



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

February, 2014 Edition

February 1, 2014 Meeting

We had 57 in attendance, including our “acting troupe” and their friends

Please note there are two other documents following this newsletter. Don't miss them!

Academy Award Performances at our February Meeting

This was a unique meeting that presented some different views of how myositis patients and their loved ones cope with and communicate about their ‘new normal’. From quotes like “It wasn’t supposed to be like this” or “I’m scared” to “I’m so lucky to have you”... each of the eight skits showed another aspect of what most of us are experiencing. Donna DeFant directed eight of her actor friends in a lighthearted look at life in a Myositis home. Marianne Moyer and Rose Ryan took the stories of many KIT members and consolidated them into stories that made us laugh, cry or just think... And for those who weren’t able to join us, you can still enjoy our skits. Go to our KIT’s Facebook page ([SW Florida Myositis K.I.T.](#)) and sit back to see the 47 minute video produced and edited by Penny Andrea-Einmo. If 47 minutes seems like a long time to sit, there is a synopsis of where in the video each skit begins. Since each is only about five minutes long, you can start and stop the video when you want. It is our hope that no one is upset that we used ‘their’ story and that by sharing these skits; we have opened up opportunities for patients and their families and friends to communicate about living with Myositis. In addition, we have provided the tape to TMA and their staff is working to make the videos available to other KITs and the general membership.

After each skit, Paula Falk from the Senior Friendship Centers led us in a brief review of our observations of that skit. We are grateful for her facilitation. And we are especially grateful to the actors and to Donna for sharing their time and talents with us. (We even discovered that one of the actors also has PM and didn’t even know about our KIT!)

On Page 3 of this newsletter is a program guide or “Play Bill” of the videos and how to access them. We thank Rose Ryan who created the paper Play Bill for the meeting. It was a great day and at the breakout sessions after lunch, there was opportunity to reflect on the various skits. It’s our hope that after the meeting, people were able to talk openly about what they’d seen and become more aware of their partners’ point of view.

May 3 Meeting...TBD

You may have noticed that this newsletter is a bit late in getting to you. My apologies but there have been a couple glitches (not the least of which is my proclivity to procrastinate!) I've not yet locked in a speaker for our May meeting though as soon as I do, I'll put out another notice to you. I'm hoping for a doctor to speak on a general Myositis topic so it will be relevant to us all. Stay tuned.

Holiday Party

Our KIT's holiday party once again was held at the University Country Club on December 7th. Thank you to the Carnevals and Karen Jacobs for making the arrangements. Our KIT really knows how to celebrate and enjoy each other's company.

A couple people have asked if instead of moving the party from 'NOS' to 'SOS' (that's north or south of the Skyway) each year, would we consider having two parties and members could choose which one to attend, or of course have the option to come to both. Hey, two parties offer twice the opportunities for fun so let's consider this for our 2014 celebrations.

TMA Annual Patient Conference in Reno Nevada

September 4-7, 2014

Peppermill Resort, Spa and Casino

Put this into your planner, I-pad, tablet, or whatever you use to keep track of your busy schedules! Room rates are just \$85, parking is free, there's free shuttle service from the airport and the resort looks lovely! Deadline for early bird registration, \$165, is May 31. After that it jumps to \$195 and after August 4 it goes to \$245. TMA will again offer financial aid for members having difficulty paying for registration and the hotel. The criteria for application will probably change a bit from last year so keep an eye out in your e-mail and plan to apply if you would like the help. Conversely, if you'd like to help TMA fund these 'scholarships', contact Bob Goldberg at TMA and he'd be happy to discuss your donation.

Because Reno is home to two huge aviation events, the Balloon Festival and Air Races and they are scheduled to be held around the same time as our conference, there may be some special offers and opportunities associated with them. You might want to hold off making your travel plans until you consider these fun events.

Keeping In Touch With Our Members

(Phone numbers provided in case you want to do just that; keep in touch!)

