



THE MYOSITIS ASSOCIATION

KEEP IN TOUCH

CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER

July 2013 ISSUE

Hello everyone. Sorry for the tardiness of the April KIT meeting newsletter.

Our members started arriving between nine and ten thirty and were greeted with coffee, juice and homemade coffee cakes. We had fourteen attendees. Unfortunately our photographer and co leader Dennis Platt was unable to attend. Since I forgot my camera, no pictures!



Our speaker for the meeting was Dr. Michael Visconti. He holds a Doctorate in Naturopathic Medicine and acupuncture physicians license. He is one of only five practitioners in the state of Florida. His degrees include a bachelors of Science in Communications with a business minor from the University of Tampa as well as a Bachelor's Degree of Science in Health Services. He also holds a four year post-graduate doctorate degree of Naturopathic medicine in addition to his study.

Dr Visconti spent most of his time talking about whole body health and the importance of keeping our immune systems healthy. He also stressed the importance of a healthy digestive system and good sleep habits.

Among the common conditions treated:

- Adrenal fatigue, diabetes, hyperglycemia,
- Obesity and thyroid disorders.
- Woman's and Men's health
- Gastrointestinal disorders
- Immune and inflammatory conditions. Including Lupus and sjogrens disease.
- Musculoskeletal conditions including arthritis, osteoporosis, fibromyalgia and back pain.

He did not offer a cure or specific treatment for Myositis, but does believe that a whole body approach to our diseases can only help especially with symptoms and pain. After his talk he was kind enough to stay around for over an hour of questions. Everyone present seemed to be very interested in what he had to say.

The KIT provided drinks and our members treated ourselves to our own sack lunch, while we had a short business meeting and a general discussion.

Our next KIT meeting was to be held July sixth, but there are so many snowbirds gone and so many away for the fourth of July weekend **we will not be meeting until the first Saturday of October.**

We will be putting out a fund raising letter in the next two weeks to highlight the 20/20 campaign through TMA, its importance and some suggested ways to help raise money for our organization.

We hope you all have a wonderful summer and look forward to seeing you all in the fall.

John, Kevin and Dennis
Co KIT leaders

How To Consider Your Ability To Remain Independent In Your Home

Your current situation:

- You live alone and are having difficulty: (difficulty here means that there are days when you simply cannot perform one of the functions below)
 - You live with someone who is helping you to perform all of the activities below, and now, they too are unable to perform them due to injury or illness
 - There is a temporary situation, like your live-in caregiver will be away for a day or longer
- In any of these current situations, if you are having difficulty performing any of the ADL's or Medical tasks, listed below, it is time to find help. Now.

Help for Activities of Daily Living (ADLs):

- Getting out of bed, either during the night or in the morning
- Bathing and dressing yourself
- Preparing, eating and cleaning up after meals
- Administering your medications (prescription and/or over-the-counter)
- Maintaining your home; cleaning, paying bills, changing light bulbs, hiring workers, etc.
- Leaving home to shop or attend doctors' appointments (driving yourself or taking public transportation)

Help for Medical Situations:

There are medical situations that may require professional medical assistance. Your doctor is the best help for deciding if you can perform these activities or if you must engage professionals.

If it is Time to Ask For Help:

- A helpful first step is to speak with another myositis patient. Their insight and experience may be invaluable and remind you that you are not alone. TMA's patient forum may offer answers.
- Visit websites that offer suggestions and input like that above. These are two I visited and liked.
- www.agingflorida.com and www.agingcare.com. While these address issues in terms of the 'elderly', the information is relevant to myositis patients as well. There are many other websites including AARP, government sites like Social Security and Medicare, and commercial sites.
- Speak with your doctor. If s/he does not usually have time for these kinds of discussions, either make an appointment to meet with them in their office (as opposed to in the examining room) or ask for a referral to someone they recommend.
- Speak with family members whom you feel can help you objectively address your issues.

Meanwhile...

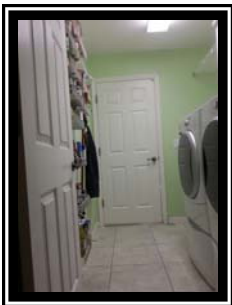
If you decide to stay in your home, consider adding some home improvements to make your current home safer. Examples are grab bars in the bathroom, handrails in hallways or stairways, ramps, extra lighting, and furniture that is easier to get into and out of. Another aid that can provide you some peace of mind is a wearable alarm like LifeLine service.

Bottom line: if you think you may need to do something to increase your personal safety, peace of mind and/or ability to maintain your best possible quality of life, do it now!

My Projects: *(if you have a project you would like to share with everyone send it to me.)*

Last year when I got into the pool I was able to stand and do several exercises. This year I thought I would have no problem getting into the pool and continuing my exercises where I left off. Big mistake. I couldn't stand without someone holding me up. It was a good thing I was wearing a flotation belt. When I got home I saw this flotation "thing" in a catalogue with a price tag of about \$80. It looked like it was a simple thing to make so I went to the hardware store and bought all the part of about \$15.

It worked great. In the water I put it over my and then my arms over it. It held me up and I was able to walk around and do my exercises. I can now enjoy the water again.



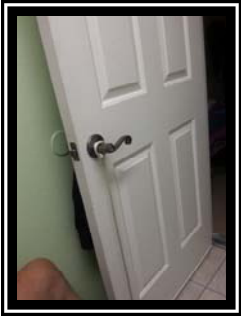
My next project was to figure out how to close the door behind me when I entered and left my house. I'm in a wheelchair and there is not enough room to turn around in my laundry room to close the door.



I had an eye hook installed in the top inside corner of the door and one installed in the wall as shown in this picture. I then had a rope tied to the eye hook on the door and had the rope go up and through the other eye hook.



When I enter the house from my garage and open the door the rope is pulled out with the door. As soon as I'm clear of the door I pull down on the rope and the door closes. Be sure to have enough rope so you can move away from the door to let it close behind you. I also put a weight on the rope to keep the rope from getting stuck in the eye hooks.



In order to close the door when I leave the house, I tied a rope to the door handle, long enough for me to get outside, I then pull the rope and the door closes.

Following is a list of used handicapped equipment that is available in Central Florida. Most of the equipment is in excellent condition and other than a few scratches look new.

They belong to my neighbor whose husband has just passed away. She wants to get rid of the stuff and is looking for any reasonable offer.

EQUIPMENT

Jazzy select 14 - Asking \$800.00 but make a reasonable offer.

Golden Companion- \$400.00 or best offer

Pride Go Go Elite traveler - \$400.00 or best offer

Silver Star lift - \$400.00 or best offer

Revco scooter - \$400.00 or best offer

Walker with seat Best offer

If have any interest call John Schell for more information 352 314-8953



Modification to the home that have been sent to me. If you have modified your home to make life easier for you, sent me some pictures and I will added them to the newsletter.

Kevin modified his bathroom.



Accessible Sink



Lift Toilet Seat



Roll-in Shower

**Change what you can, forget what you can't.
Dennis Platt
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