SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

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August 1, 2015 Meeting

We had 38 in attendance, including four new members and two partners…

Welcome to: Connie (IBM) and Tom, Stephanie (DM) and Roberto, and Linda (DM)

We had one "drop in" who found us through MDA, Shirley (DM)

Also, the Lesoines brought their daughter, Helen

Highlights of our Meeting

For even the non-techies like me (Marianne), I must say my go-to source for just about everything from recipes to myositis information is the good old Internet. But if you are in any way like me, you are always wondering if you got to the best site for what you were searching. Well, hopefully this meeting showed everyone some new and not-so-new places to find information to make our myositis lives easier. There were three handouts that are mentioned below and are separate attachments to this newsletter e-mail. That way you can look at and/or print the ones that interest you. I hope you find them helpful.

We began with Veterans' advocate Ray who explained some of the government and non-government sites he uses to ensure he gets all the benefits to which he is entitled. This is not as easy as it sounds and it helped that Camille was navigating on the big screen while Ray was describing the use of that site. Please if you are a Vet with myositis, be sure that your country can say 'thank you' by providing services to help you cope. (Please see the 2-page attachment entitled **Resources – VA and Related Others**.)

Camille followed Ray with some helpful tips about using Facebook, not only our KIT's and TMA's pages but Facebook in general. (Please see the 1-page attachment entitled **On-line Resources for Myositis**.)

Rose showed us some ways to use Google to search without getting sales pitches. I think we all learned something here and comments from the audience helped make this presentation especially valuable. (Please see the 1-page attachment entitled **Myositis Websites**. It includes recommendations from Bill Simeral who leads the computer awareness session at TMA conferences.)

Marianne admitted to learning things about TMA's website that she hadn't known before. In preparing to present this section, she visited every link on TMA's site. There was only time to see a few on the big screen but her handout does show the kinds of information there. (Please see the 2-page attachment with TMA's logo on the upper left corner. This page is a rough approximation of TMA's home page.) (Please see the 2-page attachment entitled **TMA Website Resources**.)

After lunch we celebrated our KIT's Eighth anniversary with of course, a chocolate cake. What a fabulous journey this has been and continues to be. Only three people attended our first meeting in May, 2007. We now have over 160 members on our list with an average meeting attendance of over 40. Our group became so large; we gave birth to our sister KIT that meets in Central Florida. We have met every first Saturday of February, May, August and September (and are scheduled to keep doing that for the next eight years too!) Our history is captured on a document that lists every highlight of these eight years. If you'd like an e-copy, e-mail Marianne.

We try to have a medical expert speak at our meetings but this time it proved to be impossible. So our planning team decided a workshop on finding information would be valuable to us all. We are now working to find just the right myositis expert to speak at our February 6, 2016 meeting. If you attend a session at the conference presented by a particularly interesting doctor, please give his or her name to Barb or Marianne so we can contact them for a future KIT meeting presentation.

Our Next Meeting, Saturday, November 7, 2015

But let's not get ahead of ourselves. Before our February meeting there are at least three times our group will gather! The next official KIT meeting will be on November 7 and will feature our traditional November agenda; reviewing what we learned at TMA's conference. Our members attend a myriad of sessions and then 'report back' on what they learned. In addition, for those who were not able to attend in person, they report on how they were able to 'distance learn' via live streaming video of conference sessions. Please plan to join us for what is another way to learn about what is happening in the world of myositis. Your invitation to attend will arrive in your e-mail in-box around October 3 (earlier than usual since at our regularly scheduled send date, I'll be attending my 50th high school reunion in Maryland!)

Potluck Barbecue, June 20 at 2 p.m.
When a Quarterly KIT Meeting is not Enough

It was another fun party (isn't it always when we get together?!) The Lesoines again offered their house and their new barbecue grill so the guys grilled while the girls gabbed. Ok, so that's not exactly how it was but it <u>was</u> a cookout to remember. The food was scrumptious and the 20 of us who attended again had reason to be thankful for our KIT family. The idea of these "in-between" get-togethers is a winner that we will continue! Thank you to the Lesoines. We will gladly take them up on their offer to host other events in the future.

Our next get-together will be a bit different in venue and theme but not in fellowship and fun. See the article following, entitled Myositis Awareness Event for a description of our September 20 event. And don't forget to RSVP when you get the invitation!

Our condolences to Dolores Brady who lost her husband Paul to IBM complications recently.

TMA's 2015 Patient Conference Returns to Orlando
Thursday September 10 through Sunday, September 13, 2015

TMA moves the conference around the country each year to enable the largest number of people to attend via driving. They don't get any closer than Orlando for us. (I tried to talk them into one on Anna Maria Island but TMA was afraid our scooters would get stuck in the sand.) Next year's conference location will be announced at this year's conference and all I can tell you at this point is that it's toward the center of the country.

