

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!

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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,

PROCLAMATION 50

MYOSITIS AWARENESS MONTH

MAY 1-31, 2025



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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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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!

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

***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.***