30TH ANNIVERSARY
The Myositis Association

MYONews

MAY 2023 | Issue Five

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, making medications more affordable, nutrition, and mental health.

Visit the registration page for complete summit details and a schedule of events.

Registration: $55

REGISTER TODAY

SAVE THE DATE! September 7-10, 2023

2023 INTERNATIONAL ANNUAL PATIENT CONFERENCE

Location: San Diego, CA

LEARN MORE

MAY 2023

MYOSITIS AWARENESS MONTH

4 WEBINAR: UPDATES IN DERMATOMYOSITIS WITH DR. RUTH ANN VLEUGELS

9 MYOSITIS RESEARCH WEBINAR WITH HELENE ALEXANDERSON, PHD, RPT

18 ASK THE DOC WITH ELIE NADDAF, MD

20 2023 VIRTUAL SUMMIT

31 EMPOWERMENT CLINIC: GETTING A GOOD NIGHT'S SLEEP

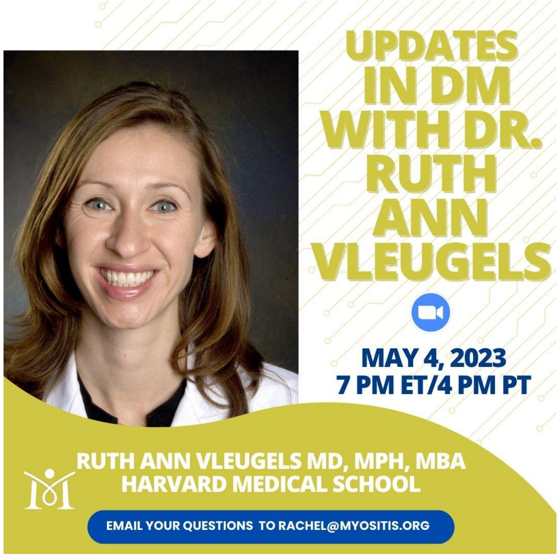
The Myositis Association

Today, we are excited to kick off National Myositis Awareness Month and invite you to celebrate with us. Join The Myositis Association in supporting those living with myositis and their care partners by raising awareness, providing resources, and advocating for better treatments and a cure.

Together, we can expand the world's understanding of myositis and work towards a stronger, more connected community. We have a lineup of virtual events all month long to support you and your loved ones. Check out our website for the Myositis Awareness Month events calendar and other resources.

Let's make this month count by coming together and showing our support for the myositis community. Whether you're a myositis warrior, caregiver, or advocate, your voice and actions matter. Let's raise awareness, promote understanding, and support one another through our myositis journeys.

LEARN MORE



Join us as Dr. Vleugels discusses updates in dermatomyositis in this special webinar in honor of Myositis Awareness Month.

About Dr. Vleugels: Ruth Ann Vleugels, MD, MPH, Heidi and Scott C. Schuster Distinguished Chair in Dermatology, Director, Connective Tissue Disease Clinics, Director, Autoimmune Skin Disease Program, Program Director, Dermatology-Rheumatology Fellowship, Vice-Chair, Brigham and Women's Hospital Department of Dermatology, Associate Professor, Harvard Medical School

REGISTER TODAY!

MYOSITIS RESEARCH WEBINAR

MAY 9, 2023
6 PM ET/3 PM PT

HELENE ALEXANDERSON, PHD, RPT
KAROLINSKA INSTITUTET
STOCKHOLM, SWEDEN

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

Dr. Helene Alexanderson is an associate professor, PhD, and registered physical therapist at Karolinska University Hospital and Karolinska Institutet in Stockholm, Sweden. She has 30 years of clinical practice prescribing exercise to patients with inflammatory rheumatic disease, the last 28 years focusing on idiopathic inflammatory myopathies (IIM).

In 2003, she earned her PhD-degree with her doctoral thesis titled “Exercise and clinical outcome measures in patients with polymyositis and dermatomyositis”. Since then, she has continued to study the clinical and molecular effects of exercise and continued to develop clinical outcome measures to measure muscle endurance in IIM.

She is chair of IMACS Rehabilitation and Exercise Scientific Interest Group leading the current project to develop evidence-based consensus exercise guidelines in IIM. She is co-chair of the OMERACT Myositis Working Group aiming to develop and validate patient-relevant, patient-reported outcome measures for patients with IIM.

In both these international research collaborations, Dr. Alexanderson works closely with patient research partners as equal members of the research group. At the Karolinska Institutet, she teaches physical therapy students about IIM and other inflammatory rheumatic diseases, and she is also developing interprofessional student activities during clinical rotations at the Karolinska University Hospital.

She has published 79 scientific papers on IIM. Dr. Alexanderson was elected a member of the TMA Medical Advisory Board, 2014-2019, and rejoined in 2023.

In this Myositis Research Webinar, Dr. Alexanderson will focus on and expand upon her research. Register Today!

REGISTER TODAY!

