



THE MYOSITIS ASSOCIATION

MYONews & Updates

January 2023 | Issue One

Upcoming Events

Please check our
[TMA Events Calendar](#)
for our regional support group
offerings and more coming this
month!

[Jan. 7 - TMA Nationwide Support
Group Meeting](#)

[Jan. 10 - Myositis Research Webinar](#)

[Jan. 19 - Ask the Doc](#)

[Jan. 26 - Empowerment Clinic](#)

[FUN FIT FLEX](#)

EMPOWERMENT CLINICS 2023



Living with IBM

Dating and Disability:
How to Make it Easier

Living with
Dermatomyositis

Illness and Identity:
Redefining Who
You Are

Getting a Good
Night's Sleep

The Four Aspects of
Psychosocial Health
and Why They Matter

How to Keep Driving
and Knowing When
to Stop

Overcoming
Caregiver Stress
Syndrome

Working While
Chronically Ill

Setting Boundaries
for Optimal Health

Honoring our Military
Veterans with Myositis

New Year Resolutions
for 2024



TIME AND DATE TBA

FOR MORE INFORMATION, CONTACT [RACHEL@MYOSITIS.ORG](mailto:rachel@myositis.org)

EMAIL QUESTIONS FOR CLINICS



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 FOR NATIONWIDE](#)

ARTICLE OF THE MONTH



Environmental Risks for Inflammatory Myopathies

- Weng Ian Che, MMSc
- Ingrid E. Lundberg, MD, PhD
- Marie Holmqvist, MD, PhD

Inflammatory myopathies are a group of heterogenous diseases. Some rare conditions in this group are associated with infections but the larger group, idiopathic inflammatory myopathies (IIMs), the focus of this review, does not have a causative agent. IIM is characterized by proximal muscle weakness accompanied by various extramuscular manifestations, for example, in skin, lungs, joints, heart, and gastrointestinal tract.^{1,2} The major subtypes of IIM classified based on clinical, serologic, and histologic features are



MYOSITIS RESEARCH WEBINAR

**JANUARY 10, 2023
6 PM EST**



**JULIE PAIK, MD, MHS
JOHNS HOPKINS UNIVERSITY
SCHOOL OF MEDICINE**

Tune into TMA's newest webinar!
Throughout 2023, we will highlight several
researchers and the amazing work they do!
For our first episode, learn about
Dr. Julie Paik's myositis research.

Dr. Paik is an Associate Professor of Medicine in the Division of Rheumatology and Director of Clinical Trials at the Johns Hopkins Myositis Center. She completed residency training and Chief Residency at UCLA-Cedars Sinai Medical Center and rheumatology fellowship at Johns Hopkins. She joined the Hopkins faculty in 2013 and her research efforts are focused in overlap myositis, scleroderma muscle disease, and novel therapeutics in refractory dermatomyositis.

[REGISTER FOR RESEARCH WEBINAR](#)

dermatomyositis (DM), polymyositis (PM), inclusion body myositis (IBM), antisynthetase syndrome (ASSD), immune-mediated necrotizing myopathy (IMNM), and juvenile IIM.¹ More homogenous subsets can be identified by using myositis-specific and myositis-associated autoantibodies (MSAs and MAAs).¹

[READ FULL ARTICLE HERE](#)



Please check out TMA's brand new 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 you have any trouble navigating, please reach out to us at tma@myositis.org.

[FIND A DOCTOR](#)

TMA Fundraising Corner



THE MYOSITIS ASSOCIATION'S

ASK

THE DOC SERIES



DAVID FIORENTINO, MD, PHD
AUTOIMMUNE DISEASE SPECIALIST
RHEUMATOLOGIC DERMATOLOGY

JANUARY 19, 2023

6:00 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

EMAIL YOUR QUESTIONS TO [RACHEL@MYOSITIS.ORG](mailto:rachel@myositis.org)

Dr. David Fiorentino is a Professor of Dermatology at the Stanford School of Medicine where he has been on faculty since 2002. He is also the Associate Program Director and has co-directed a multidisciplinary dermatology-rheumatology clinic since 2004. He earned his MD and PhD degrees at Stanford. His doctoral work was in the lab of Gerald Crabtree in which he investigated mechanism of action of macrolide immunosuppressants such as FK506 and rapamycin. Before medical school he was the key author in the discovery and characterization of interleukin 10. He did his internship at University of Colorado Health Sciences Center and completed his dermatology residency at Stanford, where he served as Chief Resident.

Dr. Fiorentino is interested in mechanisms of skin disease in dermatomyositis, with a special focus on the role of interferons. Additionally, he is focused on identification of novel autoantigens in dermatomyositis that are associated with particular clinical features or outcomes. His most recent research has identified multiple autoantibodies that are associated with protection from internal malignancy in dermatomyositis. In addition to his translational work using his tissue database, he also conducts several clinical trials for patients with dermatomyositis. He has also done work to help characterize and validate cutaneous assessment outcome instruments in these disorders. He is a founding member and past president of the



The Myositis Association depends on the generous support of people like you to continue its mission.