We were greatly saddened to hear that our member Peter Ruffalo (DM) died on January 5. Barb and Marianne attended his memorial service and our KIT made a donation to TMA in his memory. Our deepest condolences to Jayleen and we ask you to remember her in your prayers. 239-470-2873

Joanne Carnevale is again 'going under the knife', on March 26. It's going to be a discectomy and she'll become a bionic woman when it's over. Rods, pins and who-knows-what will soon hold her spine in place. Let's all remember her that day and pray that the surgeons take good care of her. 813-891-1885

Right after Thanksgiving Dennis Platt developed double pneumonia, and his lungs have not been good since then. He hasn't been out of his house in 3 months. We haven't seen him at one of our SW meetings in a while but he keeps in touch by publishing the Central Florida KIT newsletter. 561-252-1180

Jack Walsh paid for seats at the Feb meeting for him and Huey but that morning was just not feeling up to the drive (we can all relate to that, can't we?). We also missed him at the Holiday party. Hang in there Jack and we hope to see you another time! 941-423-1873

For these and ALL our KIT family, please remember them in your prayers and if you have a spare moment, call 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"!

Free to a Good Home

Marianne has a gently used shower chair with adjustable legs. If you want it, just call. 941-794-8350.

Who You Gonna Call? (No, not Ghostbusters!)

In January, I asked if you'd be willing to share the name(s) of doctors in your area, whom you would recommend to your friends. It doesn't matter if they are treating your Myositis or other medical issues. If you look at the last pages of this newsletter, you will see the names I've received so far. Please e-mail me with information for any doctors you recommend and even those you might not recommend. I often get calls from members or newly diagnosed patients asking if I can point them toward a doctor in their area. While TMA keeps a list of doctors, there's nothing like a local recommendation to give you a warm fuzzy. Please take a moment to call or e-mail Marianne with your recommendations.

Pill Factoid

Maybe everyone already knows this but I recently found a good website and link. I renewed a prescription for one of my blood pressure medicines and when I opened the bottle, was surprised to not see the large round white tablet I've been taking. Instead, the bottle was filled with green oval tablets. I went to www.drugs.com and the link for 'pill identifier'. Wow, there are 55 different formats of this medication but yes, my pharmacy sent the correct one; it was just different. At least I can rest easy that I'm taking the right medication, in the right dosage...

Program Guide to our KIT Skits

If you want to view our KIT Skits and what each one addresses; here's a quick program guide to the full 47-minute video. Go to <http://www.youtube.com/watch?v=C9MtMSQM6jw>

The first four minutes are Marianne introducing the idea of our skits. Then at approximately the following points, Donna DeFant introduces each skit and occasionally provides an 'aside' to the audience.

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| Skit 1 | 4:06 | "It's My Job" shows a caregiver who might just be a bit bossy with his IBM wife |
| Skit 2 | 11:39 | "Cleopatra, Queen of Denial" shows a lady who might not be fully acknowledging her condition |
| Skit 3 | 18:18 | "I have my Dignity" is about a lady dealing with the sometimes embarrassing facts of her new life |
| Skit 4 | 23:26 | "It's Not Supposed to Be Like This" shows what happens when life throws curve balls at our plans |
| Skit 5 | 29:50 | "Huh?" As if Myositis isn't bad enough; add the challenge of couples with 'hearing issues' |
| Skit 6 | 31:19 | "Long Distance Love" tells of a mom and daughter trying to 'help' each other from a distance |
| Skit 7 | 37:57 | "Keep on Keeping On" could be almost any of our KIT couples; how do we manage to 'keep on'? |
| Skit 8 | 41:33 | "One Day at A Time" is also any of us as we have to adjust to short term goals to manage |

The following is provided by our member, Don Klersy who provides it here for your information. Our KIT doesn't recommend or qualify the information herein. Note that TMA will soon publish a Physician's Guide to Myositis which covers all three forms of the disease and is meant to assist physicians with understanding and treating Myositis.

