



MYONews

December 2023 | Issue Twelve



**Please
Support
TMA's
Impact!**



**Thank you for
your support!**



You can make a difference!

The Myositis Association is an **invaluable resource** for those who live with this rare disease. By supporting TMA, you become a partner in providing connection and support for those with myositis and their families, evidence-based information about these challenging diseases, advocacy to support the rare disease community, and research funding to discover better treatments and, ultimately, a cure for these devastating diseases.

As a nonprofit patient support organization, TMA depends on financial gifts from individuals like you to fulfill its mission of improving the lives of those who live with myositis. Please consider making a gift to TMA today. We are incredibly grateful for your generosity!

DONATE NOW

TMA has a new Executive Director!

We're thrilled to welcome Paula Eichenbrenner to TMA. She began her position at TMA on November 29. See Interim Executive Director Rhonda Buckley-Bishop as she introduces Paula to the community.

Please join us in thanking Rhonda for leading TMA through our 30th anniversary year!

[WATCH NOW](#)



This year's Annual Patient Conference brought together the myositis community for an amazing experience of learning and sharing! If you missed this year's conference or you just can't wait to do it again, here's the scoop you've been waiting for:

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



Myositis Research Insights Webinar featuring Dr. Nicole Voet

Friday, December 1, 2023, at 12 PM ET / 9 AM PT

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 Medical Advisory Board.

[REGISTER TODAY](#)



A promotional graphic for the Myositis Research Insights Webinar. It features two circular headshots of speakers: Dr. Marie Holmqvist (top) and Dr. Valerie LeClair (bottom). The text 'MYOSITIS RESEARCH INSIGHTS WEBINAR' is prominently displayed in large, bold, yellow letters. Below this, the date and time are listed: 'TUESDAY, JANUARY 9, 2024, 10 AM ET | 7 AM PT'. A small blue video camera icon is positioned to the right of the date. At the bottom, the text 'MYOSITIS RESEARCH WEBINAR FEATURING DRs. MARIE HOLMQVIST AND VALERIE LECLAIR' is written in white. A small logo for 'THE MYOSITIS FOUNDATION' is visible in the bottom left corner. A blue button at the bottom right contains the text 'EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG'.

DR MARIE HOLMQVIST

DR. VALERIE LECLAIR

**MYOSITIS
RESEARCH
INSIGHTS
WEBINAR**

**TUESDAY,
JANUARY 9, 2024
10 AM ET | 7 AM PT**

MYOSITIS RESEARCH
WEBINAR FEATURING DRs.
MARIE HOLMQVIST AND
VALERIE LECLAIR

THE MYOSITIS FOUNDATION

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

Myositis Research Webinar featuring Dr. Marie Holmqvist and Dr. Valerie LeClair

Tuesday, January 9, 2024, 10 AM ET | 7 AM PT

Curious how an epidemiologist in Sweden would join forces with a rheumatologist in Canada to work on a PhD related to myositis? Dr. Marie Holmqvist of Karolinska Institute and Dr. Valerie LeClair of McGill University Medical Center's Jewish General Hospital will share how they came together to advance myositis research.

[REGISTER TODAY](#)



DR. ROHIT AGGARWAL, MD, MS

WEDNESDAY, JANUARY 10, 2024

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



EMAIL YOUR QUESTIONS TO [RACHEL@MYOSITIS.ORG](mailto:rachel@myositis.org)

Ask The Doc with Dr. Rohit Aggarwal

Wednesday, January 10, 2024, 6 PM ET | 3 PM PT

Have a burning question about myositis that just can't wait for your next appointment? Global myositis expert Dr. Rohit Aggarwal has answers for you. Join this webinar to learn about aspects of this condition.

REGISTER TODAY



Have you considered becoming a support group leader for TMA?

Training is provided and you are supported every step of the way! You can be part of a group in your area and/or join the TMA Nationwide team where you co-lead with several experienced TMA group leaders who can provide additional guidance. You don't have to be a myositis expert to serve in this role!

"I've been a support group leader for six years and involved with TMA for even longer. What I like about being a leader is how the situation is a win-win for all involved! I enjoy helping others, and the members help me just as much!"

-Randy Heinig, co-leader of TMA Nationwide and TMA North Carolina (Charlotte Area)

If interested, please email rachel@myositis.org.

2023 UPCOMING EVENTS

Find YOUR Community

TMA has support groups around the country and many affinity groups for those with shared interests beyond myositis. Most meet virtually, so you can attend from wherever you are. You might want to check out TMA's Nationwide Myositis Support Group Meeting on Saturday, December 2, 2023, | 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.

