



THE MYOSITIS ASSOCIATION®

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## TMA's 2024 International Annual Patient Conference: Celebrating Our Connections!

Start planning now to attend this year's International Annual Patient Conference in Baltimore! Meet myositis friends. Learn about treatments and how to live your best life. Get to know the doctors, organizations, and companies working to make myositis a more manageable condition. And have a great time while you're at it!

The tentative [Schedule-at-a-Glance](#) is now posted to our website. Registration will be open in early April.

Stay tuned for news about new programming and exciting opportunities planned for this year's conference. Can't wait to see you there!!

**RARE**  
**DISEASE WEEK**  
ON CAPITOL HILL

# Take Advantage of These Rare Opportunities for Rare Disease Day

EveryLife Foundation for Rare Diseases hosts Rare Disease Week on Capitol Hill, February 25-28 in Washington, DC. The event brings together rare disease advocates from across the country to make their voices heard by their members of Congress. Participants are educated on policy proposals affecting the rare disease community and provided opportunities to advocate for policy changes directly to their members of Congress.

TMA's Rachel Bromley will be among the participants advocating for rare disease issues with legislators. You can be there too!

[VIEW AGENDA](#)

[REGISTER HERE](#)



## The NIH Hosts Rare Disease Day at NIH 2024 February 29, 2024 at 9 am - 5 pm

This is a hybrid event with both in-person (Bethesda, MD) and virtual options. It's a way to raise awareness about rare diseases, the people they affect, and NIH collaborations that address scientific challenges and advance research for new treatments.

Let us know if you'll be there for this event! TMA's executive director Paula Eichenbrenner wants to meet up with you. Email her at [paula@myositis.org](mailto:paula@myositis.org).

[VIEW AGENDA](#)

[REGISTER HERE](#)



The FDA's Office of Orphan Products Development hosts their annual [virtual public meeting for Rare Disease Day](#) on March 1, 9 am - 4:30 pm ET. This global observance of Rare Disease Week is dedicated to patients and healthcare professionals.

[VIEW AGENDA](#)

[REGISTER HERE](#)

## **Adult Dermatomyositis Externally-Led Patient- Focused Drug Development Meeting (EL-PFDD)**

JUNE 7, 2024



### **Calling All DM Patients!**

Haven't you always wanted to let someone know how challenging it is to live with a disease for which treatments often don't work? Here's your chance!

TMA is partnering with Myositis Support and Understanding (MSU) to host an Externally Led Patient Drug Development (EL-PFDD) listening session with the FDA on adult dermatomyositis. The project's [website](#) has just been launched where you can learn more about it and add your story to the material shared with this government agency responsible for approving new drugs and treatments.

We're hoping to have a few hundred people from our community attend all or part of this town hall-style virtual meeting on June 7, 2024, from 10 am to 2 pm ET. During this conversation with the FDA, patients and care partners can share their experience of living with this rare disease and the challenges you face.

Here's your chance to tell officials at the FDA and other government agencies, doctors, scientists, and medical product developers what you need, so they can improve the clinical trials process and develop treatments for adult dermatomyositis.

[REGISTER TODAY](#)

And the winner is...

Congratulations to the winner of the Podcast Naming Contest, Holly Jones, who will receive a \$100 gift card!

The new name of TMA's podcast is



## Accessible Theater

Check out this amazing [story in the Washington Post](#) about TMA member Lisa Sniderman and a musical for people who can't go to a theater. It's a production Lisa and a pair of partners hope to produce based on Lisa's [The Grieving Project](#). Working together with Open Circle Theatre, a professional theater in D.C. dedicated to promoting the careers of disabled artists, the team have turned The Grieving Project into a multimedia musical that is rooted in "radical accessibility."

**SUPPORT THE GRIEVING PROJECT**

## 2024 UPCOMING EVENTS

Tap into the power of peer support!

Did you know that if you are a person with myositis or caring for someone with myositis and feel you need support as soon as possible, you are welcome to attend any scheduled myositis meeting, even if not in your geographical





*Tap into the power of peer support!*

1:00-2:30 PM ET | 10:00-11:30 AM PT  
FIRST SATURDAY OF EVERY MONTH

## TMA NATIONWIDE

### Myositis Support Group

*Find encouragement and motivation to persevere through tough times. Connect and learn. Breakout rooms grouped by diagnosis and led by trained, certified peer leaders from across the nation!*

[Register Now!](#)



area? Just check our events calendar and register for what interests you. TMA is an inclusive community and invites you to reach out as you need.

We would especially love to see you at TMA's Nationwide Myositis Support Group Meeting on Saturday, March 2, 2024 | 1:00 pm - 2:30 pm ET.

Visit the [TMA Events Calendar](#) to see and register for upcoming support and affinity group meetings, webinars, and more.

## AFFINITY GROUP MEETINGS

TMA encourages members to attend as many meetings as fit your support needs. In addition to our geographically based support groups, TMA offers nine different affinity groups with members from all across the nation (and sometimes the world!).

TMA's affinity groups bring together members who share a commonality in addition to a connection to myositis. These groups provide a safe space that allows people to feel supported and respected. This is especially important for people of color, members of the LGBTQIA+ community, and other marginalized groups.

We invite you to learn more about TMA's affinity groups and how they are successful in engaging our community of patients, care partners, family, friends, healthcare providers, and industry partners!

[LEARN MORE](#)



GRUPO DE AFINIDAD PARA HISPANOHABLANTES *Join Earlier!*

 CUARTO SABADO DEL MES  
1 PM ET | 10 AM PT




THE MYOSITIS ASSOCIATION'S

## CARE PARTNER

AFFINITY GROUP

 THIRD SATURDAY OF THE MONTH

7:30 AM PT | 8:30 AM MT | 9:30 AM CT | 10:30 AM ET




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 TODAY](#)

[REGISTER TODAY](#)

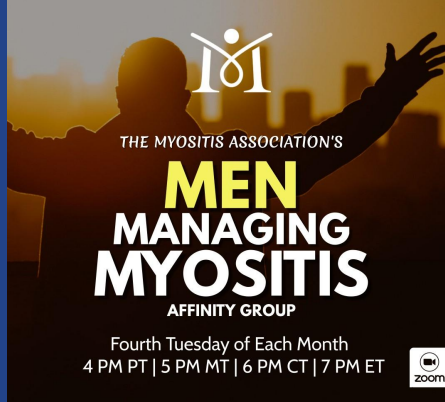
[REGISTER TODAY](#)



**TMA MEN OF COLOR  
AFFINITY GROUP MEETING**

**Monday, February 12, 2024 | 6:30 PM ET**  
Engage with Others | Share Your Story | Gather Information

**REGISTER TODAY**



**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 TODAY**



**THE MYOSITIS ASSOCIATION  
MILITARY VETERANS  
WITH MYOSITIS  
AFFINITY GROUP**

**SECOND SATURDAY OF  
THE MONTH**  
9 AM PT | 10 AM MT | 11 AM CT | 12 PM ET

**REGISTER TODAY**



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

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

**REGISTER TODAY**



**THE MYOSITIS ASSOCIATION'S  
Women of Color  
Affinity Group**

FIRST THURSDAY OF THE MONTH  
6:30 PM ET | 3:30 PM PT

**REGISTER TODAY**



**WOMEN WITH IBM  
Affinity Group**

**THIRD TUESDAY OF THE MONTH**

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

**REGISTER TODAY**



Connect with us!



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