



THE MYOSITIS ASSOCIATION

MYONews

February 2023 | Issue Two

Upcoming Events

Please check our
[TMA Events Calendar](#)
for our events, regional support
group offerings and more coming this
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 FOR NATIONWIDE](#)



Meet the new Interim Executive Director
March 2, 2023
6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

Rhonda Buckley-Bishop is a seasoned nonprofit management executive. With more than 25 years of experience in leadership roles, both interim and permanent, she is passionate about strengthening nonprofit organizations. Rhonda has worked with organizations in both growth and crisis situations, and her special talent is fortifying teams so they can achieve or expand their organizations' missions.

[REGISTER HERE](#)

ARTICLE OF THE MONTH



Physical exercise as a treatment for adult and juvenile myositis

H. Alexanderson

First published: 08 February 2016

There is growing evidence to support the safety and efficacy of exercise in patients with adult and juvenile idiopathic inflammatory myopathies.

Five randomized controlled trials including adult patients with polymyositis and dermatomyositis (DM) and additional open studies have demonstrated reduced impairment and activity limitation as well as improved quality of life.

[READ FULL ARTICLE HERE](#)



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 you have any trouble navigating,



THE MYOSITIS ASSOCIATION'S

ASK THE DOC SERIES



DR. NAMITA GOYAL
NEUROLOGIST



FEBRUARY 22, 2023

3 PM ET | 2 PM CT | 1 PM MT | 12 PM ET

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

Dr. Namita Goyal is a Professor of Neurology at University of California, Irvine, and specializes in Neuromuscular Medicine. She serves as the Director of the ALS clinic, Director of the Neuromuscular Medicine Fellowship program, and co-Director of the Neuromuscular Center at UC Irvine. Dr. Goyal has authored several neuromuscular articles and has given many national talks on neuromuscular diseases. In addition to evaluating and treating patients, she is a lead site investigator in several clinical trials involving neuromuscular diseases, with a special focus on ALS and myositis. Dr. Goyal is also a member of TMA's Medical Advisory Board.

[REGISTER FOR ASK THE DOC](#)

[SUBMIT GENERAL QUESTIONS](#)

please reach out to us at
tma@myositis.org.

[FIND A DOCTOR](#)

TMA Fundraising Corner



The mission of the CFC is to promote and support philanthropy through a program that is employee focused, cost-efficient, and effective in providing all federal employees the opportunity to improve the quality of life for all.

CFC is the world's largest and most successful annual workplace charity campaign, with almost 200 CFC campaigns throughout the country and overseas raising millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season will support eligible non-profit organizations that provide health and human service benefits throughout the world.

[Click Here to Learn More about CFC - Thank you!](#)

Community Tip



EMPOWERMENT
CLINIC

DATING AND DISABILITY

MAKING IT EASIER



KATHY O'CONNELL
LMHC, CRC CEO/OWNER



MALATI MARLENE SHINAZY
MED, CCMP



WEDNESDAY, FEBRUARY 8, 2023
6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

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

Dating with a disability can be hard! Judgments and misperceptions sometimes cause people to quickly swipe left. Meanwhile, you're longing for love and companionship, but you're about to give up. Don't! Dating and relationships can be made easier.

This presentation will show you how focusing on four areas - self esteem, confidence, a plan (not a wish), and follow through will make dating with a disability easier.

Kathy O'Connell is one of the country's leading advocates for helping people with disabilities create healthy romantic relationships and sexual identities through her unique methodology of increasing self-esteem.

malati marlene shinazy is a person with IBM who has experienced the ups and downs of dating while having myositis.

This webinar aired this week - you can watch the recording below!

[Watch Dating Webinar Here](#)

Women With Myositis - one of our TMA community members has recommended Chico's Off The Rack Weekend collection! The material is very stretchy and makes dressing so much easier! TMA will look for a good option for men as well and include that in a future newsletter!



[CLICK HERE FOR MORE
PRODUCT INFORMATION](#)

Did you miss these previously aired webinars? Click below to view the recordings!



**MYOSITIS
RESEARCH
WEBINAR**

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

JANUARY 10, 2023
6 PM EST

[Watch Research Webinar
Recording](#)



**VIRTUAL SUMMIT
BEYOND LIMITS**

MYOSITIS AWARENESS MONTH

MAY 20, 2023
10 AM - 6 PM EST
WWW.MYOSITIS.ORG

**30TH ANNIVERSARY &
2023 INTERNATIONAL ANNUAL
PATIENT CONFERENCE**

**CELEBRATING YOU
OUR MYOSITIS HEROES**

SEPTEMBER 7 - 10
Sheraton San Diego Hotel & Marina

REGISTRATION FOR BOTH
2023 TMA VIRTUAL SUMMIT
AND INTERNATIONAL APC
WILL OPEN ON
MARCH 1, 2023!



