

SW Florida Myositis KIT Newsletter

We Care, So Come and Share!



Published Quarterly

November, 2015 Edition

November 7, 2015 Meeting

We had 48 in attendance, including seven new members

**Welcome to: Karen D, Rick and Pricilla G, Julian and Jane H, Rande and Elissa S,
Marty and Carol K, Jeanne R, and Elizabeth V and Steve M**

Highlights of our Meeting

It's hard to tell exactly how many members of our group attended TMA's annual patient conference in Orlando in September but there were at least 20 members and 30+ in all, including family or friends. Our November KIT meeting has become a traditional review of some of what we learned there so we called on our members to help us with this presentation. There was no way we could review all 80+ sessions but several of us did talk about sessions that had special meaning to us.

Topics that particularly interested us included new and more specific recommendations for all myositis patients to exercise. Also, while we all roll our eyes at reminders to eat a higher protein and lower fat and sugar diet; this is proving to help people with myositis and other autoimmune diseases. Equipment manufacturer representatives demonstrated some new and innovative devices. One researcher indicated that there is progress in myositis research but that the main challenge continues to be funding. And one session was devoted to using laughter to help attendees release some of their stress and pain.

Instead of listing all the sessions we attended or reviewed, here is the link to TMA's website where anyone can access these presentations. If the speaker provided slides or other information to TMA, it has been posted on the website and you can review it at your convenience. The speakers are usually quite willing to answer questions so if you have them, just e-mail the speaker. Go to www.myositis.org and from the homepage go to the Conference link. Not all presentations are available but most are. Also, some of them are fairly technical but can still provide insight into what was said.

Barb reminded all of us that November is National Caregivers month and we all applauded every one of our beloved helpers! In addition, we gave thanks for our Veterans, whose special day is November 11. There are more meeting announcements and news elsewhere in this newsletter. But one special announcement is that Marianne asked for some editing/formatting help with this newsletter and Linda Sabatino quickly volunteered. We think you'll agree it looks pretty good, doesn't it? Thanks Linda!

Updates on members



Marty

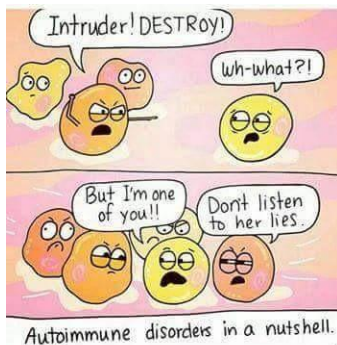
We circulated cards to remind our absent members that they are in our thoughts and prayers and that we miss them. We signed cards to: Kathy N who underwent surgery, Kathy O who is dealing with fatigue issues, Sonia G who turned 70 this month, Pete D who has had some serious surgery side-effects, Neil J and John C, who fell and John S who was again in the hospital for anemia. We hope all of them regain their strength and can join us at a future meeting or event. And this just in...Marty and Carol drove all the way from Parkland on the east coast, to join us for our meeting. This past week Marty was in a serious automobile accident and at last word was in a Critical Care unit in Orlando. Let's send some KIT prayers to the two of them! (Our KIT has sent a card.)

Our Next Meeting, Saturday, February 6, 2016

Location: Mixon's Fruit Farms in Bradenton

Were you diagnosed with myositis recently? Or has it been ten or more years? Is your doctor still treating you with exactly the same medications and treatments as always? Are you still being told to avoid exercising because your muscles are inflamed? Well, if your answer to any of these questions is 'yes', we have a special speaker to address these and other issues. Our February meeting is traditionally our largest turnout meeting and we try to have a speaker whose presentation can address all myositis patients' concerns, and also some of their family members'.

Dr. Steve Ytterberg is one of the stalwart members of TMA's Medical Advisory Board. He has spoken at numerous patient conferences, addressing topics like Prednisone, heart involvement and autoimmune antibodies. But this time he's going to address a topic we've requested: A reflection on how the diagnosis and treatment of myositis diseases has evolved over the course of his practice. Be sure to hold this date on your calendar and join us as we learn the latest in myositis diagnosis, treatment and research.



