

MYONews

April 2023 | Issue Four



TMA Myositis Awareness Month Virtual Summit

May 20, 2023 10 AM ET | 9 AM CT | 8 AM MT | 7 AM PT

The Myositis Association celebrates its 30th Anniversary by continuing to support those who live with myositis, their care partners, and the health professionals who treat them as we face the future together.

At this year's Myositis Awareness Month Virtual Summit, we will move beyond limits with presentations on new research developments, exercise, medications, nutrition, and mental health.

Registration: \$45 until April 15, 2023 Registration: \$55 after April 15, 2023



SAVE THE DATE! September 7-10, 2023

2023 INTERNATIONAL ANNUAL PATIENT CONFERENCE

Location: San Diego, CA

LEARN MORE

PITCHING IN FOR MYOSITIS AWARENESS



For the past seven years, Vance Robinson has combined his love of baseball and the need to spread awareness about myositis. In 2017, Vance, who has inclusion body myositis (IBM), started his First Pitch campaign.

Every spring since he shows up at college baseball games around central California where he lives to toss the first pitch and talk about myositis. He also documents these presentations on TikTok where his #MyositisFirstPitchCampaign videos have received more than 94,000 views.

Along with this awareness, each spring Vance creates a <u>First Pitch Fundraising</u> <u>Campaign</u> on the TMA website and encourages people to go there to donate.

His efforts have raised thousands of dollars over the years and brought much-needed awareness of this rare disease.

LEARN MORE



Malin Regardt, Ph.D., OT is an occupational therapist and researcher in myositis at Karolinska University Hospital in Sweden where she has worked for more than 20 years.

Her research focuses on how persons with PM and DM experience activities of daily living as well as hand function and quality of life, and she has published 17 papers within the area.

Malin also has an interest in patient-reported outcome measures. She is a member of TMA's Medical Advisory Board.

REGISTER TODAY



Illness and Identity: Redefining Who You Are

Being diagnosed with a debilitating muscle disease upsets every aspect of your life. Suddenly your plans for the future are disrupted and you may feel like you no longer know who you are. But never fear! Today's speakers have navigated this territory and will share their insights on how you can move forward into this unsettling world with grace and purpose.

Ingrid de Groot was working full-time as a counselor and social worker for child protection services when dermatomyositis derailed her professional career in 2015.

She decided to commit herself to patient advocacy and is now chair of the myositis working group of Spierziekten Nederland (Dutch patient association for neuromuscular disease), a patient research partner with the OMERACT (Outcome Measures in Rheumatology) Myositis Working Group, and a number of other rheumatology and myositis projects and organizations.

She lives with her husband in Rotterdam, The Netherlands.

Terry Lewis is a retired executive focused on leadership development who began experiencing symptoms of myositis in 2015 and was diagnosed with IBM roughly two years later.

He is a member of TMA and he and his wife live in Sanbornton, New Hampshire. In his free time, he enjoys playing with his two grandchildren and going out fishing on one of the many lakes in the area.

REGISTER TODAY

Did you miss one of our previously aired webinars?

Click here to view all of our past videos!



Did you know that TMA has a myositis podcast? In 2022, we had more than 500 listens in more than 10 countries! Get caught up with previous episodes and discover the most recent.

Everyone's myositis journey is different, but many things are also similar. Join in and listen to Corene's story and journey as a young adult with DM and MD5.

TMA would like to especially thank volunteer Kim Gray for making the podcast a reality!

LISTEN NOW



Join The Myositis Association in celebrating National Myositis Awareness Month this May! Together, we support those living with myositis and their care partners by raising awareness, providing resources, and advocating for better treatments and a cure.

Let's expand the world's understanding of myositis and work towards a stronger, more connected community. Visit our website for the Myositis Awareness Month events calendar and other resources.

LEARN MORE

2023 UPCOMING EVENTS

Please check our

TMA Events Calendar

for our events, regional support group offerings,
and more coming this month!





Harnessing the benefits of yoga for myositis, muscle dystrophies, and other musculoskeletal disorders

First published: 19 July, 2022

The recent global increase in popularity of home-based yoga, an ancient Indian technique practiced for thousands of years, has translated into its use as a complementary therapy for a multitude of ailments. This review aims to examine the published literature regarding the effects of yoga therapy on systemic chronic diseases; in particular on inflammatory myopathies (IMs) and other muscle disorders.

READ MORE

FIND THE CARE YOU NEED

MediFind

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Please check out TMA's Find A Doctor tool (through a new partnership with MediFind)! If you are looking for a clinician or specialist with documented experience treating the different types of myositis (or to add to your current care team), this could be a great place to start!

We are working out some things in the partnership to better feature some of the docs known to TMA, but we are so excited about the availability of this new feature for our patients! If



Each month, TMA spotlights a myositis clinical trial for your review. View current clinical trials here.

leapcure



Patients with dermatomyositis are invited to join a study opportunity to help advance research.

you have any trouble navigating, please reach out to us at tma@myositis.org.

FIND A DOCTOR

If you are aged 18+ with dermatomyositis and you do not have chronic kidney disease, you could be part of the work that may help researchers understand more about the disease, and how to possibly treat it.

CHECK YOUR ELIGIBILITY



COMMUNITY TIP

Don't rule out that event or activity!

The fatigue that comes with myositis can sometimes make you feel like everything is just too much effort. But don't give up! Planning your days to include lots of rest time and spacing out activities throughout the week will help you feel more independent. And it's important for your mental health to stay connected with other people and participate in the activities you love.

AFFINITY GROUP MEETINGS



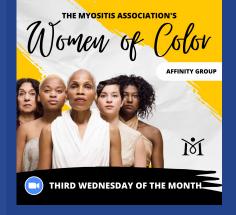




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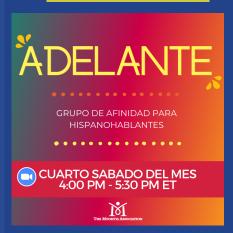
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