



## ***SW Florida Myositis KIT Newsletter***

*We Care, So Come and Share!*

Published Quarterly

August, 2012 Edition

August 4, 2012 – Our Fifth Anniversary  
There were 27 Attendees (and 4 first-timers!)

### **A Different Kind of Meeting...**

At the request of several members, we planned a different agenda for our Fifth Anniversary Meeting. There never seems to be enough time to just socialize, so instead of a presenter, we split the time for this meeting to include extra time for our breakout groups and extra time for group socializing before and during lunch. As always for our anniversaries, there was cake and this time we also enjoyed non-alcoholic champagne, donated by Karen Jacobs. We also received a congratulatory letter from Bob Goldberg; Executive Director of TMA who recognized some of our KIT's many highlights in our first five years. Comments after the meeting indicated that people enjoyed this less-structured format and would be willing to do it again occasionally.

Thank you to Matt Kluding who brought his laptop to demonstrate how to access TMA's new website, the fundraising sites of GoodSearch, GoodShop and GoodDining and also our KIT's Facebook page. It always helps to actually see these sites instead of just hearing about them. Thanks also to Donna DeFant for creating a handout that will also be available at the conference, to tell people about GoodSearch sites. Remember these when you do your holiday shopping this year! Donations to TMA that don't cost you a cent: sounds good to me.

We were happy to welcome new members, June (DM) and Addie Paul and Annie Bottoms (PM) and sister, Kitty Klein. June came to us as a neighbor of Elaine Meyers (that's that word of mouth awareness we talk about!) Annie is a patient of Dr. Chichkova and just moved back to Florida; has had PM for over 20 years and has never been part of a support group before. Thank you to Dr. Chichkova! Wouldn't it be nice if all our doctors were as conscientious to tell new patients about TMA and our KIT? Please remember to ask them, and their office staff to do so.

Our group is enriched by the addition of each and every person who attends our meetings. Whether you have myositis or know someone who does, you are always welcome to join us and to bring others.

## Holiday Party Planning

Our KIT's party planners are still trying to find a date and place that will be convenient and affordable. Some of the suggestions we received so far were a bit on the pricy side so we will keep looking. Since we have held our party in Sarasota for the last three years, we decided to look for spots north of the Skyway Bridge for 2012. We will keep you posted, but try to hold open the Saturdays of December 1 and December 8 at lunchtime.

## Fundraising

At this time we are taking a break from planning a formal event. However, we were quite successful in our request for donations to help fund the hospitality suite at the conference. So far we have received about \$1,500 and still have a few "IOU's" that may add to this total. **Thank you** to all who contributed. This should ensure that all attendees will have plenty of caffeine to keep us going! Also, we are planning an awareness/fundraising event on November 7 at Mixon's Fruit Farm (see below for details).

## Dates To Remember:

Central FL KIT Meeting: Saturday, October 6, Contact Schelljh37@comcast.net

**SW FL KIT Meeting: Saturday November 3, 2012, 10:30AM, Sarasota: Contact Marianne.moyer@verizon.net**

Mini-fundraiser and awareness event for SW FL KIT: Wednesday November 7, Mixon's, Contact Marianne

SW FL KIT Holiday Party: Date TBD but probably Saturday December 1 or 8, Location TBD near St. Petersburg

## 2012 TMA Conference in Orlando

By the time you receive this, the preparations for this year's conference should be completed and all we need now is YOU! If you will not be attending, please watch your e-mail for notice of which conference sessions will be available via streaming video. For those who are attending, we'll see you there! And don't forget that if you attend a session that is particularly good; be prepared to share what you learned with our KIT at our November meeting.

## November 3; Our Next KIT Meeting

Our presentation for this next meeting will be our traditional review of what our members saw and learned at the annual patient conference. Please plan to attend; even if you went to the conference. You never can tell what else you might learn!

## Mixon's Concert in the Grove

The nice folks at Mixon's (where we held our February meeting) have again invited our KIT to participate in one of their concerts. They hold these once a month in their large grove-side tent and one of the features of the evening is a 50/50 drawing. Half the proceeds go to Mixon's and the other half goes to us. So on Wednesday, November 7 you are welcome to join us as we listen to a local band, munch on food prepared by Mixon's and get to tell our KIT story. As we have all seen, it helps to get the word out about myositis and people need to hear about the good work of support groups in general. More details will follow as we get them but for now, save the date! And please plan to bring a friend or two to this event.

## **Marianne's Meanderings**

As you may know, I've been traveling the country visiting other KITs. The two-fold objective of this is to share with them what is happening in the world of TMA and also to talk about 'best practices' of other KITs so we can learn from each other. I've gotten some great ideas and am working to find ways to share them with other KIT leaders.

For example, one KIT has recently produced a Dysphagia Document with suggestions and recipes. If you would like a copy, let me know and I'll send it to you.

## **JDM Fundraiser**

On October 4<sup>th</sup> there will be a Cure Cara fundraiser at The Beach Club in Sarasota, for Cara Bodziak and Children's Memorial Hospital in Chicago. This fundraiser helps Cara's family with their medical expenses to travel to Chicago for her JDM treatments. The event includes a live auction, raffles, entertainment and free food for a \$5 donation. Go to <http://curecara.blogspot.com/> for more information.