



THE MYOSITIS ASSOCIATION®

MYONews June 2024 | Volume 4, Issue 6

Adult Dermatomyositis Externally-Led Patient-Focused Drug Development Meeting June 7, 2024



Raise your voice!

If you have dermatomyositis, now is your chance to tell the FDA what you need when it comes to treatments. TMA and Myositis Support and Understanding (MSU) are hosting an Externally-Led Patient Focused Drug Development (EL-PFDD) meeting with this government agency responsible for approving new medications and therapies. Don't miss this opportunity to have your voice heard.

Here's how:

[Complete the survey](#)

[Submit your comments](#)

[Register to attend the virtual meeting](#) on Friday, June 7

[Watch the community webinar](#) to learn more before the virtual meeting

REGISTER TO ATTEND THE VIRTUAL MEETING



More on immune boosting supplements for the rest of us

Our article about [immune boosting supplements](#) raised many questions about the effects of herbal products for those who live with myositis. Such products have been heavily promoted in recent years as remedies for all manner of maladies, including viral and other infections such as colds, flu, and COVID 19.

[READ MORE](#)



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

We have answers to your most [frequently asked questions](#). For example:

[How do I book my hotel room?](#)

As soon as your event registration is confirmed, you will receive via email your confirmation details that also contain a link to the hotel booking site. We have negotiated a preferential single/double occupancy rate of \$195 per night (plus taxes). These rates will be available until August 16, 2024, or until the conference guestroom block fills, whichever comes sooner.

Are there ADA rooms available at the conference hotel?

All of the ADA rooms at both the Hilton Baltimore Inner Harbor Hotel and the Baltimore Marriott at Camden Yards (across the street from the conference hotel) are being held exclusively for our attendees' use. Please indicate your need for an ADA room during the registration process. Proceed with booking a regular room at the Hilton and then a member of the TMA team will contact you regarding your ADA room request.

There are a limited number of ADA rooms available, and at this point, all the roll-in shower rooms at both the Hilton and the Marriott have been assigned to TMA conference attendees. We are keeping a waitlist and will alert you if one becomes available.

[ADA COMPLIANT HOTELS IN BALTIMORE](#)

And yes, we do have financial assistance to help you attend TMA's International Annual Patient Conference!

With a TMA scholarship, the registration fee is waived. The deadline for scholarship applications is June 10 and recipients will be notified by July 5.

[LEARN MORE](#)

You can help someone attend TMA's conference!

Scholarships for TMA's International Annual Patient Conference are available thanks to our generous donors. And right now, you can double your donation!

Two generous TMA leaders, Augie and Rich DeAugustinis, have offered to match every gift to the scholarship fund, dollar for dollar, up to \$10,000. Your generosity will help people who may feel very alone connect with others and learn more about how they can live their best lives by attending this amazing conference.

[DONATE TODAY](#)



MUSCLE
WEAKNESS?
Inflammation?

Exercises for Myositis



Exercise for myositis

Looking for more information on exercise and myositis? Dr. Neha Bhanasuli, [@PlantForwardMDlife](#), Associate Professor of Rheumatology at University of Central Florida College of Medicine, provides helpful instruction in this video.

WATCH NOW

SPONSORED BY THE SPIREA STUDY



INTRODUCTION
TO IDIOPATHIC
INFLAMMATORY
MYOPATHIES

TUESDAY
JUNE 18, 2024
3 PM ET | 12 PM PT

FEATURING
ROHIT AGGARWAL, MD



Introduction to Idiopathic Inflammatory Myopathies

June 18, 2024, 3 PM ET | 12 PM PT

Former chair of TMA's Medical Advisory Board Dr. Rohit Aggarwal will provide a comprehensive introduction to IIMs, covering their clinical features, pathogenesis, diagnostic criteria, and current therapeutic strategies.

This session is designed for patients and their care partners interested in expanding their knowledge of these challenging and multifaceted disorders. Join us for an informative and engaging discussion on idiopathic inflammatory myopathies, their impact on patients' lives, and the latest advancements in their management.

REGISTER TODAY

SPONSORED BY OCTAPHARMA

INFORMED CHOICES, IMPROVED OUTCOMES

THE POWER OF SELF-ADVOCACY IN MYOSITIS CARE

**WEDNESDAY, JUNE 26, 2024
5:30 PM ET | 2:30 PM PT**

Informed Choices, Improved Outcomes: The Power of Self-Advocacy in Myositis Care

June 26, 2024, 5:30 PM ET | 2:30 PM PT

Patient self-advocacy is the cornerstone of shared decision-making in healthcare. It empowers individuals to actively participate in their own care by exchanging vital information, discussing treatment options, and expressing personal preferences and values to their healthcare providers.

