THE MYOSITIS ASSOCIATION®

MYOSITIS AWARENESS MONTH Toolkit

Myositis Awareness Month is May 1-31. 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 contains four guides, which will help you join TMA in elevating myositis awareness.

Guides to **Proclamations**, **Media Pitches**, **Social Media**, and **Community Outreach** are included in this master toolkit.

Myositis Awareness Month

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Be sure to check out all the links in the toolkit and online!

[Myositis Awareness Month]

[Diagnosis Days, Webinars, and Special Events]

[Awareness Tools and Tips]

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.

The Myositis Association®

Myositis Awareness Month

PROCLAMATIONS GUIDE

Myositis Awareness Month is May 1-31. 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 guide will help you join TMA in elevating myositis awareness via proclamations.

Proclamations Basics

Proclamations, or official designations of Myositis Awareness Month, can be requested from elected officials in your city, county, or state (or all the above!) Proclamations are a great way to educate the public where you live about myositis and bring attention to our cause. These documents carry the full support of a key government official or governing body in your region, so they are an effective tool for public recognition.

TMA's goal for 2025 is to secure a proclamation from each state legislature! Would you like to serve as a state coordinator for this effort? Please complete our **online volunteer interest form**, and we'll contact you if your home state needs a coordinator.

All proclamations increase myositis awareness. We encourage everyone in the TMA community to pursue a proclamation from an office or institution in your hometown! Governors, county executives or commissioners, mayors, municipalities, counties, cities or towns can issue proclamations. City proclamations may be signed by a mayor, city manager, or city marshal.

How can you help?

1. **Learn**: View this example proclamation from the Georgia House of Representatives.
2. **Prepare**: Use this guide to prepare a proclamation request in your own community.
3. **Submit**: Legislator look-up tools can help you determine your representatives at the state and local levels. You may even find a tab called Proclamations, Celebratory Documents, Recognition Requests, or similar on your town's website.
4. **Report**: Tell TMA about the proclamation, share a copy, and upload a photo when you receive the signed proclamation!

If you have any questions or need help pursuing a state or local proclamation, please contact Rich DeAugustinis, TMA Board of Directors Vice Chair: proclamations@myositis.org.

Proclamation Request

Customize the message below to reach out to your state, city, or local official(s) to request a proclamation.

DATE

Dear **<TITLE & NAME OF ELECTED OFFICIAL>**,

I am writing to ask you to declare **May 2025** as **Myositis Awareness Month** in **<MUNICIPALITY>.** During this month, hundreds of our neighbors and thousands of people across the United States will join The Myositis Association (TMA) in observing this special awareness event.

As your constituent, I believe this is important because all forms of myositis combined affect an estimated 75,000 people in the U.S. Families in **<MUNICIPALITY>** are affected by this debilitating disease, and we have very few treatment options. Moreover, national statistics indicate that approximately 1 in 10 people in our state are living with a rare disease (National Institutes of Health, NIH).

<INSERT 2-3 BRIEF SENTENCES OF YOUR PERSONAL JOURNEY WITH MYOSITIS AND WHY IT IS IMPORTANT TO YOU TO ADVOCATE>

This Myositis Awareness Month, special events and activities will help us foster a deeper understanding of myositis. Individuals and families affected by myositis will be sharing their stories on social media; in radio, TV, and newspaper interviews; and at community events here in **[STATE]** and across the U.S.

<MUNICIPALITY> has a strong history of support for its citizens' causes. By declaring May 2025 as Myositis Awareness Month in **<MUNICIPALITY>,** you will help us raise awareness within our community. I hope that you will join me and let our neighbors living with myositis know that while their diseases are rare, they are not alone.

With best regards,

Your name
Your organization (if applicable)
Your address
Your email
Your phone

Proclamation Draft

Closely review the requirements for your local, city, or state to issue a proclamation. Customize the draft below to meet the guidance given by your local official(s). Sometimes, "whereas" clauses are limited to a certain number, so you may need to prioritize the statements to include in your customized draft.

