



SW FL KIT Meeting August 5, 2017
44 people attended, including two new members

Our 10th Anniversary Meeting



For many of us this meeting was special in a number of ways. First we celebrated ten years of caring and sharing. **Barb** and **Matt Kluding** and **Marianne** and **John Moyer** are the only four members who were present at that first meeting and at this one ten years later. So to share our memories and those of so many special people we have been blessed to know along this journey, our meeting started with unique entertainment!

Linda Sabatino was able to take all the pictures from our KIT's scrapbook and she created a 20-minute slide show of hundreds of pictures. People, events, celebrations, speakers and anniversary cakes appeared on the screen as we arrived for the meeting. Look at this picture to the right: how many of our original first time members do you recognize?



In addition, **Jon Paul Mendez**, a local musician friend of **Penny Andrea-Einmo's** played beautiful, uplifting music on his guitar for us. We were thrilled at the slide show and the music so we repeated this during lunch. Note that for those who did not attend, **Linda** made copies on a DVD of not only the slide show but also each individual picture. So if you would like a copy, please let **Marianne** know and they will be available at the November meeting as well.

How do you top that opening? We invited speakers who addressed a subject that unfortunately is familiar to many of us; dysphagia. **Jan Marriott** has been treated by **Diana Juble-Delgado** at USF and let us know that Diana is very knowledgeable and willing to speak to us. In addition, Diana brought her co-worker, **Mary Pyfram**. Both are Speech Pathologists and by the end of their presentation, everyone knew much more about this complication of myositis than we did before. They also presented us with a Reflux Symptom Index (RSI) to assess our symptoms that might be caused by acid reflux. For a summary of Marianne's notes on the presentation, see the last page of this newsletter. A link to the RSI form is included as well.

There were still more surprises to come! **Barb Kluding** read a moving proclamation to **Marianne** and **John Moyer** that touched off more than a few tears. Then **Matt Kluding** read a letter from TMA's Executive Director, **Bob Goldberg** who commended our KIT on our many accomplishments over the years. He acknowledged that we are the largest KIT and that all our members are 'stars' for having the courage and determination to continue showing up for one another. He also added some nice words about Marianne's contributions to our and other KITs.

And then it was time to cut the Cake! As we could see, our KIT's history records a number of celebratory cakes (mostly chocolate of course!) This one was most ably cut and served by **Susan Artabasy** of Home IGRx. She also sponsored our lunch for the day and we are most grateful. And what would a celebration be without gifts? Another good friend of our KIT, **Jeff Wolmuth** from Stand Aid donated scented candles in tins. Since the 10th anniversary contemporary gift is tin or aluminum, we thought these candles would make a nice remembrance of the day!

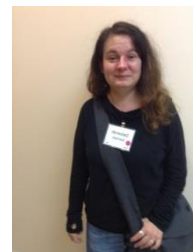
We don't always say this in our newsletters but we should...After lunch we spent an hour in what many of our attendees have said is the best part of our meetings (ok, aside from the great speakers and yummy cake). And that is our breakout groups by IBM, PM, DM and Caregivers. These four groups meet to talk about whatever they want for that hour. There is no agenda and everything that's said in that room, stays in that room unless permission is given to share. Because that day we had two new members, both newly facing myositis, this was a wonderful opportunity for them to ask questions and hear from others what we have experienced. None of us claims to be an expert or a medical professional; we just know how our lives and those of our families have been impacted by myositis. As a result, we want to do all we can to ensure the newly diagnosed know that they are not alone! One family member, who was attending for only his second time, reflected that he thought this KIT epitomized a thought he had:

Understanding is a most powerful tool. To be in the know is learning to grow!



Jennifer Laux and her husband **Cliff**. She is not yet diagnosed but is in the process and will probably be seeing Dr. Aschermann in Miami. (They are thinking she has PM) Jen and Cliff are former missionaries in Ukraine, speak fluent Russian, and are now living in Ft. Myers.

Deborah Santana Deborah is a chef from Ocala, and is a newly diagnosed DM patient. She found our KIT through TMA's forum.



