



February 22, 2018



THE MYOSITIS ASSOCIATION

Northwest FL KIT February Newsletter

The February meeting of NWF Panhandle KIT was held on the 22nd in Niceville at a member's home. We had a small group of 4 who shared Olive Garden salad with chopped ham, chicken and assorted veggies as optional additions. Our newest prospective member had a doctor appointment and was not able to attend but his wife attended for him. She was excited to learn about TMA and was impressed with the video of the Medical Board presentation from the 2017 San Diego conference which we all watched together.

Welcome Eyvin & Connie!

Eyvin, a retired Doctor of Radiology, was living a very active life when he began to experience various signs of weakness in his trunk muscles and doing things with his arms stretched in front of him became very difficult. Like so many other Myositis patients, he saw several doctors in different clinics before being diagnosed with Myositis and has yet to learn the specific type he has. Ironically, he actually self-diagnosed after reading an article in a medical journal written by Dr. Andy Mammen, who we all recognize as a member of the TMA Medical board and frequent presenter at the annual Conferences.

Meeting agenda:

The TMA Medical Board presentation from the 2017 conference was presented on a "smart" TV making it possible for us to watch together on a big screen, pause and discuss points as desired. (This may be "old hat" to some of you more "technologically" inclined but it is still fascinating to me.) We spent our time over lunch talking about our individual experiences with Myositis and viewing the video. Connie seemed impressed with the video and took with her information about

We welcomed Connie Rasmussen, attending for her husband, Eyvin. They will attend future meetings together.

Mark your calendar for our next meeting: tentatively, Thursday May 24, 2018, 11:30 a.m. in Pensacola. More info to follow.

the 2018 Conference in Louisville in September so that she and Eyvin can make plans to attend. She was also given a copy of the last Outlook and some newsletters from previous meetings to review what we and TMA have been doing the last few months. Most importantly she took with her the contact information for Dr. Mammen with the prospect of finally getting an accurate diagnosis of the type of Myositis Eyvin has and therefore possible effective treatment.

An article about our KIT meeting in our local newspaper was what brought Connie to us and that confirms the reason for KITs. They were not aware of TMA much less KITs and were meeting the same challenges so many of us have of finding anyone familiar with Myositis, personally and professionally.

***Don't forget to
make your
reservations to
attend the TMA
Conference in
Louisville
September 6 – 9
Celebrating The
Myositis
Association's
25th Anniversary!!***

The feeling of helplessness and isolation is what we hope to overcome with our KIT gatherings, by sharing secrets of how to deal with physical limitations, best sources for information and most of all how to reach experts in specific fields of study for all types of Myositis. Thanks to Betty Curry, the founder of TMA, and her sixteen cohorts back in 1993, we can now enjoy the education, support, research and advocacy activities of TMA with 8,000 members, world -wide. We do so at our conferences once a year but all year long with our KIT groups.

2018 will be a year of celebrating TMA's growth over the past 25 years. But more importantly, TMA will be announcing, promoting and celebrating the progress in research and treatments for those who have to live with Myositis. We still have a long way to go to reach the ultimate goal of a cure, but there is significant progress being made.

Special events will occur at the Annual Patient Conference in Louisville, September 6th – 9th, and there will be some ways for you to help TMA and help yourself in Celebration of the 25 years. There will also be some activities that are just purely for fun!

To our Medical Advisory Board – THANK YOU- our HEROS!

Coming Attraction: MYO-Connect

MYO-connect is a network of myositis friends with the same diagnosis who connect by phone or email as a way to give and receive emotional support. Like TMA KIT groups, this is a safe place where patients can feel free to share their honest feelings without judgement. It is also a place to share tips, strategies and devices that help you overcome particular difficulties.

The goal of **MYO-Connect** is to provide an alternative means for patients struggling with myositis to feel supported and avoid the pitfalls of loneliness. Whether you are newly diagnosed or a patient who has been living with myositis for years, everyone copes better when they feel supported, heard and understood.

LaDonna Johnson is the Member Services Manager of TMA and she gets calls every day from someone who is isolated and needs to talk to another person with (PM, IBM, DM specific). She is asking for people who are willing to lend an ear, to offer some understanding and encouragement, to please consider this opportunity to help another in need by adding your name to the **MYO-Connect list**. You may do so by contacting her at TMA, (703) 553-2632 or ladonna@myositis.org.

Please contact me if you have any questions about our KIT, TMA, the 2018 TMA Conference, MYO-Connect or any other subject you would like to address regarding our group.

Madge Chambers, leader

H-850-279-4306 *** C-478-335-0420 *** nwftmakit@cox.net