



February 2018



SW Florida Myositis K.I.T.

**SW FL KIT Meeting February 3, 2018**  
**43 people attended including three first-time couples**  
**And four new 'partners'**

We're not sure if it was the directions we provided or the wonders of GPS but 43 people managed to find our new meeting location. The Goodwill Community Room was as advertised; clean, bright and new. Insufficient toilet facilities seemed to be the only real complaint and short of the Fab Five donning hardhats and tearing down some walls, we're not likely to be able to fix that concern. In other words, most folks were happy with the new venue.



Gail Moore and her husband Mike came for their first meeting though Gail has actually been a KIT member for some time. She has PM and wanted to meet others who are sharing her journey. Our breakout group put her in touch with numerous other PM patients.

Lanelle McCrone and husband Bill also came for the first time but under different circumstances. She was diagnosed with PM just four months ago and is understandably overwhelmed. We hope she left the meeting feeling like she now has a new family.



Norm Schmitz and his wife Jacquie are snowbirds who are also new to our KIT. Norm has IBM and helps to keep it under control with regular exercise. Jacquie also has autoimmune diseases and has been taking prednisone for 20 years! Wow, she's a caregiver who can really empathize!

We also welcomed first-time attendees who came to support our members. Thanks for joining us: Rick Andrews, Doris Goese, Liisa Saarikko, and Anita Tucker.

It took a little maneuvering but by our usual start time, we managed to get everyone into a seat with their breakfast snacks. Then it was time for our presentation.



I began my introduction of Dr. Nagaraju by asking the group if they knew his medical specialty. Listening to his self-introduction at the MAB meeting at TMA's 2017 conference, I was interested to hear that he is a Veterinarian and an Immunologist. Everyone settled in to find out how these specialties led him to his interest in researching myositis diseases.

Dr. Raju pointed out that he is unique as a KIT meeting presenter because he is a pure researcher; we have never had a similar presentation. Then he told of his journey from being an animal researcher to a researcher who uses animal models to test theories of causes and treatments of muscle diseases. Usually during a presentation, I take notes so that I can put them into the newsletter. I confess that I was so fascinated with what he had to say I didn't write down much I could decipher so I am not going to try to provide a full summary of his talk and slides. I highly recommend that you set aside about an hour and a half, visit our KIT's Facebook page and view the entire presentation. It is well worth your time. I watched it again and here's a quickie review.

First, many of us tend to think that we have a myositis disease called either PM, DM, NM or IBM. Yet to a researcher, it is not that simple. There are literally thousands of proteins/genes contained in our cells. Then the diseases are made up of multiple factors (antibodies). To try to find one disease factor to treat (successfully) is not an easy or quick task.

Then when we begin administering medications for our diseases, each one may be targeting a particular facet of our disease. This was an 'aha' moment for me when I realized this is why our doctors seem to keep adding new meds on top of the ones we are currently taking. Each one is working to help the patient's body to fight a different symptom of their disease.

Trying to understand our immune system and how our body's production of cortisol (the version of prednisone we already make) is another complex task. Why does the immune system in a PM patient target and damage the proximal muscles? And why in a DM patient, in addition to the proximal muscles; the skin? IBM patients suffer a different muscle weakness pattern but the "why" is not yet understood. Various researchers are developing trials to attempt to answer some of these questions.

When a researcher wants to create a new medication (as Dr. Raju is doing), it may take more than ten years and cost over a billion dollars. The trial process is strictly regulated and takes a great deal of time. Researchers must be able to state an expected end product or result of what they expect from their trial. For example, the Follastatin trial for IBM patients apparently increased muscle mass but not as much, the muscle strength. The Rituxan trial was in a way a success but deemed not so because they did not prove the projected end-point.

The subject of medication side-effects is also a daunting challenge. If a trial lasts for even one year, how can researchers know what may appear in the patient, ten years later? So Dr. Raju and his colleagues at ReveraGen are in the process of developing a new medication: Vamorolone that may prove to be a substitute for prednisone with fewer side-effects. They have just completed stage 2A of the trial process and hope for FDA approval in as soon as a year. So while we all would love to see Vamorolone come to the market as soon as possible, we now have a little better appreciation of why it is not a guaranteed or a quick solution.

After lunch Dr. Raju answered some questions from the group then we formed our breakout groups. He visited each group and followed up with additional answers and insights. We are most grateful to him for his time and attention to our group.

It *could* cost a billion dollars to bring a new medication to the market if we are talking about a major pharmaceutical company. Because Dr. Raju is working within a small corporation, his research expenses are substantial, but not in the billions.

He mentioned that in the two decades he has been researching myositis, he has been most fortunate and grateful to receive some funding from The Myositis Association. Other funding has come from NIH (translate that to *your tax dollars*) but he and other myositis researchers are constantly trying to raise money through grants from organizations like TMA. The message was very clear. If we want research like the trials for Vamorolone and other myositis medications to progress, we should consider finding ways to help. One option is that when we donate to TMA, we dedicate at least some of each donation to research. TMA allows you to specify research in one disease or all myositis diseases. Wouldn't you like to help Dr. Raju and other researchers? More on how to help comes later in this newsletter.