Fundraising Campaigns allow us to continue expanding and improving the programs and services we offer those battling myositis.

[Click Here to Create a Fundraising Campaign](#)

Community Tip

Make toileting easier with this long-handled toilet aid. Shop around for what suits you best!



[CLICK HERE FOR MORE PRODUCT INFORMATION](#)

Did you miss these previously aired webinars? Click below to

Rheumatologic Dermatology Society.

[REGISTER FOR ASK THE DOC](#)

[SUBMIT GENERAL QUESTIONS](#)

**EMPOWERMENT
CLINIC**

LIVING WITH IBM
THE PATIENT AND CARE PARTNER EXPERIENCE

TMA COMMUNITY MEMBER

JOSEPH SANCHEZ
"MYOSITIS JOE"
PATIENT

TMA COMMUNITY MEMBER

RHONDA ROGERS
"MYOSITIS WARRIOR"
PATIENT

TMA COMMUNITY MEMBER

CYNTHIA MARKS
CARE PARTNER

TMA COMMUNITY MEMBER

JAMES SZUDZIK
"SUDZ"
PATIENT

**THURSDAY, JANUARY 26, 2023**
6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT


[EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG](mailto:rachel@myositis.org)

Join this panel discussion about living with Inclusion Body Myositis. Whether you are a person personally living with the diagnosis, or a care partner for someone who is, this will be a powerful webinar about overcoming challenges! TMA is happy to welcome Joe "Myositis Joe" Sanchez, Rhonda "Myositis Warrior" Rogers, Cynthia Marks and Jim "Sudz" Szudzik as panelists for this event. You will leave inspired!



[REGISTER FOR EMPOWERMENT CLINIC](#)

[SUBMIT GENERAL QUESTIONS](#)

view the recordings!



**THE MYOSITIS ASSOCIATION'S
ASK THE DOC
SERIES**

  **Thursday December 15, 2022
6:00 - 7:00 pm EST**

DR. MERRILEE NEEDHAM - NEUROLOGY

Professor Merrilee Needham is the current Foundation Chair in Neurology, a joint position between Fiona Stanley Hospital, Murdoch University and Notre Dame University Australia. She is a consultant neurologist at Fiona Stanley Hospital, the Director of Research for the South Metropolitan Health Service and the Group Leader, Myositis Discovery Program, Centre for Molecular Medicine & Innovative Therapeutics, Institute of Immunology and Infectious Diseases (IIID), Murdoch University.

[View Ask The Doc Recording](#)



MARILYN McDONALD
Professor of Violin - Oberlin Conservatory
TMA Community Member

SUSAN MCCLAIN
Greensleeves Harp Music
TMA Community Member

**EMPOWERMENT
CLINIC**

MUSICIANS WITH MYOSITIS

 **...for anyone with myositis who plays an instrument, whether professionally or as a hobby.**

Tuesday December 20, 2022 6:00 - 7:00 pm EST

[View Empowerment Clinic Recording](#)

[Affinity Group Meetings](#)



**THE MYOSITIS FAMILY
PODCAST**

CONNECTING NEWLY DIAGNOSED,
SEASONED PATIENTS, AND CAREGIVERS

EPISODE 12
with
KRISTA


THE MYOSITIS ASSOCIATION

Did you know that TMA has a myositis podcast? In 2022, we had over 500 listens in more than 10 countries! Get caught up with previous episodes and discover the most recent. TMA would like to especially thank volunteer Kim Gray for making the podcast a reality!

Join us and listen in as Krista shares her journey with dermatomyositis, from its harrowing start into a place of acceptance and recovery. We know that every myositis journey is different, and Krista's is a perfect example.

[Listen to TMA's Podcast](#)