Please join this TMA webinar sponsored by Octapharma (Octagam 10% for DM), featuring Iazsmin Bauer Ventura, MD. Dr. Ventura is a rheumatologist who is passionate about providing care to patients with all forms of myositis and autoimmune-related lung diseases. She works at the University of Chicago, where she is a member of the multidisciplinary interstitial lung disease team and the director of the myositis program.

Dr. Ventura serves on TMA's Board of Directors. This webinar will cover how self-

advocacy can help patients' take control of their health journey, make more informed decisions regarding their care, and work with their healthcare providers to achieve the best possible outcomes.

[REGISTER TODAY](#)



EMPOWERMENT CLINIC

HELPING VETERANS WITH IBM

THURSDAY, JULY 11, 2024
4 PM ET | 1 PM PT

FIND OUT WHAT YOU CAN DO FOR THOSE WHO SERVED!

Empowerment Clinic: Helping Veterans with IBM

July 11, 2024, 4 PM ET | 1 PM PT

Find out what simple steps you can take to help veterans with IBM get the care they need from the Veterans Administration. Advocates from TMA Military Veterans with Myositis Affinity Group have been hard at work making progress toward this goal and now turn to you for support! In this empowerment clinic, we will discuss their efforts and have a special screening of the recently released documentary *Not the Life We Wanted: An Inclusion Body Myositis Documentary*.

[REGISTER TODAY](#)



ROBERT HALLOWELL, MD

PULMONOLOGIST

THURSDAY, JULY 18

12 PM ET | 9 AM PT



HAVE MYOSITIS WITH INTERSTITIAL LUNG DISEASE?

Ask the Doc Pulmonology with Dr. Robert Hallowell

July 18, 2024, 12 PM ET | 9 AM PT

Do you have burning questions about your lung condition that can't wait for your next visit with a doctor? Would you like to know what a leading global expert on myositis and interstitial lung disease has to say about the subject?

Bring your questions to this live Q & A with TMA medical advisor Robert Hallowell, MD. Dr. Hallowell is a pulmonary and critical care specialist at the Massachusetts General Hospital. His research focuses on factors that influence outcomes in patients with ILD, particularly those associated with autoimmune and rheumatologic disorders.

[REGISTER TODAY](#)

Do you live with ILD along with your myositis diagnosis?

Linda Z. tells the story of being diagnosed with polymyositis and ILD and the challenges she lives with on a daily basis. She's become well-versed in ILD as a result and will share her experience with others who live with lung disease as the leader of the ILD breakout group in TMA's Nationwide Myositis Support Group meeting.

[READ MORE](#)





Are you sad that it's no longer Myositis Awareness Month? We are too! Our affinity group leaders have a special invitation for you to continue being engaged!

[Click play to watch now!](#)



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.

We've worked with our partners at MediFind to



Community Tips

Many community members responded when we asked them to share their stories and insights to help others. Read our blog post with some of the best wellness and self-care advice from fellow TMA members!

[READ MORE](#)

update providers and make finding the best care more accessible. Check out our [suggestions for using the tool here.](#)



Washington University in St. Louis
SCHOOL OF MEDICINE

Impact of Falling on Quality of Life in Patients with Myositis: Patient Survey

The clinical research team at Washington University in St. Louis is conducting an anonymous survey to better understand the impact of falling and fear of falling on quality of life in patients with myositis.

You may open this anonymous survey in your web browser by clicking the link below:
<https://redcap.link/os2uruws>

Or scan the QR code below:



For any questions or issues related to this survey, please contact:
NeuromuscleDisease@wustl.edu

Thank you for your participation!

Washington University in St. Louis
SCHOOL OF MEDICINE

TMA's YouTube channel has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's webinars are published on the first of the following month.

JOIN TMA'S FANTASY FOOTBALL LEAGUE

Support The Myositis Association while playing your favorite fantasy sport - anyone in the world is invited to participate!

#TMAFootball

\$50 Donation to enroll your team

Spotlight on Giving: Fantasy Football

Do you like fantasy football? Please join TMA supporters to help people with myositis while playing your favorite fantasy sport!

For the past several years, a group based in Wisconsin has been playing fantasy football for the benefit of TMA. League members, who live all over the country, donate \$50 to TMA to register a team in one of the leagues. Most members of the leagues are friends or family of people with myositis, but there are now friends of friends, as well.

This year, the leagues are looking to expand. Experienced fantasy football players and rookies are both welcome to join them. There are no overhead costs to be part of a league. If you are interested, please contact [Alan Horowitz](#) for more information.

No prizes are awarded for winning, beyond the recognition by other league members of the winner's accomplishment. The competition is always fun and friendly, although sometimes intense. Join today!

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



Connect with us!



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

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