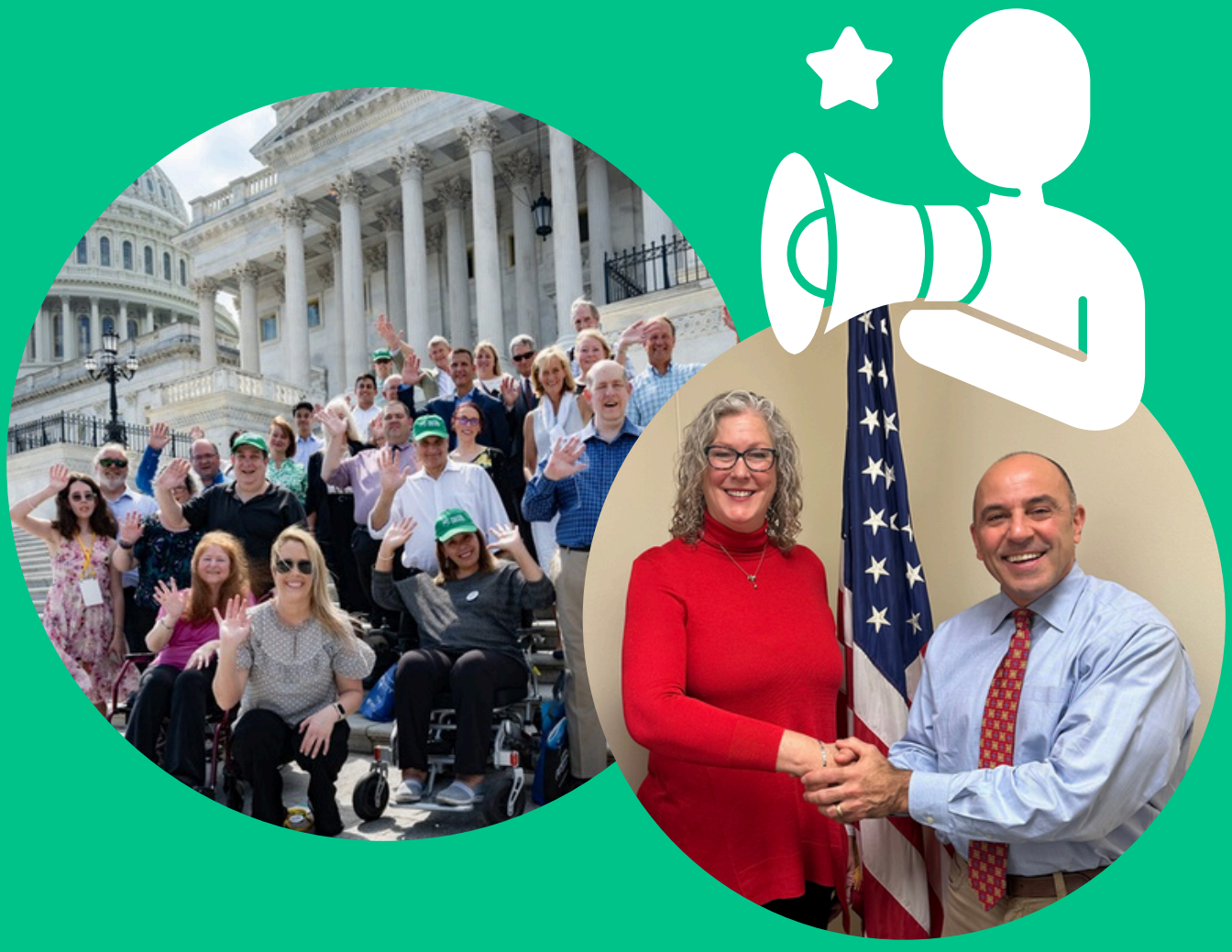
Myotonic Dystrophy FOUNDATION

www.myotonic.org

Proclamation Toolkit

Guide for Requesting Local, State, or Provincial Proclamation for International Myotonic Dystrophy Awareness Day



Myotonic Dystrophy FOUNDATION

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Myotonic Dystrophy Foundation Overview

About MDF

The Myotonic Dystrophy Foundation (MDF) is the leading global advocate helping patients and families navigate the myotonic dystrophy (DM) disease process, and is often the first resource contacted by newly-diagnosed patients, their families, their social workers and their physicians around the world. For many international patients, the Myotonic Dystrophy Foundation is often the only resource they are able to locate, and MDF has provided assistance and support for people living with DM in more than 139 countries around the world.

Currently tens of thousands of people living with myotonic dystrophy, their families & friends make up the Myotonic Dystrophy Foundation community.

Our Vision

We envision a world with treatments and a cure for myotonic dystrophy.

Our Mission

The mission of the Myotonic Dystrophy Foundation is Community, Care, and a Cure.

- We support and connect the myotonic dystrophy community.
- We provide resources and advocate for care.
- We accelerate research toward treatments and a cure.

