



SW FL KIT Meeting Tuesday, May 1, 2018

**Triple Delight: KIT Meeting, Awareness Event and Fundraiser for TMA and our KIT
42 people attended including one first-time couple
And five new 'partners'**

And what a meeting it was! First, let's mention the people. First timers **Barbara and Dwight Logan** live in Osprey. Barbara has DM and Dwight who is visually impaired, came with his service dog, **Puck**. No, he's not named for a character from A Midsummer Night's Dream. Dwight and Barbara are hockey fans.

The five new partners came because KIT members invited them to come and learn more about myositis. This meeting was a soft version of a Myositis Awareness meeting and we're glad that **Linda Sabatino** brought her sister, **Mary Moore**, **John Setzer** brought **Les Winters** and both the **Moyers** and **Lesoines** invited **Barry and Cathy Malmrose**. By the way, we call them partners because that's what our family and friends become once they know a bit more about myositis and how it impacts our lives. Call them friends, caregivers, carepartners, or whatever; we are grateful for them and their caring.

For a Tuesday meeting and one that included the scary word "fundraiser" in its name, this was a great turn-out. Catering was billed as free comfort food and it was! **Rose Ryan** ordered 'meet and greet' goodies and lunch from our local Cracker Barrel. We ordered just enough for everyone and some people got seconds or thirds (!) and we still had enough left to take to a local shelter. It appears that we've found our new food source! No meal would be complete without dessert so our good friend **Connie Ramos** of Diplomat Infusion brought two platters of delicious Detweiller's cookies. Connie also brought a friend Margie Piering from CSL Behring. We have heard that Behring will soon open a trial of subcutaneous IG for DM patients. More later.

The "Meat of the Meeting"

Almost everyone could get some 'meat' from **Marianne Moyer's** presentation about [How to Manage Your Medical Team](#). With input from doctor friends, other patients and the internet, she described how to make our relationships with our medical team most effective. Preparing for an appointment might include writing down your current situation and what questions you want answered at an appointment. Recording or taking a buddy along to help you to remember what was said can be invaluable. Keeping your records can be as techie as putting it all on your phone, tablet or computer or as basic as keeping it filed in a binder. The important part is to get and keep your relevant files and put them somewhere accessible later. She showed examples of the files she keeps including her 'monster' file, a half dozen taped together grid sheets tracking her disease components (CPK and meds) over time. Whatever works for YOU is whatever you should do. And as the ad says: Just Do It!

The REAL Meat of the Meeting - FUNDRAISING

Just as in 2016 when we participated in the Sarasota Community Foundation's Giving Challenge, we weren't sure what to expect in terms of response (translation: donations). We know it's hard for most of us to ask friends and family to donate to our cause. But we felt it was worth the effort to apply to participate in this year's Giving Challenge.

Participating in the Challenge is not easy! Our KIT's Marianne and TMA's Bob Goldberg spent countless hours producing a profile of what and who TMA and our KIT are. We documented this on a website, the Giving Partner; you can visit at www.thegivingpartner.org and read what we submitted. Based on our input, we were one of almost 600 local charities to be approved to participate in the 24-hour challenge.

While the Sarasota Community Foundation is largely responsible for organizing the Challenge, we must give a huge 'thank you' to the Patterson Foundation who provided the matching money. They do this to stimulate philanthropy in the local community. Our part in the challenge is a bit complicated because the donations must be made to a 501(c)3, non-profit organization. TMA is just such an organization. The matching dollars will come to our KIT and must be spent on local initiatives. This is why we can't turn around and give some of our money to TMA or another cause. See another article in this newsletter about this year's scholarships.

In addition to our gratitude for the Sarasota and Patterson Foundations, other sponsors made this event possible: SNN Suncoast News, Herald Tribune, Knight and Selby Foundations, Harbor Style, and the Manatee Community Foundation. We are blessed to live in such a giving community!

Now for the good news in case you haven't heard. There were 142 separate donors from 25 states who gave \$13,390 to TMA. This resulted in approximately \$12,130 in matching funds for our KIT. The numbers aren't final and there will be a small service charge assessed to TMA. Regardless, it was a phenomenal success and we couldn't have done it without all of you! Many of the donations specified that TMA use the funds for Research which we recommended. Also, many donations were in memory or honor of friends, family and KIT members. What a wonderful testimony to our KIT members! If you would like to know if someone you asked did give so you can thank them, contact Marianne who has the list of all donors. (From all the familiar family names on it, it's clear that many of you did reach out!)

