**REQUESTING A PROCLAMATION FOR MYOSITIS AWARENESS MONTH**

We appreciate your involvement with Myositis Awareness Month 2018! Myositis Awareness Month will take place during the month of May 2018.

This guide will provide you with wording and resources you may need to have your Mayor or Governor proclaim May 2018 as Myositis Awareness Month in the United States.

**Before Requesting a Proclamation:**

To ensure we have all States and major City’s involved, Myositis Support and Understanding (MSU) is reaching out to its membership, members of its support groups, and the general public through social networking sites and other means asking residents of their specific City and/or State to submit proclamation requests. (You must be a resident of the City/State for which you are requesting).

**Prior to submitting a proclamation request, please contact MSU at** [**info@understandingmyositis.org**](mailto:info@understandingmyositis.org) , or through Facebook Messenger at [Facebook.com/Understandingmyositis](https://Facebook.com/Understandingmyositis), with your name and the City and/or State for which you would like to request. Submitting more than one request will cause confusion, significant delays, and may cancel a proclamation for our cause.

**Timeline:**

**Please begin requesting proclamations TODAY!** Requests can take some time to be reviewed, approved, and issued.

**When you receive the proclamation.**

**Represent your City or State in person if able.**

Your state or local government office may invite you to attend a meeting to accept the proclamation on behalf of Myositis Awareness Month. This is a great press opportunity and way to further our awareness goals. Plan a community event and invite other Myositis Awareness Month partners and local members of the press to take part as well.

**Share your proclamation.**

Share a copy of the proclamation as well as any photos, videos, and other moments from receiving the proclamation with the Myositis Awareness Month community by submitting materials to MSU for inclusion on the Myositis Support and Understanding website (UnderstandingMyositis.org) and on social media using the hashtag #myositisawareness. Email us your materials, and a copy of the proclamation at [info@understandingmyositis.org](mailto:info@understandingmyositis.org) or upload here: [UnderstandingMyositis.org/upload](https://UnderstandingMyositis.org/upload)

**HOW TO REQUEST A MYOSITIS AWARENESS MONTH PROCLAMATION**

**Visit your state government’s website**.

The majority of States allow you to request a proclamation online via their website. To find your State’s information, we have put together an additional resource with links to the page needed. Visit [UnderstandingMyositis.org/docs/awareness/states-contacts-proclamations.pdf](https://UnderstandingMyositis.org/docs/awareness/states-contacts-proclamations.pdf) for the list. Or, you can simply do a web search for “proclamation request for State of \_\_\_\_\_\_.” Some States, however, require this in writing.

**Visit your local government’s website**.

Some City websites have an online Mayoral Proclamation Request section on their website. If they do not, send an email request to your Mayor. You can likely find the Mayors contact information, including their email address, on the City’s official web page. You can also do a web search for “proclamation request for City of \_\_\_\_\_\_.” ***(You can edit and use the draft email provided in this guide.)***

**Submit Requests Immediately.**

Proclamations requested at least **45-60 days in advance** have the best chance of being completed and provided to the requestor in time, on or before May 1, 2018 in this case. Be sure to reach out well in advance of Myositis Awareness Month. (See section above, “Before Requesting a Proclamation”)

Local and State Governments receive many requests to present both new and annually recurring proclamations each and every month. Allowing adequate time for review provides the best chance to receive the proclamation in time. Be sure to be available if chosen to present in person.

**Provide Wording.**

For State proclamations, the Governors website may request specific wording for the proclamation. We have provided the draft wording below you can use. Be sure to edit the draft to meet your specific City/State requirements and replace the highlighted elements with the actual City/State name and Mayor’s/Governor’s name.

For City proclamations, if the website does not allow online requests, reach out via email to the Mayor’s office. Include and attach the proclamation wording using the draft in this guide, making sure to edit the highlighted parts first.

*We have included a draft proclamation below for you to edit and send.*

**If Limited by “Whereas” clauses.**

Some City/States only allow a certain number of “whereas” clauses. If there are too many in the draft proclamations for your request, please remove one (or more) that you deem not required in having the proclamation issued.

**DRAFT OUTREACH EMAIL, CITY**

The following draft email offers ideas and language you can use as part of your outreach to your city and state officials for Myositis Awareness Month proclamations. Feel free to edit as you see fit for your needs as you communicate about your involvement with Myositis Awareness Month. (You can also adapt this for your State, if needed.)

Subject: Myositis Awareness Month, May 2018

Dear \_\_\_\_\_\_\_\_\_\_, (Use official titles when known: Mayor, Governor or use ‘To Whom It May Concern’)

This year, starting on Tuesday, May 1, 2018, we begin a month-long awareness campaign aimed to educate, support, and advocate for myositis patients and caregivers.

