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May 2016 Myositis And You

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SW Florida Myositis K.I.T.

Our Meeting, May 7, 2016 Celebrated Myositis Awareness Month

May = Myositis And You

We had 60 in attendance, including two first-timers and their partners.

AND, we were thrilled to welcome 15 "friends" of members!

Highlights of our Meeting

My Webster's Dictionary defines *awareness* as: "having knowledge of something and especially of something that is not generally known or apparent". So it was easy for us to design our May meeting/event to raise *myositis awareness*. To accomplish this we first sought out a larger venue for our meeting and it's a good thing we did! It would have been a bit cramped to put our 60 attendees in our usual meeting space. Secondly we invited our KIT members to 'bring a friend' to the meeting. Many of us have friends, neighbors, co-workers or family members (even our spouses) who think they understand myositis but they only know it from the perspective of that one member. Our intent this day was to raise our friends' awareness so that they could see the dichotomy that no two myositis patients experience their disease the same and at the same time, our members have a lot in common. Four brave souls were willing to share what their experience with myositis has been like and how they are dealing with it.

Sue Prive spoke first, telling us about her journey as an IBM patient. She didn't hesitate to poke some fun at herself, saying she "…can't run, skip or jump…but not like she'd want to!" She spoke of the fatigue of daily life and how each day is a new challenge. Other members chimed in as well, offering examples of IBM informational articles, mobility aids, fall prevention and navigating around even in their own homes. Sue spoke about how her husband **Wayne** is more than a caregiver to her.

Jan Marriott has had DM for a number of years, dating back to when she was in the service. She currently is challenged with dysphagia (difficulty swallowing) and dysphonia (her vocal cords are affected). There were others who spoke up to say they share these challenges and that botox and juvederm have been shown to help. Jan suffered through several rounds of misdiagnosis [rosacea and measles?] and mistreatments (like the doctor who told her she might need to get more sunshine on her skin!). Jan receives Rituxan and IVIG infusions to help keep her going and she attributed much of her positive attitude to the support she receives from her friend **Sandy** and her mother-in-law, **Mary**.

Joanne Carnevale who has PM, has also had to contend with myriad other diseases and physical challenges. Among them is in 2007 she spent several months in the hospital when her PM flared up affecting her ability to breathe. She's had a kidney transplant and several operations (plus more to come) on her spine because her muscles have misaligned her back. She spoke of not being able to care for her latest grandchild as she had previous ones, because of her weakening condition. Acknowledging that husband Bernie sometimes has more to face with her myositis than she does, is a sentiment that many of us relate to.

If you were not able to attend our event, we are most grateful to Penny Andrea-Einmo who taped these three life stories and they can be seen on YouTube at:

SUSAN
https://www.youtube.com/watch?v=vhVcYbxpeJ4

JAN
https://www.youtube.com/watch?v=uUwChRFGqXw

JOANNE
https://www.youtube.com/watch?v=3KUg7wkb_xs

Then it was **Wayne Prive**'s turn to speak about his experience as Sue's caregiver. Whether we call our partners "caregivers, caretakers ;-) or care partners", there is no question that theirs is a challenging experience. For many of us, when we said, many years ago: "for better or worse, in sickness and health, for better or worse", we had no clue what we were promising! Wayne related that he thought that once he got married, he would never have to face cooking a meal and now he finds that this is something he does to help around the home. He shared that it's been difficult watching as Sue struggles with a disease that is still so unknown and misunderstood. There were many heads nodding in agreement as he spoke. We especially thank Wayne for his willingness to speak of his caregiver challenges. Several members when asked if they would speak, said it was just too difficult to articulate this difficult life they are leading.

Each of these courageous and articulate souls, Susan, Jan, Joanne and Wayne have done a great service to our KIT and to our friends who witnessed their stories. We are blessed to have been able to peek into their lives. And there is no question that "awareness" about myositis has been raised at a personal and intimate level. The day was a success by any measure! We also thank the others who either were prepared to stand in as 'presenters, like **Linda Sabatino** or **Jim and Donna Butler** who brought up some of the aids that work for them. We are blessed to have so many generous souls who want to help their KIT family members.

There were several references to specific pieces of equipment that people have found helpful. I have been unable to find them all but at the end of this newsletter; I've listed what I did find. I'll keep trying to find more.

After the presentations, we enjoyed a barbecue lunch sponsored by our good friend, **Susan Artabasy** and her company, Patient Care America. Desserts and water were donated by members as always and for all this, we are grateful.

