SW Florida Myositis K.I.T.
Keep In touch
The Myositis Association
www.myositis.org

November 2019

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Meeting – November 2, 2019
It was another full house with 41 attendees
Including 6 new patients and 5 of their care partners
Eight members and non-members joined us via Zoom!

There are many reasons for us to be thankful and one is certainly the growth of our group. Whether you think of us as your KIT (Keep In Touch) or Support Group, we hope you think of us as your *family*. As mentioned at the meeting, it was almost like a holiday dinner; lots of people; some that you know and some new ones; it was a bit crowded but there was plenty of food, fellowship and good information sharing. It was, all in all, a good day on the Planet!

Welcome to those who attended for the first time:

John (IBM) and Pat Nordberg have been members for a while but haven't attended a meeting before. We saw them at the conference in September and reminded them that they could keep the good feelings going, by coming to our meeting. So they did!

The same can be said for Wanda (IBM) and Larry Cerling who fit right in with our group at our annual conference dinner. You meet the nicest people at myositis events!

Tony (IBM) and Diane Digiovanni contacted us and the timing of our meeting was perfect for these 'snowbirds' who were returning to Bradenton.

Nancy (IBM) and Fred Murray also found us in the nick of time. They made the drive from Venice and we hope they're glad they did.

Marie Rodriguez (Antisynthetase Syndrome) lives in Lakewood Ranch, having recently moved from Puerto Rico. She still returns to PR for some treatments; we hope our doctor list will enable her to find local treatment.

"D"(IBM) and husband "C" joined us for the first time and asked that their names and photos not be used and we honor that request. We were so happy to meet them!

One More Time About Our Room…

Again we managed to seat everyone who attended and it was again a tight fit. Everyone took it good-naturedly but again, it looks like we will have to keep looking for a new home, this time closer to the interstate and with adequate Wi-Fi capabilities. We'll keep you posted.

As Barb Kluding so eloquently said it: "We want to have our meetings at the perfect place, with perfect accommodations including dependable Wi-Fi, restrooms and parking. (And the perfect FREE price tag would be nice too)." The catch, as we continue to grow, is that so far the perfect place eludes us. We'll keep trying.

Our Next Meeting will be Saturday February 1, 2020
NOT at HealthFit;
We'll be back at Mixon's

For a number of years, to accommodate our returning winter visitors, we have moved our meeting to the Mixon's Fruit Farm conference center in Bradenton. The room is larger than the one at HealthFit but it's farther off the interstate and has fewer accessible restrooms. On the good side, they have a wonderful staff who provides us with yummy fresh foods from their deli. Our speaker and topic for the day are still under consideration so we'll let you know both, in our invitation to attend, probably being sent just after the New Year. We always try to choose a topic of interest to all myositis patients and their care partners. Reservations will be a <u>must</u> so please start thinking now about putting this date on your new calendar!

Before you jump to 2020,
Check your calendar for Friday, December 6 at noon!

Put your jingle on and join us for our annual holiday event. This year we'll do something different; a lunch at the Cheesecake Factory in the Brandon Town Center at I-75, Exit 257. A departure from our usual potluck, you won't have to cook; just come and order from the menu and enjoy an afternoon with your Keep In Touch Family! RSVP to Marianne by Tue, Dec 3.

Our KIT Continues to Support TMA
In many ways!

An original Oil painting by **Jan Marriott**, was donated to TMA for their 2019 conference silent auction. Jan entitled it "Meditation" and portrayed a young woman who might have just gotten a diagnosis of "Myositis". A member of TMA's staff bid on and won the painting and said it has a place of honor in her home. **Rose Ryan's** estate donated several beautiful handmade quilts. **Marianne** provided a SW Airlines gift card and a bracelet from her brother's estate. **Barb** gave an autographed cookbook by Chef, Robert Irvine. All these items help TMA continue its work to support myositis patients and their families.

Sadly, we also support TMA by donating $50 whenever one of our members passes on. Recently we lost Janet Garrubbo who had PM and attended our meetings in 2011 and 2012. Our group also sent a card to her family. They remain in our prayers.

Show and Tell by MobilityWorks

One of TMA's newest sponsors is a nationwide company that converts vans to assist those of us with mobility challenges. Scott Shelby one of their managers, gave a slide presentation about the kinds of conversions that are possible and then took interested attendees outside to see a van he had driven to the meeting. It was great to be able to see a product up close and personal and without a sales pitch. Scott showed that he and his company truly care about helping people stay mobile for as long as possible and with the utmost concern for safety. Scott also very kindly sponsored our breakfast snacks and lunch. We're so glad he joined us!

