May is Myositis Awareness Month

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, shoot a short video, 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 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 Support Group meeting)!
Tell your story through VIDEO

Do what?

Shoot a short video about your experience with myositis. Use your smartphone or computer camera to record your message – then, share this video with TMA and your social networks (we’ll explain more about this later.)

Now, I’m intimidated.

Don’t worry, it’s easy! Ideally, your video should be 60-90 seconds long with a very clear message (use our video prompts). It’s best if you think through what you’d like to say and write a script first. Read it through a few times, checking your timing and making sure that you can say it smoothly before recording. Think of it as your “myositis elevator speech.” You have a minute or two to talk about something you know better than anyone—your story!

We’ll walk you through it!

We know that not everyone is a computer whiz or a natural on camera, but we also know that making a video nowadays can be simple and powerful. So we’ve put together the following resources to help walk you through the process. And if you still need technical help, consider asking for help from a trusted (and tech-savvy) friend or family member to assist with next steps.

The extra pair of hands and a little cheerleading may be all that you need to make your message sing!

Stay on message: MYOSITIS!

The “recipe” for telling your story through video is to choose one of the Video Prompt Questions below to guide the theme of your message. Read through all of the video prompts to find which question you’d like to answer. Then find a Key Campaign Message to include; add in one of the Important Myositis Facts (next page), and end with one of the “closing statements” listed under “A strong finish.”

Video prompts

☐ What was your first myositis symptom?
☐ How long did it take you to receive an accurate diagnosis of myositis?
☐ 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 words or actions can others offer to best support someone living with myositis?
☐ What would you like others to understand about your disease and living with myositis?
☐ Why is myositis awareness important to you?
☐ How has TMA been helpful?

Key campaign messages

☐ Myositis awareness can save lives by informing healthcare practitioners and the general public about the signs of these rare diseases, prompting earlier diagnosis and treatment.
☐ Myositis awareness can also help improve the lives of people currently living with the disease.
☐ The Myositis Association is the best resource for myositis patients, families and physicians seeking information about the disease.
Important myositis facts

- The average myositis patient must visit five doctors over three-and-a-half years before receiving an accurate diagnosis.
- Myositis affects approximately 75,000 people in the United States.
- Myositis affects men, women, and children of all races.
- There are several forms of myositis, but each causes the weakening of skeletal muscle, often beginning with the shoulders and thighs.
- Myositis is the most common muscle disease in people over 50.

A strong finish

Just as you chose a prompt, choose the closing message (or two) that is appropriate for your video. Including one of the following phrases at the end of your message will help to create consistent messaging across all of the personal videos that are created around the world!

- We need more people to know the signs of myositis.
- This is my myositis story.
- If you’re experiencing symptoms, The Myositis Association can help.
- I’m raising awareness of myositis for other patients and families.

Putting it down on paper

Refer back to your check marks when writing your “script.” For example, here is a 90 second message.

My name is Pete and I live in Minneapolis. I was diagnosed with inclusion body myositis in 2015 after more than 2 years of increasing weakness. My first symptom was falling. I attributed the falls to clumsiness or simply getting older, but when I began to have difficulty lifting my mug of coffee in the morning, I knew something more was going on. My primary care physician and several other doctors were stumped. I visited a total of 7 doctors and specialists before being diagnosed. I went without treatment or support until I found The Myositis Association. TMA was able to refer me to a myositis expert in my state who was able to definitively diagnose inclusion body myositis. Now I’m involved in a clinical trial, I know what exercise is appropriate for me, and I have a support network of other TMA members and patients.

I’m raising awareness of myositis for the other myositis patients and families who are looking for answers. Myositis is the most common muscle disease in people over the age of 50. We need more people to know the signs of myositis.

Lights! Camera! Action!

A few things to consider:

- Keep background simple and check your lighting.
- Make sure the video is not shaky; ensure the person videoing has a steady hand!
- Speak clearly with no other noise in the background.
- Speak for 90 seconds maximum, 60 seconds preferred.
- Introduce yourself (first name) and where you live.
- Mention The Myositis Association.
- Answer only one of the video prompt questions.
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
#MyTMA
#MyositisAwareness
#TMACanHelp

**Post, tweet, like love, & share**

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

**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.

**Tweet all about it**

Get creative. Remember, you only have 280 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 with #Myositis Awareness 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. #Myositis
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. 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!

Downloadable images are available 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 ways, and then you can make the rest.

**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.

**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!
Phone for myositis

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 75,000 people in the US.
- It is a rare chronic disease that weakens muscles.
- There are several forms of the disease: polymyositis, dermatomyositis, necrotizing myopathy, 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.

Who you gonna call? +

You’re itching to make calls and spread the word to physicians, but how do you find a call list?

There are many resources available for finding local physicians. These websites are often targeting individuals looking for healthcare providers and are perfect for the purpose of raising awareness.

Some places to start online:
- Your health insurance database
- www.healthgrades.com
- www.zocdoc.com

Using the Yellow Pages?
Find physicians listed under:
- Family doctors
- General practitioners
- Internists
- Dermatologists
- Neurologists
- Rheumatologists
- Immunologists