After the morning's presentations, we lightened the mood by inviting **Ashley Strand**, a local comedian who has received awards for his stand-up comedy from as far away as the Hong Kong Comedy Festival. He regaled us with spoofs of Bass Pro Shops, Florida weather and how some of our members have little foibles worthy of a chuckle. Thank you Ashley, for sending us on our way with smiles on our faces!

TMA's 2016 Patient Conference Registration is Open

We hope you plan to attend the 2016 Conference in New Orleans. It's time to make your reservations. TMA's early-bird registration rate of $175 is only through **May 31** after which it goes up. Hotel rooms at the Hilton Riverside are $119. Handicapped rooms and roll-in shower rooms are going fast! We hope to see you there.

Our “Old Favorite Recipes” Party in March was GREAT

We continue to be grateful to **Camille and Ray Lesoine** who have hosted our in-between-the-meetings social gatherings. This one was a brainstorm of Camille’s, who invited us to bring a dish to share that has some significance in our family memories. There was some really comforting and delicious food, enjoyed by all who attended. *Camille prepared a lovely recipe booklet of the dishes served and it is another attachment to the e-mail sending this newsletter.*

Because Camille and Ray (and **PacMan**) are in Virginia, helping an ailing family member, we don’t have a date or plan for a July event but when we do, we’ll let you know. Remember these events are just for social time; no agenda. Just plan to come and spend time with your KIT family members.

Keeping In Touch With Our Members…

Several members are going through some very difficult times now. Please keep in touch with them through calls, e-mails, cards and prayers. Think how much a call would mean if it was you.

John Schell, (schelljh37@comcast.net 352-314-8953) is unable to get out of bed now; his IBM, coupled with recovering from his cancer surgery have combined to make it too difficult for him to be tiptoeing through the tulips!

Patches Bryan, (pbryan@greystonehcm.com 813-956-8838) has been doing a pretty good job of managing her IBM but when she was recently diagnosed with pancreatic cancer she decided to go to Johns Hopkins for special chemo treatments. She’ll be back in Florida in a month or so.

Lisa Elms, (lelms3@aol.com 941-749-0775) has had PM for many years but a recent bout of malignant melanoma has really caused her some new difficulties. Like falling…Ouch!

Jeanne Foster, (fosterjy@hotmail.com 239-823-4441) has been in the BYM388 trial and thought she was doing pretty well with it. Recent announcements from the drug company however, are not encouraging. Then Jeanne fell and of course it had to be her dominant wrist that broke!

Let’s end with some good news though! **Penny Andrea-Einmo** showed off her new nose after extensive MOHS and plastic surgery for skin cancer. She looked “mahvalous, dahling”. And at the meeting, it was the first time we’ve seen **Rose Ryan**’s wrist without some sort of cast or brace (remember that she broke it in a fall the day before last September’s TMA conference!) And you can’t keep a good man down; **John Moyer**’s second new knee is getting him around even better than the old one did! Let us all hope that any of our members who are facing issues will heal quickly and stay healthy!

BTW, about our Names…”redux”

Ok, I’m breaking the rule I made in the last newsletter. After being super cautious about not posting people’s names in the newsletter, I got a bunch of comments about that being a possible overkill of “PCness”. What’s a newsletter writer or editor to do? So here’s the decision we made. If you want to remain anonymous with either your printed name or picture, please let me know and of course we will honor your request. If you are okay with your moment in the limelight, you don’t have to do anything but ‘bask’ in it! Thanks for the feedback. Marianne

KITs are Popping Up all Over!

In our last newsletter, we were happy to report that there is finally a KIT forming in the Miami area. They had their first meeting in February and 14 people showed up for it. That's not bad considering that in 2007, for our KIT's first meeting, we only had three! (And we are now at over 180 and that's after the Central Florida group split off from us!)

Now we are thrilled to announce that on May 31, there will be the first meeting of the Florida Panhandle KIT, meeting in Panama City in the afternoon (that's a Tuesday). I think a lot of us got the invitation. If you know someone who might be interested in going or in 'keeping in touch' with this group, please let them know. They can contact Charlia at TMA.

Note that this makes SIX KITs in Florida. Wow and wow!

Keeping In Touch, Sadly…

We heard from two members' families recently, to let us know that their loved ones had passed away. One is **Stacy Morrison** whose mom, **Carolyn** had been a member of our KIT though she never attended a meeting. ALS was her cause of death, but we consider Carolyn to have been a KIT member. The other is **Jay Bailey**; whose husband **Mike** had IBM. I think they came to one meeting several years ago. Jay is now trying to divest herself of some practically new equipment they recently bought for Mike. If you are interested, or know anyone who can use these items, please contact her directly. She is 1mbailey@bellsouth.net located in Vero Beach.

