SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

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May 2, 2015 Meeting

We had 24 in attendance, including three new members and two partners…

Welcome Steve V., Neil & Christine J., and Andrea & Jack S.

Highlights of our Meeting

It was a true pleasure to welcome our new KIT members! **Steve** lives in Ohio and Florida and has IBM. **Neil** has H-IBM and calls Tampa home. **Andrea** lives in Bonita Springs and has IBM. We are glad they found us in time to come to our meeting. In addition, in just the week since our meeting, I've been contacted by two new additional members, **Juan J** lives in Naples and has PM/DM and **Rande** met Barb at a MDA meeting she was attending because she has IBM and didn't know about our KIT. We look forward to seeing Juan and Rande at our August meeting! Last meeting, I neglected to recognize **Janice T** who joined us for the first time; she has PM/DM and lives in Venice. Welcome all! (Note please that other than our KIT leaders, I generally don't use last names of our members; just trying to respect everyone's privacy.)

While seeing everyone and especially our 'newbies' was a highlight, of course the real highlight of our meeting was the workshop led by Rose Ryan, one of our group's leaders. Your four leaders work hard to find meeting topics that will be of interest to all myositis patients and their partners and for this one, we decided to capitalize on what we learned from our excellent speaker, Dr. Amy Wood, last month. She asked us ten questions and one of them seemed worth some extra attention. It was "What can I discard from my mind and my life?" We asked attendees to come prepared to share tangible and/or intangible burdens that make dealing with myositis harder than it has to be. Again, to protect everyone's privacy, we won't share who said what. Suffice to say that a number of the people present were able to share some of what they have been dealing with. Saying it and sharing it with people you trust can be a very healthy way to 'discard'. People talked about giving up guilt feelings, having to give up things they loved and could previously enjoy, losing good friends, using anger and humor in positive ways. There was talk of learning to accept help, not being ashamed to use aids like canes, walkers and chairs. Some people also brought tangible things they were willing to give away; hey whatever it takes to make our lives simpler! Thank you again to Rose for her insightful leadership of our discussion!

One of the ‘activities’ of the meeting was that using a speakerphone, the group called Marianne Moyer to wish her well as she continues to recover from her surgeries to remove and repair the skin cancers from her nose. The last of the ‘perfect attendance’ people finally bites the dust; the first meeting Marianne missed in our eight year history! (Note from Marianne; thanks to all who have called, e-mailed and sent good wishes. I continue to improve each day and hope to unveil my new nose at our next event!) And this newsletter is being written based on notes sent by Rose and Barb. Any omissions or errors in content are my fault and I apologize.

Other notes from the meeting:

- Barb shared News of benefits of joining local MDA clinics and the AARDA organization.
- Active or retired military can contact Disney’s Shades of Green when in Orlando. (Discounts?)
- MDA is working to have genetic testing done at very reasonable cost-some portion free for members. They are waiting for final arrangements with a gene lab.
- Tidewell Hospice has a Companionship Program-allows caregivers to take a break. Check with your local Hospice.
- There is a disabled Travelers Guide (disabledtravelersguide.com) with extensive destination guides.
- There is a phone app to alert medical emergency when you fall. It is Life Alert and it is free.

Special thanks to Rose Ryan and Barb Kluding, plus Matt Kluding, Dan Butcher and all others who helped make this meeting a success. Those of us who coordinate these efforts know that it truly does take a team effort and when key members like Donna, John and Marianne are among the missing, it means everyone else has to really step up. Our KIT is blessed to have people who epitomize “many hands make light work”. Great job everyone!

Our Next Meeting, August 1, 2015

We’re working to get a local Rheumatologist who spoke to us seven years ago, in August 2008. We are asking him to address what has changed in myositis treatment since he last saw us. Watch for your meeting invitation around July 4!

Also, don’t forget that August is our anniversary month and you know what that means! CAKE! Help us celebrate our eighth anniversary meeting. We’ve come a long way from the first meeting on August 18, 2007. We had 24 attendees (just like this past month) but our distribution list was about 40. We now count over 150 myositis patients on our mailing list. And look at how we just added at least six in the last couple months! Rare disease? Hmmm…

Potluck March 21

When a Quarterly KIT Meeting is not Enough

Because some of us want to be with our KIT family more than once a quarter, we agreed to schedule an event about half way between our regular meetings. Our second one was Saturday, March 21 at the home of Ray and Camille Lesoine. What a great afternoon! There were twenty of us who brought everything from a baked ham to brownies. Camille outdid herself with some incredible fruit smoothie drinks and a wonderful time was had by all. So…

Come to Our Next Social Gathering…
Potluck Barbecue, June 20 at 2 p.m.

