



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

August, 2013 Edition

August 3, 2013 Meeting

40 Attendees

What a Great Meeting: Not One But TWO Presentations! Plus We Celebrated Our Sixth Anniversary!

So much for the theory that August is our meeting with the least attendance because members would rather be up north than in Florida's heat and humidity. Some of us are up there, that's true, but this time all can benefit from our meeting content and I'll tell you how at the end of this section.

Our first presentation, by Heather O'Neil from Clover Medical Solutions, showed us what I was calling the "electric sock" because I didn't know what else to call it. I'm still not sure of the short version of the name but basically it is the Micro-Z Mini and Silver Conductive Garment because it can be a sock, glove or shoulder wrap. It's a new form of therapy that can help patients suffering from pain or nerve problems in their feet, hands or other body areas. Put it on, turn it on and low voltage helps your body to reduce pain and begin healing. One of our members is using it and believes it truly helps. Needless to say, there was a lot of interest from attendees. Our KIT can't make a recommendation but if you are interested you can go to one of two websites: www.clovermedicalsolutions.com and click on *pain management*. The other is www.legandfootpain.com. Call Heather on 1-888-640-1112.

Our second presentation was most ably delivered by Jessica Wind, a Speech Pathologist at the Veterans' Administration in Tampa. Ray Lesoine has seen her and recommended her to speak to us about dysphagia. Her talk and supporting slides were most informative. We not only learned about dysphagia but also saw some video of actual swallowing studies which help doctors determine how to treat a patient's swallowing problems. And that leads me to a comment in answer to some members' questions.

They were disappointed that the talk didn't present answers or treatments for specific dysphagia issues. Because there are different causes of the problem and some people have difficulty with soft food while others experience it with harder or even plain liquids, there isn't a one-size-fits-all answer or treatment. Each of us must address our specific problems with our own medical professionals. If you would like to see the presentation in its entirety, we owe a huge vote of gratitude to Penny Andrea-Einmo who with the permission of the attendees, video-taped the entire presentation and then put it onto facebook. To see it, please visit <http://www.youtube.com/watch?v=ePgj0JemTb0>. In addition, please go to

TMA's website www.myositis.org and click on their dysphagia video which is a presentation given by Dr. Todd Levine, from TMA's Medical Advisory Board. Between these two presentations, you will know more about dysphagia than you ever thought possible. And by the way, the youtube video also includes the presentation on the 'electric sock'.

Bottom line is that both presentations were outstanding and well-delivered. We are most grateful to Patches and to Ray for finding these speakers and bringing them to our KIT (and now, via YouTube, to the world!)

Going Global with Presentations?

Recently TMA hosted a conference call for KIT leaders and one new leader asked if there is a video catalog that KIT leaders can use at their meetings. The answer was that there are currently only two (both of which our KIT has now used; Falls and Dysphagia.)

Subsequent to that, our KIT had some discussion at our meeting about whether or not we should put our new video that Penny created, onto TMA's website. The feeling seemed to be that for now, we would just put it onto YouTube and let people know about it. There is no reason however, that we couldn't create a listing of videos that we and other KITs might make at their meetings. By putting the link into our newsletter and posting it on our KIT's page on TMA's website we are certainly making the link available.

The question: What is the best way to make this and other videos we (and other KITs) might make, available to others? If you have thoughts on this, please either e-mail Marianne or come to the November meeting and let's talk about it. Also, if you are coming to TMA's conference in Louisville, you might want to make your thoughts known there.

Speaking of TMA's Conference

I hope by the time you read this you have made your reservations for the conference in Louisville, KY, October 17 through 20. If you are a TMA member, you have received e-mails about the art and essay contest, dinner and other ways TMA is celebrating 20 years of service to the myositis community. To register, go to www.myositis.org.

And here's an new offer from TMA! Because there are never enough roll-in shower rooms in a hotel, TMA has reserved one for members' use. If you need a roll-in and couldn't reserve one, you can go to our registration desk, get a key and use this room (it will be yours, privately for as long as you have the key.) Details re towels, soap, etc., will be available at the conference.

If you are unable to attend the conference, please watch your e-mail for a notice from TMA about which conference sessions will be available 'real-time' via streaming video. Notice will be sent a week or so

before the conference starts. If you are unable to watch during the live presentation, remember that within a week or so after the conference, TMA puts all available presentations from the conference onto their website for you to review at your leisure.

One More Conference Item for your Information

Since a 20th Anniversary is a huge milestone, TMA will be producing a 20-year scrapbook to commemorate the occasion. There will be pictures (including those of special KIT events), articles, the history of TMA and other items of interest. A special section on KITs will reflect on how these groups have grown and prospered across the country. Ads or paid message pages are available and at our KIT meeting, we voted to take \$250 from our KIT's checking account to purchase a full-page ad. It will include the picture taken at last year's conference and some meaningful text reflecting our KIT's philosophy and efforts. The scrapbook will be provided for free to all conference attendees and those who bought ads. We'll see how many we can bring back for our group's November meeting!

Update on TMA applying to Medicare for Stand-up Scooter Option

There is nothing new to report...Bob Goldberg, our attorney and others, met with government officials to state our case. We followed up with a letter explaining how this feature is in fact a medical necessity. There are no answers yet but we are hopeful.

What's Happening with our KIT's 20 for 20 Campaigns?

