THE MYOSITIS ASSOCIATION®

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Myositis is a rare disease that affects thousands of patients and families every day. The Myositis Association (TMA) is able to support people with myositis and their families only because of the generosity of individuals like you. We are proud to share that TMA has funded nearly $8 million in myositis research grants since 2002, including over $314,800 awarded in 2024 alone.

Please support TMA today to help us continue making this impact!

Donate Today

“TMA is responsible for my correct diagnosis”

After seeing one doctor after another and receiving an incorrect diagnosis, Malati Marlene Shinazy was finally correctly diagnosed while attending her first TMA International Annual Patient Conference.

Read Her Story

TMA represents patients at NIH meeting

Three TMA representatives were among the participants at the Myositis Common Data Elements (CDEs) Consensus Conference at the NIH on November 14. The group of experts worked to identify the most important information that should be collected and how it should be collected across the broadest range of research. Standardizing these data elements will greatly support communication of findings across many different types of myositis research.

The NIH Office of Autoimmune Disease Research is also using this project as a model for creating CDEs in other autoimmune diseases.

TMA is excited to be able to include the patient's voice in this important work.

Order the 2024 International Annual Patient Conference Recordings

The 2024 International Annual Patient Conference recordings are now available! Don't miss your chance—order now for only $149 and enjoy access to 30 sessions, including keynote presentations, virtual talks, and the Heroes in the Fight Awards Ceremony. Secure your access today to watch these impactful sessions!

Conference attendees have been sent a link to access the recordings free of charge. Email IAPC@myositis.org if you did not receive a message describing how to access the virtual content.

Order Your Recordings Today

Ask the Doc featuring Dr. Adam Schiffenbauer

December 3, 2024, 3:30 PM ET | 12:30 PM PT

Please join December’s Ask the Doc webinar to ask any question you have about any type of myositis.

Adam Schiffenbauer, MD, is Deputy Head of the Environmental Autoimmunity Group at the National Institutes of Health and serves as an Associate Research Physician. He currently serves as the principal investigator on studies exploring risk factors for myositis in the military, evaluating environmental risk factors in new onset myositis, and using sodium thiosulfate to treat calcinosis. Dr. Schiffenbauer is a current member of TMA's Medical Advisory Board.

Please note that this webinar will not be recorded.

Register Today

Myositis Research Insights webinar featuring Dr. Malin Regardt

December 10, 2024, 12 PM ET | 9 AM PT

Carbonhand is a revolutionary device that assists people with impaired hand function. Pressure sensors and advanced technology ensure the glove adds power in cases where the user’s own muscles are inadequate.

In this webinar, moderated by TMA Past Board Chair Dave Mochel, TMA's Medical Advisory Board Member Dr. Malin Regardt discusses this exciting technology and its many uses. Additional topics covered will be hand exercise and function. Dr. Regardt is a researcher at Karolinska University Hospital and at the Department of Neurobiology, Care Sciences and Society, Karolinska Institutet in Sweden.

Register Today

Be a Virtual Golfer from anywhere in the world to support the TMA Holiday Open: Golf Tournament Benefiting TMA

Love golf? Love TMA? Combine both by "chipping in" at our festive tourney, and recruit your friends and neighbors! While the tournament is hosted at Blue Ridge Shadows Golf Course in Front Royal, Virginia, on Friday, December 6, anyone in the world can participate as a Virtual Golfer. You can join the fun and receive a swag bag in the mail for $125 as a solo virtual golfer. If you want to hit the links, golf a course near you and post your score on the TMA Holiday Open Facebook Event page!

All tournament proceeds support TMA's mission to support individuals and families affected by myositis.

Learn More

From the TMA Blog

Life is a Blessing

In 1999, James "Sudz" Szudzik's legs began to feel strange and weak. He started tripping because of footdrop and noticed some weakness in his arms and hands. His doctor diagnosed him by saying, "Do you know Lou Gehrig?" Fortunately, a subsequent muscle biopsy confirmed he was experiencing inclusion body myositis instead.

Ready His Story

Dermatomyositis is not my whole story

Jenna Radke's family joked that she'd someday become the doctor to cure myositis. But this spunky medical student is determined that DM is not her whole story.

