



Highlights of our Meeting

First, we welcomed two new KIT members, both of whom found us through TMA's website. **We had 31 in attendance, including two first-timers.** Both **Kevin Darby** and **Brenda Bacon** have IBM and had perfect timing; finding us just in time to attend our meeting.



★ Welcome Kevin Darby and Brenda Bacon ★

Keeping with our fall meeting tradition, our presentations this day were provided by our members who attended either live or via streaming video, TMA's annual patient conference. This year the conference was held in New Orleans and the theme, taken from reflections on how this city has rebounded from the tragedy of Hurricane Katrina, was "Resilience and Recovery". What an apropos theme for those of us who live with myositis!

As each of our members, **Andrea Sledjeski**, **Judy Kahl**, **Barb** and **Matt Kluding** and **Marianne Moyer** recounted their experience at the conference, we used a laptop connected to TMA's website to show the slides or videos of the sessions being described. For those who haven't yet accessed these presentations, please visit www.myositis.org and click on the 2016 Conference then scroll down through the list of presentations. Not all are available but most are.

Sessions that were particularly meaningful were What Happens When You Exercise, Understanding Myositis Medications, Building Resilience: Strategies that Work to Manage Depression and Stress, Reports from TMA's Medical Advisory Board, Beyond Prednisone: Towards a Better Alternative, and at the end of the conference, Comedian Brad Nieder.

Camille and **Ray Lesoine** were not with us at this meeting but both were presenters at the conference. Ray spoke about "A Full Life: What to Do When You Can't Do What You Used to Do" (something he exemplifies every day!) He also joined with Bob Greene to update Veterans Find Support. Camille presented Share Your Favorite Strategies and Devices, again, something on which she and Ray have become experts. Camille told us that the two of them decided against attending any of the regular sessions because this year they wanted to concentrate on visiting with friends from around the country and also all the exhibiting vendors. Now that's not a bad strategy! (Pacman agreed!)

KIT Dinner at the Conference

Thank you to **Andrea Sledjeski** who organized a wonderful dinner for our KIT members and their partners at the Hotel Restaurant. The roasted oysters were a special favorite!

KIT Fair at the Conference

Thursday at the conference was a special event to feature KIT membership. We proudly showed off our group portrait taken at the Orlando conference and added it to a display of some of our accomplishments. We also offered help to non-members in finding their nearest KIT. And just like last year, there was free wine and cheese. A nice new tradition!

TMA's 2017 Patient Conference

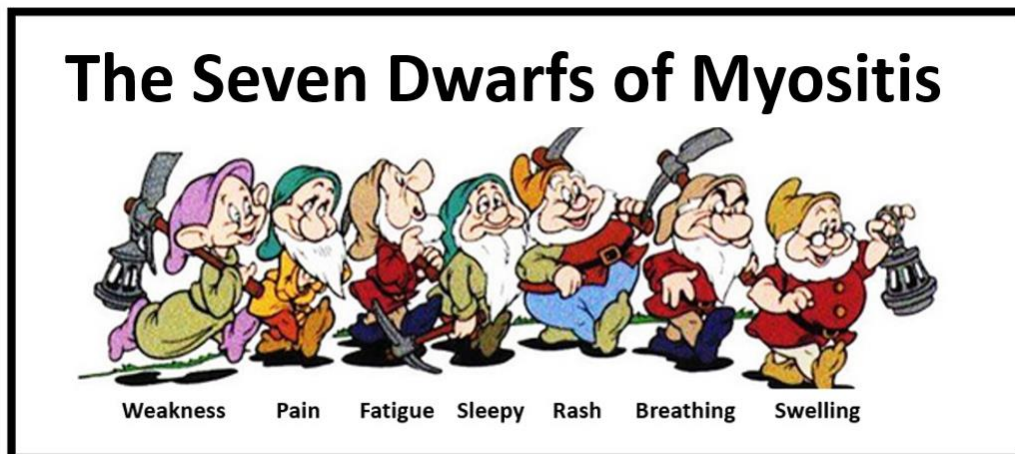
If the above article was enticing to you, we hope you plan to attend the 2017 conference in San Diego from September 7-10. TMA will announce early-bird registration and hotel rates in January. Remember that handicap rooms go quickly so be ready to register as soon as TMA sends the e-mail. We hope to see you there.