2023 FUN FIT FLEX



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

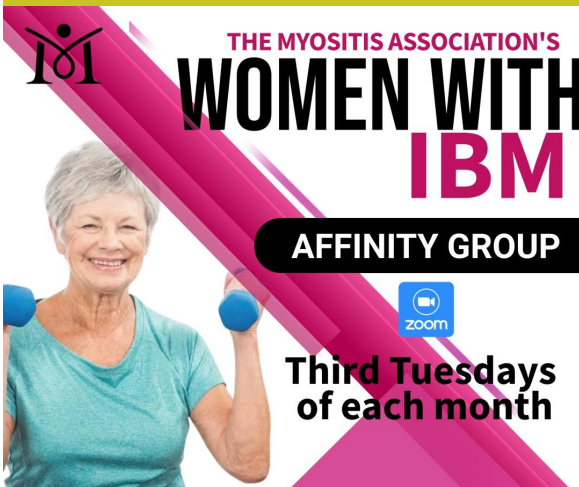
REGISTER FOR FLYING SOLO
AFFINITY GROUP






THE MYOSITIS ASSOCIATION'S
**MILITARY VETERANS
WITH MYOSITIS**
Affinity Group

 **Second Saturday
of Each Month**
9 AM PT | 10 AM MT
11 AM CT | 12 PM ET

REGISTER FOR MILITARY
VETERANS AFFINITY GROUP




THE MYOSITIS ASSOCIATION'S
**WOMEN WITH
IBM**
AFFINITY GROUP

 **Third Tuesdays
of each month**

REGISTER FOR WOMEN WITH
IBM AFFINITY GROUP

FUN FIT FLEX
2023 EVENTS

Greater Philadelphia

June 17th
Montgomery County Community College
Blue Bell, PA

DMV

July 8th
Centennial Park
Ellicott City, MD

San Diego - Annual Patient Conference

September 9th
Sheraton San Diego Hotel & Marina

Chicago

October 21st
DuSable Museum

Houston

Date TBD
Northshore Park
The Woodlands, TX

WWW.FUNFITFLEX.ORG

This year, we are having FUN FIT FLEX events in Greater Philadelphia, DMV, San Diego, Chicago, and Greater Houston.

Our 2021 and 2022 events were a huge success and we thank you so much for supporting these efforts. FUN FIT FLEX allowed the community to come together to celebrate and create awareness.

Thank you to all our participants for making this event memorable and fun. We cannot wait to FLEX with you this year.

Haven't gotten involved yet? Your support in raising awareness and funds for the research to find a cure is essential.

Our 2023 FUN FIT FLEX campaigns are now open. Click one of our events below to get started.

The Myositis Association's

Women of Color

Affinity Group



Third Wednesday of Each Month



REGISTER FOR WOMEN OF
COLOR AFFINITY GROUP



THE MYOSITIS ASSOCIATION'S CAREGIVER

Affinity Group



JOIN US! THIRD SATURDAYS OF THE MONTH
7:30 AM PT | 8:30 AM MT
9:30 AM CT | 10:30 AM ET

REGISTER FOR CAREGIVER
AFFINITY GROUP



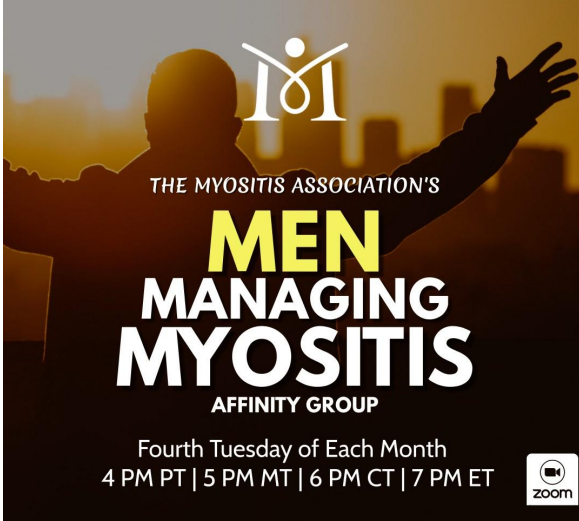
Click to join Greater Philadelphia



Click to join DMV



Click to join San Diego




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 FOR MEN
MANAGING MYOSITIS
AFFINITY GROUP



ADELANTE!

THE MYOSITIS ASSOCIATION'S NEW VIRTUAL SUPPORT GROUP IN SPANISH

Un Grupo De Apoyo Sobre Miositis Para
Hispanohablantes

fourth Saturday of each month
cuarto Sábado de cada mes

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



REGISTER FOR AFFINITY
GROUP IN SPANISH -
ADELANTE!



Click to join Virtual



Click to join Chicago



Click to join Greater Houston

A banner for the Rainbow Warriors Affinity Group. The top half features a background image of people holding rainbow flags and a rainbow heart. The Myositis Association logo is at the top center. The text "THE MYOSITIS ASSOCIATION'S" is in small white letters, followed by "RAINBOW WARRIORS" in large, bold, yellow and white letters. Below that, "AFFINITY GROUP" is in small white letters. A white box at the bottom contains the text "Fourth Sunday Each Month" and "2PM PT | 3PM MT | 4PM CT | 5PM ET" in black.


THE MYOSITIS ASSOCIATION'S
**RAINBOW
WARRIORS**
AFFINITY GROUP

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

REGISTER FOR RAINBOW
WARRIORS AFFINITY GROUP



[Click Here to make a General Donation](#)

*Happy New Year from
The Myositis Association!*

