



THE MYOSITIS ASSOCIATION®

MYONews May 2024 | Volume 4, Issue 5



Myositis Awareness Month is NOW!

TMA is raising awareness about myositis in a BIG way, and you can be part of the fun!!

Check out our [Myositis Awareness Tools and Tips](#) for ideas on how you can wage your own awareness campaign. We have downloadable social media graphics, a downloadable lawn sign, and more.

TMA board member Chip Galloway has some great ideas for raising awareness without depleting your energy reserves. [Watch his webinar here.](#)

Check out our [Myositis Awareness Month Events](#) and join us for a whole month's worth of informative and uplifting programming.


MYOSITIS AWARENESS MONTH RESOURCES

US House of Representatives to recognize Myositis Awareness Month today at 10 AM ET. Tune into [C-SPAN](#) to watch live!

May
2024

MYOSITIS AWARENESS MONTH

1	Myositis Awareness Month Kickoff with TMA Team
3	New Member Orientation
8	Inflammatory Myopathy: Integrating Lifestyle Medicine to Optimize How You Feel
9	Amplifying the Voice of Myositis Patients at FDA
14	Disclosing your Diagnosis to your Employer
15	Myositis Symposium for Occupational and Physical Therapists
16	Impact of Social Connections on Patient Health and Resilience
18	Ask the Mental Health Counselor for Care Partners
20	Pregúntale al Doctor en español
21	Myositis Research Insights with Kanneboyina Nagaraju, DVM, PhD
22	Ask the Doc with Tahseen Mozaffar, MD
23	TMA Open House with Abcuro, Columbia, Maryland
28	Raising Awareness Workshop: Explaining Myositis to Others


THE MYOSITIS ASSOCIATION®



 THE MYOSITIS ASSOCIATION®

Myositis Awareness Gear

Wear Your Awareness!

Why limit myositis awareness to just the month of May? Wear your myositis awareness message year-round with TMA's new shirts that define myositis, encourage individuals living with IBM, and promote World Myositis Day (September 21). There's even a style just for your furry friends!

The order deadline is **Wednesday, May 22**. Four designs are available in multiple styles, colors, and sizes. Your shirts and bandanas will ship directly to you at the end of May.

ORDER TODAY

Pets Can Spread Awareness Too: Join the MyoMutt Contest!

Get your furry friends to tell the world about myositis and enter them in TMA's MyoMutt Contest! Order a [TMA bandana](#) for your dog, cat, bird, bearded dragon, or other pet, snap a pic, and email it to TMA@myositis.org.

The contest ends June 30!

RESEARCH FUNDING OPPORTUNITIES



TMA announces its 2024 Research Grant opportunities

Since 2002, TMA has provided nearly \$8 million in competitive research grants for myositis projects around the world. This year we are offering two disease-specific, one-year grants, one for IBM at \$80,000 and one for JM at \$45,000.

Letters of intent are due May 23 and applications, if invited, will be due July 15.

More information is available at our website.

RESEARCH FUNDING OPPORTUNITIES



Don't miss TMA's 2024 International Annual Patient Conference

If you've ever been to a TMA patient conference, you know what a life-changing

experience it can be! If you've never been before here are some of the things you've been missing:

- Getting the most accurate information about your disease from the world's leading myositis experts.
- Speaking directly to those leading myositis experts about your own condition.
- That energizing feeling when you walk into a room with 300 people who will never ask you, "What is myositis?"
- Making a dozen or more new myositis friends.
- A notebook full of tried and true tips on overcoming the challenges of living with a debilitating condition.
- Going home filled with hope.
- And So. Much. More!

TMA's 2024 International Annual Patient Conference takes place on September 6-8, 2024 at the Hilton Baltimore Inner Harbor!

REGISTER TODAY

THE MYOSITIS ASSOCIATION

FREE IN PERSON EVENT

Physical and Occupational Therapists' Guide to Myositis

Sarasota, Florida

For OTs, PTs, OTAs, PTAs

Earn 2 CEUS

WEDNESDAY
May 15, 2024

START AT
5:00-8:00 PM ET

REGISTER BY
MAY 11

Light dinner provided

TRAINING PROVIDED BY JOHNS HOPKINS MYOSITIS CENTER

HOSTED BY TMA SW FLORIDA

SCAN TO REGISTER

May 15, 2024 5-8 Free training for PTs and OTS

TMA's SW Florida Support Group is celebrating Myositis Awareness Month by educating physical and occupational therapists on myositis and how they can treat those who live with these diseases. Up to 150 therapists in southwestern Florida will be invited

to the free presentation and earn two CEUs. Afterward, the recorded presentations will then be available to other TMA support groups, medical professionals, and TMA members.

