



Saturday February 4, 2017
A Very Special Two-Part Presentation on
Myositis Research
...and MORE!

What an incredible day we had! It seems like hyperbole to keep saying that this was the best meeting yet but it really seems to be true. Somehow we managed to pack 68 people into Mixon's Honeybell Room and of those, eight were first timers! With joy we welcomed first timers: **Nelly Barry** (DM), partner John and daughter Samantha, **Yvonne Hoy** (IBM), partner Philip, **Ed Kuehn** (IBM), partner Suzi, **Julia Ramos** (PM), partner, Vincent, **John Saarikko** (PM ?), **David Snyder** (IBM), partner Nancy, **Kimberly Wood** (DM) partners Justin Hinton and Linda Wood, and **Susan Stafford** (PM). Visiting from the Wisconsin KIT were **Dr. Marvin Lauwasser** (IBM) and partner, Marlene.



When we moved our February meeting venue to Mixon's in 2012, we thought it would be good for a long time. It appears that our KIT will need an even larger room for upcoming February and maybe other meetings. Comment sheets and members' observations bear this out and sadly, we will look for a new spot for next February. We are not likely to be able to book Mixon's outdoor pavilion because it is in high demand for weddings. We will see. What a wonderful problem to have!

Many of our KIT members have expressed an interest in research and in clinical trials so this meeting's presentations delved into both.



Our first presentation was delivered by Mark Angelicola from Bristol Myers Squibb. His slides and video explained why it may take so long (as much as 15 years) and so much money (\$2 billion) to take a medication from concept to market. Mark was joined by Kurt Schlageter also from BMS, and the two of them fielded many questions about clinical trials. BMS is preparing to begin a trial with PM and DM patients and the use of Orencia. We are most grateful that they were willing to spend the morning with us and address our many questions and concerns.

In the afternoon, one of TMA's best-loved conference presenters, Dr. Chester Oddis from the University of Pittsburgh addressed Myositis Research: Past, Present and Future. Dr. Oddis' presentation included the results of a number of research projects in recent years, including several that have just been published in 2017. He spent some time on autoimmune antibodies and how recent developments give doctors a better means of treating patients. As lead researcher on the RIM study (Rituximab in Myositis) he was able to shed light on why, while many patients think this was a successful trial, it was not considered to be because the 'end point' was not achieved. He addressed topics on many of our minds, like statin myopathy and the fact that we should all be exercising within the boundaries of what our bodies will allow. (It's interesting that almost every presentation now includes the importance of exercise to all myositis patients; we may not like it but we know we need it.) It was a true pleasure to hear Dr. Oddis speak and we appreciate his taking time from his incredibly busy schedule to spend a day with us.



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 is proud to have helped TMA fund some of this research. To date, our group has raised over \$74,000 for TMA and while it was not all for research, it certainly helped! Thank YOU!

If you are reading this now and wishing this newsletter would provide more detail on these two outstanding presentations, *your wish is granted!* Because there is another reason this day was very special for our KIT! You could say, it wasn't just for our KIT!

SW FL KIT Livestreams its February 4 Meeting Presentations!

On a recent KIT Leader conference call, Marianne asked if anyone was providing their meetings to members unable to travel to attend in person. While the consensus was that this was technically possible, apparently no one was doing it yet (or at least they were not on that call). So to make a long story short, our KIT's leaders, the Fab Five, got to work and made it happen! With the incredibly talented help of *Kat McKell* and *Adraine Kreglo*, we were able to record our meeting presentations and livestream them via YouTube. About 15 KIT members were invited to participate from their homes, as well as a couple other non-members. The reason we only asked a few to join us should be obvious: when you are 'beta' testing a new system, you want to work out the kinks before telling the world. And it's a good thing we did. We do have kinks to work out before our next KIT meeting.

Before we go any further, here are the links to view both our morning session with BMS and the afternoon presentation by Dr. Oddis.

<https://www.youtube.com/watch?v=EjnHWuWp-Bs>

<https://www.youtube.com/watch?v=5C9LNWPe27U&t=7388s>

Or go to YouTube and search on SW FL Myositis KIT and there we are!

