The Myositis Association®

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Dear Linda,

We're halfway through Myositis Awareness Month, and what an incredible start it's been! Thanks to you - our advocates, supporters, and community leaders - the first half of May has been filled with powerful moments of connection, education, and impact.

Together, we've delivered outstanding virtual programs, including our first Diagnosis Days, which brought together **330 IBM participants and 240 DM participants** to our Ask the Expert live webinars and Café Chats.

Our Open House Livestream of Ask the Expert on May 9, 2025 was a hit with over 3,400 people watching the live and replay, and we've already surpassed our First Pitch goal with a record-breaking 34 pitches and counting!

We've made legislative progress too! H.Res. 277 was introduced in the U.S. House, and **now has bipartisan support with Rep. Paul Tonko [D-NY-20] and Rep. Jake Ellzey [R-TX-6] joining Rep. Rich McCormick as co-sponsors.** And through it all, we've reached over 575,000 people with messages that demystify myositis and bring awareness to this rare disease.

Thank you for making this moment possible. Let's keep the momentum going!

With gratitude,
The TMA Team

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## Diagnosis Days

Join us for Diagnosis Days this May to learn from and connect with other community members who know exactly what that life-altering experience feels like. On each Diagnosis Day, an educational **"Ask the Expert" webinar** features a TMA Medical

Advisor and world-renowned myositis expert. Each webinar is paired with an informal **"Café Chat"** where your family can gather with others affected by your form of myositis.

Upcoming Diagnosis Days

- Necrotizing Myopathy (NM): May 21
- Polymyositis (PM) & Overlap Myositis (OM): May 30

**Learn More**

On May 7, we kicked off our Diagnosis Days series with an incredible focus on Inclusion Body Myositis (IBM), followed by Dermatomyositis (DM) on May 15.

Top myositis experts answered your questions during our "Ask the Expert" webinars, and the community enjoyed connecting during our diagnosis-focused Café Chats.

Thank you to everyone who joined, asked questions, and shared their stories! Together, we're building a stronger, more informed future for those living with myositis.

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## Necrotizing Myopathy (NM): May 21

**In honor of Necrotizing Myopathy Diagnosis Day** during Myositis Awareness Month, TMA invites you to a special edition of Ask the Expert, focusing on this rare and serious form of inflammatory myopathy.

We're joined by Dr. Prateek Gandiga, a knowledgeable neurologist and myositis specialist, who will provide expert insights into Necrotizing Myopathy—including diagnosis, treatment options, and what patients and caregivers should know.

☐ **Wednesday, May 21, 2025**
☐ **11 AM ET | 8 AM PT**

**Join us for a relaxed and supportive social hour just for those diagnosed with Necrotizing Myopathy (NM, NAM, IMNM).**

This is a chance to connect, commiserate, and share experiences in a friendly, meeting-style format—camera optional, no pressure.

The conversation will be guided by TMA Group Leader Colleen Layton, bringing both compassion and community to the table. Come as you are—this is your space.

☐ **Thursday, May 21, 2025**
☐ **5 PM ET | 2 PM PT**

Register Today

Register Today

This Myositis Awareness Month, your support means more than ever. Every gift helps us provide critical resources, drive research, and uplift those living with myositis. We can’t do it without you, thank you for being part of this mission.

Donate Today

## Be Inspired by Patient Stories

Behind every diagnosis is a voice filled with strength, hope, and determination. This Myositis Awareness Month, we invite you to hear directly from patients and care partners who’ve turned hardship into advocacy and isolation into connection.

This is the greatest community you can imagine

TMA was like a life saving ring

Let them inspire you to give, share, and stand with the myositis community.

