

October 26, 2019

October 26, 2019 Meeting at Community Memorial Hospital, Menomonee Falls

32 Attendees with 4 first timers

11:30 AM – 3:00 PM

Denise and I left Wausau this morning under a beautiful sunny sky and by the time we hit Stevens Point it was mostly cloudy the rest of the day. That didn't dampen our spirits though because we would soon be with a group of great people sharing stories of the past 3 months. Gail and Orville Kamphuis greeted everyone at the door, collected the fee for lunch and gave every couple a door prize ticket. We had 4 first-time attendees. They were: Kent Yunker (IBM), Barb (PM-IBM) and Dennis Heart and their daughter Amy.



Dave started our meeting at 11:50 AM. He reminded everyone that those who wore Packer gear that they received \$1 off their meal today. Dave took a survey of the attendees of how many had fallen in the last 3 – 6 – 9 months. Most people experienced a fall in that time frame. Dave asked if anyone had any ideas for future meetings. He read off a list of possible topics or speakers. They were: EMT's, Medicare – Medicaid expert, Contractor/Architect, Travel Agents specializing with mobility issues, Aqua Therapist, Medical Equipment Providers, Real Estate Agents, Assisted Care Facility Reps, Family Counselors, VA Reps, Yoga and Meditation Instructors, Art or Music Therapists. A Rheumatologist or Neurologist on the latest trends in treatments and research. A Nutritionist on healthy eating choices, especially for those taking certain medications. Speech Therapist on dysphasia and how to cope with swallowing troubles. Physical or Occupational Therapist on aids and strategies to help with daily activities. Psychologist or Therapist on coping with the disease as a patient or care partner. If you know of one you would like to hear from please let Dave or Gail know.

Dave mentioned that the lunch price for next year is increasing to \$12 per person. If this is an issue talk with Dave. Gail and Dave mentioned that there are some privacy issues that we may need to take as communicated from the TMA headquarters. Dave mentioned that he has read the policy updates and feels we are within their guidelines. The only difference in our meetings in the future will be that we will need to sign in when we attend a support group meeting.

Dave asked the new members of the group to introduce themselves. Barb Heart stated that she was first diagnosed in 1994 with Polymyositis and recently doing a muscle biopsy to confirm a diagnosis for IBM. She is from Chili, Wisconsin and is retired now. Kent Yunker said he was diagnosed with IBM in 2018 and lives in Lake Geneva, Wisconsin. Both were happy for this support group.

Dave released everyone for a buffet style soup and sandwich lunch.



Linda Tooley gave an update on her taking part in the Arimoclomol Clinical Trial in Houston, Texas. She has been part of this trial for the past 11 months in which she has made 7 trips to Houston, Texas. The trial goes for a total of 22 months. She is on a 200mg capsule taking 6 caps per/day. She is not sure if she is receiving any of the Arimoclomol or a placebo. She stated that at the end of her trial period she will be eligible to be given a full dose of Arimoclomol to see if it will help her.

She gave her husband a lot of credit for helping her take advantage of this trial and for being by her side through all of this.

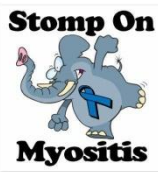
Linda has some advice for the rest of us: to get involved, exercise in a warm pool environment or just exercise, build up the muscles you have, don't look too far ahead into your future, enjoy the things you can do now, and don't give up!

Linda suggested that you go to the <https://clinicaltrials.gov/> to look for any trials that you are interested in or taking part in.

She also wanted to thank Sudz for all his advice and help in getting into the Arimoclomol trial and for helping them with what to do and where to stay in Houston, Texas as Sudz was previously going there when he was taking part in the clinical trial for BYM338.

Others asked questions about the Clinical Trial. Someone wanted to know if any travel or lodging was paid for by the trial. Linda said they are reimbursed \$275 per trip and \$10 per phone call. Sudz spoke about an "Angels Group" that would pick you up at the airport and deliver you to your hotel.

Annual Patient Conference



Gail spoke about the Annual Patient Conference held in Minneapolis, MN. She said if you get a chance to go to a future one you really should. This year there were 500 attendees and 23 professionals.

Disphasia, there are trials starting to come on. IVIG will sometimes help Disphasia.

Prednisone – They are looking into separating the good part of prednisone and taking out the bad part so the drug could be better tolerated. Target is looking into making adaptive clothing for adults and to be available in their stores in the future. Videos from the patient conference should be available online soon if not already at: <https://www.myositis.org/>

TMA's website shows there are 150 members registered for the state of Wisconsin. Not all patients on this site have identified their type of myositis.

Gail said the conference suggested some books to read, "Sick and Tired of Feeling Sick and Tired: Living with Invisible Illness" was co-authored by Mary E Siegel and Paul J. Donoghue (Mary Siegel was one of the main speakers at the conference). Another book mentioned at the conference was "Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration" By Norman Cousins.

