



Note: A cyber-grinch stole our newsletter for three weeks but now it's found and here it is. Sorry for the delay.

Meeting Saturday, November 3, 2018

35 people attended

Including SIX first-time Attendees

November is usually our smallest attendance meeting but what we may have lacked in



numbers, we certainly made up for in participation and energy. We were happy to meet **Joe and Cindy Brinck** (he has IBM). They have been members for several years but this was their first meeting.

Liliana Alvarez and her friend **Esther** joined us because Liliana's nephew recently died as a complication of DM (he was only 41, leaving a wife and two children). He had been diagnosed in August and so she wanted to come to find out more about the disease.

Portia Wilson (pictured here) joined us from Tampa. She is interested in (re)starting the central Florida KIT. Finally, our special guest was **LaDonna Johnson**, Member Services Manager at TMA.

We began our meeting with something new. When Rose and Marianne attended the local Charcot Marie Tooth (CMT) support group meeting, before the meeting began Rachel led the group through some gentle stretching and relaxation techniques. So, we decided to copy that idea! LaDonna led us through a few minutes of "centering" to prepare us for the rest of the day.

It was gratifying to experience our November meeting 'presentations' by our members and their care partners. As they each related what they experienced at this year's TMA Patient Conference, we could see that there were dozens of opportunities for each of us to learn more about myositis and how to manage it. Without trying to capture everything that everyone said, we can summarize the presentations in this way. First, to thank: **Don and Jayne Lindberg, Sue and Wayne Prive, Gail and Mike Moore, Linda Sabatino, Barb and Matt Kluding, Jo Randolph, Deb Santana and John and Marianne Moyer**. Special thanks to **Joe and Cindy Brinck**. We didn't know they were there (or we'd have invited them to have dinner with us Friday evening.) But they offered great insights, just like everyone else. Also, special thanks to **Helen Wallace**, one of our members who attended on 'scholarship' but who has not yet returned to Florida for the winter. She hand-wrote a report of her and **Harry's** experiences.

The sessions that were covered included ones on exercise, both classroom and active. There was a lot of interest in the one on Blood-Flow Restricted Exercise. While it was indicated to be

of interest to only IBM patients, it had relevance to PM and DM as well. The session on the Gut Microbiome reminded us that there are trillions of cells in our bodies and many of those are bacteria; how do you treat yours? There were sessions for men and women only. The one for women was well-attended and enabled participants to discuss topics that might be a bit uncomfortable in a mixed setting. How your heart and lungs are affected is a topic many of us visited; it's always nice to know what to look for as myositis progresses in your body. Navigating the Health Care maze was not only interesting but also valuable with specific individualized help. Autoimmune antibodies continue to reveal new aspects to existing and 'new' types of myositis (for example Necrotizing Myopathy). One member skipped dinner with our group in favor of attending one of the "Feel Good Friday" presentations: Aromatherapy. A good choice as it turned out! There were plenty of sessions aimed at care partners. Finally there was the session with the Medical Advisory Board who provided insights into trials and research.

Whether you attended the conference or not, it will be worthwhile to go to www.myositis.org and click on conference presentations and videos. They are grouped by topics and provide you with a wealth of information. It's the next best thing to being there!

We were treated to another aspect of the conference, a presentation by **LaDonna Johnson**, TMA's member services manager. She is responsible for some parts of the conference like the KIT displays at the wine and cheese reception. She shared with us some of what she does and most importantly, her commitment to help us; individuals and KITs.



Special Announcement...details yet to come

Matt Kluding has been diligently researching something that came up at the KIT Social in October. His announcement at this meeting was a preliminary notice of something your KIT leaders are considering. Here's the gist of it.

In both 2016 and 2018, our KIT was blessed to receive a total of over \$30,000 in matching grant money from The Patterson Foundation. Initially we expected to use the majority of it on scholarships for our members to attend TMA conferences. Because we had fewer applicants than expected, we only spent about \$12,000 on this. Also we stated we'd purchase equipment to livestream our meetings. This has cost us less than \$1000. Finally, we held a dinner for medical professionals to learn more about myositis. Because we had some very generous sponsors, our expenses for the dinner were minimal.

Our concern is that with a current bank balance of over \$17,000, The Patterson Foundation who provided the match money could ask why we have not spent the money they provided. We have in good faith used their money as we said we would; we just haven't spent enough.

In an effort to provide services that would benefit our KIT members, we offered the van transport for members to attend meetings and/or medical appointments. To date, no one has taken us up on this offer. So we began to look for other options.

This led us to look at what the KIT could do to positively impact a member's life. How could we spend some of our money in a way that benefits our members? What we plan to offer is that the KIT will reimburse eligible members for some expenditures including for mobility aids, exercise equipment, home improvements, etc. There are still details to work out but before our next meeting we expect to have this finalized. We may even be able to send out an e-mail that will provide full details prior to February. Please understand that this is a work in progress and your all-volunteer KIT leaders are trying to make sure we do this right. There will be a separate e-mail which provides an outline of what we are considering.

Speaking of "Please Understand"...



We all know how difficult it can be to explain our myositis to those who know and love us. It's even harder to explain to strangers. Some of us have expressed annoyance that as we park our car with a handicap hanger or tag

in a handicapped parking space, there are people who have said unkind things about us not *looking* handicapped or disabled. We can't prevent this but some of us got together and came up with an idea that might help. Starting at the Holiday social event we will make available (free) a small car magnet that simply has the words "Not all disabilities are visible" next to the universal wheelchair logo. (It will NOT say I have Myositis like this first draft). For those who want to display this magnet contact Marianne and she will see that you get one. And of course it's free to our KIT members

Did Someone Say Holiday Social Event?