## This week at TMA

### Meditation Mondays: “Making Peace with What Hurts” - A Gentle Guided Meditation

**Monday, May 19, 2025 | 9:00 – 9:30 AM ET**

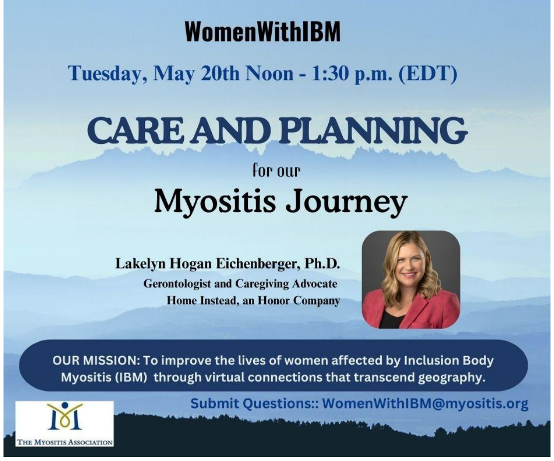
Living with chronic illness—especially myositis—can bring both physical and emotional pain that is often unseen, unspoken, and deeply felt. This 15-minute guided meditation, *Making Peace with What Hurts*, is designed specifically for people living with chronic illness and their care partners.

**Open to individuals with myositis, care partners, and all who wish to explore healing through awareness.**

RSVP Today

### Care and Planning for Your Myositis

## Journey



WomenWithIBM

Tuesday, May 20th Noon - 1:30 p.m. (EDT)

CARE AND PLANNING

for our

Myositis Journey

Lakelyn Hogan Eichenberger, Ph.D.
Gerontologist and Caregiving Advocate
Home Instead, an Honor Company

OUR MISSION: To improve the lives of women affected by Inclusion Body Myositis (IBM) through virtual connections that transcend geography.

Submit Questions:: WomenWithIBM@myositis.org

THE MYOSITIS ASSOCIATION

**Tuesday, May 20th, 12:00-1:30 pm ET | 9am PT**

TMA's WomenWithIBM Affinity Group invites you to a special session featuring Lakelyn Hogan Eichenberger, PhD, Gerontologist and Caregiving Advocate with Home Instead. Gain valuable insights into caregiving and planning strategies tailored to your journey with IBM. Submit questions to WomenWithIBM@myositis.org.

RSVP Today

## Myositis Awareness Car Show (in-person Palm Bay, FL)

**Saturday, May 24, 2025 | 12:30 pm – 6:00 pm ET**

**Space Coast Harley Davidson**
1440 Sportsman Ln NE
Palm Bay, FL 32905

Learn More

MYOSITIS AWARENESS CAR SHOW

62
AWARDS
RAFFLES
GIVE AWAYS
VENDORS
FOOD TRUCKS

ALL MONEY RASIED WILL GO TO
THE MYOSITIS ASSOCIATION (TMA)
WWW.MYOSITIS.ORG

CAR SHOW MAY 24TH

LOCATION: SPACE COAST HARLEY DAVIDSON,
1440 SPORTSMAN LN NE, PALM BAY, FL 32905

VENDOR ROLL IN 12:30,SHOW VEHICLES, 2PM
REGISTRATION CUT OFF 3:30PM, ENDS AT 6:00PM

## Member Stories: Dermatomyositis

In honor of necrotizing myopathy (NM) patients around the globe, we're sharing the powerful stories of individuals living with necrotizing myopathy (NM). Their journeys capture the resilience, challenges, and courage within our community. Read "My Journey with Necrotizing Myopathy", and visit the TMA blog for more inspiring stories all month.

## Raising Awareness with TMA

**The Myositis Association calls on every individual impacted by myositis - patients, caregivers, healthcare providers and advocates - Act now.**

Ask your Representative to co-sponsor H.Res. 277 and help bring national attention to the realities of living with myositis. Your message can drive the change that leads to faster diagnoses, better care, and lasting support for every person impacted by myositis.

**Ask your Representative to co-sponsor H.Res. 277**

TMA understands how deeply myositis can affect emotional well-being for both patients and their loved ones. Research shows that individuals with rare diseases like myositis are at a higher risk for anxiety and depression compared to those with more common conditions.

