

David Rudig & Gail Kamphuis - Group Leaders

October 27, 2018

October 27, 2018 Meeting at Community Memorial Hospital, Menomonee Falls  
28 Attendees  
11:30 AM – 3:00 PM

It was an overcast day in Menomonee Falls for our third and last Wisconsin K.I.T. group meeting of 2018. Gail Kamphuis greeted all who attended and registered them for the meeting and gave each couple a ticket for the door prizes to be drawn later and a name tag so we all can get to know each other better. Today was wear your Green Bay Packer or Wisconsin clothing Day and get \$1 off your lunch.



Dave Rudig welcomed everyone to today's support group meeting. Dave announced next year's meeting dates. They are: April 27, 2019 – July 27, 2019 – October 26, 2019, and that lunch costs will be increasing to \$11 per person next year.

Dave asked the group if anyone wanted to update their picture in our directory or if they are not getting the newsletters to see Don Skare.

Dave has asked our sponsors to attend our KIT group meetings. Dave will try to get Dr. Collins from Froedtert Hospital to attend next year.

Dave asked how many of the members present attended the Annual Patient Conference in Louisville, Kentucky last month and asked them what they liked most.

- Scott Nickle said it was very informative.
- Gail and Orville Kamphuis liked connecting with other patients over the breakfast breaks and the evening wine and cheese tasting get-togethers. Gail looked at what the other KIT groups were doing that attended the conference and found out we are among the few that have organized meetings with a newsletter for its members. Gail took a picture board to the patient conference this year showing pictures of our meetings and a sample of our newsletters for other groups to see.
- Louise Sutherland liked hearing from the medical professionals about breakthroughs in technology and treatments. It's nice being around others that can relate to your illness because they are going through it also.

Gail mentioned that next year's Patient Conference will be held in Minneapolis, Minnesota.

Gail updated the group on the status of Bob Fisher who several months back was involved in a serious car accident and sustained severe injuries. He was in the hospital a few weeks and then rehab for a few months. Bob has finally made it back home to finish recovering.

Marv talked about going back to the TMA website to look at patient conference breakout sessions. There are video presentations being added from the Patient Conference in Louisville, Kentucky.

Sudz spoke about the new patient trials for IBM taking place around the country and have been filling up fast. The closest ones to us were in Kansas City, KS that filled up before most of us even knew they were accepting participants. The other was in Columbus, OH which was just opened and filled very quickly as well. There are other locations but are a further distance away. You can look up which trials are accepting participants and their locations. IBM Arimoclolembol trials at: Irvine CA, Aurora CO, Boston MA, Rochester NY, Houston TX, Salt Lake City UT, London United Kingdom.

<https://clinicaltrials.gov/ct2/show/NCT02753530?term=ibm+kansas>

<https://clinicaltrials.gov/>

Dave mentioned we always need guest speakers to talk to our group. If anyone has any ideas for a guest speaker please let Dave or Gail know so they can work with you to get them in front of our group. Dave said, “that we haven’t had a physical therapist talk to us lately.”

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Don Skare introduced our guest speaker for the day, Sarah Arndt. Don & Denise Skare and Dan & Linda Tooley got to know Sarah as a support group programmer from the Green Bay MDA office.

She facilitated their support group meetings in Wausau. She had been promoted and left the Green Bay area to assume her new duties in Chicago. Her duties allowed her to return to Wisconsin which was always her home. Her background and degree are in social work. She now resides in West Bend.

The MDA’s Mission Statement is “We are committed to transforming the lives of people affected by muscular dystrophy, ALS and related neuromuscular diseases”. MDA is an Umbrella Organization which encompasses 43+ diseases.

### ***Innovations in Science are:***

- **RESEARCH:** MDA is the largest source of funding for neuromuscular disease research outside the federal government and has invested more than \$1 billion since its inception in 1950.
- **THERAPIES:** Research supported by MDA is directly linked to life-changing therapies across multiple neuromuscular diseases.
- **TECHNOLOGY:** MOVIR is the first and only data hub that aggregates clinical, genetic and patient reported data for multiple neuromuscular diseases to improve health outcomes and accelerate drug development.

