



THE MYOSITIS ASSOCIATION®

MAY 1-31, 2024

Myositis Awareness Month



Dear TMA Members,

As we approach the end of Myositis Awareness Month, I want to extend my heartfelt gratitude to each and every one of you. **Your dedication, support, and advocacy have made an impact in raising awareness about myositis and supporting those affected by this rare disease.** Throughout this month, you've shared TMA's social media posts, attended webinars, requested proclamations, and elevated the myositis patient voice.

From first pitches on the baseball mound to elevator pitches about myositis diseases, you've helped create awareness in your community and beyond. We've enjoyed a month full of informative webinars to meet the diverse needs of our myositis members.

To Paula, Rachel, Linda, and the entire TMA team, thank you for your hard work, compassion, and commitment throughout this month. Your efforts to make Myositis Awareness Month a memorable one focusing on advocacy, education, and support are truly appreciated.

As we wrap up Myositis Awareness Month, I am more energized than ever to continue our mission-driven work. Please consider joining me in starting a third-party campaign to help raise funds for The Myositis Association. Every dollar raised contributes to research, support programs, and advocacy efforts. Visit our website for guidance on setting up a third-party fundraiser or email TMA@myositis.org for additional support.



Thank you for being an integral part of our incredible myositis family. By uniting our passion and purpose, we can truly make a difference for myositis awareness. I look forward to seeing many of you at our International Annual Patient Conference in September.

Warm regards,

Laurie Boyer
Board Chair, The Myositis Association

Myositis Awareness Month: It's almost over!

But myositis awareness goes on all year! Check out these terrific programs.

May 28 TMA Raising Awareness Workshop: Explaining Myositis to Others

[REGISTER TODAY](#)

*Raising Awareness Workshop:
Explaining Myositis to Others*

TUESDAY, MAY 28, 2024 12 PM ET | 9 AM PT



Facilitated by Rachel Bromley
TMA Senior Manager
Patient Education, Support and Advocacy

Build your myositis elevator speech!

MYOSITIS AWARENESS MONTH
MAY 1-31, 2024



THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

SEPTEMBER 6-8, 2024

HILTON BALTIMORE INNER HARBOR

Celebrating our Connection



**May 31 Stay tuned for a
sneak peek of TMA's 2024
International Annual Patient
Conference!**

June 1 TMA Nationwide Myositis Support Group Meeting

This group offers breakout rooms for each diagnosis and for care partners with trained leaders who will facilitate discussions about what's bothering *you*.

REGISTER TODAY



*Tap into the
power of peer
support!*

1:00-2:30 PM ET | 10:00-11:30 AM PT
FIRST SATURDAY OF EVERY MONTH

TMA NATIONWIDE Myositis Support Group

*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!*

Register Now!



Adult Dermatomyositis EL-PFDD
Engage, Educate, Empower

June 7 Dermatomyositis Patient-Focused Drug Development with the FDA

REGISTER TODAY

More Stories From Our Members

Dan Lowther is a military veteran who lives with IBM. As a member of TMA's Military Veterans with Myositis Affinity Group, he and his wife Alicia are working to convince the US Congress to make it possible for others like him to receive full benefits from the Veterans Administration.

[READ
MORE](#)



Telling Your Story

Myositis Awareness Month is a time to tell the world what it's like to live with this debilitating disease.

This week, TMA member Chrysta Johnson talks about her struggle to get healthcare providers to believe her and how grateful she is for all those who supported her along the journey.

[READ MORE](#)



You too can raise awareness in your community by telling your story. Visit TMA's [Myositis Awareness page](#) for lots of ideas, tips, and tools for spreading the word about myositis.

Raising Awareness: Storytelling on Social Media

Telling your story on social media is a great way to spread awareness widely. Here are a few tips:

- If you want to keep it short and sweet, share TMA's "Ask Me about Myositis" graphic and a brief caption. [Download your graphic.](#)

Your caption could read: "I have [specific form] myositis. May is Myositis Awareness Month, and you can ask me anything about myositis! I'm a member of #TheMyositisAssociation, and we want everyone to know about this debilitating disease. Coming together is the only way to achieve our vision: A world without myositis."

- If you're willing to go deeper, think about what you want people to know

about myositis, in your own words. Asking yourself one or more of these questions will help you get started in writing what you will post on social media:

- ☐ What was your first myositis symptom?
 - ☐ How long did it take you to receive an accurate diagnosis?
 - ☐ What do you wish you knew in the early days of your diagnosis?
 - ☐ How has myositis affected your life?
 - ☐ How can a friend or family member best support you during difficult times?
 - ☐ What would you like others to understand about your disease and living with myositis?
 - ☐ How has TMA been helpful?
- **Make your story visual!** Can your TMA Support or Affinity Group take a group photo or a virtual ‘screen grab’ during your May meeting? Do you have a service dog or a pet that helps you cope? Pose a photo of your furry, scaly, or feathered friend wearing a TMA bandana. Can you snap a selfie while pursuing your favorite form of exercise or at-home PT?
 - Animate your story with TMA and myositis GIFs! **Download fun, moving versions of the TMA logo and myositis keywords** on our new Giphy page. You can also search for TMA and myositis GIFs when posting a story on Instagram.
 - You can also **tell your story in a video and post that to social media.**
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What do you do to support your wellbeing?

We asked our members, and here are some of their responses:

- If I ever feel sorry for myself, I give it five minutes of feeling bad then I go do something good for myself.
 - I use a service dog to help ease my anxiety.
 - I attend chair aerobics and chair yoga classes twice a week to stay active.
 - I write a weekly email to family and friends. It keeps my mind involved with the world and my family.
-

Back to the Basics: Helpful Video Resources

In our first Myositis Awareness Month newsletter, we shared a list of helpful myositis resources like [TMA infographics](#). As Myositis Awareness Month comes to a close, we encourage you to explore our video resources, too. TMA’s YouTube channel includes many archived webinars, past sessions from the International Annual Patience Conference, and patient stories. Here are a few highlights:

- [Myositis Awareness playlist](#): These videos help us raise our collective voices and let the world know what this rare disease is all about. This playlist is also home to archived recordings of TMA’s Awareness Clinic webinars.
- [Women of Color playlist](#): Content and sessions from the TMA Women of Color Affinity Group, organized in 2019 as a support and advocacy group that promotes awareness through the 3E’s: Encouragement, Education, and Empowerment.

- [Nutrition and Alternative Therapies](#) playlist: Learn more about how diet influences autoimmune and health, with several archived Empowerment Clinic webinars.
- [2023 conference info session](#): Travel hints and hacks, plus insights from past attendees and speakers.

Coming soon! Playlists for certain forms of myositis and archived versions of this month's programs. To stay up to date on the latest content, [follow TMA on YouTube @MyositisAssociation](#).

Start a Fundraising Campaign!

Are you interested in deepening TMA's impact and raising awareness about myositis? Please consider starting your own fundraising campaign! We make it easy to raise awareness and support among your networks. [Click here](#) to get started.

Once you're up and running, share your fundraiser link with everyone you know in every way you know how!

Myositis Awareness Month Resources



[Myositis Awareness
Month Toolkit](#)

[Myositis Awareness
Month Events Calendar](#)

[Cutest MyoMutt entries
due June 30](#)

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



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