Become a Local DM Advocate!

Many states, provinces, cities, and towns across the U.S. and Canada issue proclamations to promote public awareness and civic action on a range of important issues, including rare diseases such as myotonic dystrophy (DM).

What is a Proclamation?

A proclamation is an official and formal public announcement in support of a cause made by a government representative, including mayors, municipal or provincial council members, congresspeople, provincial premiers/ministers, or state governors. Proclamations are often passed when a community advocate requests one, the steps and timeline for this process may vary for each community.

In 2021, the Myotonic Dystrophy Foundation and Muscular Dystrophy Canada began nationwide awareness campaigns and successfully advocated for passage of the first ever government proclamations declaring September 15th as International Myotonic Dystrophy Awareness Day. The Manitoba proclamation was issued in Canada in 2021, with Senate Resolution 772 officially signed into law in the US shortly thereafter. Since then, advocates from across the U.S. and Canada have successfully petitioned their local elected officials to issue proclamations, including in Florida and Minnesota. You can read more on Page 6 about MDF advocate, Beth Feigenblatt, and her work to secure a proclamation in city of Ocala, Florida.

Civic proclamations are an excellent way to increase DM Awareness, and getting a proclamation is much easier than you might think! We encourage you to use this brief guide on how to secure a proclamation. While each state, province, city, and town may have slightly different processes for requesting a proclamation, this guide provides tips on the most common steps required to be successful.

How to Request a Proclamation:

Get Started: Contact Your Local Government

1. Ask about the process of obtaining a proclamation. You can do this by reaching out to one of your local elected representatives. This could be a governor, premier, mayor, provincial minister, state senator, state representative, assembly person, or town council person. You can call their office, send an email, or submit a question via form on their website.

- Note: Some offices may have an official application to complete. Check the government website to see if they explain the process for requesting a proclamation. If there isn't an application, send a short email or letter with your request. See sample email on page 4.

2. Request a meeting with your elected official to share your story and explain why a Proclamation for International DM Awareness Day is important to you.

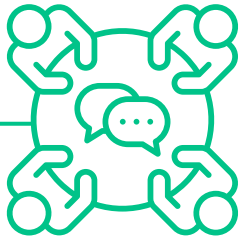
- Be sure to request your meeting several months before September 15th to ensure there is plenty of time to finalize the Proclamation Request. Sometimes, a follow up email is needed to remind them of your request!
- During your meeting, be prepared to:
  - Share that September 15th is International Myotonic Dystrophy Awareness Day around the world.
  - Provide a brief overview of what myotonic dystrophy is and why you are hoping to raise awareness. This is your opportunity to share more about how DM has impacted you and your family, and the community as a whole.
  - Ask questions- find out more details about the proclamation process is in your state, province, city, or town. Ask how a proclamation is presented, if there will be an event for the presentation, and if community members can come and take photos!
- Provide your elected official with the sample proclamation text seen on Page 4 - this may make it easier for them!

3. At the Proclamation Presentation, be sure to take photos and share your photos on social media, with local news outlets, and with MDF and MDC!

Questions?

If you have any questions, need help finding your local officials, want to practice sharing your story, or want to celebrate your local proclamation just email MDF at info@myotonic.org.

How to Request a Proclamation:



Example Outreach Email:

Use this example to help draft your email to representatives.
Get an editable version by scanning the QR code.

Subject: Support Me and My Campaign for Myotonic Dystrophy Awareness

Dear [Name],

As a community member living with/caring for a loved one with myotonic dystrophy, I am writing to ask for your assistance in promulgating a proclamation declaring September 15th as International Myotonic Dystrophy Awareness Day in the [City & State/Province].

Myotonic Dystrophy is a multi-systemic, inherited, progressive, genetic disease that affects as many as 1 in 2,100 people. It is caused by a mutation in a gene required for normal muscle function which prevents the gene from functioning properly. Individuals affected by myotonic dystrophy may have skeletal muscle problems, heart function abnormalities, breathing difficulties, cataracts, issues with speech and swallowing, cognitive impairment, excessive daytime sleepiness, or diabetic symptoms. There is currently no cure, nor any approved treatments for this disease.

I would like to schedule a meeting with you and/or the appropriate staff to discuss our interest advancing this important proclamation.

Thank you for your time and attention to our request. I look forward to your reply.

Warmly,
YOUR NAME

Proclamation Success Story

Beth's Proclamation Story:

After being inspired by the MDF Advocacy Day on Capitol Hill in 2023, Beth Feigenblatt was determined to spread awareness about DM by becoming a local advocate. She decided to reach out to MDF in spring of 2024 for help crafting a letter to her City Mayor in Ocala, Florida.

In an email sent to the mayor in May 2024, she told the story of her family's experience with DM. She wrote of their diagnostic journey that started in 2018, when her husband and three sons were all diagnosed with myotonic dystrophy type 1. After a couple months of follow up with the mayor's office, she received a response in July 2024.