Sporadic Inclusion Body Myositis (sIBM):

An Information Sheet for General Practitioners (01/30/2014)

Introduction: Sporadic inclusion body myositis (sIBM) is a type of muscle disease. It is the most frequently acquired myopathy seen after age 50. It is a poorly understood, relentlessly progressive disorder. Weakness and atrophy of both proximal and distal skeletal muscles develop over months or years, leading to profound disability (wheelchair use). No effective treatment exists. **Incidence:** sIBM is age-related. Typical onset is ~60 with wide variation: 20% of cases show symptoms before 50. Prevalence is 15/million in the population, rising to 50/million in those over 50.

Presentation: Age of onset varies from the early forties on. Presentation varies widely. People are affected in slightly differing ways, to different degrees, and at various rates. Progression rate varies in different muscle groups, and the overall rate of progression also varies widely. Progression tends to be more rapid in men and in those with late onset disease. The quadriceps are often affected first; toe drop, falling, and tripping are common first symptoms. For some, sIBM begins with weakness in the wrists and fingers, causing difficulty pinching, buttoning, making a fist, and gripping objects. Commonly affected muscles: finger flexors, quadriceps, lower leg muscles with relative sparing of shoulder and hip abductors and neck muscles. Does not affect heart muscle. Muscle pain is seldom noted in the literature but commonly reported by patients. Commonly seen more often in men.

Differential diagnosis: sIBM is commonly initially misdiagnosed as polymyositis: if prednisone is administered with no improvement, further investigation is indicated. sIBM weakness comes on over months or years and progresses steadily (polymyositis tends to have an onset of weeks or months). Forms of muscular dystrophy (e.g. limb girdle, Becker) must be considered as well.

Diagnosis: CK levels are often raised (at most ~10X normal). EMG studies usually display abnormalities. Muscle biopsy may show several abnormalities, e.g.; inflammatory cells invading cells, vacuolar degeneration, and inclusions or plaques of abnormal proteins. A blood test for antibodies against cN1A (or NT5C1A) is now available. Even with a biopsy, sIBM can be difficult to diagnose.

Treatment: No therapy has been shown to be reliably effective. sIBM is resistant to immunosuppressive treatment. Corticosteroids, cytotoxic-immunosuppressive agents, anti-TNF (tumor necrosis factor) agents, interferon beta, and intravenous gamma globulin, have all been tried.

Management: Management is symptomatic with early awareness and monitoring of potential complications (depression, fatigue, dysphagia and respiratory involvement). Prevention of falls is an early, vital consideration. Integration of palliative care may be helpful at end stages.

Complications: Cause of death commonly relates to respiratory dysfunction, aspiration, dysphagia, and cachexia. In up to 85% of cases, patients develop progressive dysphagia. Respiratory dysfunction caused by diaphragmatic weakness may present as sleep apnea: reduced lung volumes may raise carbon dioxide levels in arterial blood (well addressed using a bi-pap machine).

Pathology: sIBM muscle is said to display two major problems occurring in parallel: 1) an autoimmune process (muscle fibers express MHC-I antigens triggering invasion by CD8+ lymphocytes) and 2) a degenerative process with accumulation of a variety of pathological proteins within the muscle cell. No cause or initial trigger event has been established. A complex interplay between environmental factors, genetic susceptibility and aging is implied. sIBM is not considered a genetic disorder however it may be predisposed by genetic factors.

References: Please see <http://www.ibmmysitis.com> for further information and references.

Written by Bill Tillier, reviewed by Dr. Steve Greenberg, Harvard University Medical School.

SW FL Myositis KIT Doctors and other Medical Professionals List

(List is sorted by city but can be re-sorted by specialty or disease type who recommended)

