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May Is Myositis Awareness Month

The Myositis Association Leads Nationwide Effort to Raise Awareness, Advance Research, and Support Patients

COLUMBIA , MD, UNITED STATES, May 1, 2026 /EINPresswire.com/ -- The Myositis Association (TMA) is proud to lead Myositis Awareness Month this May, a multidimensional effort to shine a light on rare, debilitating autoimmune muscle diseases that affect more than 75,000 individuals across the United States and more around the world.
Myositis refers to a group of rare diseases characterized by chronic muscle inflammation, weakness, pain, and potential involvement of vital organs, often resulting in significant disability, reduced quality of life, and mortality. As awareness grows, TMA continues to expand programs and partnerships to improve diagnosis, treatment, and support for families living with these conditions.

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>
> *Paula Eichenbrenner, Executive Director of TMA*

Historic Momentum: U.S. House Resolution Elevates National Awareness

This year’s awareness campaign is strengthened by the introduction of House Resolution (H.Res.) 1195, a bipartisan measure formally supporting the designation of May as National Myositis Awareness Month. Introduced by Representative Rich McCormick, MD (GA-7), the resolution underscores the urgent need for public awareness, earlier diagnosis, and improved health outcomes for people living with myositis.

“TMA is honored to see myositis recognized at the highest levels of American government,” said Rich DeAugustinis, Chair of TMA’s Board of Directors from Chamblee, Georgia. “This resolution represents an important step toward ensuring those who live with myositis are seen, heard, and supported.”

Spotlight Event: Investigative News Documentary Launch – May 11

A key highlight of this year’s campaign is the release of the documentary "Diagnosis Denied" on May 11, which will go live on streaming platforms across the country and on 11alive.com. The documentary brings together news stories about TMA advocates and care partners from Colorado, Florida, Georgia, and Oregon.

Investigative reporting by Atlanta’s 11Alive has brought national attention to the experiences of military veterans with inclusion body myositis (IBM) and the challenges they face in obtaining recognition and benefits. Recent 11Alive investigations reveal how veterans diagnosed with IBM—a rare, progressive muscle disease—often endure years-long struggles to receive disability benefits, with members of TMA’s Military Veterans with Myositis advocating for the Department of Veterans Affairs (VA) to classify IBM as a presumptive service-connected condition.

The reporting highlights delays in diagnosis, possible links between environmental exposures during military service and later development of IBM, and ongoing efforts by veterans and advocates to push for policy changes that would streamline benefits and improve support.

“Each outstanding in-home interview conducted by these Emmy-award winning investigative journalists at 11Alive truly brings to life the challenges that accompany a myositis diagnosis,” said Paula Eichenbrenner, Executive Director of TMA. “We are eagerly awaiting the documentary that ties together all the local stories! Thank you to the 11Alive team for the heart and insight they brought to this series, especially producers Ciara Bríd Frisbie and Elizabeth Hendren with reporters Jennifer Titus, Rebecca Lindstrom, Chris Vanderveen, Heather Crawford, and Kyle Iboshi.”

A Month of Programs, Education, and Community Engagement

Throughout May, TMA hosts a wide range of educational programs, support events, and fundraising initiatives designed to inform, connect, and empower the myositis community. Signature programs include:

- Diagnosis Days Series (weekly): Webinars and virtual community gatherings focused on specific myositis subtypes, including dermatomyositis, immune-mediated necrotizing myopathy, inclusion body myositis, overlap myositis, and polymyositis.
- Ask the Expert Webinars: Direct access to leading myositis specialists
- Café Chats: Informal peer support sessions for patients and care partners
- Research Briefings: Updates from global leaders advancing myositis science
- Educational Workshops: Topics such as speech and swallowing, assistive technology, and disease management
- Rejected Hearts Club partnership: Turning heartbreak into action and hope with signature awareness pieces supporting TMA’s mission.

Join the Movement

TMA invites patients, care partners, healthcare professionals, and advocates to download their Myositis Awareness Toolkit and get involved this May by participating in events and webinars, sharing their personal stories, contacting elected officials to support House Resolution 1195, and spreading awareness within their communities.

About The Myositis Association

The Myositis Association is one of the leading international organizations dedicated to improving the lives of people affected by myositis through education, support, advocacy, and research. For nearly two decades, TMA has led Myositis Awareness Month, driving progress through patient education and support programs, research funding and collaboration, and advocacy efforts at the federal and state levels. Together, these initiatives aim to accelerate discoveries, improve care, and ultimately find a cure.

For more information, please visit The Myositis Association at www.myositis.org.

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