Ready Her Story

Julie Paik (Chair)
Galina Marder (Vice-Chair)
Floranne Ernste (Past Chair)
Bianca Lang (Past Chair)
Myma Albayda
Sangmee Bae
Iazsmin Bauer-Ventura
Siamak Moghadam
Kelly Rouster-Stevens
Sara Sabbagh
Didem Saygin
Caoilfhionn Connolly (Fellow Member)

Add Hoc Members
Paula Eichenbrenner (TMA)
Linda Kobert (TMA)
Peter Korsten (iMyoS)
James Minow (Cure JM)
Annet van Royen Kerkhof (JDM Working Group)

IMACS Coordinators; Ad Hoc Members
Lisa Rider (ad hoc member)
Mazen Dimachkie (ad hoc member)

The Myositis Association (TMA), Cure JM Foundation, and Priovant Therapeutics support for this meeting is gratefully ac[illegible]ledged

TMA host IMACS meeting

On October 15, TMA partnered with the International Myositis Assessment and Clinical Studies (IMACS) to host their annual meeting in Washington, DC. This group of the world's leading myositis researchers came together for a poster session, scientific presentations, and a panel discussion about recent advances in myositis research and treatment. The meeting also opened with a talk by Dr. Vicki Shanmugam, Director of the National Institutes of Health Office of Autoimmune Disease Research on how the NIH is working to harmonize autoimmune research across the many institutes under its umbrella.

Support for this meeting was provided by Priovant, TMA, and the Cure JM Foundation.

The Combined Federal Campaign (CFC) is calling on all feds to make Giving Tuesday the biggest online giving day of

the campaign. Be sure to support us by using CFC# 11526. Get started at https://GiveCFC.org.

Get Started Today

Finding a healthcare practitioner who knows how to care for someone with myositis is often a challenge.

While we can’t guarantee you’ll find an elite physician, TMA’s Find a Doctor tool can at least provide options.

We’ve worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our suggestions for using the tool here.

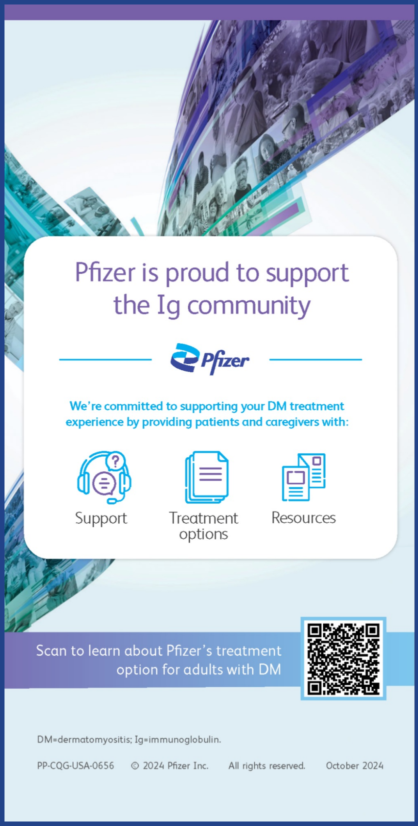
Minding your mental health: Volunteer

Research shows that giving back helps the giver as well as the receiver. Volunteering has positive benefits for mental health, including reducing stress and increasing positive feelings and relaxation. Those who spend time in service to others report feeling a sense of meaning and appreciation, which can reduce feelings of stress.

This time of year, there are lots of opportunities to lend a hand. What are your favorite volunteer activities? Send your thoughts to TMA@myositis.org, and we’ll share your ideas with the community.

Here are a few of our favorite volunteer efforts:

- Erika – In the past, I have volunteered with local charity races and at my children’s schools as a reader and in their libraries. Now that they are grown, I’m planning to use my volunteer hours to help out our local food bank and animal shelters, while still sneaking in the occasional race gig.



TMA's YouTube channel has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's webinars are published on the first of the following month.

- Linda – One of the most satisfying things I've done is to volunteer at a shelter for unhoused women. The guests at this shelter have gone through so much and are so appreciative of the gift of a warm meal and a place to spend the night.
- Paula – I enjoy helping the Honor Flights that visit DC to bring veterans from all over the country to the war memorials that reflect their service. My grandfather participated in an Honor Flight for World War II veterans, and it was an amazing experience.
- Rachel – My favorite way to volunteer is to pitch in for community races in both Maryland and Virginia. I'm on the board of directors for the Howard County Striders running club, as well as a member of others. I love how supporting these groups also promotes the many benefits of exercise.
- Susie – Most of my volunteer work currently is through my church. I serve as the vice chair of the national missions committee where we support a church in North Dakota that provides food and clothing on an Indian reservation.

We'd also like to say a special thank you to each of you who volunteers for TMA. You are the backbone of this organization and we could not do it without you.

TMA is able to support people with myositis and their families because of the generosity of individuals who support our work financially.
Please make a gift to TMA to support our impact today!

DONATE TODAY

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Connect with us!