



THE MYOSITIS ASSOCIATION®

MAY 1-31

Myositis Awareness Month



Dear Linda,

May is more than just a month, it's a movement we're building together. Myositis Awareness Month is in full swing, and this week we're focusing on Inclusion Body Myositis (IBM) through our Diagnosis Day series. All month long we're inviting you to learn from leading experts, connect with others who truly understand, and share space with the community that gets it.

This is also a time to take meaningful action. Reach out to your Representative and ask them to support [H.Res. 277](#). [Explore helpful resources](#) on mental health, daily living, and navigating your myositis journey on the TMA website.

And don't miss "Ask the Expert: LIVE" streaming on Facebook this Friday, May 9, at 1 PM ET.

We're in this together, raising awareness, building understanding, and standing by one another every step of the way.

With gratitude,

Rachel Bromley - TMA Senior Manager, Patient Education, Support and Advocacy

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.

- Inclusion Body Myositis (IBM): May 7
- Dermatomyositis (DM): May 15
- Necrotizing Myopathy (NM): May 21
- Polymyositis (PM) & Overlap Myositis (OM): May 30

[Learn More](#)

Inclusion Body Myositis (IBM): May 7



In honor of IBM Diagnosis Day during Myositis Awareness Month, join us for a powerful session of Ask the Expert, focused exclusively on Inclusion Body Myositis (IBM), and featuring internationally recognized neurologist Dr. Merrilee Needham.

This is your chance to engage directly with a global leader in IBM care and research—ask your questions, gain valuable insights, and connect with others in the IBM community.

- ☐ Wednesday, May 7
- ☐ 7:30 PM ET | 4:30 PM PT

[Register Today](#)



Join us for a relaxed and supportive social hour just for those diagnosed with Inclusion Body Myositis (IBM).

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 former Board Chair Augie DeAugustinis, living with IBM and bringing compassion to the virtual table.

- ☐ Wednesday, May 7
- ☐ 5 PM ET | 2 PM PT

[Register Today](#)

Thank You Myositis Awareness Month Sponsor

TMA Corporate Advisory Council member Abcuro is supporting IBM Diagnosis Day.

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](#)

This week at TMA

Meditation Mondays - A Space for Mindfulness & Emotional Healing

Monday, May 5, 2025 | 9:00 am – 9:30 am ET

Come together for a guided meditation session that includes brief exercises, followed by reflections. These exercises will be led either by a special guest, a member of the group, or through a pre-recorded exercise. Each week, we'll explore different types of guided mindfulness exercises, and people of all levels of experience are welcome.



[RSVP Today](#)



Living Well with Myositis Empowerment Clinic

Monday, May 5, 2025 | 4:00 pm – 5:00 pm ET

Join us for an insightful and empowering webinar, "Living Well with Myositis," where a diverse panel of individuals living with different forms of myositis—Inclusion Body Myositis (IBM), Necrotizing Myopathy (NM), Dermatomyositis (DM), Polymyositis (PM) and Overlap Myositis (OM) —along with a dedicated care partner, will share their experiences, challenges, and strategies for maintaining quality of life.

[RSVP Today](#)

MyoLive! TMA Open House (in-person and virtual)

In honor of Myositis Awareness Month, TMA is opening our doors to the myositis community for a special line-up of hybrid and in-person programs on Friday, May 9.

- 11:00 AM ET: Open House at TMA Office
- 12:00 PM ET: Lunch
- 1:00 PM ET: Ask the Expert (Hybrid) with Dr. Myma Albayda

Join online: During this special edition of TMA's popular "Ask the Expert" program, we will livestream from our TMA Facebook page 1-2 PM ET | 10-11 AM PT. Submit questions online as you join the Facebook broadcast. **No registration is required, simply open our [TMA Facebook page](#) at 1 PM ET.**

Join in-person: There is limited capacity for the in-person portion of this program. If you are near the Columbia, Maryland area, please **RSVP online**.



RSVP Today



Member Stories: Inclusion Body Myositis

In honor of inclusion body myositis (IBM) patients around the globe, we're sharing the powerful stories of individuals living with inclusion body myositis (IBM). Their journeys reflect the resilience, challenges, and courage within our community.

[Slowing IBM progression](#)
[Top 10 tips for living with IBM](#)



Struggling to Find a Myositis-Savvy Doctor? We Can Help.

Finding a healthcare provider who truly understands myositis can be tough—but you're not alone.

TMA has partnered with MediFind to refresh our [Find a Doctor tool](#), giving you better access to providers familiar with myositis care.

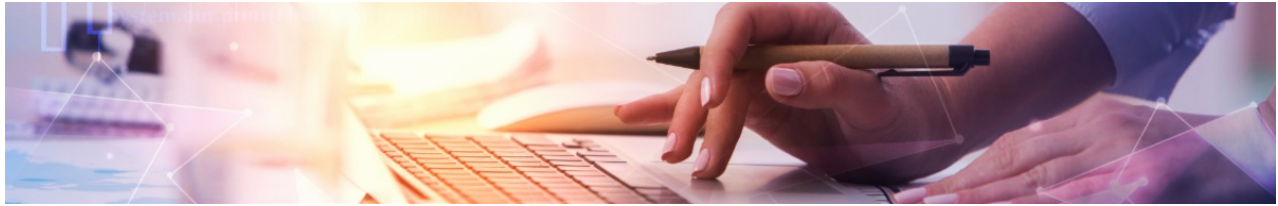


*Donate for
myositis awareness!*



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](#)



Living the Research: Exploring What Truly Matters to Myositis Patients

This is a three-part series of articles from Dr. Kevin Austin, Adjunct Professor in the Health Futures Institute's Personalized Medicine Centre in Murdoch University, Australia. He lives with IBM and conducted this patient-led research study to understand the priorities of those living with myositis and their care partners.

[Discovering priorities: An IBM patient-led research project](#)

[Coping with IBM](#)

[Help for coping with IBM](#)

[Listen to a podcast conversation about this research project](#)



TMA knows the emotional toll myositis takes on patients and families. Studies show people with rare diseases, like myositis, are more likely to suffer from anxiety and depression than people with more common diseases.

Help others navigate these challenges by submitting your tips for caring for your mental health with myositis.

[Share Your Tips](#)

We're at 29 First Pitches—Help Us Hit 31!

From Little League fields to the big leagues, Vance Robinson's (VRob) First Pitch for Myositis Awareness is taking the nation by storm this May.

We're thrilled that TMA volunteer Lindsay Guentzel is throwing out a first pitch for the Minnesota Twins, but the even bigger headline? 29 First Pitches are already scheduled! Just 2 more to reach our goal of 31, one to honor each day of May!

You can help us cross home plate.

☐ Host a First Pitch in your town! Whether it's youth ball, college, or the majors, every pitch raises awareness for myositis.



[Learn More and Join the Movement](#)

[Pitch In for Myositis](#)

Myositis Awareness Month Resources



[Myositis Awareness Month Toolkit](#)

[Myositis Awareness Month Events Calendar](#)

[TMA's YouTube Playlists](#)



THE MYOSITIS ASSOCIATION

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