



SW FL KIT Meeting November 4, 2017

36 people attended including two first-timers

It was a lovely day in Sarasota as we met for our last meeting at the Sarasota Memorial Hospital HealthFit Center. This has been our longstanding location for ten years but it is time to move on. Find the article later in this newsletter for details about our new location.

We welcomed some of our northern/southern members who are beginning to show up here in southwest Florida. I was going to try to name them but realized it's hard to tell now. Our members are quite mobile and show up at meetings whenever they are in town. So we'll just say "welcome back" and we're glad to see you.



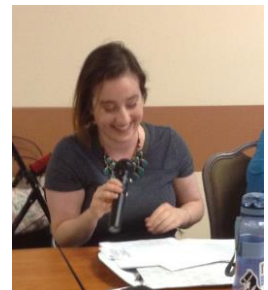
Welcome George and Pat Slater

Two new faces graced our meeting; **George and Pat Slater** from Venice. George has IBM and has been a member of our KIT for over a year but had not been to any previous meetings. We're glad he and Pat came to this one! (And we hope to see them again!)

Our agenda for the day was led by three of our KIT members who attended TMA's annual patient conference in San Diego this past September. Many more of our members intended to travel west but impending storm Irma made us cancel our plans and stay to 'hunker down'. Thankfully most of us fared well since the storm weakened somewhat before hitting Manatee and Sarasota Counties. But **Donna DeFant** reports that hurricane or not, the tornado that was apparently spawned by the storm, seemed to aim directly for the many old trees surrounding her property. Luckily the twister did not aim at her house so while there were scores of fallen trees, none of them touched her house. Whew. Now, on to the meeting content!

We were treated to a nice presentation by **Elizabeth Valkanas** who attended the conference with her boyfriend Steve. It was a first for both of them. And as many of us can remember, that first sight especially in the first general assembly of all attendees, it's a bit overwhelming. We thought we had a rare disease and here we see literally hundreds of others just like us. And for our partners or care givers, the opportunity to compare notes and share best practices makes this trip one of immeasurable value. Steve, who is new to the world of myositis, found the caregiver sessions to be informative and reassuring. Elizabeth told us about some of the sessions that most impressed her.

Some of Elizabeth's observations:



- The theory of exercise is it may slow the disease progress and reduce inflammation
- A recent creatinine trial was not conclusive but some were helped
- Heart disease may be an issue for myositis patients; the heart is a muscle, after all
 - We should watch our cholesterol and see our cardiologist annually
- We should be aware of the risk of infections; antibiotics are an issue to consider
- Vaccines are generally considered safe (flu or pneumonia) as long as they are a dead vaccine. (You cannot get the flu from a flu shot!)
- Our antibodies can tell so much about us and our potential for additional health issues
- DM patients should be screened for cancer (antibodies can help identify which cancers)
- Nutrition continues to be important
- Focus on an anti-inflammatory diet (many of them on line)
- Carbs aren't always bad and Omega oils aren't all good; Omega 3=good. Omega 6=bad
- New research indicates that a plant based or vegetarian diet is helpful
- High fructose corn syrup should be avoided whenever possible.
- Fermented products like yogurt, Kombucha, Saurkraut, or Kimche can help your gut
- Screening your children for myositis or other 'overlap' issues is not really needed
- Her overall impression of the conference was very positive.

After Elizabeth spoke, **Jo Randolph** was quite direct in speaking to those who have never attended a conference. She provided some astute observations about why attending is so valuable. In the past, others have described these conferences as "KIT meetings on steroids". Many of us can relate and wholeheartedly agree. She agreed that the exercise presentations were very helpful and easy to understand. Jo found that one of the most interesting sessions wasn't medical at all. It was "Finding Strength through Faith" given by **Augie DeAugustinis**. Each year he presents it on Sunday morning and many of us have found it to be a soothing break from the frenzied pace of the rest of the conference. Jo handed out Augie's sheet of observations. I found his slides on the 2012 Conference site.