As for the future...Yes, in answer to a comment sheet question; yes we intend to do this for every KIT meeting presentation. We will cover some of the announcements and other administrative issues but not the breakout sessions. As for improvements; we will have better video and audio and a camera operator who will track the speakers as they move around the room.

We also thought that we had provided for our watchers to be able to send questions and comments to us that we could share but that did not happen. We're not sure why; whether no one tried or they did and it just didn't work. One more 'kink' to straighten out!

Meanwhile, if you missed the meeting or just would like to see one of the presentations again, go for it!

Speaking of Trials...

But is this about a clinical trial or a case of trials and tribulations? Of course, it's a clinical trial but it also includes a true test of patience. Barbara K shared the news of her recent enrollment in a Phase 2 Clinical Trial with Idera Pharmaceuticals. This is a six month study for DM patients with Dr. Dana Aschermann at the University of Miami. Dr. A is a member and current Chairman of TMA's Medical Advisory Board. IMO-8400 is an investigational medication designed to block the activity of specific Toll-like receptors. These are proteins that play an important role in the immune system. Researchers believe that blocking the activity of specific TLRs could interrupt the cycle of inflammation and tissue damage in DM.

This trial is still recruiting new patient participants and if you have DM you are encouraged to apply.

To learn more about this study contact patientinfo@iderapharma.com or call 877-888-6550. Or contact Barbara who would be happy to discuss your questions. She promises to keep us updated on her involvement with this promising trial for DM patients.

Holiday Potluck Party Saturday, December 10 at 1 p.m. at the Lesoine's

It seems like the holidays are already in the distant past but it's only been two months since our fun party at the Lesoine's. Camille suggested that we bring a new, unwrapped toy to be donated to Toys for Tots and many of the twenty attendees did just that. (Check out our Facebook page for a picture of all the gifts.)

Speaking of Pot-Luck Parties...

Let's do it again: March 25



Camille and Ray continue to be the hosts with the most! Our group loves an excuse to get together so we'll be doing it again, half way between the February and May meetings. Bring something to share and come to Camille, Ray and Pacman's home. A special invitation e-mail should arrive in your inbox around the end of February. The time is 1:00 p.m. All are invited. Remember, no agenda except to have fun! Directions will be in the invitation e-mail.

Shirts with our KIT's Logo

At the February meeting, Donna and Marianne handed out shirts embroidered with our logo, that members had dropped off in November. We can still do this. Just contact Marianne or Donna and arrange to get them a cotton shirt on which you'd like to see our KIT's logo. It's only \$10. Some of us have already gotten several shirts done and the stitching quality is great. Stitching is offered in many colors but you may only have one color per shirt.

TMA's Annual Patient Conference In San Diego, September 7-10, 2017

Any day now TMA will begin accepting reservations for this year's conference, and the hotel will also begin taking reservations. If you want a handicap-accessible room, be sure to book early.

Speaking of the Patient Conference

All SW FL KIT members should have received earlier this week, an invitation to apply for financial aid to attend the conference. The e-mail and two-page attachment tell the whole story. We hope that you will apply (deadline for applications to be sent to Donna DeFant is Monday, April 3). Remember there is some flexibility in the criteria and you are not required to disclose financial data. Ten members and their caregiver/partner will be eligible to have their conference registration and three nights in the hotel, covered. This is possible because of the grant we received from the Sarasota Foundation Giving Challenge.

May is Myositis Awareness Month And our KIT is Going All-Out to Raise Local Awareness!

It's great that TMA designated the month of May as Awareness Month since that is traditionally one of our KIT's regularly scheduled meetings. So our normal date of Saturday, May 6 will be our KIT meeting date. However, before that, on Thursday, May 4, we will hold another awareness event that should really make a difference in many ways. Here are the details and following this section, there are two 'save the date' cards you can copy and/or cut out to share as appropriate.

Thursday, May 4, 2017 from 5:30 to 7:30 p.m. at the Ranch Grill, 14475 SR 70, Lakewood Ranch

NOTE: there was a mistake on the info provided at the KIT meeting. I said the Grill is on SR 64 but it's really on SR 70 at Lorraine Road, 3.5 miles east of I-75, Exit 217

Symposium for Medical Professionals in Manatee and Sarasota Counties (CMEs to be offered)

For many of us, more than five years elapsed between the onset of our symptoms and our eventual myositis diagnosis. This is sometimes due to the fact that our disease is still considered 'rare' and many doctors go through their entire career never seeing a patient with it. Doctors tell us that during their training (which may have been decades ago), they spent a very short amount of time on all the autoimmune diseases and myositis may or may not have been one that was covered.