Myositis (Idiopathic Inflammatory Myopathy), which includes dermatomyositis, polymyositis, inclusion body myositis, juvenile myositis, and necrotizing myopathy, is a class of rare, autoimmune muscle and skin diseases that may also affect the lungs and other organs. Myositis is a complicated disease that can be completely disabling. Myositis strikes both children and adults, women and men, and has no cure and limited-to-no effective therapies.

As a rare disease, the average time to a correct myositis diagnosis is about 3.5 years. There are approximately 50K people living with myositis in the U.S.

Myositis can cause complete and total disability. Treatments for one form, inclusion body myositis, are non-existent at this time, and for other forms, therapies consist of limited, off-use medications commonly used for other autoimmune diseases.

As a partner of Myositis Awareness Month from the City of \_\_\_\_\_\_\_\_\_\_\_\_\_, I would like to respectfully request that the City of \_\_\_\_\_\_\_\_\_\_\_ officially proclaim May 2018 as Myositis Awareness Month. The City of \_\_\_\_\_\_\_\_\_\_\_\_ can really help generate awareness and promote education for the rare disease Myositis, and for those fighting for their lives.

For additional information, please visit the MSU website at UnderstandingMyositis.org

It would truly be an honor to have the City of \_\_\_\_\_\_\_\_\_\_ formally proclaim Myositis Awareness Month. I have attached the example proclamation wording and I thank you for considering my request.

Your Name  
Myositis Support and Understanding Association

(Remember to attach the proclamation wording)

**SAMPLE CITY MYOSITIS AWARENESS MONTH PROCLAMATION**

WHEREAS, “Myositis” is the general term used to describe the Idiopathic Inflammatory Myopathies which include dermatomyositis, polymyositis, necrotizing myopathy, inclusion body myositis, and the juvenile forms of myositis, which are rare, autoimmune muscle and skin diseases that may also affect the lungs and other organs; and

WHEREAS, Myositis affects roughly 50,000 people in the United States and takes on average 3.5 years to diagnose, and is often misdiagnosed causing a delay in potentially helpful therapies which may lead to permanent muscle loss, organ damage, and total disability; and

WHEREAS, Education for patients, caregivers, family members, physicians, other healthcare providers, medical decision-makers, and lawmakers is essential to the overall health and well being of patients; and

WHEREAS, Myositis affects every aspect of patients’ lives including emotional, physical, financial, and relationships, patients deserve emotional support, financial assistance, and understanding; and

WHEREAS, Raising awareness of and increasing funding for Myositis are important factors in advancing research and developing more effective treatments with a goal of a cure for Myositis; and

WHEREAS, Congress passed a House Resolution in 2006 proclaiming September 21st as National Myositis Awareness Day, and now, as in past years, we celebrate during the month of May, and the CITY NAME, STATE would like to join Congress, Myositis and Rare Disease organizations, and patients in raising awareness of Myositis during the month of May; and

NOW, THEREFORE, I, MAYOR'S NAME, Mayor of the City of CITY NAME, do hereby proclaim May 2018 as **MYOSITIS AWARENESS MONTH** in the CITY NAME, and encourage all citizens of CITY NAME to join together and learn more about Myositis and advocate for increased research funding and education programs.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Seal of the City of CITY NAME, STATE, to be affixed this 1st day of May 2018.

**SAMPLE STATE MYOSITIS AWARENESS MONTH PROCLAMATION**

WHEREAS, “Myositis” is the general term used to describe the Idiopathic Inflammatory Myopathies which include dermatomyositis, polymyositis, necrotizing myopathy, inclusion body myositis, and the juvenile forms of myositis, which are rare, autoimmune muscle and skin diseases that may also affect the lungs and other organs; and

WHEREAS, Myositis affects roughly 50,000 people in the United States and takes on average 3.5 years to diagnose, and is often misdiagnosed causing a delay in potentially helpful therapies which may lead to permanent muscle loss, organ damage, and total disability; and

WHEREAS, Education for patients, caregivers, family members, physicians, other healthcare providers, medical decision-makers, and lawmakers is essential to the overall health and well being of patients; and

WHEREAS, Myositis affects every aspect of patients’ lives including emotional, physical, financial, and relationships, patients deserve emotional support, financial assistance, and understanding; and

WHEREAS, Raising awareness of and increasing funding for Myositis are important factors in advancing research and developing more effective treatments with a goal of a cure for Myositis; and

WHEREAS, Congress passed a House Resolution in 2006 proclaiming September 21st as National Myositis Awareness Day, and now, as in past years, we celebrate during the month of May, and the State of STATE NAME would like to join Congress, Myositis and Rare Disease organizations, and patients in raising awareness of Myositis during the month of May; and

NOW, THEREFORE, I, GOVERNOR’S NAME, Governor, do hereby proclaim May 2018 as **MYOSITIS AWARENESS MONTH** in the State of STATE NAME, and encourage all citizens of STATE NAME to join together and learn more about Myositis and advocate for increased research funding and education programs.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Seal of the STATE of STATE NAME, to be affixed this 1st day of May 2018.