Please be aware that this program is *not* for patients.

PTs, OTs, PTAs, & OTAs in FLORIDA REGISTER HERE

Spotlight on Giving

Every May for eight seasons now, Vance Robinson has taken to the mound to raise myositis awareness. In his annual First Pitch campaign Vance, who lives with IBM, has attended college baseball games around the central California coast where he lives.

While he throws out the first pitch of the game, the announcer tells attendees about myositis and its impact on the lives of those who live with this rare disease. Vance also visits with players and coaches, giving each a myositis awareness wristband, which they wear proudly.



[See news coverage of Vance's first pitch from his local news station KSBY in Paso Robles.](#)

Vance also pitches TMA with his personal giving page on the TMA website. This year his goal is \$1200, and with thousands of followers on social media, we're sure he'll hit a home run!!

DONATE TO VANCE'S CAUSE

You Can Start Your Own Fundraising Campaign in 3 Easy Steps!

Step 1. Visit TMA's [Start a Campaign](#) page and complete the easy form.

Step 2. Review your personalized web page. TMA team will email you a proof within 2 business days!

Step 3. Send the link to everyone you know and post it on social media, then watch as the contributions add up!

START YOUR OWN FUNDRAISER

Collating the Voice of people living with Autoimmune Diseases survey

We request a few minutes of your time to help us understand well-being of people with autoimmune diseases



Holistic care

Q. Who can fill the survey?

ANYONE
18 years or older



SCAN

Q. Can I fill the survey if I do not have an autoimmune disease?

YES, you can!

Contact us: covadstudy@gmail.com

TAKE THE SURVEY

**Adult Dermatomyositis Externally-Led
Patient-Focused Drug Development Meeting
(DM EL-PFDD)**

JUNE 7, 2024



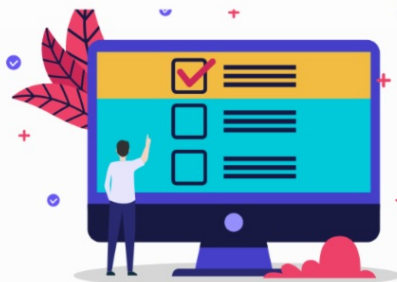
The Time is Here!

Are you ready to have an impact on future treatments?

Go to our website NOW!

- **Take the Survey** - The first ever joint MSU-TMA survey of the DM community
- **Leave Comments** - Your voice matters! The Voice of the Patient Report needs YOU!
- **Watch the Orientation Video** - Learn more about the EL-PFDD and how you can participate virtually

**It doesn't matter where you live or where you are in your
Dermatomyositis journey, what matters is your story!
Don't wait! Take the survey today.**



<https://dermatomyositis-el-pfdd.org/dermatomyositis-survey/>



REGISTER TODAY

FIND THE CARE YOU NEED

MediFind



THE MYOSITIS ASSOCIATION

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](#).




Community Tips: Don't Fry Day is every day!

The National Council on Skin Cancer Prevention has designated the Friday before Memorial Day as Don't Fry Day. Sun safety awareness is important for everyone. For those who live with dermatomyositis, though, UV exposure can cause a flare. Here is what our community recommends:

- Wear sunscreen SPF 70 or higher every day, even when you're indoors, and reapply every two hours.
- Keep drapes closed and consider light-blocking window coverings.
- Wear UPF clothing or use a UPF additive to wash your clothes.
- Limit the time you spend in the sun, especially between 10 am and 4 pm when the sun's rays are the strongest.
- Cover your skin and wear sunglasses and maybe even gloves even on cloudy days and while driving in the car.
- Never use a tanning bed.
- Avoid gel nail color at the salon. The UV lights used to dry your nails can give you a flare.


[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

1001 Approved & Not Pre-qualified
1001 Approved & Not Pre-qualified



Looking for a
different treatment
option for your
dermatomyositis?

To learn more, talk to your
doctor and visit
www.VALORStudy.com



Proivant Therapeutics - The VALOR Study
e-newsletter ad - 2-Oct-2023 - English (principal) - V21

resources. Each month's webinars are published on the first of the following month.

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



Connect with us!



The Myositis Association | 6950 Columbia Gateway Drive, Suite 370, Columbia, MD 21046

[Unsubscribe tma@myositis.org](mailto:Unsubscribe_tma@myositis.org)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by tma@myositis.org powered by



Try email marketing for free today!