Specialty	Doctor	City, contact info	DX, Referring member	Notes (Date info rec'd)
Rheumatologist	Kenneth Crager	Bradenton 941-792-8329	PM Marianne Moyer	11-19-13 Has treated my PM since 2004; is very collaborative re meds and treatments
Rheumatologist	Kenneth Crager	Bradenton 941-792-8329	PM Lisa Elms	11-20-13 Is very collaborative
Neurologist	Ralph Gonzalez	Bradenton 941-746-3115	PM Lisa Elms	11-20-13
Rheumatologist	Brian McKinley	Bradenton 941-792-8329	PM/DM Linda Mulrooney	12-6-13 Linda's local doctor. Works well with Walker in PA. Is cautiously aggressive with medications
Pulmonologist	Michael Seeman	Bradenton 941-792-0611	PM Marianne Moyer	12-15-13 Has been treating me since 2010. Familiar with myositis. Works with my rheumatologist. Very practical.
Dermatologist	Bruce Fuller	Bradenton 941-792-5040	PM Marianne Moyer	12-15-13 Treating me since 6-13. Knows myositis and has doctorate in immunology
Rheumatologist	Westley Reeves	Gainesville 352-265-0139	PM Joanne Carnevale	12-11-13 Has been treating her since 2007. Works w/my other doctors; knows about myositis.
Pulmonologist	Dr. Faruqi	Gainesville 352-265-0139	PM Joanne Carnevale	12-11-13 has been treating her for ILD since 2007. Works with my doctors; knows about myositis
Physical Therapist	Janis Ballard Tranquil Touch PT	Lakewood Ranch 941-713-3131	IBM Sarah Dare	12-23-13 Does not accept insurance (\$85/hr) but comes to your home. Very qualified; researched myositis.
Neurologist	Lance Kim	Ocala 352-867-9877	DM Nilda Conrad	11-19-13 Has treated DM since 2007, is very collaborative re meds and treatments
Dermatologist	David Sax	Sarasota 941-360-2477 www.upderm.com	DM Donna DeFant	11-19-13 He tested me for DM and found it and referred me to a rheumatologist
Rheumatologist	Desmond O'Duffy	Sarasota 941-366-3062	DM Barb Kluding	11-25-13 He was head of rheumatology at the Mayo Clinic. Dr. Kelly is the other rheumatologist in the office.
Neurologist	Gregory Hanes	Sarasota (Healthplex) 941-917-6222	IBM Judy Kahl IBM Susan Prive	2-1-14 MDA doctor – well read, very thorough, knowledgeable about all three myositis diseases
Dermatologist	Heidi Anderson	Sarasota (Healthplex) 941-925 DOCS (3627)	DM Barb Kluding	2-1-14 Excellent; has an interest in myositis; is very thorough

Rheumatologist	Chad Walker	Scranton, PA 570-961-3823	PM/DM Linda Mulrooney	12-6-13 First appointment in May, 2013. Works well with McKinley
Neurologist	Alberto Vasquez	St Petersburg 727-824-7132	DM Kathy O'Connell	11-23-13 I have researched Myositis, asked many questions, and found my Dr to be very responsive to all of my needs.
Neurologist	Lora Katzen	Tampa USF 813-974-4115	DM Jan Marriott	2-1-14 Very knowledgeable about myositis; has several patients
Neurologist	Rossitza Chichkova	Tampa USF 813-250-2171	Several members with PM and IBM	2-1-14 Spoke to our KIT. Is especially interested in diagnosing myositis. Good listener.
Dermatologist	David Lam	Tarpon Springs 727-934-7638	PM Joanne Carnevale	12-11-13 Familiar with myositis. Also has offices in Tampa and New Port Richey
IVIG Infusion	Walgreen's	Throughout Florida 800-396-2933	PM Marianne Moyer	12-15-13 Got home infusions from them for two years. They handle insurance, ship meds and equipment
IVIG Infusion	MedPro RX	Throughout Florida 888-571-3100	PM Marianne Moyer	12-15-13 Getting home infusions from them since 6-13. They handle insurance; nurse is dependable; ship meds and equipment
Neurologist	Juliette Coleman	Venice 941-486-6600	DM June Paul	2-1-14 Good listener – communicates well with other doctors

These are medical professionals with whom at least one of us had a negative experience and therefore do not recommend

Specialty	Doctor	City	DX, Referring member	Notes (contact member for details)
Neurologist	Sanjay Yathiraj	Bradenton	PM Marianne Moyer PM Lisa Elms	
Dermatologist	Susan Weinkle	Bradenton	PM Marianne Moyer	