Whereas, residents of **<MUNICIPALITY>** are among those affected by myositis and other rare diseases, because nearly one in ten Americans have rare diseases; and,

Whereas, idiopathic inflammatory myopathies (collectively referred to as myositis) are rare, chronic, autoimmune muscle wasting diseases; and, myositis often features debilitating muscle inflammation and other symptoms, such as pain, fatigue, and trouble swallowing; and, myositis can result in myositis-associated interstitial lung disease; and,

Whereas, more research is needed to identify the causes of and modes of treatments for the myositis group of diseases, which includes anti-MDA5 autoantibody positive myositis; antisynthetase syndrome; dermatomyositis; juvenile dermatomyositis; immune-mediated necrotizing myopathy; inclusion body myositis; and polymyositis; and,

Whereas, myositis is difficult to diagnose, so treatment is often delayed, and individuals generally experience difficulty finding a health care provider with expertise in their condition; and,

Whereas, all who suffer with myositis experience reduced quality of life, especially as no cure has been found and life expectancy is shortened, especially for those with inclusion body myositis; and, women and people of color with all forms of myositis experience particularly pronounced health disparities; and,

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Myositis Awareness Month

PROCLAMATIONS GUIDE

Whereas, The Myositis Association (TMA) is the leading international patient advocacy organization serving the myositis community, focusing on patient services, education, research, and public awareness, so as to achieve a world without myositis; and,

Whereas, The Myositis Association is organizing a nationwide observance of Myositis Awareness Month from May 1-31, 2025;

Therefore, be it resolved that May 2025 will be observed as Myositis Awareness Month in **<MUNICIPALITY>**, and that all citizens of **<MUNICIPALITY>** are encouraged to come together, learn more about all the forms of myositis and its symptoms, and support the families in our community who will benefit from greater awareness of these rare diseases.

Myositis Awareness Assets from TMA

The official TMA Myositis Awareness Month web page features shareable images, tools and tips, events, and a hi-resolution copy of the TMA logo.

The official TMA social media accounts are linked below. Please tag us if you attend an event where your proclamation is presented!

- www.facebook.com/Myositis/
- www.instagram.com/themyositisassociation/
- www.linkedin.com/company/the-myositis-association/
- 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.

The Myositis Association®

Myositis Awareness Month

MEDIA PITCH GUIDE

Myositis Awareness Month is May 1-31. During this period, it is imperative to 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 guide will help you join TMA in elevating myositis awareness in local media.

A Note from Our Executive Director

Dear myositis advocate,

TMA thanks you for your efforts to help educate your local media, newspapers, radio, podcasts, and television about myositis. Who better to conduct this essential outreach than **you**, who live with courage and strength every day despite this currently incurable, rare, chronic, disease?

Reporters in your community are genuinely 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.

After your story appears in the newspaper, on radio, or on television, send me a link. We will not only make everyone associated with TMA aware of the media hit, but I will send a letter directly to the writer, on-air talent, editor, or producer to thank them personally. This will allow TMA to develop a more comprehensive and nationwide media list to contact when we are promoting Myositis Awareness Month each May.

TMA can and will provide key facts and figures to include in any coverage. Keep in mind that official statements on behalf of TMA can be provided only by authorized representatives of TMA – and we'd be delighted to do so! If you need a quote, have questions, or would like help pursuing a media opportunity, please contact me: paula@myositis.org.

To your success, Paula Eichenbrenner, Executive Director, TMA

Paula

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Myositis Awareness Month

MEDIA PITCH GUIDE

Finding Media Contacts: Best Practices

How you identify and approach media contacts in your community is critical to getting an interview. Do some research. Find out the best person to whom you should write.

For television, radio, and podcasts:

- You may try to reach a television personality, or radio personality.
- If you cannot get to the television or radio personality, call the stations and ask who is the producer to whom you can pitch a story. Television and most radio stations also have producers.

For newspapers:

- With editors, department editors, and writers, the best person to contact at a newspaper is a writer. Writers or columnists get fewer letters and appreciate that a reader contacts them.
- All newspapers have Opinion Editors. Opinion Editors are responsible for the newspaper's editorial page and the Op Eds. They are responsible for an editorial announcing that May is Myositis Awareness Month. These editors often let you appear before their board to make a case for the newspaper to write about myositis. Opinion Editors are second-best contacts at a newspaper.
- The Editor-in-Chief is the most powerful, but usually is the most difficult for you to get to actually read your letter.

Conducting Media Outreach: Best Practices

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① **First**, let the media you are contacting know that you are an avid reader, listener, or viewer of the publication, outlet, or channel. Include an observation of how you value the media. Give an example of how you learned something or enjoyed something from the columnist, radio host, or television personality.

② **Second**, write a short letter explaining who you are, where you reside, and that you live with myositis. Explain what myositis is and how long you have lived with it. A suggested template for your letter is included in this guide. But remember – the media receives many of these letters every day. **You need to differentiate your letter** from everyone else's!