Marianne Moyer, who was unable to attend the conference, presented **Linda Sabatino's** notes on her conference experience. Linda was able to receive the materials to set up our KIT's display at the annual wine and cheese reception. This had been designed to let KIT leaders share best practices but not too many KITs participated.

Linda reported that it was unanimous; the exercise sessions were well presented, helpful and easy to participate in. She liked the pool exercises too. Something as simple as moving your hand against the resistance of the water does qualify as exercise! Pool exercise has been shown to allow more movement with less pain or the danger of falling. The class she liked the most was a very hands-on opportunity for participants to learn things like a better way to get out of bed in the morning. Her final thoughts were what many of us already know but that bear repeating (the first is to consult with your doctors before beginning an exercise program):

- Set goals
- Keep an exercise diary
- Find a friend to exercise with you (and who will keep you focused!)

Linda also reminded us that while many of us with myositis are in our 'golden' years, there were some young people at the conference as well. One young woman was concerned about trying to get pregnant with myositis while on multiple medications... Linda also recommended that if you want more information about specific exercise suggestions, go to TMA's website and the conference sessions to access: The Theory of Exercise and Home Exercise Program. These two links are provided here:

http://www.myositis.org/storage/documents/2017_APC/2017_presentations/Getting_started_and_sticking_to_an_exercise_plan_Kompatibilitetsl%C3%A4ge.pdf

http://www.myositis.org/storage/documents/2017_APC/2017_presentations/Theory_of_exercise_and_why_it_is_important_in_myositis_-_submit_Kompatibilitetsl%C3%A4ge.pdf

Actually a good place to start is www.myositis.org and click on conferences. As mentioned previously, if you can't find a conference session in one year, try going back a year or two. TMA leaves these presentations on their site so that you can 'attend' all the recent conferences any time, from the comfort of your own home and from your own computer.

Many thanks to Elizabeth and Steve, Jo and Linda for bringing back so much useful information.

**Our Next KIT Event – Annual Holiday Soiree!
Saturday, December 2, 2017 starting at 1:00 p.m.
The Location is the Lovely Lesoine Home!**

Camille, Ray and Pacman have again opened their fully accessible home to our KIT for a Holiday Soiree and Toys for Tots Collection. Please bring an unwrapped gift for a child and a pot-luck item to share with your KIT family. You should have received an e-mail inviting you to attend and to reply to the Lesoines. See you there.

Big Thanks to Those Who Step Up to Help Our KIT

At the November meeting, we circulated a sign-up sheet for people to help with some small and yet, very important KIT duties. The sheet made its way around the room and came back filled out to the margins with many names. I will send them to **Bernie Carnevale** who coordinates water for the meeting, **John** and **Sue Corning** who coordinate desserts and will hold close those who will help with sign-in at the start of the meeting and who can take digital photos. Thank you to the following people: **Judy Kahl, Addie and June Paul, Elizabeth Valkanas, Jo Randolph, Pat Lawrence, Susan Prive, Don Lindberg, Jan Marriott, Julian Hansen, Sheila Vander Sanden, John Setzer.** You are all heroes!



**Our KIT Chen Crew Breakfast
Lunch Setup and Cleanup**

TMA's 2018 Conference is Now Scheduled
September 6-9, 2018
Louisville, KY

TMA will once again present the annual patient conference in Louisville. It's the same hotel as in 2013 but it's been completely renovated. Watch your e-mails from TMA for information about registering (sometime after January 1).

TMA On-line Chat on Complementary Treatments
Tuesday, November 14, 2017

I confess that I bounced between typing this newsletter and the chat. They didn't answer my question (not important) but much of the chat was about people either currently using or inquiring about 'alternative' supplements. I'd never heard of most of the herbs and supplements mentioned. It was everything from yoga to creatinine. Based on the feedback we got from our conference attendees and this chat, there's no question that a healthy diet, exercise and limits on things like sugar and red meat are a good thing for us. For those of us into moderately moderate approaches, we tend to accept some of what we are hearing and keep on doing what we've been doing for the rest. If you want to access this chat, go to TMA's homepage and click on live chat (even though it's not live anymore).

