

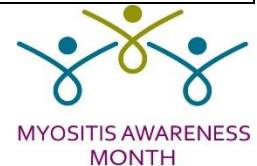
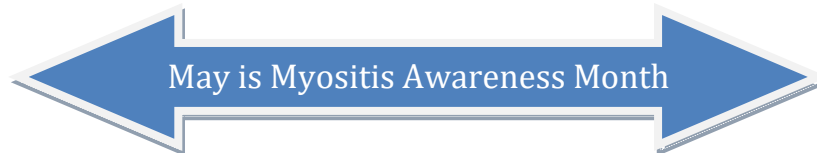
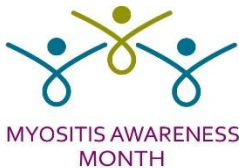
Wisconsin KIT Group – Newsletter

Group Leaders

David Rudig & Gail Kamphuis & Don Skare

May 16, 2020

May 16, 2020 Meeting on Zoom – Sponsored by TMA
22 participants logged in with 2 first time attendees
11:00 AM – 1:00 PM



Typically, Denise and I would travel from Wausau to Menomonee Falls for the meeting, but it was much quicker today with the speed of the Internet. This was our first KIT group meeting over the Internet via Zoom. All we needed was a computer, tablet, or smart phone to connect to the meeting. We had two first-time attendees today. They were Mark (IBM) and Robert (IBM).



We started the meeting by going over some of the ground rules for the meeting. Using the mute feature on the screen to mute yourself from any background noises.

Don introduced a guest from Kansas City – Fran, who had been recently diagnosed with DM. She asked to attend this meeting to find out anything she could about DM and what others are going through because of having DM.

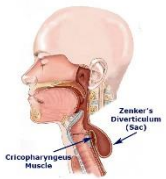
Dave asked the new attendees to introduce themselves to the group and tell us about themselves. Attendees took turns updating the group on their current situations and any updates they wanted to talk about.



Linda and Dan updated us on the Arimoclomol trial in Texas that Linda has been in since November 28, 2018. She will be done this October; however, she does not know if she has been getting the drug and will not know until all the participants have completed the trial. Once the results are in for all participants the trial participants will be given the opportunity to take Arimoclomol and not a placebo.

Dave took a show of hands how many people have fallen in the past several months and there were quite a few. Dave updated us that Milwaukee is still in lockdown due to the Covid19 virus even after the supreme court of Wisconsin struck down our governor's "safer at home mandate".

In some areas of our state several taverns re-opened within minutes following the court's decision. The guidelines concerning social distancing do not seem to be followed. There is much concern over a resurgence of the Covid19 virus among our group due to our compromised immune systems.



Marv updated us about a throat surgery he mentioned at our last meeting. He had surgery for Zenker's Diverticulum and said that his choking and swallowing issues have been resolved and can eat just about anything now! Marlene said he has gained weight because of being able to swallow better. Someone asked if the throat surgery was outpatient? Marv said he was in overnight and was discharged the following day.



Gene talked about his recent purchase of the Alinker walking bicycle, it weighs 26 pounds and fold down to fit in the trunk of your vehicle. He said the seat wasn't all that comfortable, but it is nice to get on and walk for exercise. The web link is: <https://www.thealinker.com/products/the-alinker-r-volution>



Robert spoke next about a drafting chair that raises up and has arms on it. Makes it easier to get on and off due to the elevated seat height. Available at most office supply stores such as officemax/office depot and staples. Sudz sent me a link to amazon for wheel stays to keep his chair from moving around when getting onto or off the chair. https://www.amazon.com/gp/product/B07215FC8N/ref=ppx_yo_dt_b_asin_title_o06_s00?ie=UTF8&psc=1



There was discussion about how many of us are in a powerchair or a scooter. Several attendees raised their hand. Someone asked if their insurance picked up any of the costs for their mobility devices or did, they purchase them outright? Nobody answered that they received any help from insurance. I do believe if you need one and a doctor prescribes one for you, insurance will pick up some or all the cost. The device must be medically necessary for mobility around the "inside" of your house. Make sure you get the right specifications for the chair you need now and in the future. Specifications can be found on TMA's website for people with IBM. Linda spoke about her scooter and how nice it was that it folds up and stows easily.

Heidi, Jean, and Fran talked back and forth about their lives coping with DM. Their exchange was beneficial for all of us to hear because we seldom hear about DM patients' experiences with Myositis.

