

## MYONews October 2024 | Volume 4, Issue 10



## Watch Now: Sneak Peek of the 2024 International Annual Patient Conference Recordings

Get a sneak peek of the 2024 International Annual Patient Conference recordings! We're excited to share this exclusive preview of the Opening Session. Don't miss your chance to see what this year's conference has to offer, featuring invaluable insights and highlights from the event!

WATCH THE SNEAK PEEK NOW

## Pre-order the 2024 International Annual Patient Conference Recordings

Pre-order your 2024 Conference Recordings today! The complete package includes video recordings of keynotes, pre- and post-conference sessions, 30+ audio sessions synced with slides, and the Heroes in the Fight Awards Ceremony. All of this is available for \$149 for non-attendees. Conference attendees will receive the

recordings automatically free of charge.

**ORDER RECORDINGS TODAY** 



The Meredith C. Thomas Myositis Research Fellowship was created to fund research grants for early-career clinicians focused on Antisynthetase Syndrome and ILD.

This new fellowship within TMA's long-running research grants program is a perfect tribute to Meredith's passion for learning and community spirit.

Join TMA by donating to the fellowship fund.

**DONATE TODAY** 

In the greater Chicago area? Register for the 1st Annual Meredith C. Thomas Trivia Night Fundraiser on November 1, an unforgettable evening of fun, community, and friendly competition. Date: Friday, November 1st, 2024 Time: 6:00 PM - 10:00 PM Location: Butterfield Country Club (2800 Midwest Road, Oak Brook, IL 60523)

The fundraiser will include exciting trivia rounds, buffet dinner, cash bar, with host local radio personality and podcaster, Steve Cochran.

**LEARN MORE** 

# Celebrating our Myositis Connection: Reflections on TMA's 2024 International Annual Patient Conference

Stanley Erickson, whose wife Nancy Marx Erickson has IBM, sums up his experience at TMA's International Annual Patient Conference.



**READ MORE** 

## TMA Colorado Myositis Support Group is reactivating!

Meet Jim Milani, a TMA member who was moved by the efforts of the late Marianne Moyer and the TMA Southwest Florida's success in organizing a Myositis Symposium for Physical and Occupational Therapists for this year's Myositis Awareness Month.



He called Rachel Bromley, TMA's Senior Manager of Patient Education, Support and Advocacy to offer to organize one in his home state of Colorado. Marianne's vision had always been for this event to branch out to other TMA groups! One catch though: TMA Colorado had been dormant for quite some time. So Rachel swung for the fences and said, "How about reactivating the Colorado group at the same time? You can connect more PTs and OTs that way, find a few volunteers to possibly help your efforts, and provide and receive support for myositis along the way!" Jim replied with one word "SURE!" And so this journey began.

For the past 20 years, Jim has been a Physical Therapist and is Board Certified as a Geriatric Specialist. After several years of misdiagnoses, he was correctly diagnosed with IBM in late 2023. Despite this, Jim continues to pursue his love for activity and sports. He is passionate about sharing his personal and professional "fitness forward" philosophy, helping people understand how to modify and adapt exercises to their functional level. Jim lives in Colorado with his wife, Laura. He is a proud father of six

adult children and has two grandchildren. He says his family and faith help him get through each day. While there is much about IBM that he cannot control, he focuses on what he can: his attitude and effort. #justkeepswimming

Anyone can join his next meeting, Colorado resident or not. The first meeting is on October 12 at noon MT. If you're interested in reactivating a group in your area, email <u>rachel@myositis.org</u>.





#### TMA's New Member Orientation October 4, 2024, 12 PM ET | 9 AM PT

Living with myositis can be challenging, but you are not alone. Please join us virtually to learn more about education and resources to help you on your myositis journey and make new friends who know, understand, and share your new normal. Connect with people like you, connect with resources you need, connect with global myositis experts - connect with TMA!

**REGISTER TODAY** 



### Clinical Trials Webinar October 7th, 2024, 4:00 PM ET | 1 PM PT

For the month of October, we're exploring new technologies used in autoimmune disease clinical trials. Specifically, we will focus on CAR-T therapy to give patients a better understanding of the technology involved. We've invited former TMA medical advisory Dr. Dimachkie and Dr. Mamatha Pasnoor to present their research.

**REGISTER TODAY** 

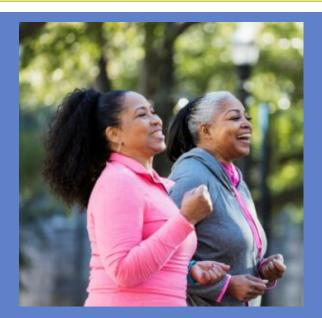


October 24, 2024, 4 PM ET | 1 PM PT

Join us for our upcoming webinar, Management of Dermatomyositis: Focus on IG Therapy. In this live educational webinar sponsored by Octapharma, Dr. Christina Charles-Schoeman will discuss intravenous immunoglobulin (IVIg) therapy for adults with dermatomyositis (DM). Learn how IVIg therapy works, how it affects patient outcomes, and why it's important for patients to understand IVIg within the current treatment paradigm. The webinar will be followed by a Q&A session.