KIT Meeting Follow-up

It seems that each time I come home from a meeting and start unpacking my boxes and bags, I find something that was not 'handled' at the meeting. This time, there were at least three for which I apologize and will try to make amends. They are:

- I forgot to offer copies of the DVD seen at our KIT's anniversary celebration. **Linda Sabatino** created this compilation of hundreds of pictures of our first ten years and it's now available for free, to you as a Powerpoint show on a DVD. Only a few remain. First to request them, get them.
- There were two yummy desserts brought by **Pat Lawrence** and somehow our kitchen help missed putting them out. Guess what I'm bringing to the Dec. 2 party? (OK so I'll make something else too.)
- Linda brought additional give-aways from the conference and I forgot to put them on the table that was mostly cleaned off (thank you everyone). I will bring them to the next meeting.

Speaking of our Next Meeting...
Saturday, February 3, 2018

We have two important topics to share, about our next meeting. First, let's celebrate how once again we have managed to entice one of TMA's Medical Advisory Board doctors to come to Florida in February to speak to our KIT. What a smart bunch they are! First it was Dr. Oddis from Pittsburgh, then Dr. Ytterberg from Rochester, Minnesota. Now we have Dr. Kanneboyina Nagaraju from upper New York State. Aren't we lucky to have a location that attracts these doctors to join us? "Raju" as he is known, is very well known for the research he is conducting

that aims to find a substitute for prednisone that will not have any side-effects! Wow, I can hear a collective sigh of wistfulness as you read that! For those of us with DM or PM, this is certainly promising news.

However, I've also asked the good doctor if he would address some potential good news for our IBM friends. Recently one of our KIT members came across a Google note about some IBM medication research and she sent it to me. I forwarded it to Raju. He enthusiastically thanked me and said he'd welcome additional questions. So...KIT members, if you have questions about future medications, send them to me and I will forward them.

The rest of our meeting will be 'normal' because after Dr. Nagaraju speaks and we have lunch, we will break for our disease-specific and caregiver groups.

In the afternoon, we will have some fun/exciting/serious matters to discuss; it's time for the Sarasota Community Foundation Giving Challenge. More on this later in this newsletter but we will still be talking about it in February.

February 3 KIT Meeting at NEW LOCATION

Yes, it's true; we have outgrown our Sarasota Hospital location. Those who attended our August or November meetings (you know, the ones where *not too many people attend?*) were actually pretty crowded with not everyone able to sit at a table. This makes it difficult to eat lunch or converse with your neighbors. Your KIT's Fab Five leaders were desperate; we had to find a new meeting venue by February (traditionally our *best-attended* meeting). We searched long and hard for a 'perfect' place and what we came up with is what we hope you will find accommodating. Perfect doesn't seem to exist but our new location meets almost all our requirements. A map and directions are on the next page of this newsletter.

- The location is new, clean and bright
- It is easily accessible by all forms of walkers and scooters
- It is easy to find from I-75 (only two turns from the south, three from the north)
- It comfortably seats up to 100
- We can bring in our own food and drink
- We have scheduled it for all four 2018 meetings
- It has adequate restroom facilities (not great but adequate)
- There are areas for our afternoon breakouts
- There is a back entrance to facilitate bringing in coolers, etc.
- There is plenty of handicapped parking
- It has a wide-screen TV visible from anywhere in the room and a laptop hookup
- It does not have a PA system but we do, as part of our livestream equipment
- For our KIT members coming from the north, it will be about the same distance
- For KIT members coming from the south, you'll need to plan for some extra drive time.
- When we send the Feb. meeting invitation, we'll ask if anyone wants to carpool and we'll coordinate the answers.

See Map on the next page!

Please print this page if you need directions.

From the North

1 h 2 mins (53.7 miles)
1 h 7 mins (57.0 miles)

Exit 220 SR 64
Exit 217 SR 70

Goodwill Manasota
Thrift Store - 3465 Cortez Rd W

Coming from the north on I-75, take Exit 220 West, SR 64 (there is some construction). SR 64 becomes Manatee Ave. Go west about 15 miles* through Bradenton and turn left on 26th St., W. Turn right on Cortez Road. On Cortez Road, the easiest way to enter is at the light at 37th St., W at the huge Goodwill sign and by the Culvers Ice Cream Store and McDonalds. The main entrance to the building is right in front of you.

