



# TMA WOC



April - June 2024

NEWSLETTER

Edition

## Our Vision

To champion and advocate for all Women of Color living with, or caregiving for, any form of myositis. WOC promotes awareness through the 3E's: Encouragement, Education, and Empowerment.

## Our Mission

Women of Color is a TMA support and advocacy group that strengthens women who are known to be disproportionately affected by myositis disease. "Non-white women are twice as likely to die than others with myositis, and they are four times more likely to die than white men with the disease". With the backing of TMA's Medical Advisory Board and research team, we plan to educate, empower, and encourage women, caregivers, and communities of color through workshops, meetings and supportive activities. This will enable participants of WOC to go into their communities, and convey factual information about myositis.

## Message From The Leaders

Thank you to all the ladies who participated in the Double Good Fundraiser. We met our goal!

Our 1st Listening and Information Session with Privant Therapeutics and TMA Staff was a success. Thank you for your engagement!

Holly Jones & Kaniah Gunter



Happy Birthday to everyone celebrating a birthday in the month of Apr, May, and June.

## Set Your Calendar

*Please note EST for event times*

### April

- Apr 1 Registration opens for TMA International Annual Patient Conference
- Apr 4 WOC Affinity Group Meeting, 6:30 -8:30 pm
- Apr 9 Ask the Doc: Dermatologist w/ Dr. Victoria Werth, 6:00 -7:00 pm
- Apr 11 Meet and Greet w/ Dr. Narita Goyal, TMA Medical Advisory Board Chair, 4:00 - 5:00 pm
- Apr 18 TMA Empowerment Clinic, 6:00 - 7:00pm

### May is Myositis Awareness Month!

- May 1 Myositis Awareness Month Kickoff Webinar, 4:00 - 4:30 pm
- May 2 WOC Affinity Group Meeting, 6:30 -8:30 pm
- May 8 Empowerment Clinic, 6:00 -7:00 pm
- May 14 Raising Awareness Clinic: Disclosing Your Diagnosis to Your Employer, 6:00 - 7:00 pm
- May 18 Patient 360 IgNS Virtual Conference (2 day conference)
- May 18 Ask The Counselor hosted by TMA Care Partner Affinity Group
- May 21 Myositis Research Webinar, 6:00 - 7:00 pm
- TBD 3-Part Women of Color Health Webinar Series Launch

### June

- Jun 6 WOC Affinity Group Meeting,
- Jun 7 Patient Focused Drug Development w/FDA, 10:00 - 3:00 pm
- Jun 7-9 Relaxation Retreat, Charlotte Bay, FL

### July Sneak Peek

- Part 2 of Women of Color Health Series

TMA Events and Times can be located on the TMA's Website



## Stay Connected With Us

We want to stay in contact with you while you navigate your journey with Myositis. If you have not updated your information on our Google Form please visit

<https://forms.gle/hVUQMv4mJmXnnDghZ>

or click the link in the Facebook Group.

**Facebook** @The Myositis Association Women of Color Affinity Group (Private)

**Email:** [tmawoc@gmail.com](mailto:tmawoc@gmail.com)



# TMA Women of Color



This May we are celebrating 5 years that the Women Of Color Affinity Group has been established as a group under TMA.

We are honoring the women that paved the way, set the foundation, and supported the cause of WOC.

May we celebrate, remember, and honor the women that paved the way for us to elevate our voices

*Today*

For the sisters we loss over the years we remember their cause and honor their memory.





# Honoring Women of Color



## HONORING THE GROUND BREAKERS 5 YEARS ESTABLISHED



HOLLY



KANIAH



LADONNA



LASHAN

Women who paved the way for  
WOC and honoring the fallen



DONNA



LAURIE



REGINA



DR. VENTURA

# Navigating Grief

Get ready to relax, refresh, focus

**WELLNESS  
COMMITTEE**



## What is Grief?

Grief is a very sad feeling that happens when you experience losing a love one, loss of a job, loss of good health, or a place important to you

### Stages of Grief

Denial

Anger

Bargaining

Depression

Acceptance



## Identifying the 5 Stages of Grief

### The 5 Stages of Grief

#### KEY CAUSES:

- Loss of love one
- Living with illness
- Loss of job,
- Moving

#### KEY FACTORS:

- Listen
- Provide support
- Show compassion
- Show empathy



#### Denial

"This can't be happening"

Shock  
Confusion  
Fear



#### Anger

"Why is this happening"

Frustration  
Irritation  
Anxiety



#### Bargaining

"I will do anything to find meaning"

Guilt  
Shame



#### Depression

"Feeling of giving up"

Isolation  
Sadness



#### Acceptance

"I am going to be ok"

Support  
Hope  
Purpose

### Resources

<https://my.clevelandclinic.org/health/diseases/24787-grief>

[www.GetintoNeurodiversity.com](http://www.GetintoNeurodiversity.com)

### Kubler-Ross Grief Cycle

[https://en.wikipedia.org/wiki/Five\\_stages\\_of\\_grief](https://en.wikipedia.org/wiki/Five_stages_of_grief)





# Social Media Committee

Email: [Wocsocialmediateam@gmail.com](mailto:Wocsocialmediateam@gmail.com)

## HOW CAN YOU HELP?

Do you have a talent in Video Editing, content creation, social media background, website, or a desire to help? We could use your help! If interested please reach out to the social media team or the WOC leaders.