From Rose: Update On our Many Attempts to Have Streaming Video

As I keep saying, I am not a computer or tech person. The Fab 5 has worked with consultants (now on our 3rd) to get streaming video of our meeting to those of you who cannot attend. When Marianne asked TMA about how to do this, they said "it's easy." Well - it is not easy. There are many ways to do this and all require many pieces of equipment that talk to each other. We have tried Hangouts with YouTube without success. We are now working with Facebook which in some ways is easier.

Most of the issues are the equipment. The speakers will not talk to the computer. The camera will not talk to the computer. The microphone will not talk to the computer or the speakers. See where I am going with this?

I am currently working with a teacher who is a techie teaching video production. Through his research he has found that the equipment we have is not completely compatible. We have ordered a new camera and have software that will zoom the cameras. He is researching how to make this all work together and have the computer save the settings so I do not have to set up the system every time. All I will have to do is open the computer and hook up all the cables and piece-parts.

I cannot promise we will have this working for our August meeting, but we will do everything we can to make it happen. The professionals make it look so easy. But we are not professionals. We are patients and family who just want to Keep in Touch.

If there is anyone out there who understands this please raise your hand and help. We will also need a second person to get trained as a backup.

Note from Marianne: Rose claims to not be a techie but she is more so than I, thus I asked her to prepare the article above. Also, please know that we order all our equipment and peripherals from Amazon; they are usually the least expensive and as in the case of our cameras, are willing to accept returns. We continue to try to provide a least expensive but totally workable solution. Bear with us please.

Conference News and Scholarship Announcements

TMA's 2018 Annual Patient Conference will be September 6-9, 2018 at the Louisville Marriott Downtown. For those who have never attended one of these events, it is an incredible opportunity to learn more about myositis. And the learning does not just come from the many medical experts in attendance. Sometimes the biggest 'aha' comes when we are at lunch with someone who shares a similar symptom, concern or solution. Some people have described these conferences as a KIT meeting on steroids—for four days!

Because this is such a fabulous opportunity, our KIT designated during the 2016 and 2018 Giving Challenges that some of our money would go for scholarships to send our KIT members and a companion to the conference. Our KIT works with TMA to have our scholarship recipients' hotel rooms and conference registration covered by our KIT, amounting to about \$1,050 per couple. They will be responsible for their own transportation and incidentals.

This year there were nine applicants for scholarship and all nine were approved by a unanimous vote by an anonymous team of three of our KIT members. They did not see any identifying information on the application so the voting was completely objective. Each recipient has promised to come to our November KIT meeting to share what they and their partner learned. This is a valuable way to share the knowledge provided at the conference.

For those not attending this year, we offer two suggestions. First; watch live the presentations from the conference. TMA will send info on how to do this. You can also go to TMA's website to view both this year's and previous years' presentations. Second, consider applying for a scholarship next year. The focus is not on financial need but more on what the member offers as their reason for wanting to attend and what they hope to bring back to the KIT.

Another Conference Item – The Reception

As in years past, TMA will host a free wine and cheese reception on Friday evening after the day's presentations have ended. And again, each KIT is invited to set up a small display of what makes their KIT unique. As a special incentive, **LaDonna Johnson**, TMA's Member Services Manager, has asked each KIT to find one word that first comes to mind when we think of our group. We started talking about this at the May meeting and the best we could do was to find 13 words that describe us. Now we need to find the ONE best word. There will be e-mail about this for you to vote on your choice.

Besides the display board with our "word", we will have pictures and other graphics to tell our story. If you would like to provide input for our board, or be one of our KIT's representatives that evening please let Marianne know.

One Last Conference Item – Dinner Friday!

If you are planning to attend on your own (not on a scholarship), please let Marianne know. We are planning a light dinner in the hotel Porch restaurant, probably Friday night after the reception (you will still be hungry) and would like all our KIT members to be invited. We just need to know who's coming!

Bob Goldberg Reflects...

TMA is 25 years young this year and there are many milestones to mark this occasion. One that we will all feel is the retirement of Bob Goldberg, TMA's Executive Director for the past 13 years. He has helped this organization in ways too numerous to mention but primary has to be his fundraising skills and how TMA has helped research in myositis diseases to progress. We don't know who will be filling his spot but we hope s/he has very big feet because Bob leaves some big shoes to fill!

