

July 27, 2019

July 27, 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 cloudy sky and by the time we hit Oshkosh the sun was shining, and it was looking to be a beautiful day. Didn't see many planes today at the air show. That seemed odd to us and the same when we drove back later in the day. All in all, it was a great day for a drive. 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: Maria Schmelzer (DM), Arthur Rapkin (IBM) with Kitty Streidner and caregiver Christine Cronk.



Dave started our meeting at 11:50 AM by going over the agenda for the day. He had a couple of announcements such as: *The Annual Patient Conference September 5th – 8th in Minneapolis, MN. Three of our members plan on attending. *Our third and final meeting is scheduled for Saturday, October 26, 2019. If you wear Packer apparel, you'll get \$1 off your lunch. *Fantasy Football. He and Marv Lauwasser to give a brief overview. Marv has organized 2 to 3 leagues p/yr. over the past 3 years and has raised over \$4,000 each year. Your entrance fee of \$50 p/team will be donated to The Myositis Association. If interested email Marv soon at vin17246@aol.com. This has been a way for our KIT Group to raise funds for TMA. After the announcements and introduction of the new members we broke for lunch.

Near the end of lunch Dave introduced Jim Daehling and Doug S. from A & J Mobility.



Jim is a Mobility Consultant with A & J Mobility in Richfield, WI. If you are looking to get a vehicle equipped with driving aids or you're interested in buying a new/used minivan, it's a good idea to stop by A & J Mobility or similar vendor to see what would be needed for you. They can show you products that make it easier to get in and out of your vehicles or show you new or used vehicles that will accommodate your disability.

Jim spoke about getting together with a driver-evaluator prior to purchasing any hand controls for your vehicle. There are restrictions to just getting hand controls and then going out and driving with your hand controls without an endorsement on your driver's license. Much like having an eyeglasses restriction on your license. For specifics on this contact your vehicle dealer and have them help you with those questions and/or contact the DMV to see what the law is and whether you will have to take another exam or driving test. Wisconsin does require an endorsement or restriction if you must use the "hand controls".

That means your caregiver as well. If your vehicle is set up to only drive with hand controls, then the caregiver needs the endorsement on their license also. If you have it so you can switch to use either hand controls or drive as a normal vehicle configuration, then your caregiver doesn't need the endorsement if driving only with the normal vehicle configuration. Ken asked if a spinner knob was okay to put on the steering wheel? Jim said he heard it was a \$179 fine because you are modifying your vehicle's steering.

There is a wide range of products out there to help disabled people be more mobile. They range from:

- Lowered floor accessible minivans and full-size vans, Dodge, Chrysler, Toyota, Honda, GM, Ford
- 8-way transfer seats
- Turning automotive seating
- Fully automatic wheelchair lifts
- Electronic mobility controls
- EZ-Lock wheelchair securement
- Power side door openers
- Hand controls, Left-foot gas pedal
- Scooter lifts, trailer hitch mounted or inside mounted lift or swivel boom lifts



For more information about this subject, here are a few vendor websites for you to look up.

<https://www.aandjmobility.com/> or <https://www.rollxvans.com/> There are others out there also, but you would need to Google them. Jim suggests purchasing the extended warranty for both the vehicle and an extended service agreement on the conversion.

Jim finished with his presentation inside and invited everyone outside to look at a couple of accessible vans they brought with them. Several members went outside to look at the vans to see what options are available. People went inside the vans, sat in them, operated the ramp, and looked at literature for different options.

Door prizes for today were donated by Denise and Don Skare. Door prize winners today were: Orville Kamphuis, Heidi Burns, Susan Schneider, Judy Kagel, Bob Fisher, and Arthur Rapkin. Thank you, Denise Skare. Nobody volunteered to bring door prizes to the October 26, 2019 meeting.



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, October 26, 2019. Meetings will be at the Community Memorial Hospital at W180 N8085 Town Hall Road, Menomonee Falls, Wisconsin 53051.

