



# MYONews

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February 2024 | Issue Two

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During Black History Month, we reflect on the struggles and triumphs of the Black community throughout history, highlighting the achievements of individuals who have made important contributions in various fields, including civil rights, science, literature, arts, and more.

At TMA we honor the significant impacts made by our TMA Women of Color Affinity Group, which celebrates its 5th anniversary this year! We will have more great information about this active and engaged TMA affinity group throughout the year, including some amazing new initiatives. So stay tuned!

*“The TMA Women of Color Affinity Group means I’m not alone! When I was first diagnosed 20 years ago, I was told that this disease affected an older Caucasian population. Every appointment I stood out and felt isolated. Even at my local myositis support group, I felt as if I wasn’t supposed to be there. But this community of women who look like me and battle the same problems as me made me feel seen and no longer isolated. They are so encouraging and supportive!” - Therese Bandy*

[Join TMA](#) for invitations to meetings and events for this and all Affinity Groups.

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# Welcome



## TO THE BOARD OF DIRECTORS

Chip Galloway  
Jane Myles  
Meriel Parker  
Mustafa Shameem

*We are excited to have you on the team!*

## TMA has some new faces on the Board of Directors

Each January, TMA's Board of Directors brings in new members and reconfigures its leadership to add fresh energy and ideas to the organization's governing body.

This year, we're thrilled to welcome new members Chip Galloway, Jane Myers, Meriel Parker, and Mustafa Shameen. We are fortunate to have such talented, professional, and passionate people steering our course into the future!

And speaking of talent, we're also grateful to those who are stepping into new leadership roles on the Board: Laurie Boyer as chair, Frank Lipiecki as secretary, and Rich DeAugustinis as treasurer.

[Take a peek behind the scenes at TMA](#). And be sure to read the Spring issue of the Outlook magazine, arriving in digital format in March, to learn more about the devoted members of the myositis community who volunteer their time to help us meet our mission to improve the lives of those who live with myositis, fund innovative research, and increase myositis awareness and advocacy.

**This afternoon TMA is hosting a Meet and Greet with TMA Leadership webinar** where you can find out so much more about Laurie and Paula and their vision for TMA. Keep reading to find all the details!

### Meet and greet with new TMA leadership

February 1, 2024, 4 PM ET | 1 PM PT

Bring your questions to this live, virtual meet and greet with the new TMA leadership. Get to know more about our new board chair and executive director while they also discuss the vision for TMA's future.

**REGISTER TODAY**





TMA's 2023 Annual Patient Conference brought together the myositis community for an amazing experience of learning and sharing! If you missed last year's conference or you just can't wait to do it again, here's the scoop you've been waiting for:

**TMA's 2024 International Annual Patient Conference will take place on September 6-8, 2024 at the Hilton Baltimore Inner Harbor!**

**Registration opens in early April**



## **TMA webinar: The why and how of legislative advocacy**

**February 8, 2024, at 6 PM ET / 3 PM PT**

Legislators may not always have a firsthand understanding of the challenges and needs of patients. Patient advocates can provide a valuable perspective, sharing real-life experiences to help lawmakers make more informed decisions.

Overall, patient advocacy in the legislature plays a crucial role in ensuring that the healthcare system is responsive to the needs of individuals, promotes equity, and addresses the diverse challenges faced by patients.

Join us on February 8 at 6 pm ET for this TMA Empowerment Clinic to learn about this vital process and how you can get involved. We will speak with Shannon von Felden of EveryLife Foundation to prepare us for Rare Disease Week.

[REGISTER HERE](#)

[SUBMIT A QUESTION](#)



## New TMA Men of Color Affinity Group

February 12, 2024, at 6 PM ET / 3 PM PT

TMA is excited to announce our newest virtual offering: TMA Men of Color Affinity Group. Thanks to the initiative of TMA's Women of Color Affinity Group in getting this off the ground, **this new group will launch its first meeting during Black History Month on Monday, February 12 at 6:30 pm ET.**

The group will meet quarterly as a way for men of color who are living with myositis to connect, share their stories, and learn more about myositis and how they can navigate the challenges of chronic disease.

