



**THE MYOSITIS ASSOCIATION**  
*KEEP IN TOUCH*

**CENTRAL FLORIDA MYOSITIS KIT NEWSLETTER**

**October 2014 ISSUE**



WE HAD 28 IN ATTENDANCE INCLUDING FOUR NEW MEMBERS AND ONE VISITOR FROM TALLAHASSEE. OUR SPEAKER FOR THIS MEETING WAS VANCE FORDE LPTA REPRESENTING PHYSIO MED OUTPATIENT REHABILITATION CENTER IN LEESBURG FLORIDA.

**INTRODUCTIONS**

We were especially pleased to welcome several new attendees that came to us as a result of the publicity we received in the "Village Sun" Newspaper thanks to the good work of Tom and Joanne Smith and another interview with Dennis Platt. This was in conjunction with Myositis Awareness Month. They received numerous phone calls from people who live in the Villages wanting to learn more about Myositis. We are very happy to have several new members representing DM, PM & IBM. It was wonderful to see some old members whom we have not seen for a while, Lyndia and Louis Vazques.



**RICK SCOTT**  
GOVERNOR

**MYOSITIS AWARENESS DAY**

WHEREAS, thousands of people are affected by myositis in the United States, many of whom remain undiagnosed or misdiagnosed; and

WHEREAS, myositis is a general term used to describe swelling of the muscles, but the effects of the inflammatory myopathy (often referred to as "myositis") are much more severe than just inflammation, and are thought to be autoimmune diseases, such that the body's immune system, which normally fights infections and viruses, does not stop fighting once the infection or virus is gone, and myositis patients suffer from their immune systems attacking their body's own normal, healthy tissue, resulting in inflammation or swelling; and

WHEREAS, myositis can cause muscle weakness, and patients often live in chronic pain and have long-term health problems that lead to permanent disability because myositis is difficult to diagnose, and treatment is often delayed, resulting in unnecessary suffering; and

WHEREAS, some myositis patients may die at a much earlier age due to improper care, particularly children who may have permanent scarring and deformities due to improper treatment; and

WHEREAS, National Myositis Awareness Day educates communities across the nation about myositis and the need for accurate diagnosis and effective treatments;

NOW, THEREFORE, I, Rick Scott, Governor of the State of Florida, do hereby extend greetings and best wishes to all observing September 21, 2014, as *Myositis Awareness Day*.

IN WITNESS WHEREOF, I have hereunto set my hand and caused the Great Seal of the State of Florida to be affixed at Tallahassee, the Capital, this 19<sup>th</sup> day of September, in the year two thousand fourteen.



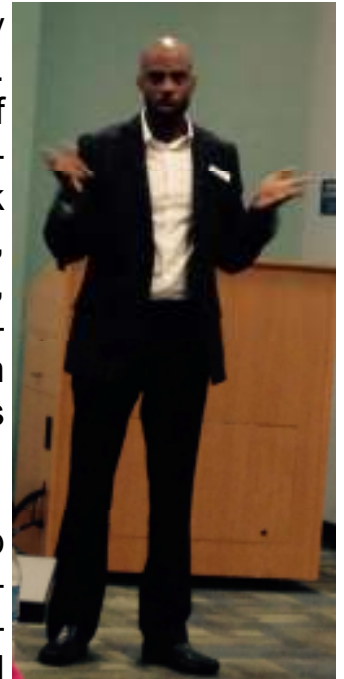
  
Governor

## SAD NOTE TO BEGIN WITH

Just as we were about to start our meeting we received word from Marianne Moyer that one of our old time members Chris Parsons had passed away. Chris and his wife Laura had become close friends to many of us over the past several years. Chris was a Vietnam Vet and worked tirelessly to get the VA to consider agent orange as a possible cause of IBM. He was in many studies over the years offering his person to try new possible treatments for IBM. He and his wife Laura became a couple of heroes to many of us when we first came to TMA. He will be missed. I just found out that there was a memorial service on Sunday November 16, 2014 at 2:00 pm at the Rockledge Presbyterian Church, at 921 Rockledge Drive, Rockledge Fl. 32955. Cards can be sent to Laura Parsons, 20 A Ohio St, Satellite Beach Fl. 32237.

## SPEAKER HIGHLIGHTS

Vance first discussed the different types of muscles and how they pertain to our disease types and why it is important to exercise. Muscles not used will atrophy even if not disease affected. All of us have muscles that support other muscles which may be affected by myositis diseases. Non-use of muscles can lead to lack of stability, in our basic baby learned skills: supine, sidelying, prone, prone on elbows, quadruped, high kneeling, half kneel, standing, etc. Therefore by maintaining core strength, we can assist other skills like rolling over and sitting up in bed. Vance then gave some examples of important exercises to train the muscles of the trunk and extremities.