There had been some consideration of having a "Laughter Yoga" speaker in February but upon reflection, we are moving that topic to May, to be included in our Myositis Awareness event that will be held in conjunction with our May KIT meeting. Find more on that in another section of this newsletter.

TMA's 2015 Patient Conference in Orlando September 10 - 13, 2015

TMA moves the conference around the country each year to enable the largest number of people to attend by driving. They don't get any closer than Orlando for us Floridians so we had a great turnout. Our own Camille L did a fantastic job of helping TMA coordinate volunteers and greeters during the conference. Maybe next year we should offer to do the same but for a nice consulting fee!?



KIT Dinner at the Conference

Donna D organized a wonderful dinner for our KIT members and their partners at the Caribe Royale. In addition to about 30 of us, we invited some other conference attendees and enjoyed their company too.

KIT Fair at the Conference

Thursday at the conference was a special event to feature KIT membership. Camille created a wonderful display to help non-members find their nearest KIT and each KIT at the conference had a table showing what their group is doing. We of course had a pretty great display and were able to share some of our 'best practices' with other groups. Did I mention that there was free wine and cheese?

Next Year's TMA Conference: New Orleans, September 1-4, 2016

Yes, it's the "big easy" for our conference in 2016. Put these dates on your calendar and be ready to head for "NOLA". And yes, that is the weekend before Labor Day so plan to make it a long weekend!

Keeping In Touch With...Doctors

Don't forget to recommend doctors who treat you for anything! Contact Marianne for a copy or to provide input. Also, be sure to share with all your medical professionals a copy of TMA's booklet "A Physician's Guide to Myositis".

Myositis Awareness Event Sunday, September 20, at Gecko's



About 40 of us descended upon the Gecko's next to HealthFit, to watch the SF Giants and AZ Diamondbacks baseball game that was a special celebration in the name of myositis awareness. Mike Krukow is the color commentator for the Giants who recently announced that he has IBM. The Giants organization held special events during the game to bring recognition to Mike and to myositis. TMA was there and helped educate the public about myositis.

So here on this coast, we put up banners and signs, handed out information flyers and of course had a party. The primary purpose of this event was myositis awareness, not fundraising, though we raised through raffles and donations over \$900 for TMA's research program!

If you'd like to see the entire game with TMA announcements and Mike's comments, go to https://youtube/IH_ew-lkBC8.

Exercise, Exercise, Exercise

Marianne circulated a number of technical medical papers published in the last year or so, on the topic of exercise for myopathy patients. Electronic copies have been sent to all who requested them. If you were not at the meeting and are interested in the topic, please e-mail Marianne and she can share what is available, then send them to you (some of the files are pretty big so we didn't want to just add them to this newsletter.)

Show Me the Money

John M reminded everyone who attended the conference to be sure to deduct from their taxes for this year, their expenses (patient and caregiver) for transportation including parking, tolls and mileage plus what they paid for the conference registration. Sorry, hotel and food aren't deductible. And of course, please check with your tax advisor to ensure you are doing it correctly!

Sometimes it's About the Money We Give

Here's one more tradition our KIT observes. Our meeting facility at the Sarasota Hospital HealthFit is provided to us three times a year at no cost to us. So each year, our KIT donates to the Hospital Foundation as our way of saying "Thank You". Again this year, we are sending a check for \$200 to help them in the charitable work they do in our community. Thank you to the members who voted unanimously at the meeting, to make this donation!

Let's Party!

Holiday Potluck Party Saturday, December 5 at 1 p.m. at the Lesoine's

This year we are combining two traditions; our holiday party and our ongoing social gatherings between meetings. For the potluck, please bring a dish to share and the Lesoines will provide plates and utensils, soft drinks and cocktail punch. BYOB if you want something else.