The city of Ocala, Florida was ready to formally proclaim September 15th as International Myotonic Dystrophy Awareness Day! Just a few short months later, in September, Beth, her sons, and DM researchers from the University of Florida, were invited to join City Council at City Hall to receive their Proclamation.

Example Proclamation

Use this example to help draft your proclamation.
Please note: some governments may have requirements on how long a proclamation can be. Get an editable version by scanning the QR code.

Recognizing the seriousness of myotonic dystrophy and expressing support for the designation of September 15, as "International Myotonic Dystrophy Awareness Day".
Whereas myotonic dystrophy is a rare, multi-systemic, inherited disease that affects approximately 1 in 2,100 individuals, yet thousands of individuals do not know they have the disease and are in need of care[1];
Whereas myotonic dystrophy is the most common form of adult-onset muscular dystrophy[2], and the symptoms of the disease become more severe with each generation[2];
Whereas the disease is caused by a mutation in the DMPK gene, resulting in myotonic dystrophy type 1, or the CNBP gene, resulting in myotonic dystrophy type 2[2];
Whereas those mutations prevent those genes from functioning properly, impacting multiple body systems[2];
Whereas those mutations are autosomal dominant mutations, in which one copy of the altered gene is sufficient to cause the disorder, and affected individuals have a 50 percent chance of passing on the mutated gene to their children[3];
Whereas, through this inherited genetic anomaly, individuals with myotonic dystrophy experience varied and complex symptoms, ranging from skeletal muscle problems, early cataracts, and excessive daytime sleepiness to heart, breathing, digestive, hormonal, speech, swallowing, diabetic, immune, vision, and cognitive difficulties[2];
Whereas myotonic dystrophy is a highly variable and complicated disorder, and the younger an individual is when symptoms first appear, the more severe symptoms are likely to be[2];
Whereas misdiagnoses have persisted for decades, and delays in diagnosing myotonic dystrophy are common[4];
Whereas there are currently no treatments approved by the Food and Drug Administration/Health Canada for myotonic dystrophy;
Whereas the Myotonic Dystrophy Foundation was founded in 2007 with a mission to enhance the quality of life of individuals living with myotonic dystrophy around the world and accelerate research focused on finding treatments and a cure;
Whereas a more robust scientific investment in myotonic dystrophy research will improve health outcomes, reduce disability, and increase life expectancy for individuals living with myotonic dystrophy, and holds great promise for helping individuals with similar genetic diseases:
Now, therefore, be it Resolved, That the Community/State/Province of [XXX] —

1. Expresses support for the designation of September 15, as "International Myotonic Dystrophy Awareness Day";
2. Recognizes the seriousness of myotonic dystrophy; and
3. Supports the goals and ideals of International Myotonic Dystrophy Awareness Day, which include—
    a. committing to promoting and advancing the health, well-being, and inherent dignity of all children and adults with myotonic dystrophy;
    b. supporting the advancement of scientific and medical myotonic dystrophy research;
    c. fostering biopharmaceutical innovation that will lead to approved treatments and eventually a cure for myotonic dystrophy;
    d. advancing programs and policies that assist individuals living with myotonic dystrophy and the caregivers of such individuals; and
    e. encouraging awareness and education of myotonic dystrophy for patients, caregivers, clinicians, and researchers.

Thank You!

MDF is so grateful to you for your advocacy efforts! We appreciate your partnership in amplifying our mission of Community, Care, and a Cure. Together, we are changing the future of myotonic dystrophy!

If you have any questions or need additional support at any step in your proclamation journey, or want to learn how you can raise awareness outside of the United States and Canada, please reach out to MDF. We are here to help you!

Email	info@myotonic.org
Phone	1-415-800-7777
Website	www.myotonic.org

Find Support in Canada with Muscular Dystrophy Canada (MDC)

Our partners at Muscular Dystrophy Canada (MDC) can help identify the appropriate provincial or municipal office, review proclamation requests, provide Canadian statistics and background information, help advocates prepare for meetings with elected officials, and celebrate and promote successful proclamations across the country.

MUSCULAR DYSTROPHY CANADA
DYSTROPHIE MUSCULAIRE CANADA

Connect with MDC at research@muscle.ca

Medical References & Citations

1. Nicholas E. Johnson, Russell J. Butterfield, Katie Mayne, Tara Newcomb, Carina Imburgia, Diane Dunn, Brett Duval, Marcia L. Feldkamp, Robert B. Weiss. Population-Based Prevalence of Myotonic Dystrophy Type 1 Using Genetic Analysis of Statewide Blood Screening Program, Neurology Feb 2021, 96 (7) e1045-e1053, 2021.
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4. Sarah Howe, Marigold Foundation and the Christopher Project Reference Group. The Christopher Project: Report to the Myotonic Dystrophy Community. Marigold Foundation. Pages 23-24. Spring 2019.

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