



TMA MYOSITIS SUPPORT GROUP

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

Support Group News

FYI

HAPPY SPRING!

Greetings from
Jenna and Bitsy!



Although we have been teased a little we are looking forward to the beginning of SPRING on March 21 st. Looking around we see signs in the daffodils, cherry blossoms, forsythia and 60- degree weather.

SUPPORT GROUP MEETING FEBRUARY 18 TH RECAP.

IBM- Bob Nudelman with TMA addressed the functional rating scale will be 1/2 of the proposed IBMFRS correlation study. The other 1/2 was about finding out what equipment is presently being used most. When finished there was data as to what medical equipment is used most for the entire 40 point IBMFRS range or for ranges of point groupings. The goals of this proposed study and the resulting data is to help prevent IBMer falls and injuries by having the proper medical equipment purchased and utilized when needed or before it is needed. It will also drive and reinforce medical professionals DME recommendations. It will help prevent the purchase of the wrong, often expensive, DME medical equipment. It will help IBMers plan and prepare for their future. The goal simply is to help IBMers by mining and utilizing a correlation study data in order to reduce our falls and injuries, to support medical professional recommendations and to prevent us from squandering our resources on bad equipment purchases.

FACEBOOK

- THE WORLD IS ACCESSIBLE
 - WHEELCHAIR ACCESSIBILITY
 - ACCESSIBLE TRAVEL
- JONATHAN FLETCHER

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 FEBRUARY 18 TH RECAP CONT.

DM – Taryn Smith, PA-C , the patient evaluation manager at Priovant Therapeutics addressed the VALOR Study that still needs participants. This is a phase 3 study for adults with dermatomyositis that has both skin and muscle involvement. The medication they are testing is Brepocitinib. They are looking for 225 adults to participate in the study lasting 15 months. For more information go to patientsupport@prioantrix.com or email Taryn directly at taryn.smith@prioantrix.com.

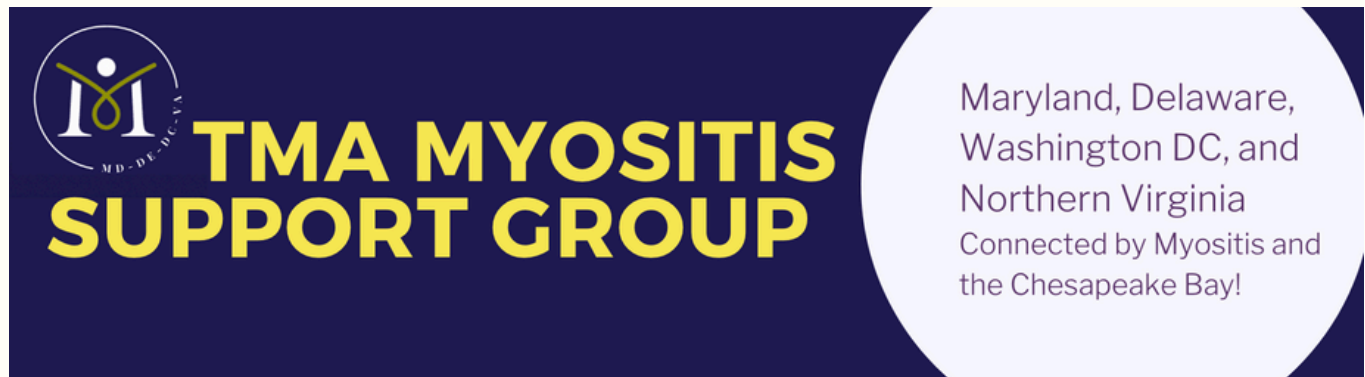
Caregivers – Terry Anderson who is retired military, a past chairman of the TMA Board of Directors, and a caregiver for a patient that has had IBM for 15 years. He shared a video and discussed asking for help.

PM - Holly Jones who is a Past TMA Board Member and the Affinity Women of Color Group Leader was set to address “Maintaining a Positive Attitude.” We did not have any Polymyositis members attend this past meeting. Holly is anxious to come back to address the whole group at a later date.

Something to look forward to hearing!

There is an old saying that you are a person that sees the glass half-full or half- empty. Being a person of faith, I choose to be thankful for the glass. I use this metaphor as my life represents the glass and the water represents moments throughout my daily life. There will be some experiences in life that will leave you feeling empty inside and there will be times when you have so much joy that you can share with others. So many times, I have been told that I have a poor quality of life. Hearing that phrase repeatedly caused me to live in fear and depression. In recent years I have decided to reclaim my life and not allow others to determine how I view it. Once I drew the line in the sand, I took back control of the narrative and determined that I am living the best quality of life for who I am today. It saddens me that the level of quality I live with today is deemed to be poor by most people. It shows me that people really aren't living their lives to the fullest capacity. So, I challenge you to ask yourself, what does poor quality of life look like for you? Asking yourself this question, will free your mind to start the development of a positive mindset.

March, 2023



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Upcoming Meeting Information

Our next meeting will be held on April 15th at 1:00 pm and will be over zoom. Dr. Lisa Christopher-Stine, the Director of Johns Hopkins Myositis Center and Dr. Julie Paik, the Director of Clinical Trials will be presenting to the whole group at this time.



Dr. Lisa Christopher-Stine: the Director of Johns Hopkins Myositis Center



Dr. Julie Paik: the Director of Clinical Trials at Johns Hopkins Myositis Center



Please Follow our new Facebook Group at
TMA Chesapeake Support Group
Thank You!!!