**THE MYOSITIS FAMILY
PODCAST**

CONNECTING NEWLY DIAGNOSED,
SEASONED PATIENTS, AND CAREGIVERS

**SEASON 2
EPISODE 1**
with
ERIC

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.

In this episode, Eric shares his journey with dermatomyositis, from its gradual start to full-blown symptom manifestation and then the beginnings of recovery. We know that every myositis journey is different, and Eric's is a perfect example.



THE MYOSITIS ASSOCIATION'S

ASK THE DOC SERIES

DAVID FIORENTINO, MD, PHD
 AUTOIMMUNE DISEASE SPECIALIST
 RHEUMATOLOGIC DERMATOLOGY

JANUARY 19, 2023
 6 PM ET | 5 PM CT | 4 PM MT | 3 PM PT

EMAIL YOUR QUESTIONS TO RACHEL@MYOSITIS.ORG

[View Ask The Doc Recording](#)



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

[View Empowerment Clinic Recording](#)

Affinity Group Meetings

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

[Listen to TMA's Podcast](#)

2023 FUN FIT FLEX



The Myositis Association judiciously stewards funding in all of its programming. This year the Board of Directors has decided to pause the Fun Fit Flex program as it conducts an overall analysis of all development efforts of the organization.



Each month, TMA will spotlight a myositis clinical trial for your review.

Researchers from the
**Department of Medical Social Sciences at the
 Feinberg School of Medicine
 of Northwestern University**

in Chicago, IL, USA, in collaboration with investigators from the **National Organization for Rare Disorders** are looking for individuals diagnosed with Idiopathic Pulmonary Fibrosis, Myositis, and/or Systemic Sclerosis to participate in a research study to develop a set

WOMEN WITH IBM
Affinity Group



**DOES IBM PRESENT
DIFFERENTLY IN
WOMEN THAN MEN?**

LISA CHRISTOPHER - STINE
MD, MPH
PROFESSOR OF MEDICINE
DIRECTOR, JOHNS HOPKINS MYOSITIS CENTER
JOHNS HOPKINS DIVISION OF RHEUMATOLOGY

**TUESDAY, FEBRUARY 21
12:00 PM - 1:30 PM ET**

PLEASE FORWARD QUESTIONS TO WOMENWITHIBM@MYOSITIS.ORG

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

**REGISTER FOR WOMEN WITH
IBM AFFINITY GROUP**



**TMA MILITARY VETERANS
WITH MYOSITIS
AFFINITY GROUP**

The Myositis Association

Second Saturday of Each Month
12:00 PM ET - 11:00 AM CT - 10:00 AM MT - 9:00 AM PT

**REGISTER FOR MILITARY
VETERANS AFFINITY GROUP**



**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**

of questionnaires that assesses physical impacts associated with those conditions. Once developed, the questionnaires will help researchers and clinicians understand the physical impacts associated with a range of conditions for use in clinical research and trials.

These new questionnaires will be important for use in clinical trials to expand treatment options for individuals with rare diseases. The title of the study is

**UH3 Qualitative Study to Inform
Development and Selection of Cross-Cutting
Patient Reported and Performance Outcome
Assessments of Physical Function.**

You may be eligible to participate if you are 18 years or older and have been diagnosed with Idiopathic Pulmonary Fibrosis, Myositis, and/or

Systemic Sclerosis and you are able to participate in a 60-minute phone interview in English. If you are eligible, you will participate in one telephone interview during which you will complete a questionnaire and provide feedback on the questionnaire. The interview will last approximately 60 minutes and will be scheduled at a time that is convenient for you.

**After completing an interview, you will
receive an electronic Visa gift card for the
equivalent of \$75 USD.**

This study is funded by the U.S. Food and Drug Administration (FDA) and been approved by the Northwestern University Internal Review Board (IRB) under study ID STU00216175175.

Prior to scheduling a call with a member of our research team, we invite you to complete an online screening questionnaire to see if you are eligible for the study. If eligible, you will be invited to provide your contact information and a member of our study team will reach out to you to discuss the study and schedule an interview.

**To complete the online screening
form, please follow the link:**

<https://redcap.link/raredisordersnucoat>

**For questions please contact:
NUCOAT_study@northwestern.edu**

Project PI: David Cella, PhD, Department of

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

If you are an organization promoting a current or upcoming clinical trial, please [email here](#). Thank you!



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!



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