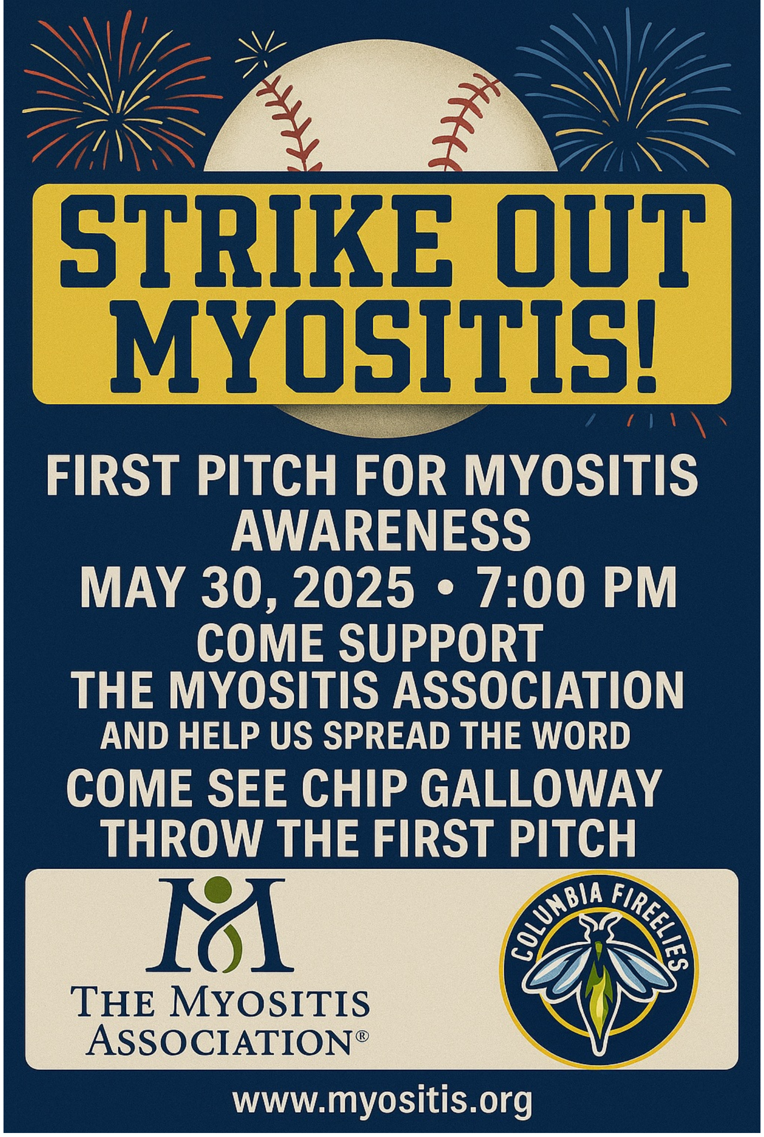
If you've found ways to care for your mental health while living with myositis, we invite you to share your tips. Your experience could make a meaningful difference for someone else on the same journey.

**Share Your Tips**

## Explore Stories that Inspire and Empower

Visit TMA's Myositis Awareness Month Page to experience the powerful voices of our community. From heartfelt patient and care partner stories to expert insights from clinicians and advocates, these blogs, videos, and interviews shine a light on the strength and resilience behind every myositis journey.

**Visit our Website**



STRIKE OUT MYOSITIS!

FIRST PITCH FOR MYOSITIS AWARENESS

MAY 30, 2025 • 7:00 PM

COME SUPPORT
THE MYOSITIS ASSOCIATION
AND HELP US SPREAD THE WORD

COME SEE CHIP GALLOWAY
THROW THE FIRST PITCH

THE MYOSITIS ASSOCIATION®

COLUMBIA FIREFLIES

www.myositis.org

Secure Your Tickets Today!

## Myositis Awareness Month Resources

Myositis Awareness Month Toolkit

Myositis Awareness Month Events Calendar

TMA's YouTube Playlists

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Connect with us!

THE MYOSITIS ASSOCIATION