

July 28, 2018

July 28, 2018 Meeting at Community Memorial Hospital, Menomonee Falls

30 Attendees - Including

Bob Goldberg - Retiring TMA Executive Director & Mary McGowen Incoming TMA Executive Director

11:30 AM – 3:00 PM

Another beautiful day for a drive to Menomonee Falls for our second Wisconsin K.I.T. group meeting of 2018. Gail Kamphuis greeted all who attended and registered them for the meeting as well as a ticket for the door prizes to be drawn later and a name tag so we all can get to know each other better.

Dave Rudig started the meeting today by making a few announcements:



- ❖ Our two honored guests today, the retiring Executive Director of TMA (The Myositis Association) Bob Goldberg and his successor Mary McGowan who will assume Bob's duties later this year.
- ❖ The Annual Myositis Patient Conference is in Louisville, Kentucky September 5th through the 9th and is the 25th Anniversary of the Patient Conference.
- ❖ Next meeting is set for October 27th and if you wear a Green Bay Packers shirt/jersey you will get \$1 off your \$10 lunch cost (\$9).
- ❖ You no longer need to sign into TMA's website. It's open to everyone, except the Community Forum. You will need your special login and password as you did before.
- ❖ Fantasy Football is starting up again and Dave has asked for all interested to send a check to: Marv Lauwasser, 2043 Hidden Reserve Court, Mequon, WI 53092 and send him an email at vin@wi.rr.com and let him know that you are interested. If you've never played fantasy football, Marv has great tutorials for learning how to play. Last year \$4,300 was raised for TMA. Make the check payable to TMA and send to Marv.

Gail Kamphuis had a couple of announcements:

- ❖ Sheila Vander Sanden, who is a member of our group, is participating in a swallowing study through Froedtert Hospital.
- ❖ Door prizes for today were donated by Cindy & Randy Glass.
- ❖ Lunch costs are going up by \$1 next year to cover the increase in costs. In April 2019 the cost will be \$11 per person.

We broke for lunch. Lunch was provided by the Froedtert Hospital for a cost of \$10 per person. The buffet today consisted of club sandwiches (sliders), soup, mixed fruits, and an assortment of cookies along with lemonade, ice water, and coffee.



Dave introduced our speakers for the day. They were: Menomonee Falls Assistant Fire Chief James Mollet and two of his firefighter/paramedic/EMT's Andrea and Tony. James Mollet, who has been in the fire service for over 28 years, gave some statistics about their fire department which has 30 part-time and 15 full-time employees, all of whom he is very proud of. His part-time employees handle the calls for the City of Menomonee Falls. So far in 2018, they have handled 4,500 calls.

James had Andrea and Tony speak about the equipment they use on their calls. A few examples were:



A scope that allows them to see down the patient's throat when intubating them.



A Zoll Cardiac Monitor is used on site to get a good picture of what your heart is doing when they arrive on scene.



A Lucas 3 device is for performing chest compressions for patients experiencing heart failure.

Tony mentioned that some patients who are experiencing the symptoms of a stroke, may be just experiencing low glucose levels. They will then do a finger stick to check their sugar levels to eliminate that possibility.

In the Menomonee Falls area you may be sent to the nearest hospital that would be best for your symptoms instead of taking you to your choice of hospital. A life alert pendant or similar device is a good idea to have if your balance is a problem and you experience falls.

Chief Mollet mentioned a Knox Box for the exterior of your house so a firefighter or paramedic can gain access into your residence without having to cause property damage. You can find out more information on their website: <https://www.knoxbox.com/>

Several people in attendance asked many good questions of the EMT's. We were all impressed with their knowledge and experience. Menomonee Falls can feel very safe with staff like them.



Dave introduced Bob Goldberg who is TMA's Executive Director and has decided to retire later this year. Bob talked about TMA and what it does for those of us with Myositis, through education, advocacy, support, and by spending the donated dollars wisely.

Bob talked about the annual patient conference in Louisville, Kentucky and the benefits of attending it. By attending the conference you will be more aware of the disease and learn ways to talk to your doctors and obtain materials to take to your doctors.

If you are interested in being on the Board of Directors for TMA, let Bob Goldberg know by sending him an email at: Goldberg@myositis.org

Bob said 5 years ago we had only 2,500 members and today we have 8,000 members. He said there is more research being done now than ever before. TMA is willing to spend \$500,000 to fund research this year. Currently there are 16 different applications applying for the research money. They intend on narrowing that down to 5 or 6. The Board of Directors will make that recommendation.

Look into “planned giving” whether it be now each month or later when you specify funds or securities to be donated upon your death. Search “planned giving” on the TMA website.

If you’re interested in taking part in a clinical trial, go to the NIH Clinical Trials website: <https://clinicaltrials.gov/> and search for a trial you’re interested in and contact them about participating. All the information you need about each trial and how to contact them is listed in the trial information on that page.

Bob was asked if they had DVDs of the Myositis information for people who don’t have computers. He said not at this time, but they are available on YouTube:

https://www.youtube.com/results?search_query=the+myositis+association

Bob mentioned that a drug called Rapamycin is being researched now for IBM.



Bob introduced his successor Mary McGowan, the new Executive Director for TMA. She will be installed later this year when Bob retires.

Mary has served as past Chief Operating Officer and is currently the Chief Executive Officer of Women Heart, a non-profit group that promotes women’s health.

Mary served as Executive Director of the Allergy & Asthma Network, the leading nonprofit organization dedicated to eliminating suffering and death due to asthma, allergies and related conditions. She held various positions with the American Academy of Pediatrics (AAP) during her service of 18 years. Following the events of September 11, she was director of multiple pediatric terrorism disaster preparedness grants focusing on the needs of children.

Mary holds a Master’s Degree in Human Resources Development from George Washington University and a B.A. from Trinity University.

Mary has over 35 years of non-profit organization experience in healthcare. She said TMA will be a challenge for her as Myositis is a rare disease.

August 20, 2018 will be her first day on the job and is looking forward to it.

Dave had a few more comments at the closing of our meeting today:

- ❖ TMA needs funds to keep up the research and we can help by contributing money. Donations are tax deductible.
- ❖ 30,000 people diagnosed with Myositis in the United States.

- ❖ Please tell friends at Christmas or other special occasions that instead of giving you a gift, to donate a gift of money to TMA in your name and they will get the tax deduction.



Door prize winners today were: Dave Rudig, Scott Nickel, Roger Klukas, Don Skare, Bob Fisher, and Mike McKenzie. Thank you, Cindy Glass, for donating the door prizes today. Nancy Szudzik has volunteered to bring door prizes to the October 27, 2018 meeting.

Dave Rudig ended the meeting and invited everyone to stick around and socialize with each other since we have the room until 3:00pm. We all look forward to seeing everyone again in October 2018.



If you haven't been to a meeting yet, we meet in Menomonee Falls at the Froedtert Community 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 27, 2018. Meetings will be at the Community Memorial Hospital at W180 N8085 Town Hall Road, Menomonee Falls, Wisconsin 53051.

Submitted By: Don Skare

No New Members Today!

Some pictures from today's conference:



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