



TMA MYOSITIS SUPPORT GROUP

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

Support Group News

FYI

IT'S US AGAIN!

Greetings from
Jenna and Bitsy!



Now that the spring weather has arrived in full force, we can enjoy the outdoors again (as long as the pollen isn't too bad). We hope you are all doing well and living your best lives.

SUPPORT GROUP MEETING APRIL 15TH RECAP.

Is your treatment regime "good enough"? Sometimes you and your physician need to have the courage to see if its possible to be better than just "good enough". This past weekend our group listened to Dr. Christopher-Stine and Dr. Julie Paik talk about the current drug trials for myositis at Johns Hopkins. Wow! They had a lot to talk about, a lot of work is currently happening in the trial landscape for myositis. They mentioned 8 different trials for dermatomyositis and polymyositis, and 5 trials for inclusion body myositis . They talked a lot about different pathways, mechanisms of action, and genes. It was very interesting to hear them talk about how these trials can teach us about myositis and give hope for new treatments in the future. To hear the specifics about the recent talk, you can watch a recording of the zoom meeting. Please email jenna.radke@gmail.com for access to the recording.

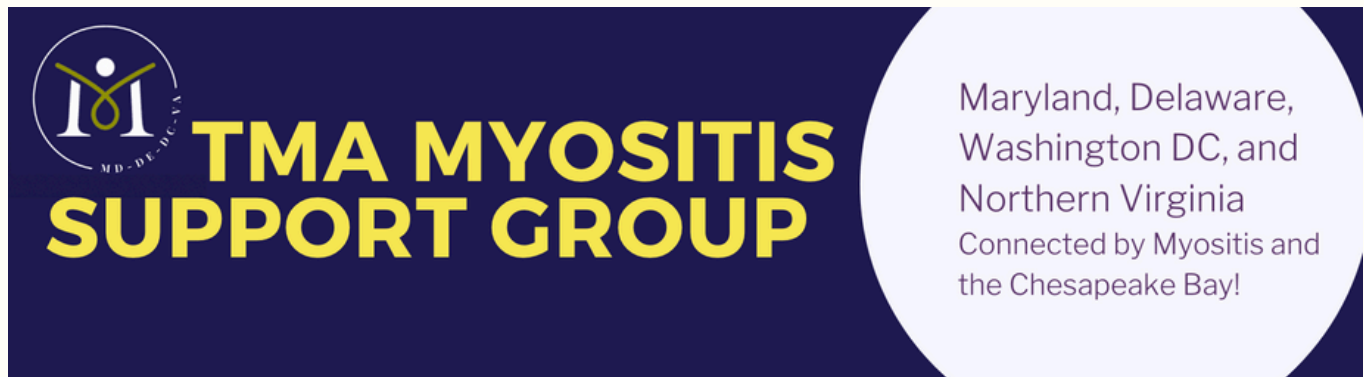
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MYOSITIS SUPPORT GROUP
- DC, MD, DE, & NO.VA
GROUP

YOU TUBE
• JERRY KING IBM'ERS

CLINICALTRIALS.GOV

**VIRTUAL SUMMIT "BEYOND
LIMITS", IS MAY 20TH**

ANNUAL 2023
INTERNATIONAL PATIENT
CONFERENCE IN SAN
DIEGO, CA
SEPTEMBER 7 TH – 10 TH
GO TO
WWW.MYOSITIS.ORG FOR
MORE INFORMATION



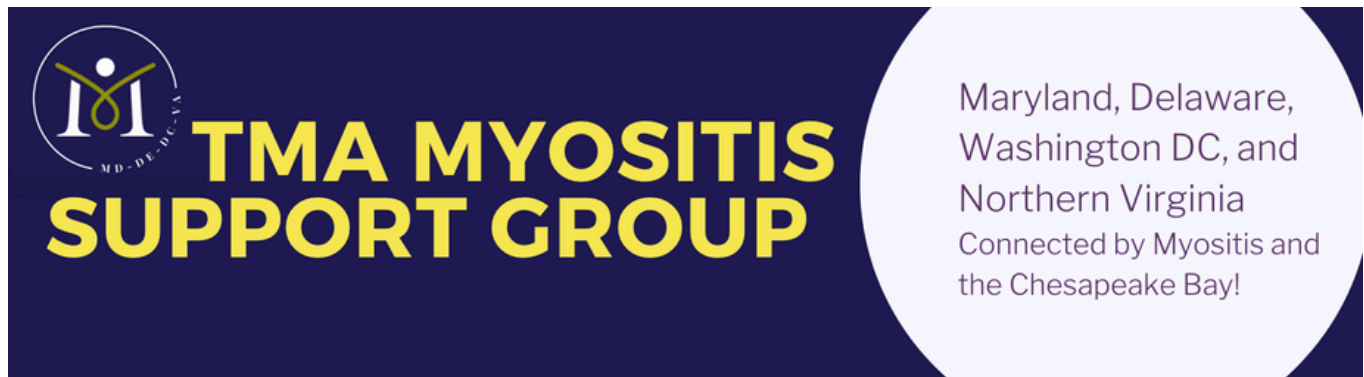
Support Group News

SUPPORT GROUP MEETING APRIL 15TH RECAP CONT.

Some interesting things about the trials that were mentioned was how in some of the trials there was a 40% placebo response. This indicates that more patients are needed for trials. There was also a discussion about how there is a trade off in medicine between efficiency and convenience for the patient. For example, IV treatments may be more efficient for patients, but they are not as easy for a patient to handle as oral medications would be. Both doctors brought up the point that clinical trials need to be a partnership between patients and physicians. Patients may have a better idea of what needs to be studied and what patients are willing to go through for treatment, while the physicians determine how to help that goal come about. The doctors also brought up how there should be more personalized medicine in myositis care. They mentioned potentially doing a study in the future on nutritional supplements based on personalized metabolic profiles of individual patients. It would certainly be interesting to see personalized treatment plans for each individual patient.

There was certainly useful information from Dr. Christopher-Stine and Dr. Paik. One thing Dr. Christopher-Stine said was that if exercise were a drug it would already be FDA approved as a treatment for myositis. She went on to say that based on data, exercise needs to be consistent and repetitive, and not weight lifting. There is data in cardiac cases that using wearable tech, such as a fitbit or apple watch, encourages patients to comply with exercise regimens. It was also mentioned that going to physical therapy at an academic center can be beneficial because they are more likely to get quantitative measurements about your progress and keep records that are easily transferable to your doctor.





Support Group News

Upcoming Meeting Information

Our next meeting will be held on June 17th at 1 pm to discuss Sharing your Success and Challenges. The entire meeting will be dedicated to discussion between myositis patients. Sharing each others highs and lows, talking about resources that can be beneficial to other patients. Our meetings are a place of support, care, and love between myositis patients. We are going to be taking the entire meeting to helping each other cope with our disease. There will be whole group discussion as well as breakout group discussion for each individual disease and a caregiver group. Come prepared to talk, listen, and further your myositis journey.