We're Proud of our Keep In Touch Group and Want the World to Know It!

Usually when we have a speaker, we give them a small token gift to say "thank you". We decided it would be nice if they would receive something to remind them of our group so we recently purchased some coffee mugs to give as gifts to speakers. Our intent was NOT to make them available for sale or to use as a fundraiser but on reflection; there might be some members who'd like to enjoy their morning coffee or tea in a mug like the one below. Right now there is a lot going on that precludes us setting up a sales opportunity but next year we will look into this if any members are interested.

In addition, we've had some inquiries about the shirts some of us wear that proudly display our group logo. We have an ongoing relationship with a company in Bradenton that will embroider our logo on any shirt or hat, for just $10. You buy the shirt; they make it special. Contact **Donna DeFant** or **Marianne** if you want to place an order.

Keeping In Touch With Members

We send prayers and support to **Neil Johnson** (h-IBM) who recently lost his wife, **Christine**. **Tina Carter-Pearson** is getting around much better now that she can put both feet on the ground! **Ruth Peto-Wieclaw** missed our last meeting because she thought a hospital bed might be more comfortable than a meeting chair. NOT! She's home and doing much better. **Deb Santana** continues to have challenges with her meds and insurance. What a shame to be hospitalized because she couldn't get her medication! **Gail Moore** missed the meeting because of a nasty cold. We hope she's feeling better. **Wayne Prive** was also a bit under the weather. **Joan Rinkin** continues to strengthen after her fall, and care partner **Nancy** is also in our prayers. **John Setzer** stayed home as he recuperated from a fall but he joined us via Zoom. We're glad to make our meetings available even when members can't get out!

Please keep these KIT family members in your thoughts and prayers. And let someone know if you or someone you know needs a kind word, card or call.

More Ways to Learn About Myositis

Miami Myositis Clinic—Our good friend **Susan Artabasy**, at Soleo Health, e-mailed recently that there is a new myositis clinic on Thursday afternoons every week from 1-5 pm at the University of Miami. New and follow up patients with polymyositis, dermatomyositis, Inclusion body myositis and necrotizing myopathy can be seen. Their director, Olimpia Carbunar, Asst Prof of Neurology says this is not a multidisciplinary clinic like ALS or MDA. It is just a regular clinic and will try to gather as many patients as possible with myositis. Call 305-243-6732 for information.

Webinar on Care Giving—There will be a webinar on Wednesday, November 20 at 7:00 p.m., addressing Caring for Care Givers. It is jointly sponsored by TMA and MSU (Myositis Support and Understanding). Go to myositis.org or understandingmyositis.org to register.

IG Living Advocate—this magazine while focused on Immune globulin issues, also offers patient support on a number of issues. They have an upcoming podcast on Planning for Retirement with a Chronic Illness. While many of us are already retired, we may have to re-examine our plan as we continue to manage our health. There is no date given for the podcast but they request registration by November 19. Go to igliving.com for information.

The “Meat” of our Meeting

Members’ Reports on TMA’s Annual Patient Conference

For those who’ve never attended a conference, imagine a KIT meeting, only it’s one with 500 attendees and lasts for three days! Probably anyone who <u>has</u> attended will tell you that you really have to experience it to believe it. So for the main part of our November meeting, six of our members took the microphone to share their experiences. **Tina Carter-Pearson, Wanda Cerling, John Nordberg, Linda Sabatino, Jo Randolph** and **Marianne Moyer** all shared what was most memorable for them.

But before we started, our projection screen ran a continuous loop of TMA Executive Director, **Mary McGowan**’s opening remarks and it was amazing! TMA’s accomplishments along with a variety of support group activities, are telling our story in new and impressive ways. We’ll repeat this reminder at the end of this section but <u>please</u> find time to go to TMA’s website; scroll down to the 2019 conference and watch her presentation. It will make you proud!

Our members were unanimous in our praise of the variety of session topics and the knowledge of the presenters. Nutrition, Swallowing, Clinical Trials, Aqua Therapy, and disease-specific sessions were mentioned. In addition, this year there were more vendors with a variety of messages for patients and care partners, alike. The general sessions, were especially valuable. Hearing the Medical Advisory Board talk about research is always inspiring. Meeting the Board of Directors showed the diversity of talent and concern of those who lead TMA. Of special interest were the presentations on traveling with a disability and by the designers of clothing for Target Stores. Target, now another of TMA’s sponsors, is working with TMA to create clothing and shoes that will enable those with limited abilities to dress themselves and in style. They have been in the forefront of this movement with a line of children’s clothing and now they were willing to hear what we adults had to say. Bravo.

