



THE MYOSITIS ASSOCIATION

MYONews & Updates

November 2022 | Issue Eleven

Upcoming Events

Please note some groups will not be meeting in November due to the holiday. Please check our [calendar](#) for our regional support group offerings and more coming this month!

NEW EPISODE! TMA Myositis Family Podcast

[Nov. 5 - TMA Nationwide Support Group Meeting](#)

[Nov. 15 - Empowerment Clinic](#)

[Nov. 17 - Ask the Doc Physical Therapy](#)

[FUN FIT FLEX](#)



CHRISTINA MARTINEZ
Licensed Mental Health Counselor

HOLLY JONES
TMA Community Member

EMPOWERMENT CLINIC

MANAGING MENTAL HEALTH THROUGH THE HOLIDAYS

Tuesday November 15, 2022 6:00 - 7:00 pm EST

Christina Martinez is a Licensed Mental Health Counselor (LMHC) in Florida. She is a Certified Crisis Trauma Professional (CCTP), and Eye Movement Desensitization and Reprocessing (EMDR) trained to treat trauma and related stressors. She has experience in treating depression, anxiety, trauma, mood disorders, and psychotic disorders. Her specialization is treating individuals who experience chronic illness; inspired by her client's experiences and her personal experiences with chronic disease, and the changes in physical health, emotional health, mental health, and quality of life. Christina practices at Mindful Living Counseling Services, located in beautiful Downtown Orlando, FL.

In 2003, at the age of 19 years old **Holly Jones** was diagnosed with Polymyositis with

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.

The Tony Nestico Memorial 5K Campaign was created in loving memory of Tony Nestico, who lost a 3 year battle with Polymyositis on November 22, 2018. Over the years, the campaign has not only raised money for TMA, but it has also created awareness for people who have never heard of Polymyositis.


This years goal is \$10,000, can we

Interstitial Lung Disease at a CPK level over 20,000. In 2014, her lung disease progressed causing her to develop Pulmonary Hypertension that required her to be on oxygen daily. After six years of being in clinical remission, the Pulmonary Hypertension progressed into Congestive Heart Failure in October 2020. Living with diseases that attack her muscles, lungs, and heart; it has not stopped Holly from accomplishing her life goals. A social media entrepreneur, Holly also serves on TMA's Board of Directors, as well as co-leader for TMA's Women of Color Affinity Group, and Support Group Leader for the Houston, Tx regional support group. Holly lives in Porter, TX with her husband and children.

REGISTER FOR EMPOWERMENT CLINIC

SUBMIT GENERAL QUESTIONS

THE MYOSITIS ASSOCIATION'S
ASK THE DOC
SERIES

 **Thursday November 17, 2022**
6:00 - 7:00 pm EST

DR. LINDSAY ALFANO - PHYSICAL THERAPY

Dr. Lindsay Alfano is a physical therapist with expertise in the care and evaluation of patients with neuromuscular disease including outcome measure development, evaluation, and administration. Dr. Alfano and the physical therapy team at Nationwide Children's Hospital have led initiatives to understand and validate remote testing for patients with neuromuscular diseases for clinical and research purposes.

Dr. Lindsay Alfano is a physical therapist with expertise in the care and evaluation of patients with neuromuscular disease including outcome measure development, evaluation, and administration. She plays an integral role in planning and designing clinical trials and contributes to protocol development, outcome measure selection, statistical analysis, and interpretation for ongoing clinical trials. Dr. Alfano serves on

count on your support to share the campaign and/or donate?

[Click Here to Support the Tony Nestico Memorial 5K Campaign](#)

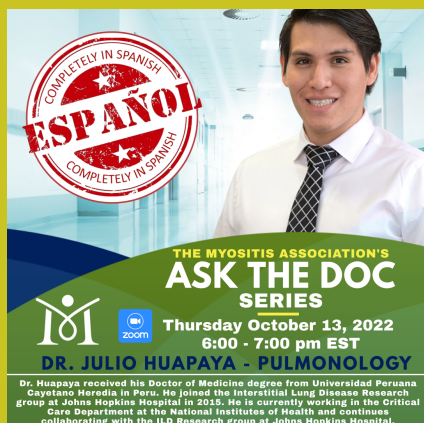
Community Tip

Make traveling easier with a portable bidet. Shop around for what suits you best! Here is an option with 4 stars.



