THE MYOSITIS ASSOCIATION®

MYONews March 2024 | Volume 3, Issue 3

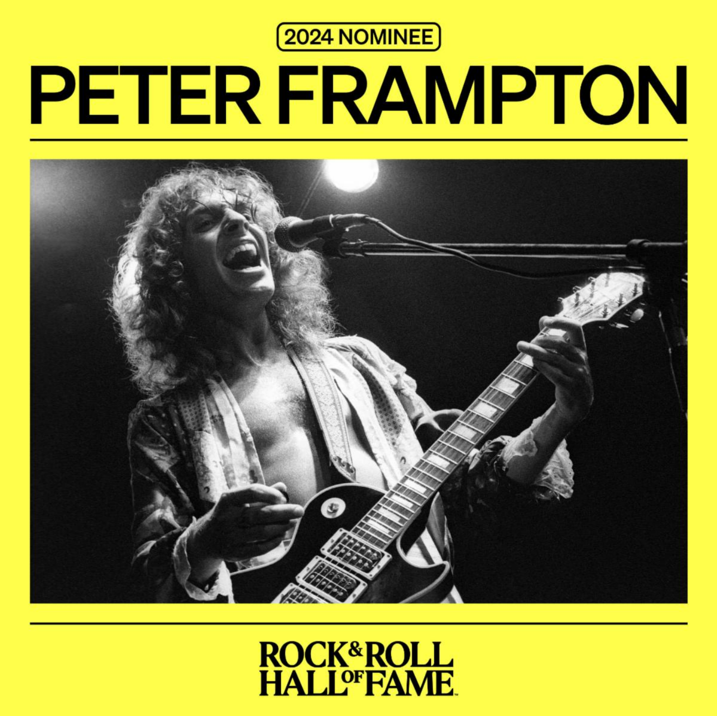
Myositis Awareness Month: Coming Soon

TMA is preparing a month of marvelous myositis material for members in May!

Stay tuned for a great lineup of educational webinars, featuring topics such as "How to Talk to Your Family and Friends about Myositis," "Disclosing Your Diagnosis to Your Employer," "Lifestyle Adaptation," Research and Ask the Doc webinars, and more.

We'll also have a Myositis Awareness Toolkit to help you wage your own awareness campaign, including social media graphics, how to get your local officials to make a proclamation of Myositis Awareness Month, a downloadable lawn sign, and more.

So get ready to tell the world about myositis and what it means to you! TMA is here to help you spread the word!



Peter Frampton, legendary musician and recipient of TMA’s Patient Ambassador Award, has been nominated for induction into the **Rock & Roll Hall of Fame**! Let’s rally behind Peter, who was diagnosed with inclusion body myositis in 2015.

You can vote for Peter Frampton every day, once per day, at vote.rockhall.com. It’s easy to vote by providing an email address or social media handle. Voting ends on April 26!

Peter’s generosity of time, influence, and resources has been crucial to furthering the understanding and response to myositis. Meanwhile, he continues to record and deliver electrifying live concerts. Did you hear his tracks on the Dolly Parton *Rockstar* album? Are you attending any of the Never EVER Say Never Tour dates? Learn more about this inspirational artist at www.frampton.com.

VOTE NOW

TMA’s Meet & Greet Leadership Series

April 11, 2024, 4-5 PM ET | 1-2 PM PT

TMA leaders want to connect virtually with you! Our new Meet & Greet series continues with the chair of TMA’s Medical Advisory Board (MAB), Dr. Namita Goyal, joining board chair, Laurie Boyer, and executive director, Paula Eichenbrenner. During this informal gathering, we will share information about the TMA research program and ask for feedback from the community. Learn more about the myositis medical experts that make up our MAB, and how this distinguished group supports TMA’s efforts.

Looking for a time to ask questions about your own myositis journey? Bring your “Ask the Doc” questions to our March 26 program with Dr. Latika Gupta (info below!)

Namita Goyal, MD is a Professor of Neurology at the University of California, Irvine and co-director of the Neuromuscular Center at UC Irvine. She is a lead site investigator in several myositis clinical trials and serves as Chair of TMA’s Medical Advisory Board.

REGISTER & ASK A QUESTION

Ask The Doc with Dr. Latika Gupta

March 26, 2024, at 11 AM ET | 8 AM PT

Do you have a burning question about myositis that just can't wait for your next appointment? Dr. Latika Gupta has answers for you.