We are resuming our practice of a gift exchange that's totally optional. So in addition to your potluck goodie, we invite you to bring a wrapped gift valued at \$20 or less. If you bring one, you get to pick one.

An invitation e-mail should have hit your inbox around November 13. Don't forget to RSVP to Lesoinefamily@aol.com or call (941) 417-7647.

Ray and Camille Lesoine's: 11406 Walden Loop, Parrish, FL 34219. Their home is accessible with ramp, high toilet with grab bars, and ample room for wheelchairs, scooters, and walkers.

We hope to see you there!

Speaking of the Holidays

As a gift from your KIT leaders, with a little financial help from our dear friends at MedProRX Infusion Services, each KIT member at the meeting was given a 2016 calendar that is unique! At the top is a photo of our group at TMA's conference. Below on the 'regular' calendar part, is color-coded notation of all our KIT meetings in 2016, Myositis Awareness Month and TMA's conference. Now we all will know when to expect our next opportunity to be with our KIT family.

For those who were not at the meeting, Marianne has tried to verify everyone's snail mail address so we can send calendars to them. Not everyone has responded yet and Marianne will be out of town for Thanksgiving week. Calendars will go in the mail shortly after she returns. Happy Holidays!

Did we Just Say Myositis Awareness MONTH?

In a word, yes. For a number of reasons, TMA has decided to move traditional Myositis Awareness Day (September 21) to the entire month of May, starting in 2016. See the following article for what our KIT is planning.

MAY Myositis Awareness Month or Myositis And You!

It has been a challenge for some KIT leaders to organize a myositis awareness event in September when they are also planning to attend the conference. Add to that in many states, September begins the cold weather which precludes an outdoor event. Therefore, TMA is changing our awareness focus to be a whole month. This will allow KITs to plan and hold events with less stress.

While cold weather is not an issue for us, the timing *Vis a Vis* the conference certainly was. And now, how convenient that MAY (Myositis And You) will fall in the month in which we hold one of our regular meetings. While we've always tried to make our meetings open to the public, now we will have an opportunity to expand our reach.

Our May KIT meeting (check your new calendar; it's on Saturday, May 7) will be a special one and we hope you will join us. Rose R has been working feverishly (she's on her way to Morocco as I type this) to prepare a grant request of Global Genes, to fund an expanded format to our meeting. In the morning will be workshops on various subjects, for any KIT member or their family. There will be a special lunch (as much as we love Chick-fil-a, it's time to 'step it up'). And in the afternoon, our presentation will be the one we talked about at the November meeting; using laughter to help us relieve some of the stresses of dealing with myositis. It's not just a clinical discussion of laughter; it's going to be some real fun and will hopefully cause you to feel those laughing muscles working away!

More information will be coming to you but this is another "don't miss" date to save!

Short Notes from our November Meeting

Most of you received an e-mail requesting you contact your congressperson about H.R. 3229/S. 2196, legislation that would help preserve patient access to complex rehabilitative technologies (CRT), which play a critical role in the lives of patients living with neuromuscular diseases. If you need an electronic copy, please contact Marianne.

TMA now has put many of its myositis brochures online, in Spanish. When you go to the site and click on one of the brochures, go to the bottom of the links and there is a Spanish option. Ole!

Remember that if you do ANY shopping online this holiday season, please go to GoodShop.com first. Enter TMA as your charity of choice and then shop as you normally would at hundreds of retailers. A portion of your total order amount will be donated to TMA at no cost to you.



TMA is considering forming a Fantasy Football league in 2016. While no one in attendance at our November meeting currently participates, we did have one volunteer to work with TMA if this does happen. We'll keep you updated. 🏈

Finally, your KIT co-leaders, Barb, Camille, Donna, Marianne and Rose want to wish everyone a blessed Thanksgiving. And we hope to see you at our Holiday Party on December 5!

Welcome to some of our new members!



Ray (old member) & Pacman (new!)



Jeanne Rosenberg



Julian Hansen and daughter Jane



Carol Kartagener