As he leaves, Bob will be opening up to TMA members as he reflects on the last 25 years. He will lead a live chat conversation on Friday, May 18 at 4:00 Eastern Time. You may submit questions or comments in advance on TMA's website. Be sure to tune in to hear what our 'fearless leader' has to say.

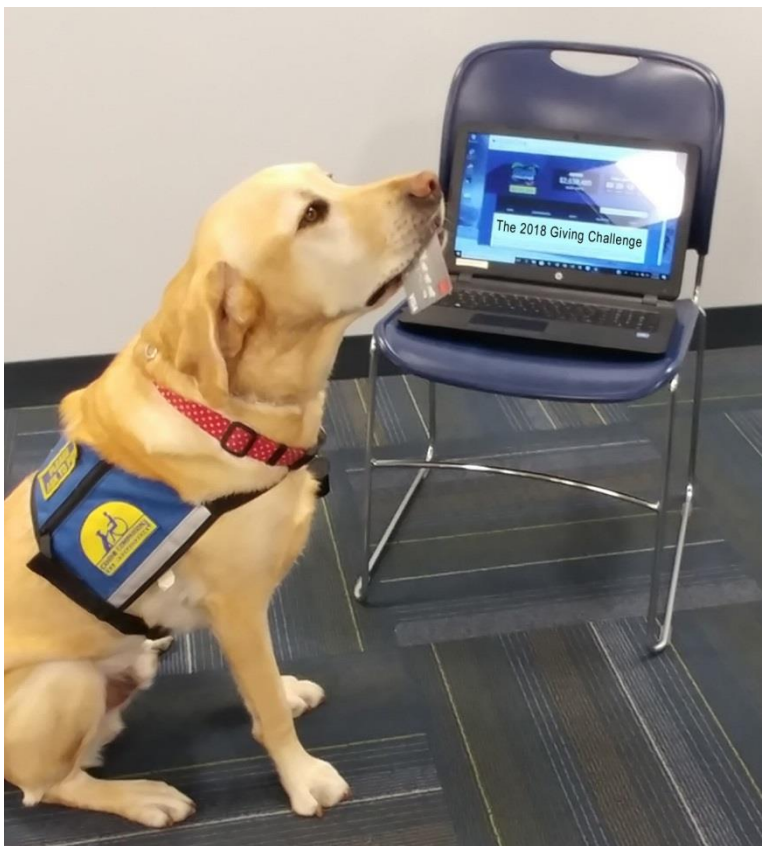
Our Next Meeting – August 4, 2018

Again we call upon our KIT's rich source of information and Linda Sabatino will be our presenter at this 11th Anniversary meeting. As a retired IT manager, she has varied and wide experience in all that techie stuff that some of us lack. She's titled her talk "Safe Surfing" and will present tips on how to navigate the internet to find good healthcare information. Since TMA's new website will be up and running by then, she will also help us find the best parts of it.

August is a time when many of our members are cooling their heels in their northern abodes. We will miss them but will think of them as we cut our 11th Anniversary Cake! Remember you can always bring a friend to our meetings. This topic should prove to be another that is not just relevant to myositis patients and their partners but all of us.

A Different Way to Spread Myositis Awareness

You just never know when you will have an opportunity to share our story. After the May meeting as we were packing up all the paraphernalia it takes to supply a meeting, **John Moyer** went out to the front of the building where he had painstakingly put up our KIT's banner. It was gone! We stood there for a few minutes trying to figure out what could have happened to it. There was no hurricane to blow it away. We didn't think anyone would steal it. It wasn't in the dumpster. So we figured it had to be the building management. We found and called the manager and sure enough, he had taken it down and luckily for us, taken it home with him. Apparently no one told us the building has a "no signs" policy. He took the sign home because he intended to try to find us the next day (he even went on TMA's website listed on our banner). When we went to pick it up and thank him, he asked about our group so of course he got the full story. You just never know...



**We Said There Were 142 Donors...but we didn't say they were all human...
Ray Lesoine's Service Dog, PacMan couldn't wait to make his donation.**



Thank you to our Friends and Sponsors



SAFETY • STABILITY • SECURITY