Jet 3 Ultra Power Wheel Chair	(negotiable)
Bizee Transfer Board	$100
Invacare Auto Lift	$650
TI Lite Wheelchair	$500
Invacare Shower Wheelchair (new)	$350

We send our condolences to these two families and hope that they can find peace.

Our Next Meeting, Saturday August 6, 2016

We're working to getting a local Dermatologist to come and speak to us about skin issues for myositis patients. A few years ago, we might have thought that this would only be of interest to DM patients but we all know differently now. Anyone who is on prednisone knows what effect a short time in the sun can have. Skin cancer has reared its ugly head in at least three of us, all of whom were sporting scars, bandages and stitches at our May meeting. Pressure sores from sitting in a chair or scooter are nothing to take lightly. And the list of dermo concerns goes on. Please keep an eye out for our next meeting invitation, due to hit your e-mail inbox around July 9th. We plan to meet at our usual venue, the Sarasota Hospital HealthFit on Clark Road.

Also, don't forget that August is our anniversary month and you know what that means! CAKE! Help us celebrate our **ninth** anniversary meeting. We've come a long way from our first meeting on August 18, 2007.

What Would Our KIT do with $50,000?

Did that get your attention? Some of you know that your KIT's leaders have recently applied for several grants, trying to raise extra money for our KIT. Why, you may ask? In several grant applications, we've specified the following proposed uses for any funding we raise:

1. We'd like to do what TMA is doing, to help our members attend the annual patient conference. Currently registration for the conference is $175 and a hotel room in New Orleans is $119 per night. So for a member and their caregiver to attend for four days, the cost would be over $800. Add in the tax that the hotel will charge and you might as well round this off to $1,000. And then there is transportation and some meals. TMA's financial aid provides for conference registration and hotel and we'd like to do the same for as many as ten KIT members and their caregivers.
2. During Myositis Awareness Month, many of us have tried to spread the word to our doctors about what they need to know about diagnosing and treating Myositis. We would like to initiate a real campaign with press, materials, mailings and activities; not just in May but through the year, to help the medical community here in Southwest Florida to be the leaders in Myositis Awareness and treatment.
3. Our current meeting room is becoming very cramped and it may be time to look for another spot for our quarterly meetings. To facilitate a group our size is likely to cost us at least $200 per meeting.

So where can we get this money? Those of us living in the Manatee/Sarasota County area have probably heard of and maybe participated in what has been called "Giving Partners". It is a one day on-line event to raise *awareness* (there's that word again) and money for local non-profits.

Some statistics from 2015's event:

- 449 non-profits participated
- There were approximately 36,500 donations made
- They raised about $6,674,600 in just 24 hours of on-line giving
- Many of the non-profits are familiar (everything from Cat Depot to Marie Selby Gardens to Habitat for Humanity). But one of the biggest success stories came from a disease foundation called Phelan McDermid Syndrome that raised almost $75,000! What if SW FL KIT and TMA raised that kind of money?
- All a donor has to do is click on the Giving Partner website during the specified 24-hour period on September 21, 2016, choose the non-profit they want to support and designate an amount to donate (there is a $25 minimum). To visit their website (without donating), go to www.thegivingpartner.guidestar.org and look around.

I'll stop now to let this sink in. In our next newsletter you will hear more. Hopefully you will consider this opportunity and will let your friends and neighbors know through social media or word of mouth about this incredible way to support our KIT and TMA.

Equipment mentioned at the May, Myositis Awareness Meeting and Event

EZ-Step www.ez-step.com made locally here in FL and the inventor has visited our KIT in the past. This special cane features:

- walking stability of a standard quad cane
- reduce the pain of stair climbing
- make stairways easier to go up and down
- work on any kind of stairway (or to get in and out of a pool)
- very lightweight

Golden Lift chairs: www.goldentech.com can offer not only forward push but also provides vertical lift as well. Free shipping in some cases.

Belts: I didn't find a particular manufacturer for a webbed belt that is recommended to help someone who is trying to help you get up from a fall. A medical supply company can provide one.

Leg braces: will let you know when we hear from the Butlers with their recommendation…

TMA's community forum www.myositis.org has many discussion threads about the pros and cons of various pieces of equipment.

Thank you to our Friends and Sponsors

EZ-STEP
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