Keeping In Touch With Our Members...

As always, unfortunately, several of our members are going through some difficult times. Please keep in touch with them through calls, e-mails, cards and prayers. Think how much a call would mean if it was you. **Lisa Elms**, (lelms3@aol.com 941-749-0775) has put her recent bout of malignant melanoma behind her but now must deal with diverticulitis and a hysterectomy in December. This is not how she should be starting the holiday season!

Joanne Carnevale (jcarnevale@tampabay.rr.com 813-891-1885) will be enduring several additional surgeries on her neck and back over the next few months. If the choice is surgeries or wheelchair, we know which way our girl will go!

Joan Rinken (joanrinken@hotmail.com 630-243-0183) decided to try flying without a plane or wings and the resulting fall broke several ribs and her clavicle. Next time, Joan, try flapping your arms a bit harder! At the meeting we signed cards to **Charlie Childes** who lost his partner **Gary Aube** and to **Paul McQuay** whose wife, **Shirl** who had IBM, recently passed on. Our deepest sympathies go to them and their families.



Our Next Meeting, Saturday February 4, 2017
A Very Special Two-Part Presentation on
Myositis Research

TMA recently announced a milestone of providing over \$6 million in grant money to myositis researchers. While this amount to most of us is a pretty large number, in the world of medical research, it's a drop in the bucket. Our KIT has helped TMA fund some of this research but there is more to the story than just money.

For our February meeting which is generally our best-attended (welcome back winter visitors!), we will provide some insight into what's going on in the world of myositis research. Our first presentation that day will be delivered by folks from Bristol Myers Squibb who are preparing to roll out a new medication targeting PM and DM patients. Their presentation will walk us through why it takes so long (and so much money) to take a medication from concept to market. In the afternoon, one of TMA's best-loved conference presenters, Dr. Chester Oddis from the University of Pittsburgh, will speak about Myositis Research: Past, Present and Future.

As in the past, we will hold this meeting at the Mixon's Fruit Farm Conference Center in Bradenton. There is plenty of parking, the food is great and the real-orange-juice ice cream is fabulous. Watch for your e-mail invitation around January 7, 2017!

Speaking of Future Meetings...

Your KIT leaders (Barb, Camille, Donna, Marianne and Rose) are already planning our May Myositis Awareness Event. Our 2016 effort was a tremendous success and in 2017, we plan to surpass that in a number of ways. Be sure to watch for more information about it!

Holiday Potluck Party Saturday, December 10 at 1 p.m. at the Lesoine's
(This date is one week later than what we published on our 2016 calendar!)

This year we are again combining two traditions; our holiday party and our social gatherings between meetings. For the potluck, please bring a dish to share and the Lesoines will provide plates and utensils, soft drinks and cocktail punch. BYOB if you want something else.

What we will be doing differently is our gift practice. Camille suggested that we bring a new, unwrapped toy to be donated to Toys for Tots. This is totally optional.

An invitation e-mail has been sent to you. RSVP to Lesoinefamily@aol.com or call (941) 417-7647.

Ray and Camille Lesoine's: 11406 Walden Loop, Parrish, FL 34219. Their home is accessible with ramp, high toilet with grab bars, and ample room for wheelchairs, scooters, and walkers. We hope to see you there!

Let's Talk About M-O-N-E-Y!

It should come as no surprise to anyone reading this newsletter that when our KIT members decide to do something, they don't do it half-way. The September Giving Challenge was one huge example of this 'can-do' attitude. You have already seen several e-mails and newsletters telling you how this single 24-hour on-line donation opportunity raised over \$14,000 for TMA and about \$21,000 for our KIT. (These numbers are approximate at this time because the final accounting of donations won't be available until November 30.) Regardless of the final amounts, this was a tremendous first effort in this arena.

Our KIT, as part of the grant request process, had to designate how we intended to allocate the money we raised. As such, we decided to plan to provide up to \$10,000 for scholarships for our KIT members to attend TMA's 2017 conference. (More on this in a minute.) The next \$5,000 we designated for our aforementioned 2017 Myositis Awareness Event. (More on that too.)