**Triceps** – (located at the back of the upper arm) used to push up to a standing position, also crucial in lifting the body from one surface to another. Important in transferring and important to maintain. Only exercise every other day. With myositis, muscles will deteriorate quite quickly without use.

**Biceps** – (located in the front of the upper arm) Useful in pulling up. Strength can be built and maintained with exercise, but are affected by myositis, especially with lack of use.

**Latissimus Dorsi** – (wings) – powerful large back and arm muscle used to push up to standing position and maintaining a standing position on a walker; crucial for maintaining sitting balance especially if abs are comprised. Work in concert with triceps. Can exercise daily.

**Abdominals** (abs) – crucial for maintaining sitting/standing balance and curling up to a sitting position; postural controls with sitting and reaching/performing tasks. Exercise daily.

**Gluteus** – Scooting in bed, maintaining a standing position. **Gluteus maximus** to stand upright and **gluteus medius** to maintain a level pelvis. Can exercise every day. One might assume that what is being described is only possible with weights, a trainer and an accessible gym. John Schell and Vance have been working out at Physio Med with rubber exercise bands. They are easy to adapt at home by tying them to hooks, tops of doors, doorknobs etc. John does them while sitting in his wheelchair or lying in bed. It is not how much you raise your hips up, but that you practice the skill the best you can. Obviously if you have IBM you can't lie on the floor or stand up when you do them so you practice while sitting. Be creative. And do them. You will feel better and be more able to do them daily.



1. Lie on back with knees bent
2. Cross arms over chest
3. Raise head and shoulders, curl trunk upward as shown
4. Hold 2 seconds
5. 20 repetitions, once per day

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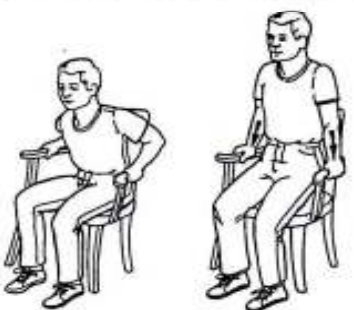
1. Lie on back with knees bent and feet together, arms out to the side
2. Rotate knees as shown, until you feel a stretch
3. Hold 2 seconds
4. 20 repetitions to each side, once per day

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1. Lie on back with legs bent as shown
2. Tighten buttocks and raise them off floor as high as you can
3. Keep pelvis level
4. Hold 2 seconds, slowly relax
5. 20 repetitions, once per day

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1. Sit in chair with arms as shown
2. Push yourself up from the chair, using the arms as much as you can
3. It is ok to use the legs to help as necessary
4. Hold 2 seconds, slowly lower
5. 10-20 repetitions, once a day



1. Hold arms out to sides as shown
2. Begin making small backward circles
3. Now begin making forward circles
4. Repeat slowly 20 times in each direction
5. once every other day



1. Secure band in door, then hold elastic tubing with hand
2. Place arm out to side with elbow bent as shown
3. Move arm forward to straighten elbow
4. Hold 2 seconds, slowly relax
5. 20 repetitions, once every other day



1. Anchor middle of rubber tubing to solid object
2. Hold tubing in one hand (not two as shown), arm straight in front of you as shown
3. Pinch shoulder blades backward as you bend elbow and pull elbows straight backward
4. Hold 2 seconds and slowly relax
5. 20 repetitions once daily

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1. Sit on chair or table
2. Place rubber tubing around knees as shown
3. Spread knees apart as far as possible
4. Hold 3 seconds, slowly relax
5. 20 repetitions, once daily

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1. Stand holding elastic band with palm facing forward as shown
2. Bend elbow as shown
3. Hold 2 seconds, slowly lower
4. 20 repetitions, once every other day



1. Hold elastic band as shown, with moving hand on bottom
2. Straighten the elbow as shown, holding firmly to the other end to provide resistance
3. Hold 2 seconds, slowly relax
4. 20 repetitions, every other day

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1. Sit relaxed in the position shown
- 2 Place your hands on your abdomen
3. Breathe in slowly but deeply through your nose keeping shoulders relaxed and upper chest quiet allowing your abdomen to rise
4. Slowly breathe out through your mouth
5. Tighten your abdominal muscles and press with your hands to empty the air out of your lungs
6. Repeat 20 times, several times per day

## LUNCH AND AFTERNOON SESSIONS

After lunch, we discussed the presentation, talked about the Reno presentations that can be found on the [www.tma.org](http://www.tma.org) website and the upcoming patient conference that will be held again at the Caribe Royale Conference Center in Orlando from Thursday, September 10 through Sunday, September 13, 2015.