### ***Innovations in Care are:***

- **CARE CENTERS:** We support the largest network of multidisciplinary clinics, providing best-in-class care at more than 150 of the nation’s top medical institutions.
- **RESOURCES:** Our Resource Center serves the community with one-on-one specialized support and we offer educational conferences, events, and materials for families and healthcare providers
- **RECREATIONAL PROGRAMS:** Each year thousands of children and young adults learn vital life skills and gain independence at summer camp and through recreational programs, at no cost to families

**MDA National Resource Center** - Their Resource Center connects families and individuals with trained resource specialists, many of whom are living with neuromuscular disease, to provide one-on-one, personalized counseling and answers about disease information, support services, community resources and more. 1-833-ASK-MDA1 or [resourcecenter@mdausa.org](mailto:resourcecenter@mdausa.org)

MDA has a clinical trial finder tool and can be found by clicking on this link or typing it in your browser. <https://www.mda.org/research/clinical-trials> Once there, you can scroll down to type in your disease and search for your desired trial.

Sarah asked for any questions from the group:

➤ ***Are any of us on a registry?***

Sarah said we should ask our doctors if we are on any registry for tracking data.

➤ ***Do you have a list of Physicians on the MDA Site, especially for the state of Wisconsin?***

Sarah said to look at the MDA.org site <https://www.mda.org/care/mda-resource-center> and type in your zip code to search for a care center near you.

Sarah asked if anyone was currently receiving the MDA's QUEST magazine? You can contact the MDA resource center office at 1-833-ASK MDA1 OR 1-833-275-6321 and register to be a client. They will send you a packet of information about the MDA and what services they offer as well as the QUEST magazine. Myositis is a disease that is covered under the MDA umbrella.

Marv Lauwasser updated the group on the Fantasy Football League this year. He raised \$4,000 for TMA from the 4 leagues that he organized.

Door prizes for today were donated by Nancy and Jim Szudzik. Door prize winners today were: June Rudig, Don Skare, Mike Mckenzie, Jan Nelson, Janet Wetzel, Diane Moe, Sheila Vander Sanden and Louise Sutherland. Thank you, Nancy Szudzik. Denise Skare has volunteered to bring door prizes to the April 27, 2019 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 April 2019.



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, April 27, 2019. Meetings will be at the Community Memorial Hospital at W180 N8085 Town Hall Road, Menomonee Falls, Wisconsin 53051.

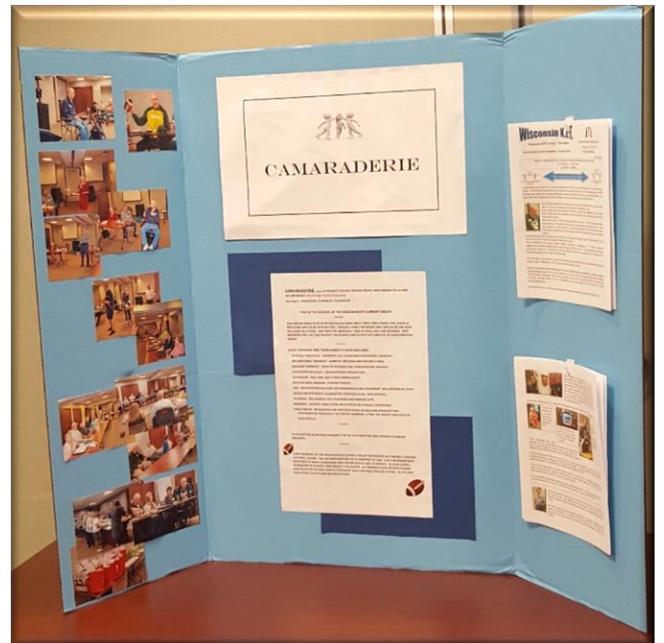
***Submitted By: Don Skare***

# No New Members Today!

Some pictures from today's conference:



Guest Speaker Sarah Arndt from MDA



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