



MYONews

AUGUST 2023 | Issue Eight



38 Days until the 2023 Annual Patient Conference!

Only 38 more days until TMA's [International Annual Patient Conference](#)! We are proud to be a part of the biggest event of the year for those who live with myositis.

There is still time to register and join us for this event as we take a deep dive into all things myositis during this 4-day, in-person event **Celebrating YOU Our Myositis Heroes**.

Join us September 7-10 in San Diego, California!

This year's Conference includes educational workshops, research-based presentations, breakout sessions addressing all stages of the myositis journey, a focus on care partners, social activities, exhibitors, and much more!

We can't wait to see you all in sunny San Diego!



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 this event, but you can add it on to your [Annual Patient Conference registration](#). If you want to attend the [Heroes in the Fight dinner only](#), tickets can be purchased for \$50 per person.

This special dinner event honors the dedicated researchers and clinicians working hard to make progress in the care and treatment of myositis diseases as well as celebrates the extraordinary resilience and strength of our patient community.

Awardees include

Patient Ambassador Award: Grammy-winning rockstar Peter Frampton, *who will attend the ceremony in person.*

Heroes in Research Award: Dr. Rohit Aggarwal

Heroes in Healthcare Award: the University of California at Irvine ALS and Neuromuscular Center

We are also thrilled to offer special recognition to **Octapharma**, the pharmaceutical company that conducted the clinical trials that persuaded the FDA to approve Octagam, an immune globulin therapy, for the treatment of dermatomyositis. As they celebrate 40 years, we celebrate with them at TMA's 30th anniversary.

GET YOUR TICKET

Annual Patient Conference Info Session Replay



If you've never attended TMA's Annual Patient Conference and wonder what it's like, check out this webinar we hosted featuring patients, a care partner, and a physician. Many common questions were answered, including those about accessibility, why you should attend, and more!

[WATCH NOW](#)

The Myositis Family Podcast returns starting September 1 featuring a new host.



Meet your new host! Cara Zanella is an experienced communications professional who has earned several national awards for her shows and publications. Zanella was diagnosed with rheumatoid arthritis 17 years ago and was recently diagnosed with polymyositis.

Catch up on past episodes today! A new podcast episode airs monthly, or you can binge the archives on Spotify.

[LISTEN NOW](#)



Ask The Doc with Sonye Danoff, MD, PhD Pulmonologist

August 17, 2023 6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

Dr. Danoff is a pulmonologist and professor of medicine at Johns Hopkins University where she co-directs the Interstitial Lung Disease/Pulmonary Fibrosis Program and works closely with the Hopkins Myositis Center. Dr. Danoff is a member of the TMA Medical Advisory Board.

[REGISTER TODAY](#)



Overcoming Caregiver/Care Partner Stress Syndrome

With Expert Guest Natasha D'Arcangelo and TMA Community Member Meriel Parker
August 31, 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](#)



We're following Peter Frampton on his 2023 Never Say Never Tour! Read more and follow along on our blog!

[READ MORE](#)

2023 UPCOMING EVENTS

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



TMA'S NATIONWIDE VIRTUAL SUPPORT GROUP

PROVIDING SUPPORT TO THOSE
WHO NEED IT - EVERYWHERE!

FIRST SATURDAY OF EACH MONTH

10 AM PT | 11 AM MT | 12 PM CT | 1 PM ET

[REGISTER TODAY](#)



CLINICAL TRIALS CORNER

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

ARTICLE OF THE MONTH



Working towards a patient-centered Global Myositis Alliance: A call for partnership

Myositis patient support organizations have formed all over the world over the last several years, and they're joining together to amplify the voice of those who live with myositis. This article highlights this movement, which includes efforts to make doctors and scientists around the globe aware of the challenges of patients and their care partners.

TMA will have more information about this global movement in the coming weeks. If you would like to help TMA engage in this important effort, please be in touch with us at tma@myositis.org.

[READ MORE](#)

**To read this article, please click the button above. On the page that opens, click the PDF icon to the right.*

distances or spending time away from your familiar surroundings.

**CHECK YOUR
ELIGIBILITY**

Or scan the QR code with your phone.



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.



COMMUNITY TIP

Self-care is one of the most important things we all need to pay attention to. When we asked our members about the things they do for themselves to recharge, here are the things that helped the most:

- Taking time to look outside or be outside in nature.
- Being with people who can hold space for me to share without fixing or advising. They just listen and allow me to be heard deeply.
- Spending time with our cat.
- Doing something that brings me joy, like singing or playing with my grandchildren.
- Saying "no" to things that do not nourish or support me.
- Practicing self-compassion and compassion for others.
- Staying positive.

Annual Patient Conference Platinum Sponsors

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FIND A DOCTOR

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Proud to support
The Myositis Association

Octapharma joins the myositis community in celebrating the 30th anniversary of TMA, and their continuing mission to improve the lives of those affected by myositis, fund innovative research, and increase myositis awareness and advocacy.

www.octapharmaUSA.com

40 years of octapharma

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Annual Patient Conference
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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

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FOR
THOSE
WHO LIVE
ALONE

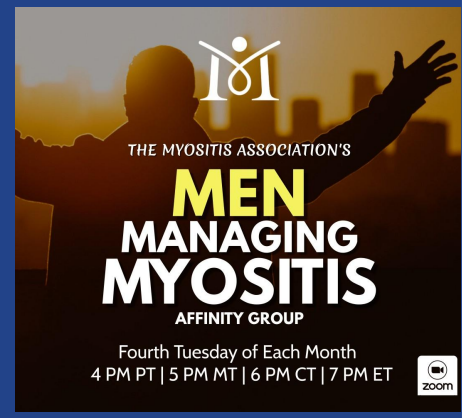
THE MYOSITIS ASSOCIATION'S
FLYING SOLO
AFFINITY GROUP

First Wednesday of Each Month
5 PM PT | 6 PM MT | 7 PM CT | 8 PM ET

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THE MYOSITIS ASSOCIATION

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