



THE MYOSITIS ASSOCIATION

MYONews & Updates

October 2022 | Issue Ten

Upcoming Events

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

NEW EPISODE! TMA Myositis Family Podcast

[Oct. 1 - TMA Nationwide Support Group Meeting](#)

[Oct. 13 - Ask the Doc Series EN ESPAÑOL](#)

[Oct. 20 - Ask the Doc Rheumatology](#)

[Oct. 27 - Empowerment Clinic TMA's Support and Affinity Group Program](#)

[FUN FIT FLEX](#)



COMPLETAMENTE EN ESPAÑOL
ESPAÑOL
COMPLETAMENTE EN ESPAÑOL

THE MYOSITIS ASSOCIATION'S
ASK THE DOC SERIES

Thursday October 13, 2022
6:00 - 7:00 pm EST

DR. JULIO HUAPAYA - PULMONOLOGY

Dr. Huapaya received his Doctor of Medicine degree from Universidad Peruana Cayetano Heredia in Peru. He joined the Interstitial Lung Disease Research group at Johns Hopkins Hospital in 2015. He is currently working in the Critical Care Department at the National Institutes of Health and continues collaborating with the ILD Research group at Johns Hopkins Hospital.

In honor of National Hispanic Heritage Month, TMA is delighted to offer an Ask The Doc series webinar completely in Spanish.

Dr. Julio Huapaya received his Doctor of Medicine degree from Universidad Peruana Cayetano Heredia in Peru. He joined the Interstitial Lung Disease Research group at Johns Hopkins Hospital in 2015. Dr. Huapaya has completed residency training in Internal Medicine at Georgetown University Hospital and Fellowship in Pulmonary Medicine at the University of Maryland. He is currently working in the Critical Care Department at the National Institutes of Health and continues collaborating with the ILD Research group at Johns Hopkins Hospital.

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

A great way to help support The Myositis Association is by creating your own Personal Fundraising Campaign.

Donations from personal fundraising campaigns allow us to continue expanding and improving the programs and services we offer those battling myositis.

[Click Here to Start A Campaign](#)

[REGISTER FOR ASK THE DOC EN ESPANOL](#)

[SUBMIT GENERAL QUESTIONS](#)

A promotional graphic for the Myositis Association's 'Ask The Doc Series'. It features a photograph of Dr. Lesley Saketkoo, a woman with blonde hair, in a red top, standing in a hospital hallway. Below the photo is a green banner with the text 'THE MYOSITIS ASSOCIATION'S ASK THE DOC SERIES'. To the left of the banner is the Myositis Association logo (a stylized 'M' with a person figure) and a Zoom logo. To the right of the banner, it says 'Thursday October 20, 2022 6:00 - 7:00 pm EST'. Below the banner, it says 'DR. LESLEY SAKETKOO - RHEUMATOLOGY'. At the bottom, there is a small text block: 'Dr. Saketkoo, a member of the medical advisory board for TMA, is a trained in pediatrics, internal medicine and rheumatology. She is director and founder of New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center. She is a clinical researcher in multi-organ system diseases (such as myositis, scleroderma and sarcoidosis) and has a strong focus on muscle and cardiopulmonary manifestations.'

Dr. Lesley Saketkoo, a member of the medical advisory board for TMA, is trained in pediatrics, internal medicine and rheumatology. She is director and founder of *New Orleans Scleroderma and Sarcoidosis Patient Care and Research Center*. She is a clinical researcher in multi-organ system diseases (such as myositis, scleroderma and sarcoidosis) and has a strong focus on muscle and cardiopulmonary manifestations. Her research focuses on disease modifying effects of exercise, clinical trial design, identifying patients' priorities, and developing research tools with patients (of which one being used in myositis clinical trials is the *Mawdsley Calcinosis Questionnaire*) including targeting self-management strategies with yoga, dance and singing for lung health rehabilitation as well as mindfulness practices. She is co-director/co-founder of *UMC Comprehensive Pulmonary Hypertension Center and Interstitial Lung Disease Clinic Programs* a collaboration between Louisiana State University and Tulane University Schools of Medicine. In 2018, she was honored with Doctor of the Year from the Scleroderma Foundation.

Community Tip

Make grabbing items easier with a pair of 17 inch tongs. Shop around for what suits you best! Here is an option with 4.5 stars.



