



THE MYOSITIS ASSOCIATION®

MYONews April 2024 | Volume 4, Issue 4



May is on its Way!!

Myositis Awareness Month is right around the corner, and you won't want to miss this chance to spread the word about this rare disease and what it means to you. And TMA is here to help you do just that.

Check out the great lineup of educational webinars TMA is offering.

[MAM EVENTS](#)

Our Myositis Awareness Toolkit will soon be available to help you wage your own awareness campaign. You'll find advice on how to get your local officials to make a proclamation of Myositis Awareness Month, how to get the word out on social media, and so much 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!

[LEARN MORE](#)



THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024
HILTON BALTIMORE INNER HARBOR



Sign up now for 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! We'll have a full slate of educational programming, some pre-event virtual sessions, and even some field trips! Check out the [tentative agenda](#) today!

Plan now to meet us in Baltimore!

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

REGISTER TODAY

TMA MD, DE, DC, Northern VA Myositis Support Group *presents*



**REGISTER
TODAY**



Fall Prevention and Safety

Rachel Seltzer, MS, OTR/L,
CAPS, SHSS, ECHM, CFPS
Certified Fall Prevention
Specialist with
Motion PT

**April 6, 2024
1:00 PM**



**Fall Prevention and Safety hosted by
TMA MD, DE, DC, and Northern VA Support Group**

TMA MD, DE, DC, and Northern Virginia Support Group is pleased to host guest speaker Rachel Seltzer to talk about fall prevention and safety. Rachel is passionate about working with older adults and their families to help them age in place successfully. She enjoys helping them create a customized plan so they can continue to live independently in their homes.

Recognized as an aging-in-place leader, built on her 25+ years of experience as an occupational therapist, Rachel's clinical background includes a wide variety of practice areas across the medical and rehabilitation fields, including acute and sub-acute care, and skilled rehabilitation, cardiac, orthopedic, and neurological disorders.

Rachel is a certified aging-in-place specialist with the National Association of Home Builders and a senior safety specialist with Age Safe America. In addition, she received an executive certificate in home modification from the University of Southern California Leonard Davis School of Gerontology and is a certified fall prevention specialist.

[REGISTER & ASK A QUESTION](#)

The poster is for the 2024 Regional Conference for Myositis Patients (Virtual). It features a blue and yellow color scheme. At the top, the title "2024 REGIONAL CONFERENCE FOR MYOSITIS PATIENTS (VIRTUAL)" is prominently displayed. Below the title, a list of topics is provided: INCLUSION BODY MYOSITIS, IMMUNE-MEDIATED NECROTIZING MYOPATHY, DERMATOMYOSITIS, POLYMYOSITIS, ANTI-SYNTHEASE SYNDROME, and OVERLAP SYNDROME. A circular inset image shows a group of people in a meeting, with a lightbulb glowing above them. The bottom left section indicates the date "SATURDAY, APRIL 6" and the times "7 AM - 11 AM PT", "8 AM - 12 PM MT", "9 AM - 1 PM CT", and "10 AM - 2 PM ET". A yellow button states "REGISTRATION CLOSES APRIL 4". The bottom right section features the "KU MEDICAL CENTER" logo and "The University of Kansas" text. The TMA logo is in the top right corner.

2024 REGIONAL CONFERENCE FOR MYOSITIS PATIENTS (VIRTUAL)

INCLUSION BODY MYOSITIS
IMMUNE-MEDIATED NECROTIZING MYOPATHY
DERMATOMYOSITIS
POLYMYOSITIS
ANTI-SYNTHEASE SYNDROME
OVERLAP SYNDROME

SATURDAY, APRIL 6

7 AM - 11 AM PT
8 AM - 12 PM MT
9 AM - 1 PM CT
10 AM - 2 PM ET

REGISTRATION CLOSES APRIL 4

KU MEDICAL CENTER
The University of Kansas

THE MYOSITIS ASSOCIATION

2024 Regional Conference for Myositis Patients

April 6 10 AM - 2 PM ET | 7 AM - 1 AM PT

University of Kansas Medical Center and TMA host the 2024 Regional Conference for Myositis Patients. This virtual, half-day conference features sessions covering cancer in myositis, speech and swallowing issues, pulmonary and rheumatologic complications, physiotherapy treatment and exercise, as well as break-out rooms by diagnosis for research updates and physical therapy considerations.

This event is no cost to the myositis community. Registration closes on April 4.

[REGISTER & ASK A QUESTION](#)



VICTORIA WERTH, MD

TUESDAY, APRIL 9, 2024

6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT



Ask The Doc - Dermatology with Victoria Werth, MD

April 9, 2024 at 6 PM ET | 3 PM PT

Do you have a burning question about dermatomyositis that cannot wait for your next appointment or are you curious what a global expert in DM has to say about illness? Please bring your questions to this Ask the Doc webinar featuring Dr. Victoria Werth.

Victoria Werth, MD is professor of dermatology and medicine at the University of Pennsylvania School of Medicine and chief of the division of dermatology at the Philadelphia Veterans Administration Hospital. She has a longstanding interest in clinical and translational research pertaining to cutaneous dermatomyositis. Dr. Werth is a member of TMA's Medical Advisory Board.

[REGISTER & ASK A QUESTION](#)



TMA's Meet & Greet Leadership Series

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

TMA leaders want to connect 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 April 9 Ask the Doc with dermatologist Dr. Victoria Werth.