Dr. Charles-Schoeman is a Professor of Medicine and Chief of the Division of Rheumatology at the University of California Los Angeles (UCLA). She specializes in the care of patients with inflammatory myositis and rheumatoid arthritis, often treating patients with aggressive systemic disease including interstitial lung disease. Her research interests include the study of accelerated vascular disease and inflammatory lipoproteins as targets for disease treatment in myositis and RA. She is a former member of TMA's Medical Advisory Board.

**REGISTER TODAY** 



#### Spotlight on Giving

TMA's Women of Color Affinity Group celebrates its fifth anniversary this year. In honor of that milestone, they are sponsoring a TMA Fundraiser: Step Up and Roll On.

"Our mission is to unite and empower women of color affected by myositis and to advocate for their health and well-being. By providing education, support, resources, and with the backing of TMA's expertise, we are determined to reduce the disparity gap in myositis outcomes for people of color. As we foster a community of strength, resilience, and inspiration, together we will break barriers, challenge inequalities, and create a future where every woman, care partner, and loved one affected by myositis, regardless of their race, can thrive."

Join them in their goal of raising \$5,000 to aid in providing resources and support to the myositis community.

#### DONATE TODAY

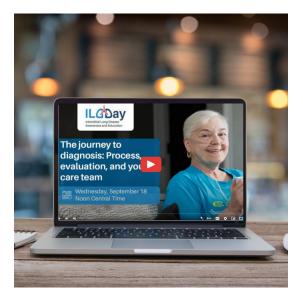


In recognition of World Myositis Day (September 21), TMA is recognizing our members who live abroad. Check out these patient stories from the global myositis community.

**Meet Scott Griffiths from Australia** 

Meet Cynthia Ikediashi from Nigeria

Support for global patient stories provided by Bristol-Myers Squibb.



#### **ILD Day**

TMA recognized ILD Day on September 18 with this very informative webinar on interstitial lung disease. Presentations featured TMA medical advisor Dr. Sonye Danoff and TMA research grant recipient Dr. Erin Wilfong.

WATCH NOW



TMA board members find purpose in helping others who live with myositis.

## Mind Your Mental Health

Research shows that having a purpose in life—a sense of direction in your life and a belief that your life is important—is good for your mental health. Feeling as if what you do in the world is valuable is associated with lower levels of anxiety and depression. This is also beneficial to your physical health!

Purpose can change throughout one's life. Here are some suggestions for how to cultivate a greater sense of purpose. Coincidentally, many of these ideas are things that TMA can help you manifest.

- Volunteer for a cause that is important to you.
- Serve as a mentor for someone else.
- Write or tell your own story and share it with others.
- $\cdot$  Think about obstacles you have overcome and find ways to help others who are going through the same thing.
- Find someone whom you admire and let them serve as a role model.

If TMA can be part of your purpose, please let us know. Email us at **TMA@myositis.org.** 



Dianne Eveler attended TMA's International Annual Patient Conference where she met the one person who has inspired her in her myositis journey. She shared her experience of the conference in this post on CaringBridge.

Photo: Dianne (on the right) with her inspiration, Lindsay Guentzel

**READ MORE** 



"Thank you so much for this wonderful opportunity to go to this amazing event. The entire conference was so informative and fun. The networking opportunities were great. In a rare disease sometimes you feel alone but this changes the outlook on things when you realize and meet others experiencing the same things. I cannot say enough how thankful I am to have gone to this conference!!" - Deanna Case, lives with IBM

Photo: Deanna Case (on the right) with her sister Suzanne Bourque (on the left). Deanna is from Georgia and has IBM.

Dianne and Deanna are among the 24 individuals who, together with their care partners, were able to attend TMA's International Annual Patient Conference thanks to scholarships. TMA is grateful to the 75 individuals who donated to the scholarship fund to make this possible.

You can still donate to this fund, making it possible for even more deserving members to be part of this life-changing experience in 2025!

**DONATE TODAY** 



# FIND THE CARE YOU NEED

MediFind

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, <u>TMA's Find a</u> <u>Doctor</u> tool can at least provide options.

We've worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our suggestions for using the tool here.





## **Community Tips**

Share your tips for making life with myositis easier by emailing us at <u>tma@myositis.org</u> we'd love to hear from you!

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.

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially. Please <u>make a gift</u> to TMA to support our impact today!

**DONATE TODAY** 



Connect with us!



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