SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly August, 2014 Edition

August 2, 2014 Meeting

We had 36 in attendance, including one first-timer (Welcome Ruth P!)

Brett Walker, Walgreen's Pharmacist

Ah, our medications. How we hate them and how we know we need them…or at least our doctors think we do. Our speaker at this meeting was Brett Walker who walked us through the myriad of drugs that are used to treat myositis. (Note: Brett was unable to show his slide presentation because once again the projector in our meeting room was uncooperative. Apologies to all and we think we have the situation corrected. Brett's presentation is attached to this newsletter's e-mail). Despite the technical challenges, Brett was most adept at handling our questions and concerns (even one on medical marijuana—not yet recommended for us) and Susan Artabasy from Walgreens Infusion services also helped. It is especially nice to know that Brett includes his contact information on his last slide and has offered to be a contact for anyone with additional or confidential questions.

Stem Cell Treatment Discussion

A number of us attended the Central Florida KIT meeting last week and reported back on what we learned. Dr. Gionas and Dr. Nia from the Boca Raton Stem Cell Center presented an overview of the treatment they developed for several diseases and conditions, one of which is IBM (and also PM and DM). Also at the meeting were five KIT members who have received the treatment. Three of the five spoke of and demonstrated some amazing results. The other two have not had time to experience any improvement yet. The Q&A session revealed some interesting information and we will all keep our eyes and ears open for future developments. At least one more SW FL KIT member has signed up for the treatment and we hope to hear more after he returns. If you would like more information, visit www.miamistemcellsusa.com or contact Marianne for names of those who received the treatment.

Special Thanks to John Stocker of EZ-Step

John is the new owner of the company that produces the EZ-Step which helps us by cutting those challenging stairs in half. He donated one for our doorprize drawing and Linda B who won it says it will come in very handy. Go to www.ez-step.com for more information and be sure to mention our KIT! Thanks John and best wishes in your new business venture helping people like US!

Seven Years of Our KIT!

And what better way to celebrate than with a decadent chocolate cake! The chocoholics among us were thrilled with this year's cake and the more conservative among us enjoyed two sugar-free offerings that were homemade by Jan M. Yummy!

To help us reflect on the past seven years, we distributed "Our KIT's History" that details each KIT meeting, event and celebration. An electronic copy is attached to this newsletter's e-mail. We've come a long way, Baby!

TMA Annual Patient Conference in Reno Nevada
September 4-7, 2014
Peppermill Resort, Spa and Casino

At the KIT meeting, it appeared that very few of us plan to attend this year's conference. Those of us who do go will come back, prepared to give full reports of what we learned, at our KIT's November meeting. Please plan to join us November 1!

Keeping In Touch With Our Members

As always, we circulated cards for members unable to attend for health or other reasons. They include some very sad news. We signed a card to Martha S, whose husband Ernest succumbed to his IBM and heart issues. Millie H's family let us know that she passed away in May. Bob R had been hospitalized for swallowing and lung issues and died in June and we offered our thoughts and prayers to Mary Jane. Gloria M has left this earth and we sent our condolences to her husband, Rich. That is four IBM members who have passed on since our last meeting. It's just one more reminder that we need to live each day to the fullest… We also sent a card to Joan R and Nancy G, both of whom broke bones recently. We pray for their speedy recovery. Finally, Sandi R has returned home from rehab where she too was dealing with a broken bone. NO more falling Sandi!

Doctor Referrals

We continue to develop our list of doctors whom you would recommend to your friends. It doesn't matter if they are treating your Myositis or other issues. I often get calls from members or newly diagnosed patients asking if I can recommend a doctor in their area. TMA keeps a list of doctors, but there's nothing like a *local* recommendation. If you'd like a copy of the list, please contact Marianne.

When a Quarterly KIT Meeting is Just Not Enough

We've been hearing through the KIT leader network that some groups meet monthly! Wow; that's cool but not practical for a group as large and geographically diverse as ours; especially for a full-blown KIT meeting. But since many of us think one of the best parts of our meetings is the fellowship, we've decided to expand on that. Starting next month, at the mid-way point between 'official' meetings, we will offer an opportunity for anyone who wants to, to get together for lunch; alternating locations either to the north of Sarasota, or to the south. Camille L has volunteered to organize this.