KIT Dinner at the Conference

Donna DeFant is organizing a dinner for our KIT members and their partners at the Caribe Royale. It will be at 6 p.m. on Saturday, September 12. The last conference sessions end at 4:30 that day so you will have time to rest before dinner (no need to get into your evening gowns and tuxedos; dress is like the rest of the conference; comfortable!) We will be in the Martinique Room and order from a mid-price menu. For those who have already signed up, Donna will be in touch to confirm. If you haven't signed up and want to join us, there are more seats available. Contact Donna via e-mail: doozerdona@Verizon.net. Or watch your e-mail for an invitation! Then be quick like a bunny to respond to Donna!

KIT Fair at the Conference

We KNOW the value of KIT membership but there are still those out there who do not. So on Thursday at 5:30 there will be a special event to feature KIT membership. Camille has created a wonderful display to help non-members find their nearest KIT. Each KIT that is attending the conference will have a table showing some of what their group is doing. We of course will have a table full of the good things we have done and are doing. If you would like to help us at this table, please contact Marianne. The other potentially neat thing about this event is that we will have an opportunity to visit other KIT tables and share best practices with them. Please plan to attend. Did I mention that there will be free wine and cheese? Of course, then there are the evening sessions to attend so I guess we should sip sparingly!

Keeping In Touch With…Doctors

We continue to develop our list of doctors you recommend and at our August meeting we got several new doctor contacts. It doesn't matter if they are treating your Myositis or other conditions; tell us about them. Don't forget to recommend doctors that you travel to see at places like Hopkins or Mayo. If you'd like a copy of the list, contact Marianne. Also, please be sure to share with all your medical professionals a copy of TMA's booklet "A Physician's Guide to Myositis". We will have copies available at our Awareness Event on September 20.

Myositis Awareness Event – Update
Sunday, September 20, 4p.m. at Gecko's on Clark Road, Sarasota

Hopefully this is truly an update; and you know about this event and plan to attend. AND, you plan to bring a friend or neighbor who cares about you and would like to learn more about myositis.

On the other side of the country, in San Francisco, there is going to be a special Myositis Awareness event on Sunday, September 20 this year during a SF Giants baseball game. While our 'normal' Myositis Awareness Day is September 21, this date presented TMA with simply too great an opportunity to pass up. Mike Krukow is the color commentator for the Giants who recently announced that he has IBM. We all know how difficult that must have been for him; an athlete, active working guy and public persona. The Giants organization will hold special events during this game to bring recognition to Mike and to myositis. TMA will be there and will help make this an opportunity to educate the public about us.

So what about those of us on this coast? Since most of us can't plan to fly to San Francisco and attend the game, we came up with a "Plan B" that should be almost as much fun and definitely less expensive.

Come and join us for our September 'in between meetings' KIT gathering. The Giants are playing the Arizona Diamondbacks, in San Francisco, starting at 1:05 p.m. PDT. (That's 4:05 Eastern). We have reserved an area of Gecko's with several large screen TVs that will be tuned to this game. This Gecko's is essentially next door to the HealthFit complex where we hold our regular meetings. They have offered us the opportunity to bring up to 50 people, put up banners and signs, hand out information flyers and of course have a party.

As yet another attachment to this newsletter is a flyer about this event which we hope you will print and post wherever you think might generate some interest. There are two versions, one with my contact information and one without. Feel free to post the one with. It will really help if I get at least an idea of how many people to expect.

For those who haven't been to a Gecko's, they have reasonably priced sports-bar food and beverages. We will order food and drinks via individual checks. We can have as many seats as we need, up to about 50 and that's the number we are shooting for. Right now we have 17 signed up.

The primary purpose of this event is myositis awareness, not fundraising though we will probably throw in a raffle, 50/50 or other game. The Giants have donated some caps you can win. Other prizes have been donated as well and should make the afternoon interesting.

Bottom line is PLEASE SAVE THE DATE for this fun event. Sunday September 20 at 4 p.m. at Gecko's in Sarasota. I will send an invitation via e-mail, on about September 1. And by the way, In case you think you aren't a big fan of baseball, neither am I. But think back to Super Bowl parties you have attended. The fanatical fans are bunched around the TV(s), yelling their heads off. The rest of us are on the other side of the room, eating, drinking and socializing. This event will be our September KIT party (one weekend after the conference by the way) and it will be a great way to sit back, sip a libation and reflect on how grateful we are for TMA and our KIT. Most importantly, it will be an opportunity for us to spread the word to increase awareness of myositis diseases. See you there and then!

Final thought for this newsletter…

In the section on the KIT Fair, I mentioned sharing best practices with other KITs. Here's an idea Joanne presented at our meeting that came from a KIT friend who is moving from NY to CA. She, like many of us, abhors the drudgery of setting up a garage sale. So instead, she turned it into a win-win for both her and TMA. Instead of pricing items and then 'dickering' over a few pennies, she put out a sign saying "Take what you want: give what you can; all donations go to TMA". At the end of the day, she had collected over $1,000 for TMA and most importantly, did her bit to raise awareness! Yay Katie!