Don talked about the **Myositis Tracker** that is available on the TMA website and can be downloaded and saved on your computer for future use. Don attended a Zoom meeting regarding the tracker. During the meeting, the doctor said all myositis patients should fill one out as they notice changes and bring it to their doctor's appointments so the doctors can track any changes in your health. https://37fa343y5czt13hd4izqghj1-wpengine.netdna-ssl.com/wp-content/uploads/2020/05/MyMyositisTracker_FINAL.pdf

Marv talked about fantasy football and that he was not going to be doing it this year. He said he would help someone else get it up and running. If anyone is interested, please email Marv. He still has his tutorials that he would email to anyone interested in organizing the fantasy football leagues. Last year Marv raised over \$4,000 for TMA.

Jim sent me a link to a video from the Myositis Support and Understanding group about exercise and it may be of use for your exercise routine. I encourage you to give it a look.

<https://www.youtube.com/watch?v=XJDfs-zUALw&feature=youtu.be>

If you have not joined The Myositis Association (TMA) yet, please think about it as they do not send out emails to anyone that is not a member. How could they if they do not know your email address? Go to the website at: <https://www.myositis.org/> at the top of the page select Join TMA and fill out the form there. That is all you must do to join, there are no fees, but you have support and resources at your fingertips.

The next meeting has been set. It will be July 25, 2020 by Zoom meeting on your PC/Devices at 11:00AM – 1:00PM. Don Skare will send an email link to all of you for this meeting. We hope that our October 24, 2020 meeting will be back at Froedtert Memorial Hospital in Menomonee Falls, WI

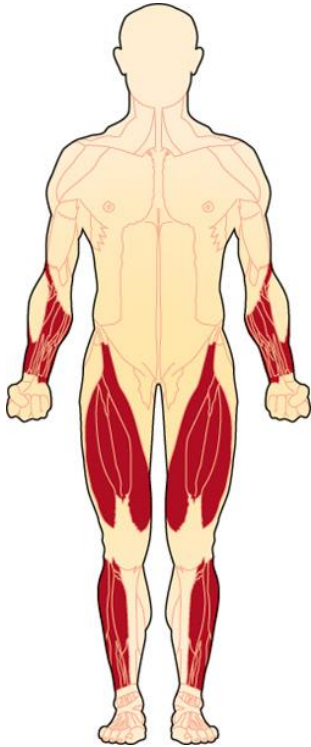
Submitted By: Don Skare

CORPORATE SUPPORTERS OF TMA



Muscles Affected by The Different Types of Myositis

IBM



Inclusion body myositis (IBM) is one of the most common disabling inflammatory myopathies among patients older than age 50. Based on two small studies conducted in the '80s and '90s, 1 to nearly 8 annual incidences of IBM are expected in every 1 million Americans.

Another word for inflammatory myopathy is myositis. The “myo” root means muscle, and the “itis” root means inflammation; thus, a myositis is an inflammatory muscle disease.

IBM is classified along with polymyositis, dermatomyositis, and autoimmune necrotizing myopathy as one of the idiopathic inflammatory myopathies (a group of disorders characterized by inflammation of the skeletal muscle). Inflammatory cells invade the muscle tissue and concentrate between the muscle fibers. A biopsy, taken from a patient diagnosed with IBM, presents multiple inclusion bodies that contain cellular material of dead tissue. IBM is named for the clumps of discarded cellular material — the “bodies” — that collect in the muscle tissues. Immune cells concentrate around these bodies.

There are some genetic forms of IBM in which, for the most part, inflammation is not a major part of the picture. For this reason, these forms are often called *inclusion-body myopathy* (muscle disorder), leaving out the “itis” in the disease name to reflect the relative lack of inflammation.

For More Information See - <https://www.myositis.org/>

What is polymyositis (PM)?



Polymyositis is one of the inflammatory myopathies, a group of muscle diseases that involves inflammation of the muscles or associated tissues, such as the blood vessels that supply the muscles. A myopathy is a muscle disease, and inflammation is response to cell damage.

Another word for inflammatory myopathy is myositis. The *myo* root means muscle, and the *itis* root means inflammation; so a myositis is an inflammatory muscle disease.



Explore Myositis

DERMATOMYOSITIS

INFLAMMATORY MYOPATHY

Dermatomyositis: rare, chronic, autoimmune disease which may present with a violet-colored, heliotrope rash followed by progressive muscle weakness, usually in the muscles closest to the body's core and those involved with movement. Symptoms may include skin rashes, muscle weakness, muscle pain, fatigue, lung disease, trouble swallowing, and, in some cases, may necessitate the need for assistive devices. The exact cause of DM is unknown and there is no cure..

UNDERSTANDINGMYOSITIS.ORG