From the South

1 h 45 mins (72.4 miles)
1 h 39 mins (65.4 miles)

Exit 220B
Exit 217B

Goodwill Manasota
Thrift Store - 3465 Cortez Rd W
Nonprofit standby for secondhand goods
Open until 8:00 PM

Coming from the south on I-75 take Exit 217B West, SR 70. SR 70 is also 53rd Ave. Go west about 15 miles.* Turn right on 34th St., W, and go to where it looks like it's coming to an end (it does—at Cortez Rd). Before you get to the light at Cortez Road, there is a left turn lane into the shopping center (at a Bank of America). Turn left and the Goodwill store is on your left.

Enter through the doors to the right of the main Goodwill store doors; by DaVita Dialysis or if you want to enter through the store, feel free, then go to the Community Room door in the back right corner of the store. We will have signs at the doors to help you find your way. *I've said 'about 15 miles' because I'm assuming that most people will be using their GPS to find the Goodwill Store at 3465 Cortez Road West.

**Do You Remember What Our KIT Accomplished
During Last Year's Giving Challenge?**

If you don't remember, look around and you'll see the results of our efforts. In one 24-hour period, our KIT generated about 100 donations to TMA and our KIT, and the result to us is that we were able to:

- Sponsor our first myositis awareness event for local medical professionals
- Offer scholarships for KIT members to attend TMA's conference
- Invite and pay for top-notch speakers like Dr. Nagaraju to speak to our KIT
- We also invested in some technology that is not yet where it needs to be, to livestream our meetings, but we are working on it.
- And we still have nearly \$15,000 in our checking account!

Believe it or not, it's time to start thinking about next year's Giving Challenge. Here are the main points you need to know. There will be more information coming to you as we receive it.

2018 Giving Challenge, Tuesday, May 1 – Wednesday, May 2, from noon to noon

- It will again be only for those 24 hours and only for online giving
- A minimum donation of \$25 will be required
- Our KIT in partnership with TMA will participate. We do not yet know the details of the split or how matching funds may be offered. One thing we do know:

**For the first time in our KIT's history, we are changing a meeting date.
It will not be a Saturday because it would have been three days after the
Sarasota Community Foundation Giving Challenge!**

Therefore, our May meeting date will be Tuesday, May 1, 2018

This will be a triple event:

K.I.T. Meeting

Myositis Awareness Event

Fundraising for Myositis: TMA and our KIT

**The times will be the same as a normal meeting. We will have meet and greet from 10:30 to 11:00 and the agenda is fluid from there on. Keep In Touch and we'll let you know what the special meeting topic will be.
Here's a hint. Pacman thinks this meeting will be grreat!**

Bits of this and that...

Yes, we are still struggling with our meeting livestream. No one is more annoyed than your KIT leaders. We continue to work on it. Meanwhile, we are going to break down and find a real expert (translation: we will pay them) who can get us up and going—glitchless. Many apologies to all who have tried to join us. Please keep the faith.

Did you see the tips in a recent AARP newsletter about help for caregivers? I think some of these are for all of us:

1. Put reflective tape on a light switch you don't often use but might need at night. No more fumbling (or stumbling) in the dark..
2. My favorite; put a soap bar (or scraps) into the toe of a stocking and tie it to your shower head or faucet knob so you can grab it and use it without worrying about having to pick up a slippery bar you dropped on the floor.

Remember that we still have some copies of Physicians' Guide to Myositis produced this year by TMA and written by many of their MAB members. If you still have a doctor who has trouble pronouncing *myositis*, contact Marianne for a copy to give the doctor. (And then tell them that on your next appointment, there will be a test!)

One last note: at the meeting, many of us shared the things in our lives that make us thankful. At the top of many of our lists was this KIT family. Amen to that. Have a blessed Thanksgiving!



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