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When a Quarterly KIT Meeting is Just Not Enough (cont'd)

We have scheduled our first "Social KIT Meeting". It will be south of our usual meeting space in Sarasota. It's open to anyone (KIT members, family and friends) regardless of where they live. But hopefully it's an easier drive for our southern members. The date will be **Saturday, September 20**, and we'll plan to arrive around 1:00 p.m. This is the day before Myositis Awareness Day so let's celebrate! And if you still haven't gotten a WinPin, let me know and I'll bring some!

We'll meet at the **Olde World Restaurant**. The address is 14415 Tamiami Trail, North Port 34287. They have a varied and affordable menu and come highly recommended by Penny. No reservations are needed and we'll ask for tables in the back and push them together as we need. No agenda. No handouts. Just time to be with the folks we love. Watch your e-mail for a reminder.

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.myoisitis.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!

September 21 is Myositis Awareness Day, but some of us are unsure how to spread the word about it. Now, we have a way to expand myositis awareness AND also participate in a fun contest! Here's how:

- Each of us is asked to wear a WinPin during the month of September. Wear it to work, shopping, out with friends or wherever you go. When someone asks about what it is and why you are wearing it, give them a short 'elevator' speech about your experience with myositis. (Do you have it or are you a family member of a patient?) Then show them as you click the button on the top of the pin and watch the electronic counter track that you have just raised myositis awareness in another person. At the end of September, I'll send an e-mail to the KIT asking, on the honor system, how many 'clicks' you have logged on your WinPin. The top two (one patient and one 'partner') will get to choose a $100 gift card from one of several attractive retailers/restaurants.

WinPin Contest info (cont'd)

- You say you don't have a WinPin yet? If you didn't attend our meeting or receive one through another way, please contact me NOW. I will mail one to you in time for you to start using it September 1st. Call me on 941-794-8350 or e-mail Marianne.moyer@verizon.net. Do it now!
- If you are with folks who already know about myositis, tell them more. Seize the opportunity to share with them about our KIT or TMA or how YOU are doing. (And you get to add another 'click'!)
- Finally, if you feel comfortable, consider asking the person if they'd like to make a contribution to TMA. While MAD is NOT about fundraising, many of us have friends and relatives who know about TMA and want to help. You probably know about the three current ways to donate: mail a check, call TMA's 800 number or give on line. But now there is a new and even easier way to donate. It's a special matching offer during September, 2014 only. It's called Text to Donate $10, and you've probably seen it on TV for appeals like ones from the Red Cross.
- Text to donate $10 during September, 2014. TMA will receive from the EveryLife Foundation, a matching grant, up to $1,000, for donations to our 'text to donate' program. This is a one-month offer, though TMA will consider extending the program (without the match) beyond September. To participate, cell phone users access their phone's 'text' option and enter **85944**. When prompted to enter a text message, they type in **RARE** (EveryLife supports non-profits who support rare diseases). The user will then receive a reply to verify they wish to make a $10 donation and upon confirmation, a $10 charge will be added to their cellular phone bill. TMA will then receive $20 ($10 from the donor, $10 from EveryLife.) KIT members are encouraged to also ask family and friends to participate by texting to donate in September. (I'll remind you of this around September 1).
- This is also a simple message to deliver via your personal Facebook page or other social medium.

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!

A Word About our KIT Meeting Breakout Groups

There have been comments about there not being a fair distribution of 'talk time' in some groups. No names or finger-pointing. But if you find yourself in a group where this is happening, it's ok to remind someone who's been talking more than a few minutes to suggest there may be others who would like to speak. It should be an objective of each group that everyone gets a chance to say what's on their mind. If they choose not to speak up, that is their privilege but at least they were asked. Thanks everyone.

Our Next Meeting November 1, 2014

Those who attended TMA's conference (either in person or via the live feed from Reno) can share what they learned. We will reflect on how the 'Social KIT' lunch in September worked. And we'll plan the next one which will be our Holiday Soiree in December. Till then, be well, and Keep in Touch!

Photos on the following page were taken by Penny A-E—many thanks to her!

Above: Our speaker Brett Walker (with a little help from his friend Susan)

Below: look at that chocolate-raspberry decadence!