…we are going to do it again! The Lesoines tell us that their house survived the onrush of KIT members and their families so they have offered to do it again. This time we will recruit a few guys (Matt and John our Lunch Organizers) to grill some burgers and dogs. The invitation is already in your e-mail in-box so please check your calendar and RSVP to let us know you are coming. Meat and drinks are provided; just bring a side, munchie or dessert to share.

TMA's 2015 Patient Conference Returns to Orlando

Once again the conference will be at the Caribe Royale from Thursday September 10 through Sunday, September 13, 2015. TMA and the hotel are taking reservations so visit TMA's website and register. The deadline for early conference registration at the discounted rate of $165 is May 31. The special room rate at the hotel will only be good through August 9. We hope to see you there.

TMA moves the conference around the country each year to enable the most people to attend via driving. They don't get any closer than this for us.

Clip and save:

TMA Annual Patient Conference

When: Thursday, September 10-Sunday September 13, 2015
Where: Caribe Royale Hotel in Orlando FL
Contact: TMA to register for conference www.myositis.org and
Caribe Royale 1-888-258-7501 or www.thecaribeorlando.com
Costs: Hotel suite $109, Villa $169. Conference $165
Deadlines for discount registration: Aug 9 for hotel, May 31 for conference early-bird registration!

Keeping In Touch With…Doctors

We continue to develop our list of doctors you recommend. It doesn't matter if they are treating your Myositis or other conditions. Don't forget to recommend doctors that you travel to see at places like Hopkins or other sites! If you'd like a copy of the list, contact Marianne. Also, please be sure to share with all your medical professionals a copy of TMA's recently released booklet "A Physician's Guide to Myositis". We've handed them out at meetings and still have a few on hand. Contact Marianne if you'd like one. Or go to www.myositis.org to order one or to download the PDF version.

Myositis Medical Symposium Scheduled For September 11

As in past years, TMA's Medical Advisory Board will be hosting a symposium during the annual conference. It is open to physicians only, who are interested in learning more about our diseases. It will be from about 10 a.m. to 3:30 p.m. and will cover a wide variety of topics (way too technical to list here). If you would like for TMA to invite one of your doctors, please ask your doctor if they are interested and then provide their contact information to tma@myositis.org

KIT Dinner at the Conference

Donna DeFant is organizing a dinner for our KIT members and their partners, for one evening at the Caribe Royale. We now have a date, Saturday, September 12. No other details yet but you might want to be sure this date is 'free' so you can join us. You will RSVP to Donna and seating will probably be limited to about 30 in the private dining area. Watch your e-mail for the invitation!

Myositis Awareness Event

You have probably seen either in your e-mail or on TMA's website that there is going to be a special Myositis Awareness event on Sunday, September 20 this year. While our 'normal' Myositis Awareness Day is September 21, this date presented TMA with simply too great an opportunity to pass up. Mike Krukow is the color commentator for the San Francisco Giants baseball team and he recently announced that he has been diagnosed with IBM. We all know how difficult that must have been for him; an athlete, active working guy and public persona. The Giants organization will hold some special events during their game on the 20th, to bring recognition to Mike and to myositis. TMA will be there and will help to turn this into an opportunity to educate the public about us.

We don't have all the details yet but it should be a great opportunity to raise awareness about myositis.

So what about those of us on the other coast? Of course, you could plan to fly to San Francisco and attend the game (the Giants are providing 50 tickets for TMA members). Or you could buy a MLB-TV package and watch the game and festivities from your easy chair. Or….

Come and join us as we again hold one of our 'in between meeting' KIT gatherings (we need to come up with a catchy name for these potlucks and other events…) Anyway, here's the special deal we have arranged for that afternoon. The Giants are playing the Arizona Diamondbacks, in San Francisco, starting at 1:05 p.m. PDT. (That's 4:05 Eastern). We have a special party room reserved, with several large screen TVs at the Gecko's Grill that is essentially next door to the HealthFit complex where we hold our regular meetings. They have offered us the opportunity to bring up to 50 people, put up banners and signs, hand out information flyers and of course have a party.

We're still working on the details of whether we would order from the menu or from a limited list of 'game food'. Drinks would be via cash bar. The primary purpose of this event is myositis awareness, not fundraising though we might throw in a raffle or 50/50 or something like that. The Giants might even donate caps, autographed balls or other memorabilia.

Bottom line is PLEASE do a 'save the date' for this fun event. Sunday September 20 at 4 p.m. at Gecko's in Sarasota. And by the way, are you thinking that you aren't a big fan of baseball? Confession time; neither am I. But think back to some Super Bowl parties you have attended. The fanatical fans are bunched around the TV(s), yelling their heads off. The rest of us are on the other side of the room, eating, drinking and socializing. This event will be our September KIT party (one weekend after the conference by the way) and it will be a great way to sit back, sip a libation and reflect on how grateful we are for TMA and our KIT. See you there and then!