Dr. Gupta is a rheumatologist and immunologist in the UK. She leads a number of research initiatives, including leveraging social media as a tool for collaborative research and educating patients, devising a training module for assessment of myositis patients, building a biorepository of myositis patient data, exploring ethnic differences in myositis patients, and more. She is passionate about improving access, quality, and equity in rheumatology care globally.

REGISTER TODAY **SUBMIT A QUESTION**

Don't miss TMA's 2024 International Annual Patient Conference

This year's conference promises to be better than ever! This premier event brings together members of the myositis community for a truly life-changing experience of learning and sharing! Plan now to meet us in Baltimore!

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

Registration opens in early April

TMA's New Jersey Myositis Support Group is Reactivating!

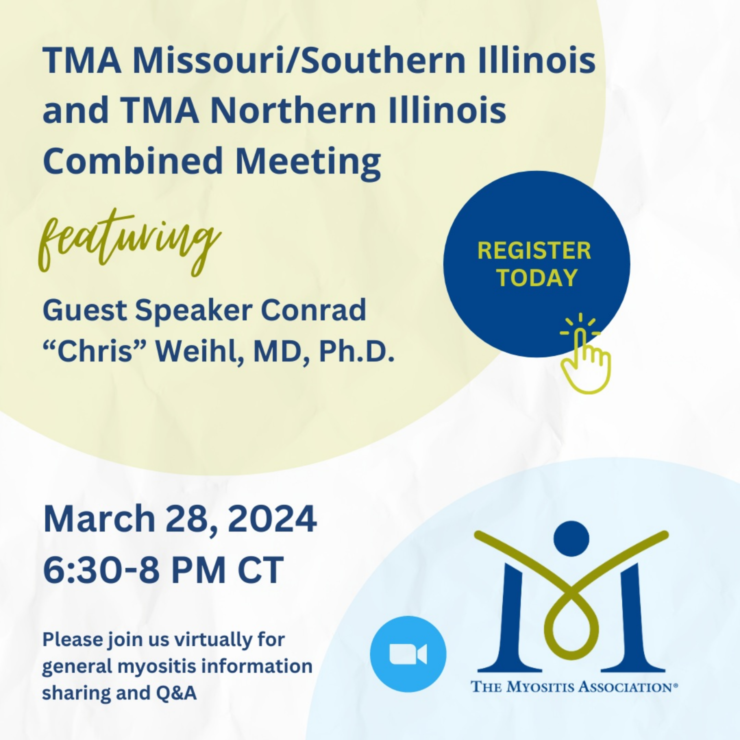
You may have seen Colleen Layton on TMA webinars or at our Annual Patient Conference. She is a retired nurse who was diagnosed with necrotizing myopathy ten years ago. Colleen is a member of the TMA Patient and Family Advisory Council. She and her husband have two sons and live in New Jersey.

Despite her disease, Colleen still engages in her hobby of horse racing and is excited to share how she adapted her hobby to her illness! A resident of New Jersey, she is eager to take on leadership of the group, which plans to meet quarterly virtually. The first meeting will be April 8 6:30 PM ET.

If you're interested in reactivating a group in your area, schedule a 30-minute Zoom meeting with Rachel Bromley, TMA Senior Manager of Patient Education, Support, and Advocacy.

Thanks to Colleen for volunteering to serve those living with myositis in New Jersey!

REGISTER TODAY



TMA Missouri/Southern Illinois and TMA Northern Illinois Combined Meeting

featuring

Guest Speaker Conrad “Chris” Weihl, MD, Ph.D.

REGISTER TODAY

March 28, 2024
6:30-8 PM CT

Please join us virtually for general myositis information sharing and Q&A

THE MYOSITIS ASSOCIATION®

TMA Support Groups Join Together to Host Dr. Chris Weihl

Thursday, March 28, 2024, 6:30 PM CT | 3:30 PM PT

TMA Missouri/Southern Illinois Myositis Support Group and TMA Northern Illinois Myositis Support Group will host a virtual combined support group meeting featuring guest speaker Conrad “Chris” Weihl, MD, PhD.

Dr. Weihl is a former chair of TMA’s Medical Advisory Board and a professor of neurology at Washington University School of Medicine in St. Louis. In addition to caring for patients with myositis, he has a particular interest in understanding the underlying cause of these enigmatic diseases.

REGISTER TODAY **SUBMIT A QUESTION**

2024
GIVING
CHALLENGE
Be The One

Presented by the
Community Foundation of Sarasota County

TMA Fundraising: Florida and Beyond

TMA has a wonderful opportunity to be part of the Giving Challenge, a special day of giving hosted by the Community Foundation of Sarasota County, Florida.