The details of the [scholarship process](#) and timelines are still under development but we can share the following:

- KIT members may apply for themselves and a partner to attend the 2017 conference
- Scholarships will cover two conference registrations and three nights in the conference hotel (double occupancy) for up to ten members
- Three members of our KIT (who for now will remain un-named) will be the determining body and this group will be led by Donna DeFant who will be a non-voting member
- We will e-mail an application to our members around January 1
- Applications will be due back by April 1 and 'winners' will be announced by April 15
- This timetable will allow those who won to begin planning for their transportation costs to San Diego. Those who did not win can still apply for TMA's conference financial aid
- Details will be provided on January 1. Until then, that's all the information available.

Details about the [May Myositis Awareness event](#) are very preliminary at this time. Some ideas under review are:

- Hold a doctors' symposium for local Rheumatologists, Neurologists, Family Practitioners and others—to be presented by one or two of TMA's MAB members and probably provide continuing education units for attendees
- Hold a second event, presented by the same MAB doctors, for our members and friends (possibly again in the format of a 'bring a friend')
- Visit local medical offices to provide myositis materials and maybe even a cookie tray
- Contact local media outlets to get interviews with our members about the value of support groups and having a means of getting information from sources other than our doctors

And About That "Extra" Money...

As mentioned above, when we started the process to participate in the Giving Challenge, we had no idea what to expect in the way of donations. We thought we were setting a pretty lofty goal of raising between \$10,000 and \$15,000 for our KIT. As the donations began to pour in, it became clear that we'd be receiving more than we dreamed! Currently, it appears that our KIT will receive approximately \$21,000. Since in our grant application we only specified plans for \$15,000 we needed to consider what to do with the other approximately \$6,000.

About a month ago, an e-mail was sent to all KIT members, asking their input on this topic and we received 19 responses with 13 saying we should give some of that money to TMA and keep the rest, and six members said we should keep it all.

At the meeting we had a lively discussion about this and after a while it became clear that the overwhelming desire of all present was to keep all the money and use it for one of several possible projects to benefit our KIT. And if we are successful with any of our ideas, these would also benefit other KITs around the country. The ideas include:

- Getting a process in place to enable home-bound or distant KIT members to attend KIT meetings electronically
- Asking TMA to provide more 'streaming videos' of conference sessions
- Setting up a distant location for our KIT members to attend an off-site conference session

These three ideas probably raise more questions in your mind than they answer. If there is any inkling in your mind that you'd like to actually help with any or all of these, please contact any of your KIT Fab Five. We'll start working on this as soon as we can, probably after January 1.

And speaking of January 1, traditionally a time to toast our past and future with a glass of 'bubbly', which is what we did at our November meeting. We enjoyed a glass of sparkling cider to toast our success with the Giving Challenge and our past year in general. And of course, we all have so very much to celebrate as we look forward to the coming year.

Sometimes it's About the Money We Give not Receive

Our meeting facility at the Sarasota Hospital HealthFit is provided to us at no cost. So each year, our KIT donates to the Hospital Foundation as our way of saying "Thank You". Again this year, we are sending a check for \$200 to help them in the charitable work they do in our community.

Shirts with KIT Logo

At the meeting, Donna and Marianne did receive some shirts to have embroidered with our Logo at the Red Barn Flea Market in Bradenton. (We'll let the two people who brought them know as soon as the shirts are ready.) If you want to get a shirt or two as well, contact Marianne (marianne.moyer@verizon.net) and arrange to get a shirt to her (tee, polo, even a dress shirt!) with \$10. Some of us have already gotten several shirts and the stitching quality is great. Stitching is offered in many colors but you may only have one color per shirt.

In closing...

Thank you to everyone who has made this year's KIT activities so successful, fun and uplifting. There are many behind-the-scenes people who keep this group thriving and growing. May this Thanksgiving season be one for you and your family to reflect upon with joy and awe.

"As we express our gratitude, we must never forget that the highest appreciation is not to utter words but to live by them."

John F. Kennedy