



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

REGISTER TODAY



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 [First Pitch Fundraising Campaign](#) 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](#)



THE MYOSITIS ASSOCIATION'S
ASK THE DOC SERIES

DR. MALIN REGARDT
OCCUPATIONAL THERAPY
MONDAY, APRIL 17, 2023
1 PM ET | 12 PM CT | 11 AM MT | 10 PM PT

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

[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](#)



EMPOWERMENT
CLINIC

ILLNESS AND IDENTITY
REDEFINING WHO YOU ARE



INGRID DE GROOT, LCSW
MYOSITIS RESEARCHER AND
PATIENT



TERRY LEWIS
TMA COMMUNITY MEMBER



WEDNESDAY, APRIL 26, 2023
1 PM ET | 12 PM CT | 11 AM MT | 10 AM PT

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

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](#)



MAY IS
Myositis
AWARENESS
MONTH

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!

ARTICLE
OF THE
MONTH



TMA'S NATIONWIDE VIRTUAL SUPPORT GROUP
 PROVIDING SUPPORT TO THOSE WHO NEED IT - EVERYWHERE!

FIRST SATURDAY OF EACH MONTH
 10 AM PT | 11 AM MT | 12 PM CT | 1 PM ET

REGISTER TODAY

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



THE MYOSITIS ASSOCIATION

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

CLINICAL TRIALS CORNER

Each month, TMA spotlights a myositis clinical trial for your review. View current clinical trials [here](#).

leapcure

DERMATOMYOSITIS CLINICAL TRIAL

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

WOMEN WITH IBM
Affinity Group

THIRD TUESDAY OF THE MONTH

To improve the lives of women affected by Inclusion Body Myositis (IBM) through virtual connections that transcend geography.

[REGISTER TODAY](#)

THE MYOSITIS ASSOCIATION

MILITARY VETERANS WITH MYOSITIS

AFFINITY GROUP

SECOND SATURDAY OF THE MONTH

9 AM PT | 10 AM MT | 11 AM CT | 12 PM ET

[REGISTER TODAY](#)

FOR THOSE WHO LIVE ALONE

THE MYOSITIS ASSOCIATION'S

FLYING SOLO

AFFINITY GROUP

First Wednesday of Each Month

5 PM PT | 6 PM MT | 7 PM CT | 8 PM ET

[REGISTER TODAY](#)

THE MYOSITIS ASSOCIATION'S

Women of Color

AFFINITY GROUP

THIRD WEDNESDAY OF THE MONTH

REGISTER TODAY

THE MYOSITIS ASSOCIATION'S

CARE PARTNER

AFFINITY GROUP

THIRD SATURDAY OF THE MONTH

7:30 AM PT | 8:30 AM MT | 9:30 AM CT | 10:30 AM ET

REGISTER TODAY

THE MYOSITIS ASSOCIATION'S

MEN MANAGING MYOSITIS

AFFINITY GROUP

Fourth Tuesday of Each Month

4 PM PT | 5 PM MT | 6 PM CT | 7 PM ET

REGISTER TODAY

ADELANTE

GRUPO DE AFINIDAD PARA HISPANOHABLANTES

CUARTO SABADO DEL MES

4:00 PM - 5:30 PM ET

REGISTER TODAY

THE MYOSITIS ASSOCIATION'S

RAINBOW WARRIORS

AFFINITY GROUP

Fourth Sunday Each Month

2PM PT | 3PM MT | 4PM CT | 5PM ET

REGISTER TODAY



THE MYOSITIS ASSOCIATION

Connect with us!