[CLICK HERE FOR MORE PRODUCT INFORMATION](#)

MDA Advocacy

Virtual Summit and Hill Day

Wednesday & Thursday
September 28th & 29th 2022



TMA is pleased to announce its participation in the Virtual Summit and Hill Day organized by the Muscular Dystrophy Association. Advocates met with legislators to discuss improving air travel for people living with a disability, increasing access to genetic counseling services, and ensuring all critical reforms and innovations within the House and Senate user fee bills are passed by the end of this year at the very latest. Thank you to MDA for making these efforts possible!

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

[REGISTER FOR ASK THE DOC](#)

[SUBMIT GENERAL QUESTIONS](#)

RACHEL BROMLEY
The Myositis Association

ERIC ROCHELEAU & SHAWNA NIELSEN
TMA Community Members

EMPOWERMENT CLINIC

TMA'S SUPPORT & AFFINITY GROUP PROGRAM

Thursday October 27, 2022 6:00 - 7:00 pm EST

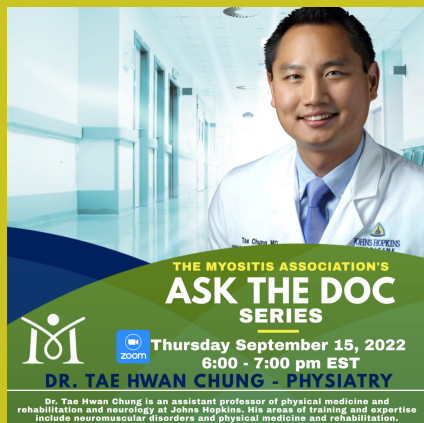
Eric Rocheleau is from central Connecticut and leads the affinity support group Men Managing Myositis. He was diagnosed with Dermatomyositis in 2021. After nearly 30 years in Law Enforcement, Eric retired in April of 2022 at the rank of Police Captain. He is currently a reserve officer working in Hartford County. He is married and has 3 children.

Shawna Nielsen has been a registered nurse (BSN) for 36 years and a myositis patient with DM for over 24 years. She teaches patient advocacy to nurses through Independent RN Patient Advocates in Tucson AZ. She is a Co-Leader for the TMA Northern California Keep In Touch support group as well as manages two Facebook support groups related to myositis. Shawna is passionate about the science and medical advances in myositis research and care. Her goal is for others to not suffer as she did early on. Shawna is now thriving with myositis and enjoys cooking, hiking and taking bird photos.

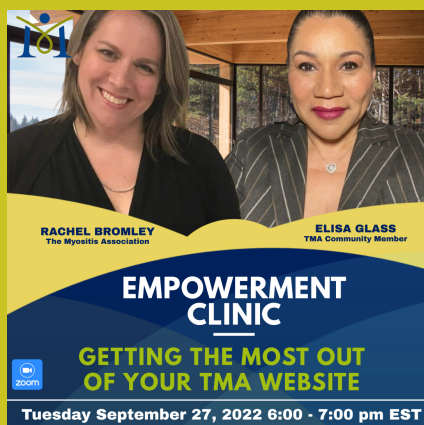
Rachel Bromley is TMA's Senior Manager of Patient Education, Support and Advocacy. She has been a nonprofit executive for ten years,

raising awareness and funds for the causes of mental health, domestic violence and sexual assault before transitioning to the rare disease space. She has learned so much from the myositis community since starting her journey with TMA.

REGISTER FOR EMPOWERMENT CLINIC

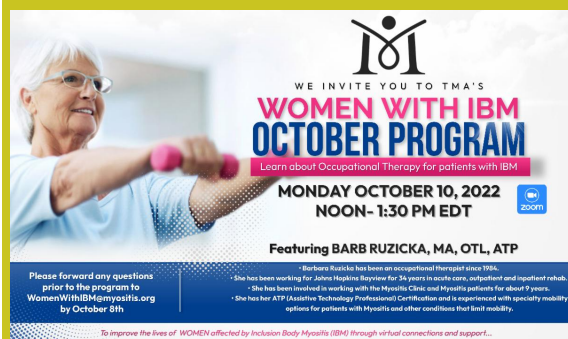


[View Dr. Chung Recording](#)



[View Empowerment Clinic Recording](#)

Affinity Group Meetings



[REGISTER FOR WOMEN WITH IBM AFFINITY GROUP](#)

FUN FIT FLEX Orlando



FUN FIT FLEX Orlando was a great success! We all got the chance to come together as a community to celebrate and create awareness.

Thank you to all our participants for making this event memorable and fun. Haven't gotten involved yet? Your support in raising funds for the research to find a cure is essential.

Sign up for our next FUN FIT FLEX or create your own fundraiser. Reach out to us or [click here](#) for more information.