[REGISTER HERE](#)

A promotional graphic for the 'Ask the Doc Series' featuring Dr. Rohit Aggarwal. It has a green geometric background. On the left, the TMA logo is at the top, followed by 'THE MYOSITIS ASSOCIATION'S' and 'ASK THE DOC SERIES' in large white letters. On the right is a circular portrait of Dr. Rohit Aggarwal, a man with glasses and a suit. Below the portrait, the text 'Encore Webinar!' is written in a pink script font. At the bottom, a dark blue banner contains the text 'DR. ROHIT AGGARWAL, MD, MS', 'MONDAY, FEBRUARY 26, 2024', and '6 PM ET | 3 PM PT'. A small video camera icon is in the bottom left corner.

## Ask The Doc with Dr. Rohit Aggarwal

Wednesday, February 26, 2024, 6 PM ET | 3 PM PT

Last month our Ask the Doc with Dr. Rohit Aggarwal ended with 40 questions still in the queue! Dr. Aggarwal has graciously agreed to appear in an encore webinar to provide answers to these pending questions. Join us on February 26, 2024, at 6 PM ET | 3 PM PT.

REGISTER TODAY

SUBMIT A QUESTION



### Rare Disease Day is here!

Rare Disease Day is an awareness event that takes place every year on the last day of February. This year, it's February 29—the rarest day on the calendar! The idea is to focus public attention on rare diseases like myositis as a public health concern.

You can celebrate all month long. Let [these resources](#) from the National Organization for Rare Diseases spark your imagination for how you can *Show Your Stripes*!

### Spotlight on Giving

TMA was thrilled to be the beneficiary of a My Cause My Cleats fundraising campaign through the New England Patriots. Thanks to Pats staff member Chelsi Boiardi for choosing TMA as her cause in honor of her father-in-law. And thanks to TMA cheerleaders who supported both the team and the cause, TMA came out the winner!

[Read the whole story here.](#)





## Global Conference on Myositis 2024

TMA is leading a coalition of representatives from at least ten global myositis patient organizations to focus attention on the patient's voice in myositis research at the 5<sup>th</sup> biannual Global Conference on Myositis.

While this is not a patient conference and there will be no educational sessions for patients, the meeting will be held as a hybrid, and there is a reduced registration rate (€65 = ~\$70) for patients who want to sit in on the scientific sessions and participate in the patient advocacy program.

For those who attend in Pittsburgh, be sure to stop by the lobby right outside the main conference room. Coalition members will be displaying posters highlighting our organizations' successes throughout the conference.

And in-person or virtual, don't miss these two important sessions led by the patient organizations:

- Thursday at 1:00pm ET - Meet the Patient Experts panel, featuring five patient experts sharing about their disease and answering questions from the doctors!
- Friday at 2:30pm ET - Patient-Centered Research Collaborations, a panel discussion moderated by TMA's Research and Communications Specialist Linda Kobert, RN, MSN, MFA.

[REGISTER TODAY](#)

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## Have you considered becoming a support group leader for TMA?

Training is provided and you are supported every step of the way! You can be part of a group in your area and/or join the TMA Nationwide team where you co-lead with several experienced TMA group leaders who can provide additional guidance. And you don't have to be a myositis expert to serve in this role!

*"As a support group leader, it is a unique privilege to help engage, educate, equip, and encourage those who are battling myositis. Meeting regularly to share 'who we are, where we are, and how we are' seems in the end to be more of a celebration gathering as we realize we are not alone. We are together, and we can live our best life possible under the circumstances. We are a band of warriors fighting the same battles, who together understand and empathize. We have become friends. More so, we have become family in a wonderfully unique way. " - Kent Yunker, Co-Leader, TMA Wisconsin*

**The next training session takes place virtually on March 29-30.**

If interested, please schedule a 30-minute Zoom meeting with Rachel Bromley, TMA Senior Manager of Patient Education, Support, and Advocacy.

[SCHEDULE NOW](#)

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*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!](#)



## 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 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, February 3, 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.




## FIND THE CARE YOU NEED

### MediFind



THE MYOSITIS ASSOCIATION

Finding a healthcare



## MINDING YOUR MENTAL HEALTH

## Minding Your Mental Health

Last year, the US Surgeon General, Vivek Murthy, declared the country to be in an [epidemic of loneliness and isolation](#).

Mental health challenges, such as anxiety and

practitioner who knows how to care for someone with myositis is often a challenge.