Donna and **Jim Butler** also attended the conference though were unable to come to our meeting. Donna generously documented her thoughts and sent them to me. Her comments were to be included here but somehow I've misfiled them. Apologies to Donna and all.

Marianne Moyer was fortunate to be invited to attend the 8th Annual IGNS (Immune Globulin National Society) conference in Las Vegas a few weeks after TMA's conference. During the week prior to patients attending, Ig vendors from around the world and nurses and other clinicians attended seminars and presentations about this blood-product immune modulating treatment. Marianne participated in the one-day patient seminar and found it incredibly illuminating. Anything and everything you could want to know about Ig was addressed.

From this event, she offered a suggestion. If you have trouble answering your doctor when they ask "how have you been?" you might want to start a log to keep by your bathroom sink. At the end of each day you can rate that day on a scale of 1-10 and the next time the doc asks, you can say you have had X number of days that were 10 and Y number of days that were a 2, or whatever. This is also a great way to track new medications and their impact. Each day after starting a new regimen, log the day (for the symptom you are trying to impact) with a 1-10 rating. Then you will be able to report back to the doctor on how the new med or treatment is working for you.

One of the hot topics among Ig users is its availability. Not everyone knows but a batch of IVIg might contain plasma and its immune properties from over 1,000 donors. And these donors specifically donate plasma, not blood. There is a huge shortage of plasma donors in the US and we as immune-compromised individuals can do something about it!

We can help by encouraging family and friends to become plasma donors. It's a very different process than regular blood donating and because your red cells are returned to you, you can donate as often as weekly! Please, for the sake of those of us who depend on Ig products, find us some new donors! Go to donatingplasma.org (and yes you can get paid for donating!)

Finally, the conference was very enlightening about sub-cutaneous Ig. As an alternative to **IV**Ig, this is a self-administered treatment with usually fewer or no side-effects. Of the 75 or so patients attending, about one third were on sub-Q as it's sometimes known. No space to go into this deeper but this may be a topic for a future meeting.

TMA News

At the beginning of our meeting, Marianne introduced new procedures and forms instituted by TMA. Each member (and their partner) will be asked to sign two forms: a non-disclosure and a photo-release form. The non-disclosure form will remind us all that 'what is said and done at a KIT meeting stays at the KIT meeting." The photo-release ensures that if our newsletter (like this one with people's pictures) is published anywhere, especially on the Internet, we have obtained permission from people to use their photos. Our group leaders are also asked to sign special non-disclosure forms since we often are in contact with members outside a meeting. TMA is trying to determine if each KIT member is also a TMA member so we are asking that as well. After our meetings, TMA will also receive copies of our sign-in sheets with an indication of who is a TMA member. These are important processes that we hope all members will support.

When TMA participates in a grant application, they are often asked questions like how many members are there, how often they meet and how much time and money is expended to put together a meeting. Having the actual numbers enables TMA to make more compelling requests for research funding…something we should all appreciate. So thank you for participating in these form completions and know that it's all for a good cause (our own.)

Speaking of grants; the good news is that our local foundation, the Rita B. Lamere Foundation has this year increased its research donation to TMA from $10,000 to $15,000. The other news is that we have not yet heard if TMA will participate in the 2020 Sarasota Community Giving Challenge so we will just have to wait to see if this happens.

TMA's Annual Patient Conference in 2020 will be in Seattle September 10-13, 2020. More information will come later. Remember that our group can help you pay for your hotel and conference registration, via a 'scholarship'. Watch TMA's website and Facebook page.

KIT News

The Merry Month of May sounds like a long time from now but it's never too early to begin thinking about what we can do to celebrate Myositis Awareness Month. Our last two major efforts have been spectacularly successful**. Now it's time to try to top those efforts. It's long been a desire of some of us, to get into LECOM (Lake Erie College of Medicine) in Bradenton to get to their med students while they are still in school. Previous efforts have not been successful but maybe 2020 will be our year. Alternatively, if anyone has an idea or question about another alternative, please contact Barb, Donna or Marianne.