Donations made during a 24-hour period will be matched dollar for dollar by the Patterson Foundation, so every gift TMA gets through the Giving Challenge will be doubled! (up to $100 per donor) Some of the proceeds will go to support our TMA Southwest Florida Support Group, which supports hundreds of myositis patients and has brought this amazing local opportunity to TMA.

From noon on April 9 to noon on April 10, Eastern Time, please visit GivingChallenge.org and make a donation to TMA. Your generous gift will be multiplied to help TMA provide information, support, advocacy, connectivity, and research to support those affected by myositis. Please tell your friends to join us in making a significant impact!

LEARN MORE

Spotlight on Giving

Did you know that TMA offers individuals the opportunity to create their own fundraising campaign from our website? Dozens of members of our community have offered their relatives, friends, neighbors, coworkers, and others the opportunity to support a cause close to their heart. TMA wants to thank these incredible folks and call out the great work they're doing in support of our mission.

Zev's Mitzvah Project is a campaign started by Zev Karotkin to honor his grandfather who lives with IBM. While his original goal was $2,000, Zev's community blew that out of the water, donating an astonishing $10,552!

To Zev, we say *mazel tov*!! And thank you from the bottom of our hearts for this generous and amazing good deed!!

Global Conference on Myositis 2024

TMA will be in Pittsburgh this month for the 5th biannual GCOM on March 13-16. This international scientific meeting brings together the world's leading researchers and clinicians from all the different myositis specialties to share their unique perspectives on the science of myositis diseases.

Representatives from patient support and advocacy organizations from around the world—including TMA—will also be there to network and collaborate. TMA is playing a leading role in convening this international collaboration of patient advocacy organizations, assuring the voice of the patient is heard throughout the work of the scientific community.

Special thanks to the individuals living with myositis who are contributing GCOM content! For example, during a “Meet the patient experts” session, TMA Board member Martha Arnold (IBM) joins a panel with Karen Cheng (PM/IMNM), Rodney Jansen (IBM), Ingrid de Groot (DM), Benita Moyers (MDA5), and Silke Schlüter (Overlap Myositis). Two TMA members, Elijah Older and Rhonda Rogers, also recorded videos that will play during a session focused on “Extramuscular manifestations.

If you plan to be in Pittsburgh for GCOM, **please let us know** so we include you in meet ups with other patient advocates!

LEARN MORE

Calling All DM Patients!

Haven’t you always wanted to let someone know how challenging it is to live with a disease for which treatments often don’t work? Here’s your chance!

TMA is partnering with Myositis Support and Understanding (MSU) to host an Externally Led Patient Drug Development (EL-PFDD) listening session with the FDA on adult dermatomyositis. The project’s website has just been launched where you can learn more about it and add your story to the material shared with this government agency responsible for approving new drugs and treatments.

We’re hoping to have a few hundred people from our community attend all or part of this townhall-style virtual meeting on **June 7, 2024, from 10am to 2pm ET.** During this conversation with the FDA, patients and care partners can share their experience of living with this rare disease and the challenges you face.

Here’s your chance to tell officials at the FDA and other government agencies, doctors, scientists, and medical product developers what you need, so they can improve the clinical trials process and develop treatments for adult dermatomyositis.

REGISTER TODAY

MHB ZVF-BB
Zentrum für Versorgungsforschung Brandenburg

Share your experience!

Qualitative Study on Social Media in Myositis

The aim of the study is to investigate the role of social media in myositis care.
Your experiences are invaluable to us!

Participation requirements:
You live with myositis, have experience with social media and are willing to share your personal experience in an phone / video conference interview.
You are able to conduct the interview in either German or English.

Please contact us!
E-Mail: katharina.boy@mhb-fontane.de

EMAIL TODAY

Find encouragement and motivation to persevere through tough times. Connect and learn. Breakout rooms grouped by diagnosis and led by trained, certified peer leaders from across the nation!

2024 UPCOMING EVENTS

Tap into the power of peer support!

Did you know that if you are a person with myositis or caring for someone with myositis and feel you need support as soon as possible, you are welcome to attend any scheduled myositis meeting, even if not in your geographical area? Just check our events calendar and register for what interests you. TMA is an inclusive community and invites you to reach out as you need.

We would especially love to see you at TMA's Nationwide Myositis Support Group Meeting on Saturday, March 2, 2024 | 1:00 pm – 2:30 pm ET.

Visit the TMA Events Calendar to see and register for upcoming support and affinity group meetings, webinars, and more.