### **Keeping in Touch With Members Not Able to Join Us**

As we usually do, the members who attended signed and circulated greeting cards for those unable to attend. If you have a moment, consider calling, e-mailing or even saying a little prayer for:

- Yvonne Hoy whose husband recently suffered a heart attack
- John Corning broke his leg (again) and bless his heart, he still arranged for meeting desserts!
- Kena Alonso's daughter recently posted a heartfelt essay on how her mom is struggling with her IBM
- Kathy Neubaum's husband had his shoulder replaced (so she got to be the caregiver for a while)
- Judy and Jim Kahl caught that awful flu bug and stayed home to recuperate
- Finally, we were at the meeting but Rose Ryan, Linda Sabatino and Marianne Moyer came back from their Iceland adventure and were immediately laid low with pulmonary 'issues'.

### **There Were Many New Aspects to this Meeting**



We have already said that this was our first meeting in our new location and it worked out well. But the big accomplishment was that with the help of our new 'consultant', Richard, our meeting was livestreamed to members unable to attend. With one exception, all features of our system worked. All we need to do now is get the two laptops talking to each other. We realize some members were disappointed that we did not also 'stream' the Q&A after lunch but we hope to be able to include that kind of additional time in the future. Thank you again to all who have been patient with us!

### **Next KIT Event is a Spring Fling on March 24 at the Lesoine's!**

Camille, Ray and Pacman are once again inviting our KIT and friends to a pot-luck lunch at their lovely, fully accessible home. Watch for an e-mail around March 1 inviting you to RSVP to Camille.

## Conference News

TMA's 2018 Annual Patient Conference will be September 6-9, 2018 at the Louisville Marriott Downtown. **Please mark your calendar now!** If you want to reserve a handicapped accessible room, you should make your reservations now.

Watch for a notice that our KIT will again offer financial aid for our members to attend the conference. The application and 'rules' will be similar to last year's.

### **Our Next KIT MEETING is also an EVENT that will be unique!**

For ten years, our KIT has met every quarter on the first Saturday of Feb, May, Aug and Nov. The more compulsive of us have already entered these dates into our calendars for the next two years. And now we have a change! For the first time we will be moving our meeting date to a weekday; Tuesday, May 1. At our November, 2017 meeting, we opened this for discussion and those in attendance agreed; this occasion is worth the 'deviation'.

You will receive more information in the coming weeks and we hope you will consider how important this meeting will be. Whether you can attend in person or not, your presence online that day will have meaning beyond measure.

Some background:

In 2016, our KIT participated in a bold fundraising effort called the Sarasota Community Foundation Giving Challenge. To make a long story short, our KIT members and the Staff of TMA asked friends and family to donate during a specific 24-hour period. All donations had to be online and there was a \$25 minimum. All donations went to TMA (because they are a 501c3 and our KIT is not). However, the Patterson Foundation, a local philanthropic group, offered a match of nearly \$2 for every \$1 donated. The match money went to our KIT. The result was TMA received about \$14,000 and our KIT received almost \$21,000.

We turned the event into a fun KIT party. Thanks to the Lesoines hosting us we invited members and friends to come to participate in the online challenge. Adding to the festive atmosphere, we watched the 'thermometer' that tracked donations received (we almost ran out of marker ink!)

Because all matching funds must be spent in the SW Florida area, our KIT has been able to accomplish several meaningful goals with the money we received. We offered first ever financial aid for our members to attend TMA's conference. Plus we organized a first time medical symposium in Manatee County, to provide myositis education to local medical professionals. Finally, we have been working to provide a unique livestream process for our members to attend meetings when they are not physically able.



Our results were so encouraging that we're going to do it again! Because we would normally hold our May KIT meeting on the first Saturday but the Giving Challenge is that same week, we decided to combine the two. That is why our KIT meeting will be on Tuesday, May 1. One thought about giving through this event...your donation from \$25 to \$100 will be matched, 1:1 between TMA and our KIT. You may certainly give more AND, if you wish to specify that your donation to TMA go to research and/or you want to give in memory of or honor of someone, you may do that as well. It's a great opportunity to help researchers like Dr. Raju!

It will still be a KIT meeting with a few twists including: a surprise speaker on a topic relevant to us all; PM, DM, IBM, NM and caregivers. There will be food but *not* our usual nuggets and wraps. Our lunch will be catered with real food! And the best part is that it will be free! For the past two years we have asked you to "bring a friend" to our May Myositis event. Now you have even more incentive to do so. Hear about how to Manage Your Medical Team, enjoy a nice lunch and participate in a fundraiser for TMA and our KIT. Registrations will still be necessary but you will get your invitation in plenty of time.

Please watch for additional e-mails with the following topics:

- March 24 pot-luck at Lesoine's
- Giving Challenge Info Sheet
- Financial Aid for members to attend TMA conference
- May Meeting invitation

### Finally...

One of our newer members recently e-mailed the following thoughts about our February meeting. He's talking about everyone reading this newsletter...

First, that has to be the most friendly, humor loving and overall pleasant group of people ever assembled in one place. In spite of their difficulties....optimism is everywhere!!

Second, kudos to whoever is involved in selecting the annual speakers. Last year we had a practical hands-on presenter and this year a research scientist.

That's what I call covering all bases and presenting the successes, failures and difficulties encountered by different participants in this difficult journey.

EZ-STEP



SAFETY · STABILITY · SECURITY



RITA B LAMERE MEMORIAL  
FOUNDATION

Thank you to our Friends and  
Sponsors