**Successful is a relative term. In 2019 we sponsored the symposium for OTs and PTs to learn about treating myositis patients. We did make one mistake that we only recently realized. We did not capture names and contact information of Therapists willing to be contacted by myositis patients. Marianne tried to reach out to all 60+ who attended, asking if we could distribute their names and only four responded. Darn it all. Anyone looking for a therapist can contact Marianne and she will look for a therapist nearby.

You know you have Myositis when your favorite holiday gifts are PJs, slippers, robe, electric blanket, heating pad and warm fuzzy socks. But what REALLY want is a PAIN FREE DAY!

Two of the products we discussed in the meeting were:

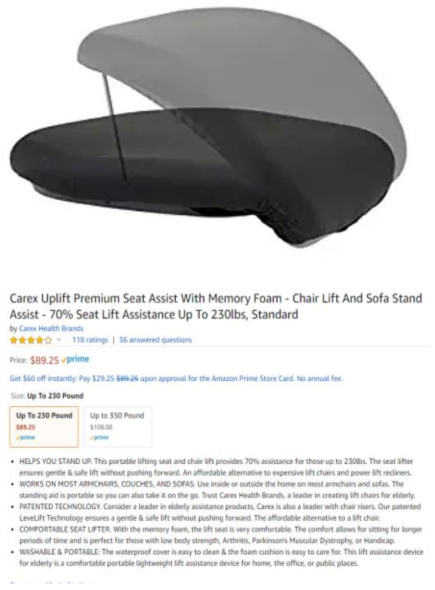
The hand exerciser

Rolyan Basic Ergonomic Hand Exerciser, Strengthening Device for Fingers, Hands, and Thumbs, Comes with 4 Pairs of Graded Rubber Band...

★★★★☆ 128

$13.52 ~~$18.26~~

Easy Lift Seat



Carex Uplift Premium Seat Assist With Memory Foam - Chair Lift And Sofa Stand Assist - 70% Seat Lift Assistance Up To 230lbs, Standard

by Carex Health Brands

★★★★☆ 118 ratings | 36 answered questions

Price: $89.25 ✓prime

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Size: Up To 230 Pound

Up To 230 Pound $89.25 ✓prime

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- HELPS YOU STAND UP. This portable lifting seat and chair lift provides 70% assistance for those up to 230lbs. The seat lifter ensures gentle & safe lift without pushing forward. An affordable alternative to expensive lift chairs and power lift recliners.
- WORKS ON MOST ARMCHAIRS, COUCHES, AND SOFAS. Use inside or outside the home on most armchairs and sofas. The standing aid is portable so you can also take it on the go. Trust Carex Health Brands, a leader in creating lift chairs for elderly.
- PATENTED TECHNOLOGY. Consider a leader in elderly assistance products, Carex is also a leader with chair risers. Our patented LeveLift Technology ensures a gentle & safe lift without pushing forward. The affordable alternative to a lift chair.
- COMFORTABLE SEAT LIFTER. With the memory foam, the lift seat is very comfortable. The comfort allows for sitting for longer periods of time and is perfect for those with low body strength, Arthritis, Parkinson's Muscular Dystrophy, or Handicap.
- WASHABLE & PORTABLE: The waterproof cover is easy to clean & the foam cushion is easy to care for. This lift assistance device for elderly is a comfortable portable lightweight lift assistance device for home, the office, or public places.

To close this very long newsletter, it is with joy and pride that we recognize Mrs. Barbara Kluding. Barb could be identified as the one who really kicked off the beginning of this support group over twelve years ago. After all, it was she who after hearing Marianne say she'd look into starting a group, approached and said "Ok, I'm in; what can we do to get started?" And the rest is history. So while many people think of "M" as our KIT leader, it's the "B" Lady who deserves equal or greater credit. So, at the meeting Marianne presented Barb with a certificate of appreciation from the KIT and a hand-made quilt made by Rose Ryan and donated to the KIT by her estate. This quilt is quite special because on the back, Rose included a lovely thought on what it means to have myositis and a dedication to our KIT. Who could be a more fitting recipient than Barb? Your KIT thanks and appreciates you for all you do. **We love you, Barb!**

Thanks and appreciation to all who contribute to the wellbeing of our group. It's hard to name them alll but certainly our group's sponsors plus those who sponsor TMA. People who work to set up and clean up our meeting room are the best! Dessert and water/ice donors keep us happy and hydrated. As we enter the holiday season, here's to a blessed Thanksgiving, warm and loving Christmas or Channukah and a healthier New Year.