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](#)

TMA
WomenWithIBM
Affinity Group
presents

**REGISTER
TODAY**



Incontinence and IBM

Is it Prevalent?

Dr. Genevieve Simkovics
Fiona Stanley Hospital

April 16, 2024
7:00 PM



A Research Study
Incontinence and IBM hosted by
TMA Women with IBM Affinity Group

April 16, 2024 at 7 PM ET | 4 PM PT

Is there a prevalence between incontinence and IBM? Join TMA's Women with IBM Affinity Group to hear about the recent findings from researcher Dr. Genevieve Simkovics and Kerry Maclaurin, the patient who initiated this project, from Fiona Stanley Hospital's Department of Neurology in Murdoch, Australia. This presentation will show their findings on whether or not incontinence is prevalent in IBM.

We hope you can join us !

REGISTER & ASK A QUESTION



Myositis Awareness Month Kickoff Webinar

May 1, 2024 at 4-4:30 PM ET | 1-1:30 PM PT

Join the staff of TMA as they kick off a full month of activities to raise awareness for myositis in the month of May! Receive information on how to observe Myositis Awareness Month with your family, friends, and community! And start the month off with a bang!

[REGISTER & ASK A QUESTION](#)

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.



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

[REGISTER TODAY](#)



Presented by the
Community Foundation of Sarasota County

2024 Giving Challenge

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. 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 Southwest Florida KIT, 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 you can create your own fundraising campaign right from our website?

Dozens of members of our community have offered their relatives, friends, neighbors, coworkers, and others the chance to support the cause that's 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.

We are so grateful to TMA member **Carol Jones**, who was diagnosed with dermatomyositis in October and started her fundraiser in January hoping to raise \$500. With the help of her amazing friends and family, she more than doubled that goal, bringing in \$1,075.

Thank you, Carol, for your passion and commitment to the myositis community and cause!

[START YOUR OWN FUNDRAISER](#)



Global Conference on Myositis 2024

TMA participated in the 5th biannual Global Conference on Myositis (GCOM) in Pittsburgh, Pennsylvania on March 13-16. TMA is proud of the role we played in bringing the patient's voice to this international scientific meeting that brought together the world's leading researchers and clinicians from all the different myositis specialties to share in the science of myositis diseases.

[Read about TMA's GCOM successes.](#)

[Read the first-person reflections of a TMA leader.](#)

Adult Dermatomyositis Externally-Led Patient- Focused Drug Development Meeting (EL-PFDD)

JUNE 7, 2024



Engage, Educate, Empower

MSU MYOSITIS SUPPORT
EMPOWERING THE MYOSITIS COMMUNITY

181
THE MYOSITIS ASSOCIATION

Community Orientation Webinar

Wednesday, April 17, 4-5 PM ET



Let the countdown begin! DM patients - Join us for a *Community Orientation Webinar* to learn how you can participate virtually in the first ever Adult DM EL-PFDD. Help us make sure the collective voice of hundreds of patients is heard by the FDA, academia and industry.

Agenda

- What is patient focused drug development?
- What is the purpose of the Adult DM EL-PFDD?
- What does it mean to the community?
- How can you get involved?
 - Survey
 - Written testimonials
 - Video testimonials



<https://bit.ly/492kzIS>

AMGEN

argenx

CSL Behring


Galapagos

janssen
PHARMACEUTICAL COMPANIES
OF **JOHNSON & JOHNSON**

priovant
THERAPEUTICS

FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

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.](#)



CLINICAL
TRIALS
CORNER



MINDING
YOUR
MENTAL
HEALTH

Minding Your Mental Health

Those who care for a person living with a chronic, debilitating disease like myositis are especially susceptible to caregiver stress syndrome.

This is a condition that comes with physical, mental, and emotional exhaustion, typically because the care partner neglects their own physical and emotional health as they focus on caring for their loved one.

During Stress Awareness Month, we offer this recording of a TMA empowerment clinic originally broadcast in October 2023. Learn how to recover from and prevent caregiver stress syndrome, recognize signs and symptoms, and develop a plan that is more than self-care.

We are pleased to share that the presenter, Natasha D'Arcelangelo, QS, LMHC, NCC, CCTP, CCFP will be returning to visit with care partners during the May TMA Care Partner Affinity Group meeting on May 18. Get to know her beforehand by viewing this webinar!

[WATCH NOW](#)

[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.

101 Approved & Not Practitioner
102 04 2021



Looking for a different treatment option for your **dermatomyositis?**

To learn more, talk to your doctor and visit www.VALORStudy.com



Proivant Therapeutics - The VALOR Study
e-newsletter ad - 2-Oct-2023 - English (principal) - V21

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



ADELANTE

GRUPO DE AFINIDAD PARA HISPANOHABLANTES

Now Earlier!

CUARTO SABADO DEL MES
1 PM ET | 10 AM PT

 THE MYOSITIS ASSOCIATION



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



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

REGISTER TODAY

REGISTER TODAY



**TMA MEN OF COLOR
AFFINITY GROUP MEETING**

Wednesday, May 29, 2024 | 6:30 PM ET
Engage with Others | Share Your Story | Gather Information



**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



**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

REGISTER TODAY

REGISTER TODAY



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

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



**THE MYOSITIS ASSOCIATION'S
Women of Color
Affinity Group**

FIRST THURSDAY OF THE MONTH
6:30 PM ET | 3:30 PM PT



**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

REGISTER TODAY

REGISTER TODAY

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

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