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 update providers and make finding the best care more accessible. Check out our suggestions for using the tool here.

Minding Your Mental Health

Anyone who has ever tossed and turned, struggling to fall asleep knows that lack of sleep can affect your mood and mental health.

Mental health challenges, like depression and anxiety, can also keep you from getting a good night's sleep. If getting to sleep or staying asleep are affecting your quality of life, it may be helpful to evaluate your "sleep hygiene."

Creating good sleep habits and a bedroom setting that is conducive to sleep can go a long way toward improving your mental health. Here are some ways to do that:

- Go to sleep and wake up at the same time every day.
- Make a regular bedtime routine that starts an hour or so before you want to fall asleep.
- Include some calming activities, such as listening to music or meditating, during your wind-down time.
- Avoiding alcohol, tobacco, and caffeine in the late afternoon and evening.
- Dim lights and avoid electronic devices for an hour or more before you want to

Myositis Interstitial Lung Disease Nintedanib Trial - MINT

If you have been diagnosed with ILD and you also have myositis or myositis autoantibodies you may be eligible to take part in this research study.

The goal of this study is to gain a better understanding of whether a drug called nintedanib (Ofev) can help symptoms of ILD associated with myositis.

The exciting part is that this clinical trial is its unique design 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. Several patients have already joined the clinical trial from various parts of the country from California to Florida.

To learn more about the study and whether you qualify, use this special link or scan the QR code with your phone.

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fall sleep.
- Get some regular exercise and spend some time outdoors to expose yourself to natural light every day.
- Close the curtains at night and turn off that night light to avoid excess light in your bedroom.
- Keep your bedroom cool but your feet warm.

Learn more from this TMA Empowerment Clinic video on **Getting a Good Night's Sleep.**

Community Tips for National Nutrition Month

Eat a healthy diet is one of the most frequent responses from our community when we ask what someone with myositis can do to live their best life. But what is a healthy diet?

The Mediterranean diet has been studied extensively for its beneficial effects on inflammation. Recent research also supports the benefits of this healthy eating habit for those with autoimmune diseases like myositis.

It includes lots of fresh fruits and vegetables, whole grains, fish, healthy fats like olive oil and avocadoes, and even an occasional glass of red wine and a bit of dark chocolate!

Here is a handy handout you can print out and tape to your refrigerator to remind you what will help ease your inflammation and—

hopefully!—reduce your myositis symptoms.

And here are additional suggestions for eating a healthy diet.

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.

AFFINITY GROUP MEETINGS

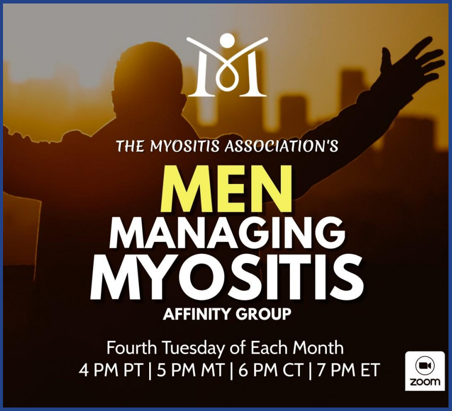
TMA encourages members to attend as many meetings as fit your support needs. In addition to our geographically based support groups, TMA offers nine different affinity groups with members from all across the nation (and sometimes the world!).

TMA's affinity groups bring together members who share a commonality in addition to a connection to myositis. These groups provide a safe space that allows people to feel supported and respected. This is especially important for people of color, members of the LGBTQIA+ community, and other marginalized groups.

We invite you to learn more about TMA's affinity groups and how they are successful in engaging our community of patients, care partners, family, friends, healthcare providers, and industry partners!

LEARN MORE

REGISTER TODAY **REGISTER TODAY** **REGISTER TODAY**



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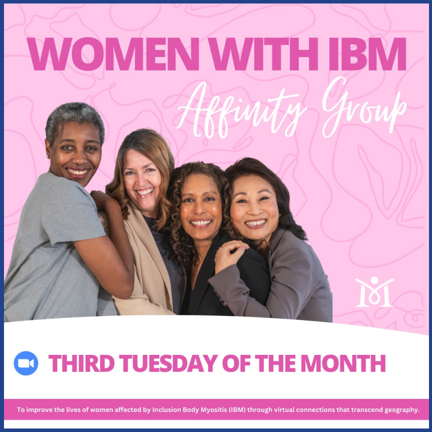

REGISTER TODAY **REGISTER TODAY** **REGISTER TODAY**

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Connect with us!