Most of us, upon noticing that we were experiencing muscle weakness, made our first inquiries to our family doctor (Internist, DO, Family Practitioner, etc.). We then experienced what may have been non-productive tests, trial and error medications or treatments and referrals to specialists. And most of us already know this story; we lived it, or our friends in the KIT have told us about it.

Once we have been diagnosed, the challenges continue. When we visit our other doctors (Pulmonologists, Dermatologists, Neurologists, Rheumatologists, Physical Therapists and even Pharmacists) we find we often have to educate them about our disease, medications, etc.

Our objective with this symposium is to raise myositis awareness of our local medical community. The Manatee Medical Society is working with us and will provide the certification for Continuing Medical Education credits, invite the doctors and even provide space in their newsletter for us to describe this

event. The symposium will be led by Dr. Rossitza Chichkova and the topic will be Myositis Diseases; how to diagnose and treat them.

Bottom line is that YOU can make a difference here. As you visit ANY of your doctors between now and May 4, please share with them the information in the Symposium Save the Date below and tell them that you would consider it a personal favor if they would attend. (In addition to the CMEs, they will also be invited to a delicious dinner at the Ranch Grill, compliments of our KIT and our recent fundraiser!)

Saturday, May 6, 2017 from 10:30 a.m. to 3:30 p.m. at the Ranch Grill, 14475 SR 70, Lakewood Ranch
In keeping with the tradition we began last year for our KIT's myositis awareness to be tied to our regular KIT meeting, we will again ask our members to invite friends and/or family who want to raise *their* myositis awareness. (And yes, the meeting will be livestreamed, even better than we did in February.)

Our agenda for the day will follow along the lines of a 'normal' meeting with our casual meet and greet in the morning, then a presentation of interest to all, followed by lunch. In the afternoon we hope to split into our breakout groups; we're still working on the room layout.

So it is not too early to ask someone who knows and cares about you to come to our May 6 meeting/event. Help them to help you, by learning more about how myositis impacts you and your family. We often say that the objective of our KIT is to show patients and caregivers that they are not alone. In this case, we will also help our friends to know this as well!

Our presentation that day will be an informal talk with Dr. Chichkova who presented at the symposium on Thursday evening. She will share with us what she and the doctors learned from each other. It should be very enlightening. Think how it will sound to those friends you brought; as they learn about how many doctors are not totally up to date on myositis diagnosis and treatment!

Oh, and there is something else you might do to help us on May 6. If you have any contacts with any media people (newspapers, radio, television), please provide their contact information to Marianne before February 28. We want to do much more than just a generic press release for our May events. Personal contact is the goal with at least two from each of the media listed above.

In addition to standard old-fashioned media, we also want to use social media to get out the word. Around April 1 we will ask you (and probably your children and grandchildren) to post our events on their social media accounts. We'll provide the content; all you have to do is share it.

Save the Date – Thursday May 4, 2017

Symposium: Diagnosing and Treating Myositis Diseases presented by Dr. Rossitza Chichkova and the SW FL Myositis Support Group.

5:30 to 7:30 p.m. Presentation with CMEs

7:30-8:30 Dinner (choice of grouper or steak).

**Location: The Ranch Grill, SR 70 and Lorraine Rd,
3.5 mi east of Exit 217, I-75.**

Invitations will be sent by Manatee Medical Society. All medical professionals in Manatee and Sarasota counties are invited to attend.

Save the Date – Saturday May 6, 2017

**SW FL Myositis KIT meeting-BRING A FRIEND!
Location: The Ranch Grill, SR 70 and Lorraine Rd,
3.5 mi east of Exit 217, I-75.**

Our usual KIT meeting format and agenda with presentation by Dr. Chichkova; what she and the doctors learned from each other on Thursday. More information to come; for now just ask a friend or family member to save this date!



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