THE MYOSITIS ASSOCIATION'S

ASK THE DOC SERIES

ELIE NADDAF, MD

NEUROLOGIST

MAY 18, 2023

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

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

Dr. Naddaf is a neurologist, specializing in neuromuscular medicine and muscle pathology. His research interests include inclusion body myositis and less common immune-mediated myopathies such as sporadic late-onset nemaline myopathy and graft-versus-host disease myositis. His translational research, funded by the NIH and the American Neuromuscular Foundation, is focused on the role of mitochondria in inclusion body myositis. Dr. Naddaf joined TMA's Medical Advisory Board in 2023.

REGISTER TODAY

EMPOWERMENT CLINIC

GETTING A GOOD NIGHT'S SLEEP

WEDNESDAY, MAY 31, 2023

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

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

EMPOWERMENT CLINIC: GETTING A GOOD NIGHT'S SLEEP

Sleep problems are fairly common. In fact, one in four people experiences sleep difficulties, which include trouble falling asleep, trouble staying asleep, early morning waking, sleeping too much, or restless or unsatisfying sleep.

Getting a good night's sleep can improve your mental well-being and help you to better manage your chronic illness. The good news is that there are things you can do to improve your sleep.

Register for this empowerment clinic to learn more!

REGISTER TODAY

Did you miss one of our previously aired webinars? Click here to view all of our past videos!

TMA Podcast New Co-Host Auditions!

Are you someone who lives with myositis, whether as a patient or care partner? TMA is looking for a new co-host for its Myositis Family Podcast!

Please email Rachel@myositis.org for details!

2023 UPCOMING EVENTS

Please check our
TMA Events Calendar
for our events, regional support group offerings,
and more coming this month!

REGISTER TODAY

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

Immune-Mediated Necrotizing Myopathy

First published: 26 March, 2018

Immune-mediated necrotizing myopathy (IMNM)—also known as necrotizing autoimmune myopathy (NAM) or simply necrotizing myopathy (NM)—is a type of autoimmune myopathy in which patients experience severe weakness in the muscles of the upper arms and legs, death of muscle fibers with minimal evidence of inflammation on muscle biopsy, and infrequent extra-muscular involvement, for example with lung or skin disease.

This journal article, written by myositis experts at the NIH Iago Pinal-Fernandez, Maria Casal-Dominguez, and Andrew L. Mammen, reviews what we know about NM and how it affects those who live with it.

READ MORE

feature for our patients! If you have any trouble navigating, please reach out to us at **tma@myositis.org**.

FIND A DOCTOR

COMMUNITY TIP

Use Your Spoons Wisely

When you have a chronic condition like myositis that robs you of energy—both physical and mental—it's helpful to think in terms of spoon theory.

You only have so many units of energy—symbolized by a handful of spoons—available to you when you start the day.

Every time you do something that requires effort—say grocery shopping or cooking or even getting out of bed sometimes—you use up one or more spoons.

In order to make it to the end of the day without running out of energy, you have to use your spoons wisely by planning out your activities so you still have enough spoons to, say, go to your kid's soccer game or have coffee with a friend.

Myositis Awareness Month Sponsors

Thank you to our sponsors for your support of
Myositis Awareness Month and the myositis community!

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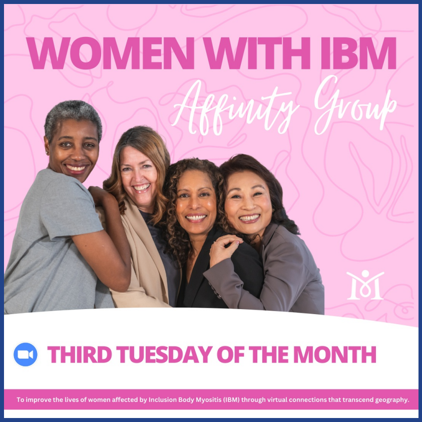
AFFINITY GROUP MEETINGS



REGISTER TODAY

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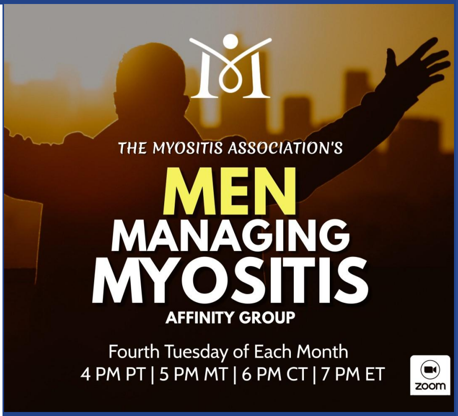

REGISTER TODAY

REGISTER TODAY

REGISTER TODAY

ADELANTE

GRUPO DE AFINIDAD PARA HISPANOHABLANTES

CUARTO SABADO DEL MES
4:00 PM - 5:30 PM ET

THE MYOSITIS ASSOCIATION

THE MYOSITIS ASSOCIATION'S
RAINBOW WARRIORS
AFFINITY GROUP

Fourth Sunday Each Month
2PM PT | 3PM MT | 4PM CT | 5PM ET

REGISTER TODAY

REGISTER TODAY

THE MYOSITIS ASSOCIATION

Connect with us!