# SW Florida Myositis KIT Newsletter

## Down with the Myositis Grinch!

This special edition of our newsletter is an update to what's been happening since our November meeting and is one more chance to say: Happy Holidays to all our KIT members and their loved ones!

Published Quarterly (plus!)



December, 2015 Special Holiday Edition

#### Holiday Potluck Party Saturday, December 5 at the Lesoine's We had 21 people, two cakes and lots of other goodies to share!

This year we were blessed to have our "Hostess with the Mostest", Camille Lesoine, offer to open her and Ray's home to our annual party so we could have more time to share, chat and be together, instead of being crammed into a couple tables in a restaurant. It was a festive afternoon of gorgeous tables set with sparkling china, crystal and fine linens, sumptuous food, decadent desserts, holiday beverages and of course, time together. Many thanks to the Camille, Ray, Helen and Pac Man.

Our gift exchange was one that allowed participants to 'steal' others' gifts, in exchange for another. We're not sure where the Florida map cutting board or pine-scented candle ended up but it was fun for all who dared to join in!

Note:

Some of us were talking at our holiday lunch about how myositis is the 'Grinch' in our holiday festivities. Myositis may be the Grinch in our lives but he sure didn't show his hairy green face at *this* party!

#### **Updates on members**

Right after our November meeting, one of our newest members, Marty Kartagener, was in a serious automobile accident. On December 9, his wife Carol in reply to my inquiry about how he's doing, said: "Unfortunately, Marty is still in critical condition at the hospital in Orlando. We were hoping to transfer this week to a long term acute care hospital closer to home, but he is not stable enough. Thank you to you and the KIT for your hugs and concern. It is appreciated." As if having IBM is not enough to manage!

Most of us know **John Schell** had lung cancer surgery the day after TMA's conference and he came through that pretty well. But since then, he's had a number of other complications that have necessitated his entering and exiting the hospital. Let's keep him in our prayers too.

**Pat Lawrence** was too ill to attend the party but I've been unable to catch up with her to see how she's doing. Here's hoping she's on the mend! And **Rose Ryan** came back from Morocco with bronchitis. Icky!

### **Additional Updates on members**

If you know members we should keep in touch with about their challenges, please contact Marianne.

### January 16 join us to raise Myositis Awareness

The Sarasota Hospital HealthFit where we meet will be holding a Health Fair on Saturday, January 16 from 9 a.m. to 1 p.m., and we will have an awareness table there. Several members have volunteered to be present to talk about myositis and our KIT. If you are available for a few hours that morning or would like to help in other ways, please contact Barb Kluding on <u>bmkfl@comcast.net</u> or on 941-923-7991.

## Our Next Meeting, Saturday, February 6, 2016 Mixon's Fruit Farms in Bradenton

Dr. Steve Ytterberg is a member of TMA's Medical Advisory Board and has spoken at numerous patient conferences, addressing topics like Prednisone, heart involvement and autoimmune antibodies. At our KIT meeting, he will address: 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 to hear the latest on myositis diagnosis, treatment and research.

## **Speaking of Research**

It's a long story but to make it simple, there is a group of myositis patients concerned about getting additional funding for research into specifically, IBM. The group formed after hearing a presentation by Dr. Steven Greenburg at TMA's conference in Orlando. The group has asked our KIT to provide a contact list of all our IBM patients and your group leaders are not comfortable with fulfilling that request. As an alternative, if anyone is interested in finding out more about the group and Dr. Greenburg's research, please contact Jeanne Foster on <u>fosterjy@hotmail.com</u> or 239-823-4441.

## **Holiday Gifts**

As mentioned in the November newsletter, those who were not at that meeting will receive a small gift in the mail from your KIT leaders. I am a bit slow in stuffing the envelopes and Santa has told me that if I don't get this done soon, I will be fired as an Elf. And I can't even blame the Myositis Grinch! They are scattered all over my dining room table so if I plan to serve Christmas dinner I'd better finish up stuffing the envelopes and sticking the stamps. THERE ARE STILL SOME OF YOU WHO HAVE NOT CONTACTED ME WITH YOUR SNAIL MAIL ADDRESS. I can't send to what I don't know. Please reply to this e-mail and then I can be an elf-extraordinaire! Take that Mr. Grinch!