Three, once your message has been received by the person you send it to, follow up – repeatedly. Email them if you have their email, but calling is better. Be persistent. Usually, you need to call them at least three times. Know they are busy. Apologize for taking up their time. Appeal to the journalist's sense of importance. Tell them how important they are in reaching and influencing others. Ask them to interview you and other members of the community with myositis. Be funny and enjoyable. Let them know they will get a good story for their audience by interviewing you and your friends.

Four, once they interview you and it appears in the newspaper, on radio, or on television, send a message to their boss and cc them, thanking the boss for hiring the person that interviewed you. Also, put the newspaper article on your Facebook page, LinkedIn or other social media.

Five, build and maintain goodwill! Print and broadcast reporters will respect you if you submit timely calendar items, do your homework on longer features, provide interesting visuals, and **never** call the publisher and advertisers to complain. Bring donuts to the newsroom, television, or radio station occasionally because you want them to interview you each time TMA has an awareness or fundraising campaign.

Interview Pitch Letter

Customize the template below to reach out to editors and local media contacts (radio, television, newspapers) to report on myositis. Tailor the letter to your own circumstances and voice, include a few facts from your own story, and be sure to include your contact information.

DATE

Dear **<TITLE & NAME of writer, columnist, editor, radio or television personality, producer>**, I live at **[PLACE]**. I read your column (or I am aware of your byline, watch you regularly on television, listen to you on radio) and I enjoyed your coverage of **[SPECIFIC EXAMPLE]**. I have a rare, currently incurable, chronic disease called myositis (or specifically state the kind of myositis you have).

I am contacting you now, because May has been declared Myositis Awareness Month by The Myositis Association. There are only an estimated 75,000 Americans who have a form of myositis. Myositis is a collection of autoimmune diseases of the muscles that cause muscle weakness, extreme fatigue, debilitating rashes, difficulty breathing, and other challenging symptoms.

[INSERT SOME OF YOUR SYMPTOMS] *Example*: I have a form of myositis called dermatomyositis, or DM. DM causes itchy rashes that make it difficult for me to sleep and function normally. *Or* I have inclusion body myositis, one of the forms of myositis that makes it impossible for me to walk upstairs or lift my arms over my head. *Or* I have polymyositis, one of the forms of myositis, along with interstitial lung disease. This makes it difficult for me to breathe normally and… **[OTHER WAYS THIS DISEASE AFFECTS YOU]**

I know you get requests from many of your readers (*or* viewers). All I ask is that you meet with me (and a couple of other locals who have this disease). I (*or* we) won't take up too much of your time. We are not looking to become well known ourselves. We are reaching out because increasing awareness of myositis — both among local physicians and within our communities — is urgently needed.

Too many of us lived with undiagnosed symptoms for years, often waiting until we were finally referred to large academic medical centers for answers. Greater awareness at the local level can change this. When both doctors and community members recognize the signs of myositis earlier, patients can access critical care sooner, leading to better outcomes and hope for the future.

Myositis is very rare, and we truly need your help. Early recognition saves time and ultimately, saves lives. The more people who understand myositis, the closer we move toward better treatments. We hope that you will partner with us to shorten the time to diagnosis and ultimately, bring us closer to the promise of a cure.

Thank you so very much for considering meeting with me (*or* us).

With best regards,

Myositis Awareness Month

MEDIA PITCH GUIDE

The Myositis Association®

Your name (add others' names, if applicable)
Your organization (if applicable)
Your address
Your email
Your phone

Write It Yourself!

If you don't hear back after submitting your pitch to a journalist, don't give up. Most media outlets today have a way to submit a story idea online, so you can try that too. You can also look for a **"From the community"** submission form (see example story, right).

If you get to know the Opinion Editor, he or she might suggest that you write an **Op Ed**, a column which generally should be about 730 words.

A **"Letter to the Editor"** can be submitted without invitation, and is usually only 150 words. The goal of letter to the editor is to offer insightful, expert, and timely commentary on issues or concerns of their readers. Include your story and why myositis awareness is important to you. Before writing a letter to the editor, check the publication's website to see if they publish recommended word counts, deadlines, or guidelines.

Southwest Florida myositis support group celebrates 12th anniversary

Community Submitted Sarasota Herald-Tribune

Aug. 5, 2019, 2:15 p.m. ET

Marianne Moyer, left, Barbara Kluding, Donna Defant, Barbara Logan, Jean Rosenberg, Jan Marriott, Pat Lawrence, Tina Carter-Pearson and Ron Gines. [SUBMITTED PHOTO] *Sarasota Herald-Tribune*

Get Inspired!

For inspiration, view these **recent stories featuring TMA advocates**.

