May is Myositis Awareness Month

Campaign Goals

Promote disease awareness:
- Among physicians and the general public to decrease the average time to diagnosis, which is currently five doctor visits over three-and-a-half years.
- Among family members and friends to foster a deeper understanding of the impact of myositis on patients’ lives and how best to support patients in every day ways.

Inspire “Myositis Messengers”:
- Within the TMA membership and broader myositis community to fuel a grassroots awareness campaign.
- Provide easy-to-use resources and ideas that can be adapted and applied by anyone, anywhere.

Why do we need awareness? On average it takes more than three-and-a-half years and five doctors to receive a correct autoimmune disease diagnosis. Myositis patients—including frantic parents of drastically weakened children—find that a great deal of damage is done during this wait. Raising awareness of myositis, its symptoms, and treatments will help these patients and families. Can you help us to help them? Please join TMA in raising awareness of myositis in the month of May. Here are some of the fun and easy ways that you can help others:

Tell your story
You, the patients and families affected by myositis are the most powerful resource we have to raise awareness about this disease. By sharing your personal stories with friends, colleagues, and neighbors, you can help others. Put on your TMA t-shirt, snap a photo, or write about your experience. Don’t worry, we’ll give you ideas to get you started.

Post, tweet, & share
With 91% of adults in the U.S. on Facebook and other social media platforms, you probably have a larger network than you think! The simple act of sharing, posting, tweeting, and promoting myositis awareness content—whether your own, something from TMA, or another personal story that has touched you—could make the difference for someone still searching for answers.

Phone physicians
It’s campaign season, and phonebanking is taking place across the country. So, we’re taking a page from the political playbook and pitching myositis awareness. The purpose is to reach general practitioners and other healthcare providers with information about myositis, so they “know the signs” and can help diagnose and treat patients more quickly than if they had never heard of the disease. We’ve made the process easy, providing scripts and resources to help you raise awareness from your kitchen table (or KIT meeting)!
Social media has become an integral part of our daily lives over the past 10 years. These social sharing platforms are now connecting people across space and time — old high-school friends, and strangers with common interests around the globe. They are powering change and raising awareness and funds for important causes.

TMA will launch a social media campaign during the month of May that will highlight facts and stories to help promote awareness of the disease. We need you (and your network) to help expand the reach of this campaign by Liking/Loving, Sharing, Re-Tweeting, and otherwise promoting these posts, images, and personal videos.

Be sure to check TMA’s Facebook and Twitter pages to see the newest available content. This will include shareable facts, stories, videos (hopefully yours), and other images to help you join the effort. You can also, download a “starter pack” of content at www.myositis.org/myositisawareness.

When posting and sharing don’t forget to use campaign hashtags!

#Myositis  #KnowMyositis
#MyositisAwareness  #TMACanHelp
#MyositisStory

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What’s your status?

Throughout the month of May, can you commit to making 2 posts per week about myositis?

Talk more about your myositis story and why myositis awareness is important for you (and others)! Share facts and shout outs!

Anytime that you post a status update related to myositis or share an image or status from TMA or others, be sure to use one or more of the campaign hashtags and also tag the TMA page! @myositis

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Tagging basics

What’s a hashtag and why/how should I use them?

A hashtag is a word or phrase preceded by a hash or pound sign (#) that is used to identify messages on a specific topic.

On Twitter, the # turns any word or group of words that directly follow it into a searchable link. This allows users to organize comments and track discussion topics based on those keywords. But remember, no spaces allowed!

How do I tag a person or group?

If you want to message a person on Twitter or Facebook, you can “tag” them. Using @ before a person’s Facebook name or Twitter handle will post/tweet to them directly, letting them know you have written. A hashtag will not.

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Tweet all about it

Get creative. Remember, you only have 140 characters to tell your story! Tag us too! @TheMyositisAssc

Here are some ideas:

#MyositisAwareness is important to me b/c I had symptoms for 10yrs b4 a doc said #myositis.