If you want to make a reservation for a handicapped room call the Caribe Royal Hotel and tell them you are with the TMA group on the above dates. We would like to get a feel for how many of our group might be considering going to the convention in September.

About four years ago the Sarasota SW KIT ordered shirts for ladies and men with the KIT logo on the breast. Dennis is trying to determine if we have enough interest in our own group to try this. It was quite neat when we were all in the SW KIT and all showed up with the shirts on. Let John or Dennis know if you are interested in ordering a shirt; [schelljh37@comcast.net](mailto:schelljh37@comcast.net) or [dennis2101@embarqmail.com](mailto:dennis2101@embarqmail.com). We need a minimum of 24 to order. I will get you the price soon.



Picture of members of the SW & Central Florida KITs



This logo will be on the shirts

We spent a little time on updates from the stem cell world. It seems that some have benefited and some have not. John Schell and Tom Smith are very sure that exercise is an important piece of the puzzle.

Pictures from the October Meeting (taken by Barb Clark)



### **Fund Raising**

Sherry Schell hosted a Myositis for Bridge event in conjunction with Myositis awareness month. And was able to send a nice contribution to TMA, for myositis research. Check it out go to [www.tma.org](http://www.tma.org) scroll down to the bottom of the page and look under member campaigns.

## **OPPORTUNITIES**

Marianne Moyers SW KIT does something that we think is most essential to a healthy KIT. That is, they have developed a list of Physicians in their area that are knowledgeable about the myositis myopathy. I think this is something we need to do, so this information is available, especially to new people.

We are looking for a volunteer who would be willing to compile this list so it is available to all. All we would have to do is send the names to that person to organize the list and then sent out to everyone via email.

Let John or Dennis know if you are interested: [schelljh37@comcast.net](mailto:schelljh37@comcast.net) or [dennis2101@embarqmail.com](mailto:dennis2101@embarqmail.com).

Finally we need your help.

If you have any ideas for speakers, especially Doctors who specialize in the myositis diseases and who would be willing to speak on a Saturday and bring us up to date from a medical standpoint. At this point we do not have a speaker for our January 31<sup>st</sup> 2015 meeting. We are also looking for sponsors to offset some of our food costs. We are working on a couple of ideas.

## **NEXT MEETING**

The next meeting will be Saturday, January 31<sup>st</sup> 2015



The following has been taken from the SW Florida KIT Newsletter that is of interest to all:

### **What's New at TMA**

TMA has been busy finding even more ways to serve our membership. Two of these initiatives include publishing on the website information about the Follastatin and BYM338 trials, and a new forum especially for those who are participating in, or are interested in learning more about these and other clinical trials for myositis treatments.

To get to the new forum go to [www.myositis.org](http://www.myositis.org) and under community forums, you should see one for clinical trials. If you don't, there is a link to View All and it will take you there. You can communicate directly with patients participating in the Follastatin and BYM338 trials.

Most exciting is how TMA is expanding its Myositis Awareness Day (MAD) support. This expansion is made possible by a grant from Questcor and will address both the medical community and us.

Many of us have experienced the feeling that we know more about myositis than our doctors. And we definitely know more about TMA than they do. Hopefully that is about to change. In the next month, TMA will send to about 2,000 doctors (mostly Rheumatologists and Neurologists) a package including a poster announcing Myositis Awareness Day, copies of Myositis 101 and A Physician's Guide to Myositis and other materials to remind them and their patients that TMA is here to help!

### **Myositis Dan Does His Bit for Myositis Awareness**

Running to an easy victory in his last race on July 14, Myositis Dan not only showed his ability to win but he got his name pronounced correctly by the race announcers! Neither is an easy task and we are proud of both. Now Dan is scheduled to run in a prestigious big-money race in Saratoga, the King's Bishop Stakes on August 23. Tune in on your Horse Racing Channel and you may be able to watch him run. And watch the word 'myositis' roll off those announcers' tongues!

### **TMA's 2015 Patient Conference Returns to Orlando**

In case you haven't heard, yes, once again the conference will be at the Caribe Royale from Thursday September 10 through Sunday, September 13, 2015. TMA and the hotel are already taking reservations so visit TMA's website and register. It's not too early if you are looking for a room to accommodate your myositis needs.

Also, we share newsletters with other support groups and so our KIT agreed that we'd like to spearhead contacting the other Florida groups (formed or forming) to consider how we might help TMA and also be welcoming to our myositis friends from around the world. More on this later!

**Change what you can, forget what you can't.**  
**Dennis Platt**  
[dennis32162@gmail.com](mailto:dennis32162@gmail.com)