

MYOSITIS AWARENESS MONTH

Toolkit

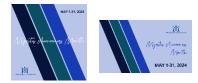
2024

Myositis Awareness Month is May 1-31, 2024. During this period, we amplify TMA's ongoing efforts to inform the public about forms of myositis. You – the individuals and families living with myositis – are the most powerful voice in raising awareness about these rare diseases.

This toolkit will help you join TMA in elevating myositis awareness.

CommunicationSocial Media Basics

Social media is an incredible avenue to increase understanding of myositis. Make sure you are following TMA on all our social media accounts, so you can like or reshare our content. You can also tag us when sharing your posts, and TMA can repost with our community!



As May approaches, you can upload TMA's social media graphics to feature Myositis Awareness Month on your own profile image, banner, or story (Facebook, Instagram, LinkedIn). <u>Download your social media graphics</u>.

To join the conversation, use a hashtag or two. A hashtag is a word or phrase preceded by a hash or pound sign (#) that is used to identify messages on a specific topic. This allows users to search posts and track discussion topics based on those keywords. But remember, no spaces allowed!

During Myositis Awareness Month 2024, TMA recommends these hash tags: **#MyositisAwareness #MyositisAwarenessMonth #MAM2024 #TheMyositisAssociation #MyTMA**

You can also contribute to the myositis dialogue by interacting with other advocates and individuals with myositis on social media. The simple act of sharing, re-posting, and promoting myositis awareness content from others could reach those who have never heard of myositis. Say myositis. Stop myositis!



Communication Social Media Storytelling

If you are ready to level up, create a post on your social accounts to tell your story.

Want to keep it short and sweet? Share **TMA's "Ask Me about Myositis"** graphic and a brief caption. <u>Download your graphic</u>.

Your caption could read: "I have [specific form] myositis. May is #MyositisAwarenessMonth, 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."



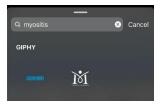
Willing to go deeper? Think about what you want people to know about myositis, in your own words. **Asking yourself one of these questions** will help you get started.

- 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 <u>wearing a TMA bandana</u>. Can you snap a selfie while pursuing your favorite form of exercise or at-home PT?

Animate your story with TMA and myositis GIFs! <u>Download fun, moving versions of the TMA logo and myositis keywords</u> on our new Giphy page. You can also search for TMA and myositis GIFs when posting a story on Instagram (pictured at right).





Community

In May, we go the extra mile to educate our communities to let people know what myositis is, how it affects us, and what we all can do about it.

TMA has downloadable "**Ask Me about Myositis**" signs in two sizes. One size can be taken to your local print shop and made into an 18x24in lawn sign. The smaller size is 8.5x11in so it can printed at home or work, and taped in your window. So easy! Can you pin up a copy at your neighborhood coffee shop?

TMA also offers an "I Love Someone with Myositis" sign for your care partner, friends, family, or neighbors to display. <u>Download your signs</u>.

You may be surprised to find television, radio, and newspaper reporters in your community are very interested in human interest stories featuring a person with a rare disease. Often, the way you present your story and the relationships you establish with reporters will be the key to success. Because May is designated as Myositis Awareness Month, there is an urgency and importance of timing for the coverage.

Check out TMA's tips on <u>raising awareness through local media</u>. For inspiration, view these **recent stories featuring TMA advocates**.

- Omni McCluney, PA-C, MMsC, MPH on CW39 in Houston, TX
- Vance Robinson with First Pitch campaign on KSBY News in San Luis Obispo, CA
- Chip Galloway with Crossing the Cooper event and fundraiser on Live 5 WCSC in Charleston, SC

Proclamations, or official designations of Myositis Awareness Month, can be requested from your city, county, or state. Proclamations are a great way to educate the public about myositis and bring attention to our cause. This effective tool for public recognition carries the full support of a key government official in your community or state. TMA's guide to proclamations contains an outreach message, template proclamation, and historic example to support your request.

What about the medical professionals in your community? Thank your care team with a short note. You can also <u>reach out to local physicians</u> who don't yet know about myositis.











Collaboration



Create a <u>personal fundraising campaign to benefit the TMA mission</u> on our website. We'll equip you with a personalized web page and a kickoff message that you can share with your network. You can use the "**I Donate for Myositis Awareness**" <u>social media graphic</u> to promote your campaign. It's easy and fun!

Some advocates organize events like community walks or happy hours during May to promote their **TMA fundraisers**.

TMA is excited to offer <u>new apparel for Myositis Awareness Month!</u> **Shop now**, support our mission, and inform members of the public about myositis. We have gear that defines myositis, encourages individuals living with IBM, and promotes World Myositis Day. Plus, there's a fleece vest and a style just for your furry, feathered, or scaly friends!

Let us know how you're marking Myositis Awareness Month! Email tma@myositis.org with pictures with friends, colleagues, and neighbors. Put on your TMA t-shirt, snap a photo, shoot a short video, and share your experience. Our "Cutest MyoMutt" contest runs through June 30!

We are always looking for powerful stories to share on the TMA blog and in the pages of Outlook magazine. If you're affected by dermatomyositis, please consider the unique opportunity to upload your testimonial for our upcoming meeting with the Food & Drug Administration (FDA). On June 7, MSU and TMA are hosting an Externally-Led Patient-Focused Drug Development (PFDD) to take the patient's voice directly to FDA.

And don't forget, myositis awareness is a year-round priority! TMA proudly partners with global patient advocacy organizations, including iMyos, to drive myositis awareness on World Myositis Day. The next **World Myositis Day is September 21, 2024**.



Myositis

Month

Myositis Awareness Assets from TMA

The official TMA MAM web page features awareness month events and awareness tools and tips.

In addition to the shareables linked within this toolkit and stored on our Myositis Awareness Month page, you may find these resources particularly useful.

- Archived TMA webinar, "Raising Awareness While Preserving Your Energy: Preparing for Myositis Awareness Month"
- TMA MAM Zoom virtual background
- TMA logo

The official TMA social media accounts are linked below.

- https://www.facebook.com/Myositis/
- https://www.instagram.com/themyositisassociation/
- https://www.linkedin.com/company/the-myositis-association/
- https://x.com/themyositisassc.

Thank you for helping TMA foster a deeper understanding of the impact of myositis on patients' lives! Your awareness efforts help others understand how best to support individuals and families living with myositis.