



# MYONews

JULY 2023 | Issue Seven



## Early Bird Registration Ends July 21!

TMA's **International Annual Patient Conference** is the biggest event of the year for those who live with myositis. You don't want to miss this opportunity to dive deep into all things myositis for this 4-day, in-person event **Celebrating YOU Our Myositis Heroes**.

This year's event takes place on **September 7-10 in San Diego, California**, and features some of the world's most distinguished myositis specialists along with expert presenters on all aspects of living with these debilitating diseases.

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!

The one thing attendees consistently say is the most important part of this gathering is the opportunity to meet and develop relationships with other people who live with their same disease.

Over and over, we hear members declare: *"Finally! Someone who knows how to pronounce 'myositis' and understands what it's like!"*

Register before July 21 and get the early registration discount!

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.

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 Grammy-winning rockstar **Peter Frampton**, *who will attend the ceremony in person* as this year's **Patient Ambassador Award** recipient. We will also honor **Dr. Rohit Aggarwal** with our **Heroes in Research Award** and the University of California at Irvine with our **Heroes in Healthcare Award**.

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.

Our annual **Heroes in the Fight Awards Dinner and Ceremony** takes place September 9 in San Diego, California. 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.

GET YOUR TICKET



The Myositis Family Podcast is on vacation this month. It will return again in August featuring a new host. Until then, you can access last season's archives.

[LISTEN NOW](#)

## Ask The Doc with Sonye Danoff, MD, PhD Pulmonologist

July 20 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

Dr. Danoff is a pulmonologist and professor of medicine at Johns Hopkins University. 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](#)



## Managing Myositis Through Psychosocial Health

Mental Health, Emotional Health, Social Health, and Spiritual Health

With Dr. Nicole Voet and TMA community member Chip Galloway

July 14, 2023 12:00 PM ET | 11:00 AM CT | 10:00 AM MT | 9:00 AM PT |

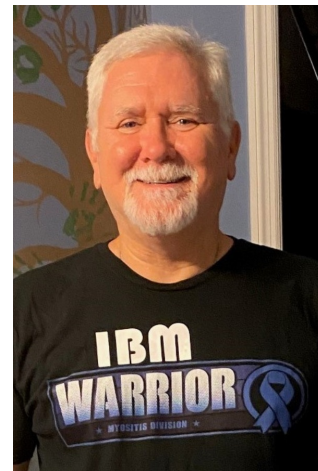
6 PM Central European Summer Time

Psychosocial health encompasses a state of mental, emotional, social, and spiritual well-being, as they relate to health and wellness. This definition extends to a person's past, their views of the present, and hopes for the future, along with how they cope under stress and pressure. Essentially, psychosocial health is the mental and emotional well-being of a person, as it relates to their identity and how others perceive them. Please join this discussion on how psychosocial health can improve your quality of life living with myositis.

**REGISTER TODAY**



**Nicole Voet, MD, PhD** is a rehabilitation physician and postdoctoral researcher at Radboud University in the Netherlands. Her research focuses on implementing evidence-based rehabilitation interventions and measuring and treating muscle fatigue in neuromuscular diseases. She is a member of the TMA



**Chip Galloway** was diagnosed with IBM in January 2020. Since then he has been on a mission to raise awareness of myositis diseases in any way possible.



Did you miss one of our previously aired webinars?  
[Click here](#) to view all of our past videos!

## 2023 UPCOMING EVENTS

Please check our  
[TMA Events Calendar](#)  
for our events, regional support group offerings,  
and more coming this month!



The graphic features a central blue banner with the text "TMA'S NATIONWIDE VIRTUAL SUPPORT GROUP" and "PROVIDING SUPPORT TO THOSE WHO NEED IT - EVERYWHERE!". Above the banner are five hexagonal photos of diverse people. To the left is a red heart icon with hands inside. To the right is a TMA logo. Below the banner, it says "FIRST SATURDAY OF EACH MONTH" and lists times for PT, MT, CT, and ET.

**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

**Next meeting August 5**

**REGISTER TODAY**

## ARTICLE OF THE MONTH



**Post-COVID-19 condition in patients with autoimmune rheumatic diseases: the COVID-19 Vaccination in Autoimmune Diseases (COVAD) study**

Patients with autoimmune conditions such as myositis are at increased risk for developing severe COVID-19 and might also be at higher risk of developing more severe long-term COVID-19 symptoms compared with the general population. This article reports the results of a survey study in which TMA members and others shared information about their COVID-19 infections and vaccination history, disease flares, current symptom status, and patient-reported outcomes.

This study adds to our understanding of how viral illness affects those who live with myositis. Thanks to those who participated in this study.

## 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 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](#)



Myositis  
Interstitial Lung



## COMMUNITY TIP

When we asked members who have myositis what advice they would give to care partners, the major response was: "Be patient with us." Here is some additional advice:

- Be encouraging.
- Understand that we have good days and bad.
- Listen.
- When it's overwhelming, please ask for help.
- Encourage us to be active advocates for our own well-being.
- Offer sincere praise when deserved.
- Maximize the positive, minimize the negative.
- Good humor can often win the day.
- Be available.

And then there was this message: "You are angels. God bless you."

**Annual Patient Conference  
Platinum Sponsors**

# 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.



octapharma



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**Annual Patient Conference  
Gold Sponsors**



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**Check out the latest TMA blog.**

**Financial resources are available for those with myositis**

When you are so sick that you can't work, it can be difficult to afford the care you need.

Check out this blog post to discover some resources that can help.

**READ NOW**

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# 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.

REGISTER TODAY



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

REGISTER TODAY



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



THE MYOSITIS ASSOCIATION'S  
*Women of Color*  
AFFINITY GROUP

THIRD WEDNESDAY OF THE MONTH

REGISTER TODAY



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

REGISTER TODAY



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

zoom

REGISTER TODAY



**ADELANTE**

GRUPO DE AFINIDAD PARA HISPANOHABLANTES

CUARTO SABADO DEL MES  
4:00 PM - 5:30 PM ET

THE MYOSITIS ASSOCIATION

REGISTER TODAY



THE MYOSITIS ASSOCIATION'S  
**RAINBOW WARRIORS**  
AFFINITY GROUP

Fourth Sunday Each Month  
2PM PT | 3PM MT | 4PM CT | 5PM ET

REGISTER TODAY





THE MYOSITIS ASSOCIATION

Connect with us!



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

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

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