Big TY to friends & fam who #KnowMyositis and get that some days I need more help than others.

As soon as my doctor said #myositis I was online. Grateful to @TheMyositisAssc for research, info & support. #TMACanHelp

1st the rash looked like sunburn but then I was so weak I couldn’t walk. I’ve been in remission now for 6 mos. #MyositisStory #KnowMyositis
Tell your story through PHOTOS

Put yourself in the picture

The trend is all about the cause. Turn the camera on yourself to highlight something that's important to you. We've created some of our own message signs (find them online at myositis.org/myositisawareness). Simply save the files and print, fill out your own message, and hold up to be included in your photo.

Enlist pets and children

Do you have a service dog or a pet that helps you cope? Children or grandchildren? Pose a photo with them holding a sign about myositis. Who doesn't love these cute photos?

We've got a few, too

There's 31 days in the month of May and we don't expect you to post a photo of your face on every one of them. So for those other days, TMA has created fact-based images that are perfectly sized for Facebook. TMA recommends posting liberally for 31 days. Doctor's orders!

TMA's images below are samples. Find full size images as email attachments or online at www.myositis.org/myositisawareness.

Show some spirit!

Social media is a visual experience. Overwhelmingly the most liked and shared content includes images. So, how can you use images to increase visibility for myositis in the month of May? We'll give you a few:

Photos & images to use in May

- Change your Facebook and Twitter cover images to one of TMA's Myositis Awareness Month images.
- Snap your own image holding a sign referring to myositis. Use one of ours or make your own.
- Use a photo of your myositis support systems: family, pets, support group. Tag everyone!
- Share TMA's facts and images (see samples below).

Get it all in one place

- Download images at www.myositis.org/myositisawareness.
- Save images to your computer and upload as you would any other image to your page.
- Or, visit www.facebook.com/myositis in May and SHARE the images that we post!

Myositis Quick Facts:

Polymyositis is nearly twice as common in women than men.

#myositisawareness www.myositis.org

Did you know?

DERMATOMYOSITIS itches, weakens muscles, and causes rashes.

#wecandobetter #myositisawareness www.myositis.org
Raise awareness with your local physicians

Raising awareness among general practitioners and specialty physicians is a critically important way to help myositis patients and those individuals who have not yet received an accurate diagnosis. You can do this by simply calling physicians in your community or a larger geographic area who might not know about myositis to ask if you can send them information about the disease. The sample phone script below does not need to be read word for word but can help as a guide. Familiarize yourself with the language so you can sound natural without reading it directly.

Ring! Ring! If you connect with the physician’s office, start with:

“Hi! I am calling on behalf of The Myositis Association to let you know that as part of National Myositis Awareness Month I would like to send you a pamphlet about myositis. If that is okay with you, shall I send it to your office?”

Yes! If they say, “Yes” to receiving a brochure, ask them for their mailing address to be sure you have the correct information. Thank them for their time and hang up. Be sure to mail the materials promptly following your calls.

No. If they respond that they do not want to receive a brochure, thank them for their time and hang up.

No answer. If your call goes to voicemail, hang up and try calling at another time.

If they ask you about myositis, share some key facts:

- Myositis affects approximately 50,000 people in the US.
- It is a rare chronic disease that weakens muscles.
- There are 3 forms of the disease: polymyositis, dermatomyositis, and inclusion body myositis, as well as a form that affects children as young as 3 years old.
- Inclusion body myositis is the most common muscle disease in people over the age of 50.
- If they seem interested in hearing more, you can share with them your personal experience with the disease.

More than just general info

This campaign will help spread the word about myositis to physicians who may never have seen a myositis patient or may never have even heard of the disease. If the physician wants more information than the general Myositis brochure, refer them to TMA for additional resources. Online at www.myositis.org, toll-free 1-800-821-7356, or email TMA@myositis.org.

If you want TMA to reimburse you for postage, contact TMA to let us know the amount of postage you used to mail out brochures.