While we can't guarantee you'll find an elite physician, [TMA's Find a Doctor](#) tool can at least provide options.

We've worked with our partners at MediFind to update providers and make finding the best care more accessible. Check out our [suggestions for using the tool here.](#)



Johns Hopkins Myositis Center invites individuals diagnosed with MDA-5 dermatomyositis to take part in our study examining the microbiome.

If you were diagnosed within the past 3 years, you could be eligible!

Your involvement will deepen our understanding of dermatomyositis and potentially shape future treatments.

To see if you meet the criteria, please contact study coordinator, Zoë Hornberger, at Johns Hopkins University.

Email: [zhornbe1@jh.edu](mailto:zhornbe1@jh.edu)  
Phone: [\(410\) 550-9005](tel:(410) 550-9005)

depression, are among the many health risks caused by social isolation. This can be especially challenging for those who already have a mental health disorder or who live with a chronic condition like myositis.

That's why it pays to spend some time actively seeking connection with others on a regular basis.

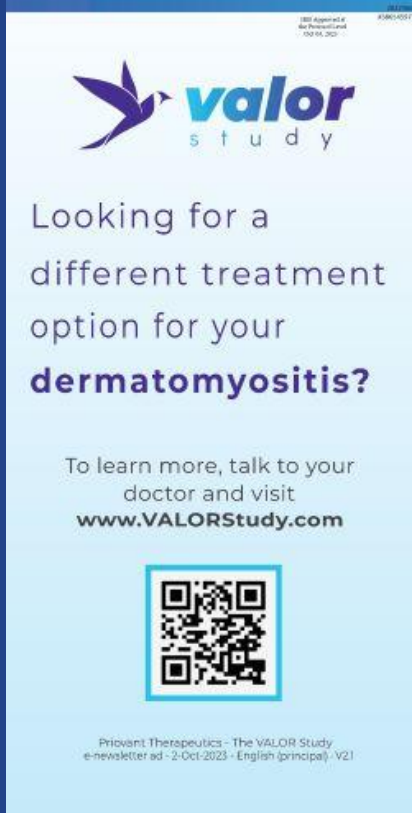
Here are some ideas:

- Participate in one or more TMA **support or affinity group meetings** every month.
- Join a local club or **Meetup group** with others who share your interests.
- Invite a friend to lunch.
- Text someone you've been thinking about just to say hello. They would love to hear from you!
- Find a spiritual community that speaks to you.
- Take a class or learn a new hobby.
- Share your exercise routine with a friend.
- And stay connected with TMA! We'd love to hear from you on this. Tell us how you avoid social isolation. We love to hear your stories!



## Community Tips

Our community members agree that staying in touch with the myositis community is one of the best ways to learn about your disease, find ways to cope with it, and share your experiences with those who understand what you're going through.



Here are their tips on how they get and stay connected.

- Attend one of TMA's many support or affinity group meetings.
- Become a TMA support or affinity group leader.
- Follow and join in the conversation on TMA's Community Forum. It helps to read that others are going through the same thing you are.
- Join a myositis Facebook group.
- Attend TMA's International Annual Patient Conference. (Early bird registration is expected to open in April.)

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**TMA's YouTube channel** has been updated with links to all the most recent myositis webinars. Check out one of our playlists to learn more about myositis and available resources. Each month's webinars are published on the first of the following month.

## 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**

**ADELANTE**

GRUPO DE AFINIDAD PARA  
HISpanOHABLANTES *Now Earlier!*

**CUARTO SABADO DEL MES**  
1 PM ET | 10 AM PT

 THE MYOSITIS ASSOCIATION

REGISTER TODAY

THE MYOSITIS ASSOCIATION'S

**CARE PARTNER**

AFFINITY GROUP

 THE MYOSITIS ASSOCIATION

**THIRD SATURDAY OF THE MONTH**  
7:30 AM PT | 8:30 AM MT | 9:30 AM CT | 10:30 AM ET

REGISTER TODAY

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



 THE MYOSITIS ASSOCIATION

**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!



The Myositis Association | 6950 Columbia Gateway Drive, Suite 370, Columbia, MD 21046

[Unsubscribe tma@myositis.org](mailto:tma@myositis.org)

[Update Profile](#) | [Constant Contact Data Notice](#)

Sent by [tma@myositis.org](mailto:tma@myositis.org) powered by



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