Attention Adult Dermatomyositis Patients

MSU and TMA Announce

Externally-Led
Patient-Focused Drug
Development
Virtual Town Hall

SAVE THE DATE

Friday, June 7, 2024

What is it? This unique community event is designed for you and your care partner to share your experience with the FDA and other government agencies, doctors, scientists, and medical product developers to help them gain a better understanding of how Adult DM affects lives.

Why participate? This is your opportunity to affect the decisions made in developing and approving drugs for your condition and highlight what is most important to you! The meeting on June 7, 2024 is hosted by MSU in partnership with TMA. We hope to recruit as many participants as possible to maximize our impact.

How do I engage? Look for our new community website launching in January 2024, where you can learn more, provide testimonials, and take surveys. If you are a member, or join TMA or MSU, we will provide notifications to keep you up to date as the process develops.



ENGAGE, EDUCATE, EMPOWER

For information contact Lynn Wilson, lynn@understandingmyositis.org

For email updates <https://form.jotform.com/232623765075055>

MSU MYOSITIS SUPPORT
& UNDERSTANDING
EMPOWERING THE MYOSITIS COMMUNITY

TMA
THE MYOSITIS ASSOCIATION

For information contact Lynn Wilson: lynn@understandingmyositis.org



IBM Patients Battle for Veterans' Benefits

Military veterans with IBM have long asserted that their disease is related to their time in service. They've struggled for years trying to convince the Veterans Administration that they should receive disability benefits because of this.

This article describes how a handful of members of TMA's Military Veterans with Myositis Affinity Group have finally achieved this goal. The group is also advocating for legislation to change the law to allow IBM to be covered as a presumptive service-connected illness.

Links to resources to help you work through the application and appeals process for disability benefits is also included.

[READ MORE](#)

Vamorolone Approved by FDA

Recently, the [FDA announced](#) the approval of a new drug, vamorolone, as a treatment for Duchenne muscular dystrophy (DMD), a genetic muscle disease that usually affects young boys. Understandably, this news hasn't made a big splash in myositis circles, but it should.

[FIND OUT WHY](#)



TMA is grateful to our Corporate Advisory Council members for supporting all the great programs and services we

offer to the myositis community!

priovant
therapeutics

argenx

EMD
SERONO

ALEXION®
AstraZeneca Rare Disease

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PHARMACEUTICAL COMPANIES
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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.

ARTICLE OF THE MONTH



Patient Reported Physical Function, Mental Health, and Treatment Patterns in Dermatomyositis

Last year, nearly 200 TMA members participated in a survey to understand patient perspectives on the impact of DM and frequently used medications on their quality of life. Findings of this study were reported at this year's Annual Patient Conference. Dr. Lisa Christopher-Stine, a member of TMA's Medical Advisory Board, also reported these findings at this year's meeting of the American College of Rheumatologists.

[READ THE REPORT HERE](#)

FIND A DOCTOR

The VALOR study logo features a stylized purple bird icon and the text 'valor study' in blue and grey.

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

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

A square QR code with a blue border.

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



Recently, former TMA Board of Directors Chair Jim Mathews was featured on the Medical Maze podcast. Listen now to hear the story of his myositis journey and the challenges he's



Community Tips

Whether you have myositis or care for someone who does, TMA community members tell us it's your attitude that makes the difference. Dozens of members shared their best advice on staying positive:

- Life is different now, but it can still be good!
- Give yourself grace.
- Be patient and find new joys.
- Make choices that enhance your quality of life.
- Stay in touch with others who have myositis.
- Focus on what you can do.
- Enjoy every day.
- Take time to breathe and relax.
- DO NOT EVER GIVE UP!

LEARN MORE



overcome.

[LISTEN TODAY](#)

Minding Your Mental Health

Along with all of the obvious symptoms, myositis also comes with challenges that are not so visible. If you're having trouble making it through the day because of things like anxiety, grieving, and depression, you're not alone! These can be just as debilitating as muscle and skin symptoms and should be taken just as seriously.

Our friends at Cure JM have created a list of reliable mental health resources available for all ages. If you're having trouble, it's okay to ask for help.

[LEARN MORE](#)

[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.



Recordings of TMA's 2023 Annual Patient Conference are now available!

The complete set of recordings includes:

- Eight video-recorded sessions, including opening and closing keynote addresses
- Thirty additional audio-recorded sessions synced with slides from the presentation
- Video of the Heroes in the Fight Awards Ceremony including Peter Frampton and other myositis heroes

All this will be delivered to you through a link where you can view the recordings at your leisure. Those who attended the conference can order the recordings at a reduced price!

2023 Conference Recordings Pricing

Regular purchase price: \$197

2023 Annual Conference attendees: \$99

ORDER NOW

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



REGISTER TODAY

REGISTER TODAY



Connect with us!



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

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