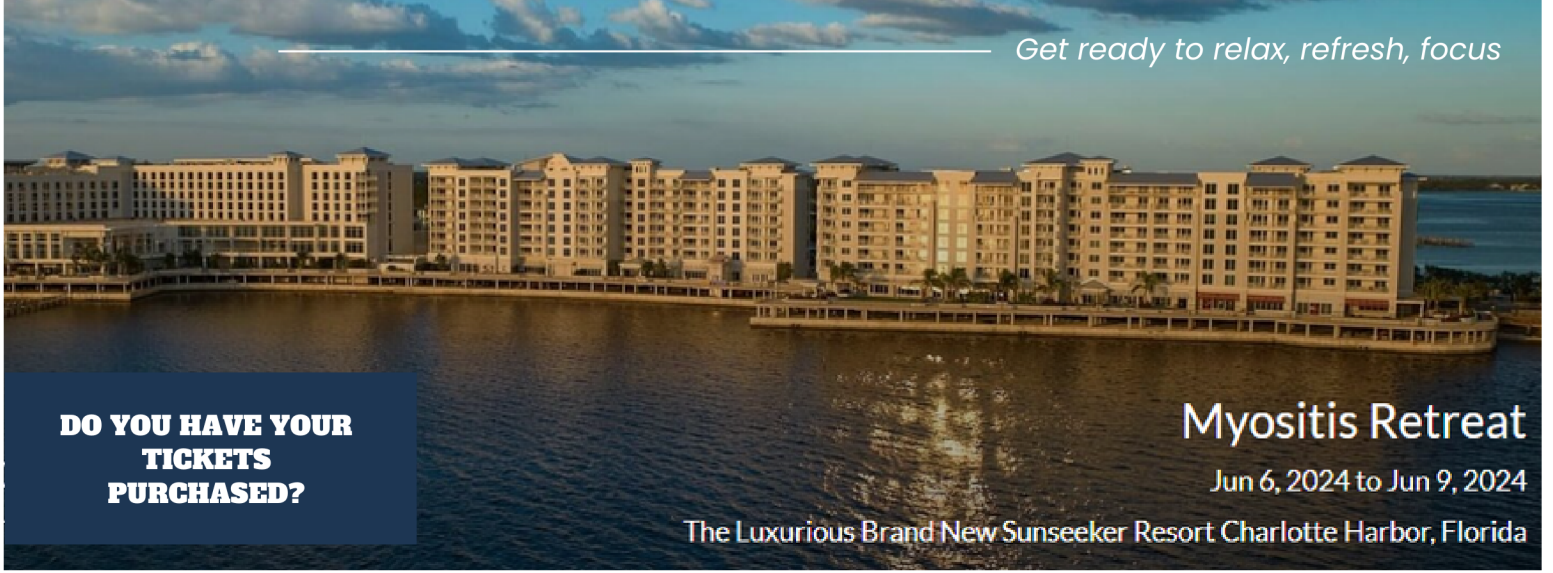
We would love to have you on the team.

Help us spread the word about Myositis.

**SIMPLY LIKING,  
FOLLOWING,  
SHARING,  
POSTING, AND  
TAGGING**

**#WOC  
#TMAWOC  
#MYOSIS**





**DO YOU HAVE YOUR  
TICKETS  
PURCHASED?**

## Myositis Retreat

Jun 6, 2024 to Jun 9, 2024

The Luxurious Brand New Sunseeker Resort Charlotte Harbor, Florida

**SHARE  
YOUR  
Story**



*HER* STORY IN COLOR

SCHEDULE YOUR INTERVIEW TODAY!



**WE WANT TO  
SEE YOU AT THE  
CONFERENCE**

Mark your calendars for this years  
International Annual Patient  
Conference.

Registration begins April 1st check  
TMA's website for details.



THE MYOSITIS ASSOCIATION®

THE INTERNATIONAL ANNUAL PATIENT CONFERENCE

**SEPTEMBER 6-8, 2024**  
HILTON BALTIMORE INNER HARBOR



*Celebrating our Connection*