



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

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February 2, 2013 Meeting at Mixon's
56 Attendees (4 first-timers)

It Was our Winter Meeting but the Subject of the Day was Fall(s)!

It doesn't matter if you have IBM, PM or DM or if you are a caregiver to someone with one of these diseases, we all need to be aware of the dangers of falling, so that was the topic of this meeting. For the meeting, held again at Mixon's in Bradenton, we had 56 people who wanted to know what they could do to avoid falls and, if one did happen, how to get up safely. We were glad to welcome many of our 'winter visitors', as well as two individuals who attended because they saw a write-up of our meeting in the local paper. Our KIT was happy to have four new members join us, **Janet Garrubbo (PM)**, **John Cundill (DM)** and his wife, **Maija**, **Steve Kelly (IBM)** and his wife, **Millie** and **Helen Wallace (IBM)** and her husband, **Harry**. We look forward to seeing more of all of them!

The meeting began with a viewing of the new Falls video produced by TMA. It stars Chair of the Board, Augie DeAugustinis. This video was Augie's brainchild and he arranged all the details to bring it to us. It is now on TMA's website and YouTube and has been watched by hundreds of people (not just those of us with myositis.) If you haven't seen it or want to see it again, or you want to recommend it to others, please go to www.myositis.org. The first half addresses how to prevent falls and while most of us think we know what to do, there were some good reminders like cleaning up clutter that might pose a tripping hazard. The second half offered many good tips on how to get up from a fall, either by yourself or if someone is with you. Many of us have been frustrated by people trying to grab us by the arm to yank us up off the floor and this of course does not work! While getting a bit of a 'wedgie' from being pulled upright by the back of our pants might not be fun, it does work!

To expand on our falls prevention awareness we were pleased to have two exercise experts offering us additional help. The first, Robbi Weaver is a Yoga instructor who specializes in chair exercises for those who are not able to safely exercise while standing, or for those who just want to exercise while sitting. Attached to this newsletter e-mail, are three pages you can print and use as a reminder of exercises you can do to help your hands and legs. For more information, contact her at yogarobbi@yahoo.com.

Then, Drew Adkison, a personal trainer, presented exercises for those of us who *can* stand up. He started with awareness and exercises geared to our feet, then worked up through our calves, thighs, trunk, shoulders and neck. He spent some time on something called the "Upper Crossed Syndrome" and recommended we visit some websites that describe it with exercises to correct it. UCS is described as a muscle imbalance pattern at the head and shoulder regions. It is most often found in individuals who work at a desk or who sit for a majority of the day and continuously exhibit poor

posture. These practices can lead to poor balance and muscles unable to correct for an impending fall. One website about UCS is www.cyberpt.com/uppercrossedsyndrome.asp and it also offers some videos of exercises to do to correct the problem. Contact Drew at drew.adkison@gmail.com for more information.

During lunch, both Drew and Robbi were available for questions and many attendees got personal attention from them. We are grateful for their interest and participation!

As a part of our 'goodie package' provided to each attendee, Donna DeFant provided a recipe for a help if you should fall. It's a home-made ice pack and she had made a few and passed them around for us to examine. The recipe is simple. Combine one part rubbing alcohol with two parts water in a zip-lock bag. Then place that bag into another bag for leak prevention and put into the freezer. Then if a fall occurs, take out the baggie and apply to the sore area. Simple, inexpensive and readily available; you can't ask for more than that! Thank you Donna!

We had a special doorprize gift, donated by a Sarasota businessman known as "Glenn, the Grab Bar Guy". He donated two nice grab bars that he'll install for the winner, John Corning. How many of us have talked about installing bars in our showers or tubs and haven't gotten around to it? Call Glenn for a free estimate on 941-780-3346. Thanks for the donation Glenn!

Next Meeting, Saturday, May 4 at HealthPlex

Our topic that day will be "Remaining Independent-for as Long as Possible". Myositis patients often wonder how long they will be able to remain in their home. Dealing with stairs, bathrooms, transferring to beds, chairs, vehicles and other issues are a real challenge. How do we make decisions? What costs are involved? How much can we depend on our caregiver? What if we live alone? These and other issues are certainly relevant for almost anyone but for those of us with muscle weakness, they become more daunting. We will provide checklists and decision charts to help as we face this serious life event. Please plan to join us.

Future Meetings

Please remember that our KIT's meetings are scheduled well into the future. We meet on the first Saturday of February, May, August and November. We realize that events like weddings, graduations, travel and winter migration all have a place in your busy lives but if you would like to know when your KIT will be meeting, you can put these dates on your calendar for at least the next couple years!

Keeping In Touch With...

There are members of our KIT who for one reason or another, have not attended a meeting recently but they do keep in touch with us and we'd like to share some of those communications

Marcia and Bill Martin: she thought she had PM but now appears to 'have something but they aren't sure what.' They are winter visitors who recently moved their NJ home to one that thankfully was not in the path of SuperStorm Sandy. Bill continues to employ acupuncture for his back pain and is happy with the improvement. They send greetings to all.

Ernest and Martha Spiva attended our first KIT meeting and that was a bit of a long haul (they live in Panama City. Ernest (IBM) was recently featured in his local paper, as someone dealing with myositis. Their Christmas card shows them in front of his classic Chevy Impala on their golden wedding anniversary. They are trying to get a Panhandle KIT started.

June Pearl and Chris Parsons (IBM for both) were unable to attend in February because of health issues. We send them best wishes and hope to see them again in the near future.

If we haven't seen or heard from you in a while, please send an e-mail or call one of us so we can Keep In Touch with you!

Brett Leake Performed Locally

For those who attended TMA's annual conference in Orlando and also read his articles in the recent Outlook newsletter, Brett Leake's name should be easily recognizable. Anyone who can apply humor to his disease like he does, is bound to be popular and entertaining. Brett was the 'stand up' comic at McCurdy's Comedy Club in Sarasota recently and a group of us attended. We took our KIT sign and held it up for pictures with him. A fun evening for all!

2013 TMA Conference in Louisville, KY October 17-20, 2013

Remember to plan for another wonderful conference experience. TMA is lining up a stellar group of speakers and presenters. Early bird (discounted) registration will be offered in the next few weeks so watch for a notice to send in your registration. And if you need a handicapped-accessible room at the hotel, these always go quickly so plan to make your reservations as soon as the information flyer arrives.

TMA Turns Twenty!

In 2013, The Myositis Association marks 20 years of supporting myositis patients and their families and it's time to celebrate! If you stop to think about what TMA has done and is doing for us, we're sure you'll agree that a lot has been accomplished. We may not yet have a cure but what we do have is new treatments, better diagnoses, regular communications and of course, our Keep In Touch support groups!

There will be announcements of special events, contests and a fundraising campaign and you will be invited to participate. Watch for notices in your mailbox, e-mail and Outlook newsletter.

Tips from our February Meeting

If you are interested in the personal alert mentioned by several members, one source is Amazon. The item is called a Freedom Alert and costs \$250. Please remember to use GoodShop if you buy one; it generates a \$3.75 donation to TMA and doesn't cost you anything.

The Upper Crossed Syndrome that Drew described is found on this website:
www.muscleimbalancesyndroms.com .

If you would like an electronic copy of the handout which listed firms that provide discounts to seniors (but ONLY if you ask), please e-mail Marianne and she'll send it to you.