[CLICK HERE FOR MORE PRODUCT INFORMATION](#)

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




[View Dr. Huapaya Recording](#)

an international consortium of neuromuscular physical therapy experts that provide industry-standard training and reliability for multisite international trials. Her research goals focus on standardizing training in rare disease, as well as developing and promoting optimal assessment tools to measure change in movement abilities while minimizing the burden of testing. She has co-developed novel outcomes including the ACTIVE & ACTIVE-mini systems, 100-meter timed test, and the Neuromuscular Gross Motor Outcome (GRO). In response to the COVID-19 pandemic, Dr. Alfano and the physical therapy team at Nationwide Children's Hospital have led initiatives to understand and validate remote testing for patients with neuromuscular diseases for clinical and research purposes.

[REGISTER FOR ASK THE DOC](#)

[SUBMIT GENERAL QUESTIONS](#)

FUN FIT FLEX October Recap




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

**Thursday October 20, 2022
6:00 - 7:00 pm EST**

DR. LESLEY SAKETKOO - RHEUMATOLOGY

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.

[View Dr. Saketkoo Recording](#)



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

[View Empowerment Clinic
Recording](#)

Affinity Group Meetings



**WE INVITE YOU TO TMA'S
WOMEN WITH IBM
NOVEMBER PROGRAM**

Dysphagia Management in IBM

**TUESDAY NOVEMBER 15, 2022
NOON- 1:30 PM EDT**

Featuring GENEVIEVE MCKEON & THERESA WALKER
SPEECH LANGUAGE PATHOLOGISTS - JOHNS HOPKINS MYOSITIS CENTER

Genevieve McKeon received her M.S. in Speech Language Pathology from University of South Florida in 1999. She has been practicing at Johns Hopkins Bayview Medical Center since 2002. Her clinical practice and primary research interests include diagnosis and management of swallowing and communication disorders related to complex conditions including inflammatory muscle diseases, neuromuscular conditions, and burn injury. She has presented nationally and internationally on a range of topics including dysphagia in the critical care setting, language recovery after stroke, diagnosis and management of dysphagia in myositis, burn injury, and neurologic injury.

Please forward any questions prior to the program to WomenWithIBM@myositis.org by November 14th

To improve the lives of WOMEN affected by Inclusion Body Myositis (IBM) through virtual connections and support...

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





REGISTER FOR FLYING SOLO
AFFINITY GROUP



REGISTER FOR MILITARY
VETERANS AFFINITY GROUP



REGISTER FOR WOMEN OF
COLOR AFFINITY GROUP



Last month, we held two FUN FIT FLEX events - Chicago and Greater Houston. Both events were a huge success. 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. Haven't gotten involved yet? Your support in raising funds for the research to find a cure is essential.



REGISTER FOR CAREGIVER
AFFINITY GROUP



REGISTER FOR MEN
MANAGING MYOSITIS
AFFINITY GROUP



REGISTER FOR AFFINITY
GROUP IN SPANISH -
ADELANTE!

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

2022 FUN FIT FLEX Incentives



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.



REGISTER FOR RAINBOW
WARRIORS AFFINITY GROUP

START YOUR FUNDRAISING TODAY!

1. Step up and show your commitment with your own donation \$ 50
2. Ask your spouse to match your donation \$ 50
3. Ask your manager \$ 50
4. Ask your coworkers (10 x \$15 each) \$ 150
5. Ask someone with myositis \$ 50
6. Ask your neighbors (10 x \$15 each) \$ 150
7. Ask your friends (10 x \$15) \$ 150
8. Ask people in a club or organization (10 x \$20) \$ 200
9. Post it on your social media (10 x \$10) \$ 100
10. Ask someone who has asked for your help in the past \$ 50

TOTAL \$ 1,000

You've earned a
FUN FIT
FLEX Event
T-Shirt.

You've earned a
FUN FIT
FLEX Zip
Pullover.
Congrats!

The Myositis
Association



FUN FIT FLEX

Join the #MYOMOVEMENT



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](#)

Happy Thanksgiving from The Myositis Association!

HAPPY
Thanksgiving