- Lindsay Guentzel on KSTP 5 News, Minneapolis, MN
- Omni McCluney, PA-C, MMsC, MPH on CW39 News, Houston, TX
- Vance Robinson with First Pitch campaign and fundraiser on KSBY News, San Luis Obispo, CA

The Elgin News

From Victim to Warrior:

Chip Galloway Is Fighting for Myositis Awareness While Fighting Myositis

- Chip Galloway with Crossing the Cooper event and fundraiser on Live 5 WCSC News, Charleston, SC

Myositis Awareness Assets from TMA

The official TMA Myositis Awareness Month web page features shareable images, tools and tips, events, and a hi-resolution copy of the TMA logo. Check out even more tips from TMA on raising awareness through local media.

The official TMA social media accounts are linked below. Please tag us if you share an interview or story about your myositis journey!

- www.facebook.com/Myositis/
- www.instagram.com/themyositisassociation/
- www.linkedin.com/company/the-myositis-association/
- 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.

TMA thanks Stanford Erickson, President of Integrated Media Consultants, for sharing his expertise in this guide.

Myositis Awareness Month

The Myositis Association

SOCIAL MEDIA GUIDE

Myositis Awareness Month is May 1-31. 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 guide will help you join TMA in elevating myositis awareness on social media.

Social 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 and reshare our content. Tag us when sharing your posts, and TMA can repost with our community!

As May arrives, upload TMA's social media graphics to feature Myositis Awareness Month through your own profile image, banner, post, or story (Facebook, Instagram, LinkedIn).

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, TMA recommends these hash tags: **#MyositisAwareness #MyositisAwarenessMonth #MAM2025 #TheMyositisAssociation #MyTMA**

MAM Facebook Cover Photo.png

MAM Instagram Story Photo.png

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.

MAM Social Media General Post.png

MAM Social Media I Donate Post.png

Say myositis. ***Stop*** myositis!

Social Media Storytelling

If you are ready to level up, create a post on your social accounts to tell your story. This year, TMA is offering a suite of all-new image files on Canva, and most are customizable. It's easier than ever to **tell your story, your way**!

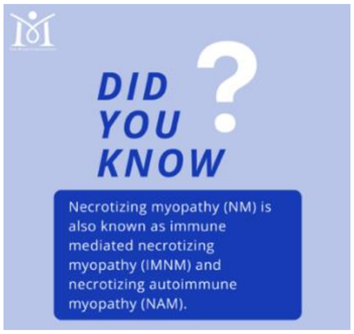
Some options are:

1. Use one of TMA's fully customizable profile frames**, featuring options to share with your "Ask Me about Myositis" graphic and a brief caption**.

   You could say: "I have [specific form of] 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."

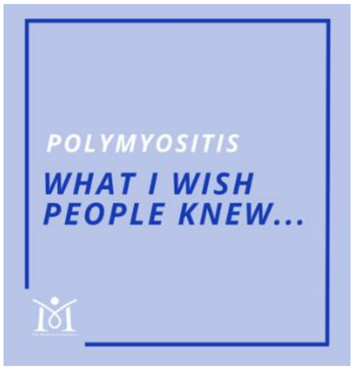
2. Share one of TMA's "Did You Know?" fact cards.

   With a dozen evidence-based and informational statements about forms of myositis, this series is great way to help your loved ones understand your journey a little better. Individual cards are not customizable, but you can re-purpose our content as you wish!



Necrotizing myopathy (NM) is also known as immune mediated necrotizing myopathy (IMNM) and necrotizing autoimmune myopathy (NAM).

3. Go deeper with one of TMA's "What I wish people knew…" diagnosis cards accompanied by quote cards. The quote cards are fully customizable, so you can share your authentic comments with your social media audience.



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?

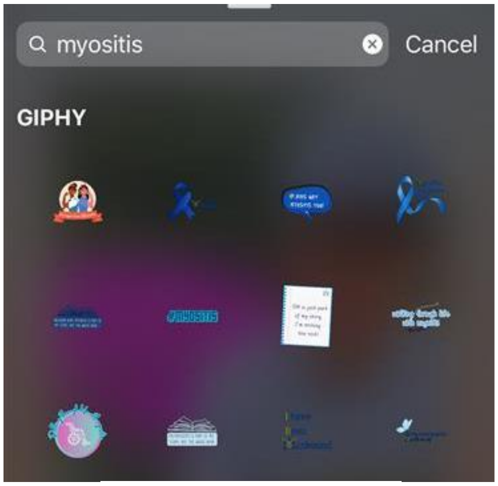
- What do you wish you knew in the early days of your diagnosis?
- How has myositis affected your life?
- How can a friend or family member best support you during difficult times?
- What would you like others to understand about your disease and living with myositis?
- How has TMA been helpful?