A quote was shared from Frank Bruni: "You cannot spend your life preparing for future losses."

Barbara Heart and Kent Yunker both attended the Annual Patient Conference. They said it was excellent for them to see that there are many others with the same disease and to hear their stories of what they were doing to make it through the day.

Dave Rudig brought up some details about seniors in the state of Wisconsin. In 2010 there were 700,000 over the age of 65 and now there are over 950,000 seniors. Statistics show that one out of 4,800 adults over 65 have some form of myositis. Most doctors have never heard of Myositis let alone even had a patient diagnosed with it. They don't know if there is a cure, Dermatomyositis can be controlled but PM & IBM cannot at this time.

Marv Lauwasser talked about the status of the fantasy football league. The money raised through fantasy football was donated to TMA. To date we raised over \$4,000. Thank you Marv for organizing this fantasy football league.



Marv showed a tool he had crafted to help him close his car doors due to weakened hands. The hook is available at your local Menards or Home Depot stores. The hook assembly itself is for hanging shovels or other outside utensils on the wall. The rest of the device is plastic tubing, some reinforced cording and a mini carabiner.



Bob Fisher said he made a card that explains what myositis is and he hands them out when people ask him questions about it. Bob has IBM. There are other members that do something similar. I've included the three forms of myositis at the end of this newsletter.

Marv recently dealt with some swallowing issues and saw an ENT doctor to see what was wrong and he stated that Marv had a muscle in his throat that a surgeon could fix to help with his swallowing issue. This is known as a Zenker's diverticulum, more formally known as a hypopharyngeal diverticulum, is a pouch that can form at the junction of the hypopharynx (lower part of the throat) and the esophagus, an area known as Killian's Triangle.



Mark Schneider mentioned that if you are a US veteran you need to register with the Veteran Administration. The Myositis Association website has some information for you in doing that at this web link: <https://www.myositis.org/patient-support/resources-veterans/> .

From there you could click on a link to go to the VA site at: <https://www.va.gov/> . After enrollment, every vet seeking VA help should make contact with a Veteran's Service Organization at: <https://www.va.gov/vso/> They are there to assist the vet in navigating through the VA, and there is no need to be a member and no charge for the service. VSO's are especially helpful in negotiating individual state's benefits that are separate from the VA's benefits.

The VA encourages veterans to take a few minutes to examine their eligibility for VA health care benefits by using its newly developed Health Benefits Explorer. The Explorer is designed to provide specific health care benefit information and possible out-of-pocket costs with just a few questions.

Your County administration offices should have a Veterans resources officer to help you through this process also. Give the County offices a call to find out your VA representative name and phone number. As a veteran myself with IBM, you are considered catastrophically disabled and qualify for services through the VA.

Door prizes for today were donated by June and Dave Rudig. Barb Heart brought a door prize as well. Door prize winners today were: Roger Klukas, Ken Thomas, Linda Tooley, Barb Heart, Mark Schneider, Mike Mckenzie, Ken Sankey. Thank you, Dave and June Rudig and Barb Heart. Mike Mckenzie and Linda Schultz volunteered to bring door prizes to the April 25, 2020 meeting

Dave announced the dates for next year's meetings. They are April 25, 2020, July 25, 2020, October 24, 2020. All at the Menomonee Falls Froedtert Memorial Hospital.



Happy Thanksgiving



If you haven't been to a meeting yet, we meet in Menomonee Falls at the Froedtert Memorial Hospital. The picture to the left is the sign that you'll see coming in on Town Hall Road. Drive around the building to the right and park by the Women's Center Entrance "D". Plenty of parking is available. It's a nice place to have a meeting.

Our next meeting is set for Saturday, April 25, 2020. Meetings will be at the Community Memorial Hospital at W180 N8085 Town Hall Road, Menomonee Falls, Wisconsin 53051.

Submitted By: Don Skare



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New Members at Today's Meeting



Dennis and Barb (IBM) Heart



Kent Yunker (IBM)

Other Pictures from the Day

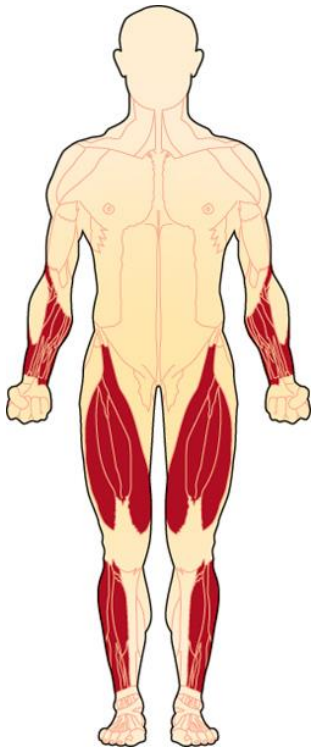


CORPORATE SUPPORTERS OF TMA



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

