MONTH



**An ER doctor shares 7 key places he still wears a mask – and explains why he didn't put one on at the US Open**

We're all hoping to put the COVID-19 crisis behind us. Thankfully we have a better handle on diagnosing and treating this deadly virus. But those who live with diseases like myositis, whose medications make them immune compromised, must still be extra cautious when out in the world.

In this article, Dr. Jeremy Faust, an emergency-medicine physician who doesn't think he has ever had COVID, outlines his own strategy for staying safe.

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](mailto:tma@myositis.org).

**FIND A DOCTOR**

**IndeeLift®**  
The People Picker Upper!

Designed specifically for those with IBM



Let IndeeLift do the work of getting you up after a fall!

Lifts from the floor to a seated or standing height. Self or assisted operation.

We are pleased to extend the special offer of a \$500 discount on our lifts, initially available exclusively to TMA Patient Conference attendees, to all TMA members for the month of October 2023! To order, you must call us at: 1-844-700-5438

[www.IndeeLift.com](http://www.IndeeLift.com)



**Myositis  
Interstitial Lung  
Disease  
Nintedanib Trial**

**READ MORE**



## Community Tips

Exercise is one thing that can help everyone maintain strength and feel better emotionally. Members of our community offer the following tips for how they stay as active as possible.

But remember: Listen to your body, and don't overdo it! It's also a good idea to consult your doctor or a physical therapist about the best way for you to workout.

- My doctor recommended I build up to a 30-minute walk every day, starting with five minutes twice a day and gradually adding an extra minute. It took months to get to 30 minutes, but I did it!
- I swim and stretch every day.
- I go to Aquafit at the pool every week. Laughing there for an hour also helps.
- Find a good physical therapist who will teach you how to maintain your condition on your own, using tools as simple as a tennis ball or foam roller to relieve pressure in the muscles or fascia. They can help you work within your own lifestyle goals.
- Exercise, exercise, exercise! That includes bed exercises after waking up, walking with whatever aid you use, hand PT with a squeeze ball, putty

## - 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.



activities for hands, riding a stationary bike...whatever keeps you moving.

- Chewing bubblegum and blowing bubbles improved my muscles and helped me with swallowing.
- I use light weights while watching TV.

**Most importantly: Don't give up! Exercise can be hard, but it's so worth it!**

**Did you miss one  
of our previously  
aired webinars?**

**Click here to view all  
of our past videos!**

## AFFINITY GROUP MEETINGS

**WOMEN WITH IBM**  
*Affinity Group*



**THIRD TUESDAY OF THE MONTH**

To improve the lives of women affected by Inclusion Body Myositis (IBM) through virtual connections that transcend geography

THE MYOSITIS ASSOCIATION

**MILITARY VETERANS  
WITH MYOSITIS**

... AFFINITY GROUP ...

**SECOND SATURDAY OF  
THE MONTH**

9 AM PT | 10 AM MT | 11 AM CT | 12 PM ET

★ ★ ★ ★ ★

FOR  
THOSE  
WHO LIVE  
ALONE

THE MYOSITIS ASSOCIATION'S

**FLYING SOLO**  
AFFINITY GROUP



**First Wednesday of Each Month**

5 PM PT | 6 PM MT | 7 PM CT | 8 PM ET



REGISTER TODAY

REGISTER TODAY

REGISTER TODAY

THE MYOSITIS ASSOCIATION'S

# Women of Color

AFFINITY GROUP



THIRD WEDNESDAY OF THE MONTH

THE MYOSITIS ASSOCIATION'S

# CARE PARTNER

AFFINITY GROUP



THIRD SATURDAY OF THE MONTH

7:30 AM PT | 8:30 AM MT | 9:30 AM CT | 10:30 AM ET

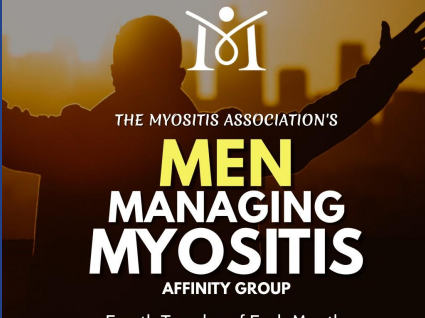
THE MYOSITIS ASSOCIATION'S

# MEN MANAGING MYOSITIS

AFFINITY GROUP

Fourth Tuesday of Each Month

4 PM PT | 5 PM MT | 6 PM CT | 7 PM ET



REGISTER TODAY

REGISTER TODAY

REGISTER TODAY

# ADELANTE

GRUPO DE AFINIDAD PARA HISPANOHABLANTES

CUARTO SABADO DEL MES

4:00 PM - 5:30 PM ET



THE MYOSITIS ASSOCIATION'S

# RAINBOW WARRIORS

AFFINITY GROUP

Fourth Sunday Each Month

2PM PT | 3PM MT | 4PM CT | 5PM ET



REGISTER TODAY

REGISTER TODAY



THE MYOSITIS ASSOCIATION

Connect with us!



[Unsubscribe tma@myositis.org](mailto:tma@myositis.org)

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

Sent by [tma@myositis.org](mailto:tma@myositis.org) powered by



Try email marketing for free today!