Submitted By: Don Skare



New Members at Today's Meeting



Kitty Streidner & Arthur Rapkin (IBM)



Maria Schmelzer (DM)



Christine Cronk (Caregiver)

Other Pictures from the Day



Gail & Orville Kamphuis

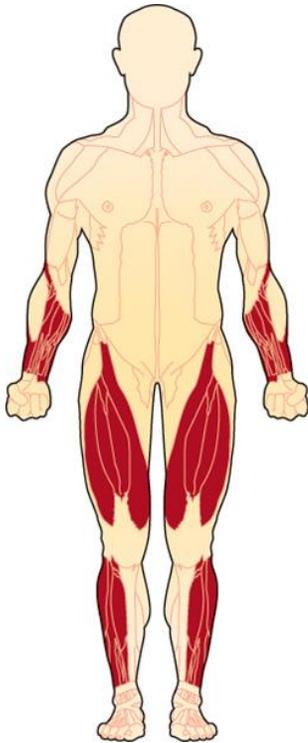


CORPORATE SUPPORTERS OF TMA



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.



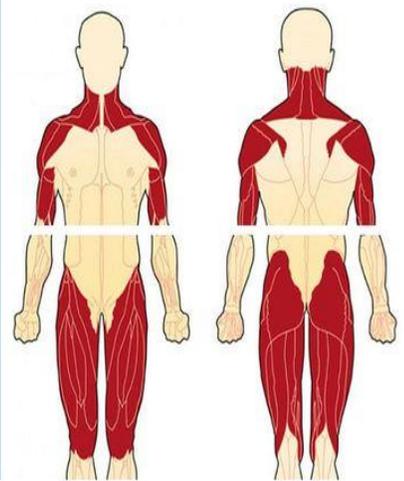
Explore Myositis

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



Information from The Myositis Association Website

Annual Patient Conference

**DoubleTree by Hilton Bloomington – Minneapolis South
September 5-8, 2019**

7800 Normandale Blvd

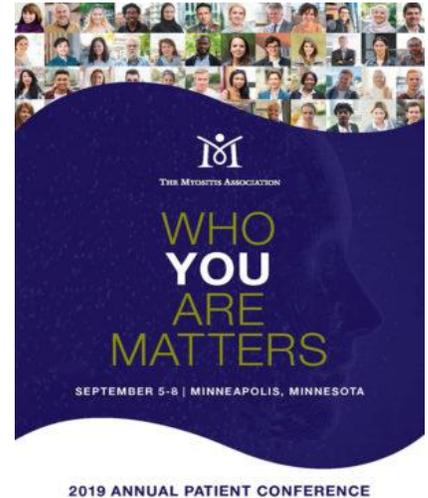
Minneapolis, MN 55439

Phone: 952-835-7800

Group code: TMA9

Reserve your hotel room [here](#)

TMA Group Rate \$112. Rate applies 9/3/19 – 9/9/19. Available until August 12, 2019.



At TMA's 2019 Annual Patient Conference in Minneapolis, Minnesota, the focus will be on addressing this diversity of needs and challenges within the myositis community.

Sessions facilitated by leading global experts in the field of myositis research, therapeutics, rehabilitation, and mental health have been expanded beyond disease-oriented sessions to provide more focused learning and network opportunities for specific interest groups, including women, younger patients, care partners, and those who are further along on the disability continuum. Practical sessions on exercise and rehab issues will also be a focus.

Conference participants can browse nearly 90 educational sessions, sample some self-care practices during Feel Good Friday night, seek answers to their own myositis questions, spend quality time with myositis friends, and much much more.

While the program has grown, we have built in some options to accommodate breaks and networking. Several popular sessions will be repeated, and evening and early morning sessions will expand the opportunities to explore topics of interest. And because so much of what you return home with comes from the conversations you have with others who live with myositis, ample time has been built into the meals and breaks, so you can sit and talk with fellow attendees about shared experiences and challenges you face. An informal wine and cheese reception will again be offered, so attendees can mingle and meet others who share their disease.

If you've never attended a TMA Annual Patient Conference, this is the year to give yourself this gift. Armed with more knowledge about your disease and how it relates specifically to you, coupled with practical advice for coping with the challenges, we hope the conference and the relationships you will develop inspire you to find new ways to move beyond the barriers this disease creates so you can bring more joy into your life. Because who you are matters!

For the agenda click on this link: <https://www.myositis.org/2019-annual-patient-conference/>