Yes, it's that time! **Camille, Ray and Pacman** are once again opening their home to the KIT for our annual holiday party. It will be a potluck on Saturday, December 1, starting at 1:00 p.m. Watch your e-mail inbox for your invitation (remember to RSVP to Camille). There will also be a list of suggested gifts you may bring to help brighten the holiday of a Guardian Ad Litem child. (Hopefully by now you have already planned to attend).

Plan to Attend our First 2019 KIT Meeting

Saturday, February 2, 2019 will be our first meeting of the new year and should be of interest to all members and their care givers. Our speaker will be **Dr. Tae Hwan Chung**, one of the newest

members of TMA's Medical Advisory Board. His specialty is fairly uncommon; he is a Physiatrist. A physiatrist is a medical doctor or doctor of osteopathic medicine who specializes in Physical Medicine and Rehabilitation (also called PM&R physicians). Physiatrists diagnose and treat both acute pain and chronic pain and specialize in a wide variety of nonsurgical treatments for the musculoskeletal system.

Dr. Chung will address some of the challenges we face when we try to determine what kind of exercise is safe, how much to do, and how often to do it. He will speak about coordinating between doctors and therapists (now that's a great idea!)

This is always our best attended meeting. Welcome back all our Northern friends!

Keeping in Touch with Members



As always at the start of our meeting, we signed cards to mail to members who could use a little cheer. **Joanne Carevale** is recovering from shoulder surgery. We send our best to her and Bernie. **John and Sue Corning** have made that tough decision to move to an assisted living facility out of this area. We will miss them and are thankful for all they did to keep our KIT's sugar high intact! **Don Broughton** continues to recover from his surgeries and **Linda** is his care partner. Some members may remember **LaShan Davis Lanier**, KIT leader in Richmond. She died the day before our meeting. She was known for her big smile and the great photos she took each year at the conference. We sent a card to her family. **Ray Lesoine** spent a couple days

in the hospital this week, apparently for a small TIA. (No, it's not the airport), he's ok. We just heard that **June Paul** was rushed into emergency open-heart surgery.

It is with great sadness that we sent a condolence card to **Marge Klersy**, on the death of her dear husband **Don** who died on October 13. Don was initially diagnosed with PM but soon learned he had IBM. He had a number of other medical challenges as well. I'd like to share one of my favorite memories of the Klersy's. When we invited **Andrew White** to speak at our KIT meeting in February, 2011, our KIT did not have much money. Don and Marge volunteered to pick up Andrew at the airport and offered him their guest room. During his talk, Andrew mentioned the extraordinary hospitality he was shown at their home. Rest in peace, Don. And one more sad announcement; **Linda Sabatino** is in PA attending the funeral of her five-month old grandson. For these and all our KIT members, please remember them in your prayers.

As You Plan Your Holiday Gift Giving

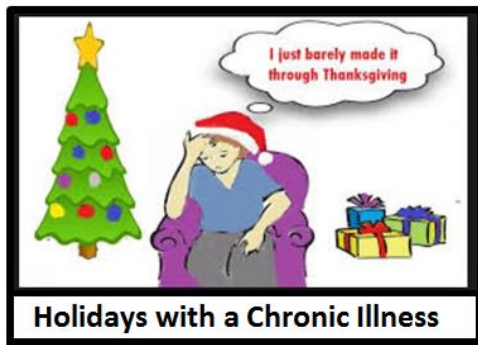
Please remember that as 2018 comes to a close, it was a significant year for myositis patients and TMA. For 25 years TMA has provided a wealth of services to all of us. Think about the Conferences so many of us have attended. Consider that this KIT group formed because **Barb** and **Marianne** met at the 2006 and were inspired by **Bob Goldberg's** plea for a KIT to form in SW Florida. Many of us have consulted with TMA's Medical Advisory Board physicians—the

very best in the field. The MAB reviews and recommends grants for TMA to provide to myositis researchers. We no longer pay dues to belong to TMA. So how can you show your appreciation for the past 25 years and years to come? Consider asking friends and family to give to TMA in your name, and then please consider also making a gift. Go to www.myositis.org to donate.

More 2019 Planning

Remember that May is Myositis Awareness Month

In our last newsletter there was an article about possibly teaming with the CMT group for a rare disease awareness day. The next National Rare Disease Awareness Day is February 28, 2019. For a number of reasons we may not be able to make this happen then. Stay tuned because by at least May, we will find a way to let our voices be heard!



Thanksgiving Greetings to All

Our upbeat, caring, supportive group is one of the blessings in our lives. We give thanks to everyone for being part of our Keep in Touch group. Have a wonderful Thanksgiving. So, now that Thanksgiving is just a juicy memory, we also wish you a blessed holiday season, however you celebrate it and also an optimistically healthy New Year!

Thank you to our Friends and Sponsors

Kroger
SPECIALTY INFUSION

Home IGRx
Specialty Infusion Services

MedPro Rx
A DIPLOMAT COMPANY

brioval_{Rx}

STAND AID

Mallinckrodt
Pharmaceuticals

EZ-STEP
SAFETY • STABILITY • SECURITY

RITA B LAMERE MEMORIAL
FOUNDATION

NuFACTOR
Specialty Pharmacy