Our KIT has a number of people who are participating in TMA's 20th Anniversary fundraising campaign called "20 for 20". All we're asked to do is ask 20 friends or family members to donate \$20 to TMA. It is amazing for those of us participating, how many of our friends just hand over a \$20 bill. Kudos to Sofia Pagan who has raised \$150 and to Jeanne Foster and others who are either near or over their 20 donors and are still going strong! While the official end of the campaign is October 20 at the conference, donations will always be accepted!

For those who believe that it's not KIT members' responsibility to raise money for TMA, this is somewhat understandable. For those of us who embrace this opportunity, we will say that this kind of activity is an opportunity to raise *awareness* as much as money. By telling people about what we are doing and why we support TMA's efforts, we are helping people learn about our disease. It's amazing how many new KIT members have joined our group because someone who doesn't have myositis heard about us in a news article or from a friend or through a flyer left in a doctor's office. For example, our KIT has received three new members who found us that way. THAT can be a real benefit of one of these fundraising campaigns. Think about the services that TMA provides, like the annual patient conference, on-line chats, newsletter, information about trials, starting and supporting KITs, and advocacy with the government, insurance agencies and pharmaceutical companies. Wow.

It's not too late to start your own 20 for 20 campaign or as we've offered before; if you would like to give \$20, let Marianne know and she'll connect you with one of our KIT members who could use another donor or two to reach their 20.

We're still working on what kind of match offer we might be able to generate which will increase the impact of our KIT's participation in 20/20. It's possible our efforts might generate additional donations based on what we are able to raise as individuals. More on this later.

Keeping In Touch With Our Members

Elaine Meyer writes that after her husband Carl suffered a cerebral hemorrhage, life has become a real challenge. He is in a rehab center and she spends most of her days with him. There is a lot of stress on her and she's having trouble with dysphagia.

Joanne Carnevale's back surgery was a great success and she's happily walking upright without a cane or walker. What great news!

Chris Parsons continues to try to find ways to deal with his worsening IBM. Laura recently lost her job and they are trying to find ways to cope.

Jim and Judy Kahl have no mercy; he says the lobsters are plentiful (and affordable) and the weather is great, as in low humidity, up there in Maine.

Since our meeting, Penny Andrea-Einmo has had heart 'issues' and been hospitalized but has managed to hold off the doctors on all the 'stuff' they want to do to her. Go Girl!

For these and ALL our KIT family, please remember them in your prayers and if you have a spare moment, call or e-mail them to let them know you care. If you have news about yourself or others in our family, please let Marianne know so we can all "Keep In Touch"!

SE FL KIT is Restarting!

The first KIT meeting for myositis patients and their families who live in the area north of Miami on the east coast of Florida, is scheduled for Saturday, September 7th from 1:00-3:00 at the Port St. Lucie Community Center. The address is 2195 SE Airoso Blvd. Port St. Lucie 34984. Please contact Chris McFarland on 772-380-7458 or montenchris@comcast.net to let her know if you are interested. And if you know others 'over there' who might be interested, please invite them to attend too.

I am still hoping/planning to try to help the Panhandle and Miami folks to start KITs in their areas; it's still in my long-range plans. Anyone interested in helping?

Questions for YOU; Please reply to Marianne.moyer@verizon.net

At our meeting, we voted on two questions. You can still vote if you contact Marianne within a week.

1. Would you prefer that we hold our annual holiday lunch at a location North of the Skyway bridge or South? The date will probably be Saturday December 7 or Saturday December 14.
2. Since our February meeting usually draws the largest crowd, we are again looking for a location that will accommodate us. Our plan is to use Mixon's Conference Center (where we have been for the last two years). Is this location acceptable to you or should we find another (that is likely to cost us more.) Our primary criteria are near I-75 and with handicap parking, restrooms and catering on-site.

SAVE THESE DATES!

Saturday, September 21 – Myositis Awareness Day

Celebrate by sharing your myositis story with someone. Send a thank you card to your doctor. Send a letter to your local paper. Find a way to reflect on what TMA and our KIT mean to you.

TMA's Annual Patient Conference

If you can join us, please do! Register at TMA's website www.myositis.org and then contact the hotel for your room. The dates of the conference are **Thursday, October 17 through Sunday, October 20**. The location is the Downtown Marriott in Louisville, KY.

Our Next Meeting; Saturday, November 2, 2013

We try to truly live our KIT's slogan, "We care, so come and share". So at our November meetings, instead of one or two presenters, we invite our members who attended that year's TMA Patient Conference, to share what they saw, heard and learned.

If you plan to attend the conference, please also plan to attend our November meeting to share your experience. If you won't be at the conference, plan to attend this meeting so you can get the benefit of another patient's or family member's experience. These have always been great meetings that generate conversation and reflection. In addition to our usual breakout time, we also will have time for general conversation with everyone present.

February 1, 2014 KIT Meeting

It's never too early to start planning what is usually our biggest attendance meeting of the year. So the planning team of the 'Fab Four' has started working on what will be our most ambitious project yet. We aren't going to provide details yet except to say that this meeting will focus on our most precious resource; our Caregivers. And this won't be one of those dry lectures about what they should and shouldn't do. Caregivers, be they our spouse, other family member, significant other, best friend or professional nurse...they are all important to us and we need to be sure our relationships are the most productive and caring we can create. Please plan to join us (probably at Mixon's), Saturday, February 1 for this valuable and informative meeting.

Best wishes to everyone for a safe and enjoyable summer. May the Hurricane forecasters be wrong, and our state (and country) be spared any storms. Hugs to all, Marianne