Join us on Saturday, October 22nd for FUN FIT FLEX Chicago and Saturday, October 29th for FUN FIT FLEX Houston



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
of Color**
Affinity Group

Third Wednesday of Each Month

REGISTER FOR WOMEN OF
COLOR AFFINITY GROUP

The Myositis Association
Fitness Festival • Fun Walk

Proceeds support TMA's programs for myositis patients and care partners.



**Saturday
Oct. 22, 2022
10:00 am
Chicago**
DuSable Museum
740 E. 56th Place, Chicago, IL 60637

TO REGISTER
visit www.funfitflex.org
Registration is FREE,
but participants are
encouraged to raise funds
to support the mission.

About the event:

- Non-competitive Walk
- DJ and Music
- Children's Activities
- Fitness Demonstrations
- Health & Wellness Information
- and more...


















Sponsorship and vendor opportunities available. Call 800-821-7356.
www.funfitflex.org

The Myositis Association
Fitness Festival • Fun Walk

Proceeds support TMA's programs for myositis patients and care partners.



**Saturday
Oct. 29, 2022
10:30 am
Greater Houston**
Northshore Park
2505 Lake Woodlands Drive, The Woodlands, TX

TO REGISTER
visit www.funfitflex.org
Registration is FREE,
but participants are
encouraged to raise funds
to support the mission.

About the event:

- Non-competitive Walk
- DJ and Music
- Children's Activities
- Fitness Demonstrations
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- and more...
















Sponsorship and vendor opportunities available. Call 800-821-7356.
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2022 FUN FIT FLEX Incentives



**REGISTER FOR CAREGIVER
AFFINITY GROUP**



**REGISTER FOR MEN
MANAGING MYOSITIS
AFFINITY GROUP**



**REGISTER FOR AFFINITY
GROUP IN SPANISH -
ADELANTE!**



We are proud to recognize our fundraisers who take an extra step to positively impact the myositis community.

Every participant who raises \$100 or more will receive a FUN FIT FLEX Commemorative Event T-Shirt.

Those going above and beyond by raising \$1,000 or more will earn a FUN FIT FLEX Zip Pullover!

We truly appreciate your dedication to help us create awareness and raise funds for people with myositis.



Join the #MYOMOVEMENT



**REGISTER FOR RAINBOW
WARRIORS AFFINITY GROUP**



Don't miss out on supporting FUN FIT FLEX. Individual and Team donations for all of our 2022 FUN FIT FLEX events will be accepted through December 31st.

Join the #MYOMOVEMENT and make a donation before the end of the year.

[Click Here to Donate](#)

October Giving Opportunity – Inclusion Body Myositis Research Fund

A poster for the October Giving Opportunity. At the top left is the Myositis Association logo and the text "THE MYOSITIS ASSOCIATION". Below this, the text "OCTOBER GIVING OPPORTUNITY" is written in large, bold, blue letters. Underneath, a blue box contains the text "HAVE YOUR GIFT MATCHED!". At the bottom left, a paragraph states: "All gifts made to The Myositis Association's Inclusion Body Myositis Research Fund through 10/31 will be MATCHED up to a total of \$30,000". The right side of the poster features a collage of images showing people with mobility aids (walkers, wheelchairs) and a person being assisted, set against a warm, orange-toned background.

Inclusion body myositis (IBM) is the most commonly acquired myopathy in patients over the age of 50. Symptoms of inclusion body myositis progress more slowly than the other types of myositis with weakness increasing gradually, sometimes over years. Some of the first signs are falling, difficulty getting up from a chair, and weakened grip. Muscles most often affected are those at the front of the thighs, those that elevate the feet, and those in the hips, fingers, wrists, upper arms, shoulders, neck, and back. Many IBM patients notice shrinking (atrophy) in the arms and thighs as the muscles become weaker. Trouble swallowing, or dysphagia, is a common problem for patients as well. There is no cure for any of the types of myositis and no approved

treatment for IBM patients at this time.

Support our annual end of summer fundraising appeal! Thanks to the generosity of the Bill M. & Cecile Autrey Ham Charitable Foundation, all October Giving Opportunity donations will be MATCHED, up to a total of \$30,000 now through October 31st! Your gift and the foundation's matching contribution will be earmarked specifically for TMA's Inclusion Body Myositis Research Fund and used to fund innovative science through research projects supporting learning of and progress for inclusion body myositis.

Don't wait! Take advantage of this incredible opportunity to have campaign gifts matched as we work to facilitate a cure for myositis.

[**Click Here to Support the Inclusion Body Myositis Research Fund**](#)