Enhance Storytelling with Photos, Animation, and Video

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? Can you snap a selfie while pursuing your favorite form of exercise or at-home PT? Add candid pictures to your story for more engagement.

Animate your story with TMA and myositis GIFs! On TMA's Giphy page, there's a Myositis Awareness Month collection with myositis mantras and fresh new graphics! You can also search for TMA and myositis GIFs when posting a story on Instagram (pictured at right).

Working on a reel or video? Check out some tips and best practices in "60 Seconds to Impact: Sharing your Myositis Story with Purpose" with TMA leader, myositis advocate, and award-winning journalist Lindsay Guentzel.



Get Inspired!

For inspiration, view these **social media feeds featuring myositis advocates**.

- Holly Jones, living with polymyositis and interstitial lung disease
- Lindsay Guentzel, living with dermatomyositis and antisynthetase syndrome
- Erica Deasza, living with antisynthetase syndrome and interstitial lung disease

- **Vance Robinson**, living with inclusion body myositis
- TMA Patient Ambassador Awardee **Karen Alexander**, living with DM
- TMA Patient Ambassador Awardee **Peter Frampton**, living with IBM

Myositis Awareness Assets from TMA

The official TMA Myositis Awareness Month web page features shareable images, tools and tips, events, and a hi-resolution copy of the TMA logo.

The official TMA social media accounts are linked below. Please tag us if you share a post or story about your myositis journey!

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

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THE MYOSITIS ASSOCIATION

Myositis Awareness Month

COMMUNITY OUTREACH GUIDE

Myositis Awareness Month is May 1-31. 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 guide will help you join TMA in elevating myositis awareness in your community.

Don't miss our guides to Proclamations, Media Pitches, and Social Media to share even more broadly in your community.

Community Outreach Signs

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 be 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.

Say myositis. ***Stop*** myositis!

Accelerating Our Impact

Myositis Awareness Month

COMMUNITY OUTREACH GUIDE

Create a [personal fundraising campaign to benefit TMA's mission]() on our website. We'll equip you with a personalized web page and a kickoff message that you can share with your network. It's easy and fun!

Some advocates organize events like community walks or happy hours during May to promote their **TMA fundraisers**. We will mail you a package of myositis info materials and TMA swag to display at your event. Is there a health fair or similar event in your city where you could share these items?

[Pitch in for Myositis Awareness]()! Athlete and TMA volunteer Vance Robinson started VRob's "First Pitch" for Myositis Awareness campaign in 2016 to bring attention to the rare and debilitating forms of myositis. The 2025 baseball season is the 9th year of his campaign. VRob and TMA have set a goal for 2025 to throw 31 First Pitches, one for each of the 31 days in May! A First Pitch can be delivered at any baseball game in your neighborhood or city.

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.

And don't forget, myositis awareness is a year-round priority! TMA proudly partners with global patient advocacy organizations to drive myositis awareness on World Myositis Day. The next **World Myositis Day is September 21, 2025**.

Share Your Insights with TMA and Others

May is **Mental Health Awareness Month**, in addition to **Myositis Awareness Month**. May is a truly opportune time to take action, raise your voice, and help change the conversation around mental health! TMA recognizes the impact that a myositis diagnosis and continued disease progression has on the emotional wellbeing of patients, families, and care partners. **Help others navigate these challenges** by [submitting your insights on mental health and myositis](). TMA will publish a compilation of the community's mental health strategies at the end of May.

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Myositis Awareness Month

COMMUNITY OUTREACH GUIDE

We are always looking for powerful stories to share on the TMA blog and in the pages of Outlook magazine! **Share your myositis journey with TMA**.

Raise awareness of myositis and autoimmune diseases by sharing your autoimmune disease story with the Autoimmune Association.

Join the dazzle of myositis zebras by sharing your rare disease story with the National Organization for Rare Diseases.

Get Inspired!

For inspiration, view these **campaigns, fundraisers, and blogs featuring myositis advocates**.

- Vance Robinson, First Pitch for Myositis Awareness Campaign and Fundraiser
- Jason and Stephanie Grucza, Myositis Awareness Car Show and Fundraiser
- All currently published patient stories on TMA's blog.

Myositis Awareness Assets from TMA

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The official TMA social media accounts are linked below. Please tag us if your community commemorates Myositis Awareness Month!

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- www.instagram.com/themyositisassociation/
- www.linkedin.com/company/the-myositis-association/
- x.com/themyositisassc

Myositis Awareness Month

COMMUNITY OUTREACH GUIDE

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