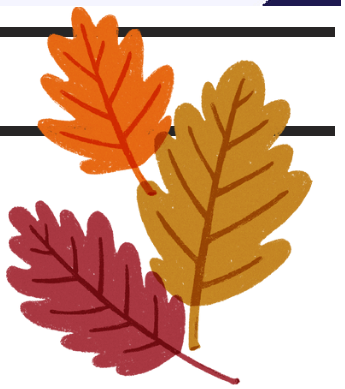
September, 2024 **Issue 13**

TMA MYOSITIS SUPPORT GROUP

Maryland, Delaware, Washington DC, and Northern Virginia
Connected by Myositis and the Chesapeake Bay!

Support Group News



HAPPY FALL!

Hello from Jenna and Bitsy!

Remember that you have more energy than your illness does!!!

Our next meeting is October 26th, 1-2:30pm EST over zoom! Link to follow

Did you attend the TMA patient conference?

Share your takeaways during our next meeting! At the start of this month was the International Annual Patient Conference and many of out members were lucky enough to attend. For our next meeting we will be hosting a session of "Hints and Hacks", where we will set aside time during our next Zoom call for attendees to talk about the activities, sessions and speakers that they most appreciated at the patient conference.

We would love to hear about what did you learn (or maybe unlearn)? What surprised you? What motivated you or made you optimistic? Did you have any difficulties? Can you offer advice for those who might attend the conference in future years?

If you would like to speak to the group about what you learned please reach out to let us know and we will reserve 3-5 minutes for you to share what you learned while at the conference.. There were too many events for any one person to attend, by sharing this information with each other, we will be able to get as much out of the conference as we can, even with it having already passed.

Let's grow together in support and understanding!

Best Regards,
Jenna and Bitsy

Dear MD, DC, DE, N. VA Myositis Group warriors,

As I sit down to write this letter, my heart is filled with a mix of emotions - sadness, gratitude, and hope. After many incredible years of serving as your support group leader, I have made the difficult decision to pass the torch to a new leader, effective October 31st.

I am deeply proud of the community we have built together, and I am honored to have had the privilege of walking alongside each of you through the ups and downs of living with Myositis. Your resilience, courage, and kindness have inspired me every step of the way.

Over the past decade and a half, we have shared laughter, tears, and countless moments of connection. Through our RUN, WALK AND ROLL we raised a great deal of money that purchased equipment for the JH Bayview Myositis Clinic and funded research through TMA. We have learned from each other's experiences, supported one another through challenging times, and celebrated every triumph. Together, we have created a safe haven where individuals and families affected by Myositis can find understanding, validation, and hope.

As I prepare to step aside, I want to assure you that this decision was not made lightly. However, I am confident that it is time for fresh leadership and new perspectives to propel our group forward. I have every faith that the next leader will build upon the foundation we have established and take our community to even greater heights.

In the coming weeks, I will ensure a smooth transition, working closely with the new leader to transfer knowledge, responsibilities, and relationships. I will also remain available to provide guidance and support as needed.

To each of you, I extend my heartfelt thanks for allowing me to be a part of your journey. Your trust, friendship, and encouragement have enriched my life in ways I never thought possible. Please join me on October 26 at our support group meeting so I can tell you in person.

As I pass the torch, I offer these final words of encouragement: continue to support one another, continue to advocate for awareness and research, and continue to live life to the fullest, despite the challenges that Myositis may bring.

With love, appreciation, and admiration,
Bitsy Anderson

This past Saturday the 21st, we celebrated National Myositis Awareness Day!

On World Myositis Day and year-round, TMA proudly partners with worldwide patient advocacy organizations to drive myositis awareness. TMA initiated “National Myositis Awareness Day” to be observed each year on September 21 as a way to drive awareness of these rare diseases among the public. A 2006 proclamation by the US House of Representatives endorsing National Myositis Awareness Day capped a years-long effort by TMA. While TMA expanded awareness efforts to the month of May as Myositis Awareness Month, September 21 continued to be observed. It is a day to applaud the resilience of the individuals and families affected by myositis in each corner of the globe.

On Saturday, October 19, 2024 at 4pm ET will be this year’s Myositis Empower Walk.

This walk will be entirely virtual, but we’re bringing the Olympic spirit to you! Get ready for a gold-medal experience with plenty of exciting ways to engage with our sponsors and connect with others with myositis. The Myositis Empower Walk was created to inspire and uplift the myositis community. With the help of supporters and community members, we will raise awareness for these invisible illnesses, so patients can receive quicker diagnosis and treatment plans by medical providers. Our goal is to make every single Myositis Warrior and their care partner(s) feel empowered, valued, and hopeful. As the signature fundraising event for MSU, the Myositis Empower Walk continues to advocate and raise funds to support their mission, financial aid programs, and medical research. While we won’t be gathering in person as in years past, we’re lighting the torch of celebration in a fun and fresh way—right in your own community. To get involved visit
https://myositisempowerwalk.org/

NATASHA D’ARCANGELO the licensed mental health counselor and director of the Lakewood Residential Treatment Center in Orlando, Florida, who spoke to us in August, left us 3 resources to aid us on the journey. Natasha, suggest 2 books and a website :

The names of the two books that were recommended are:

- The Body Keeps the Score by Bessel van der Klok
- What Happened to You by Oprah Winfrey and Bruce D. Perry

The website for a therapist consult is
www.therapyden.com