How Do You Spell a Cry of Anguish?

It's probably something like "Arghh!" Well, once again, our attempt to livestream the meeting was not successful. The details are not important except to those of us determined to fix



whatever went wrong. We had even had a practice meeting, a week earlier and everything worked. On August 5 it did not. Back to the drawing boards and a thousand apologies to those who faithfully tried to participate from all over the US. Please don't lose faith. We will get this to work. That's a promise! And to all those techies out there who told us this was a *piece of cake*, they know nothing about cake! Cake we KNOW! It's the technology that gives us anguish!

Fall Potluck, Saturday, September 16 at 1 p.m. at the Lesoine's

It's another potluck and social gathering of our KIT. Come one, come all. Invitations will be e-mailed to you around August 20. When you call or e-mail Camille with your rsvp, please let her know what you will be bringing. These relaxed afternoons are a great way to continue the conversations you didn't get to finish at the meeting. Please join us.

Next KIT meeting, Saturday, November 4 at HealthFit

We have traditionally reserved the November meeting's presentation for the opportunity for those who attended TMA's conference to report to the KIT on what they saw, heard and learned. The massive amount of information imparted by the speakers and even during the social times is something worth sharing. We are also inviting caregivers who attended to let us know what they learned as well. And, if there is enough interest, Marianne will present the session she is delivering at the conference. It is entitled "Managing Your Medical Team" and addresses not only how to communicate with doctors and therapists but also contains some tips for how to create and maintain your medical records.

TMA's Annual Patient Conference

San Diego, September 7-10

By the time you read this newsletter, the conference will only be a few days away. If you are into last minute planning and still wish to attend, go to www.myositis.org. The website also has the preliminary agenda of sessions. TMA will be sending out a notice of which sessions will be livestreamed during the conference and remember that most presenters' slides will be on TMA's website shortly after the conference ends.

On Thursday evening at the conference, there will be a wine and cheese reception and an opportunity for KITs to set up displays about their groups. Our KIT will of course be participating and will also be visiting with other KITs to share 'best practices'. We are all one big family and it's so encouraging to hear and see how other groups are helping their members cope.

Speaking of Conferences...

TMA is committed to making its conferences available to as many people as possible; thus they move the location each year to be closer to a different geographic area. That way, for those who want to drive, at least every year or two the conference should be within a few hours of them. Recently though, TMA has added another way for members to benefit from the information imparted at these conferences. They are 'Mini-Conferences'. Because TMA's Medical Advisory Board (MAB) members are often researchers at a prestigious university, they have the resources to create a mini-agenda for local TMA members. These events are announced via e-mail to TMA members and are free to attend.

One such Mini-Conference was recently held at the University of Miami, and was organized by Dr. **Dana Aschermann**. Barb attended and reported that the sessions, several of which addressed lung issues, were very informative. Hopefully everyone reading this is a TMA member so that when these opportunities arise again, you can take advantage of them!



Anthony Ungaro

Keeping in Touch with Members

It was a sad day when we heard that one of our original members who was present at our first meeting ten years ago, had passed on. We will truly miss **Tony Ungaro**. He was a fine gentleman who was instrumental in forming one of the first myositis (IBM) support groups in the country that eventually morphed into TMA. He was initially diagnosed over 50 years ago and managed to continue coming to meetings up until just a year ago. We signed a card to Cynthia and his family and as we always do; our KIT made a \$50 contribution to TMA's Research fund in his name.

The Trials and Tribulations of Trials

Barb and one of our visitors, **Augie DeAugustinis**, gave brief overviews of the clinical trials in which they have recently participated. Barb's has ended and unfortunately she didn't detect any real change in her condition. However, she was very positive in her reflections about the value of the experience, both for participants and hopefully for future patients. This trial is still recruiting so if you have DM and are interested in participating, feel free to contact Barb about it and/or go to www.clinicaltrials.gov for specific information about this and other trials.

The trial in which **Augie** participated and that has been referred to as the "Follistatin" trial is also still underway and involved injecting a modified virus into his thigh muscles. Initially he was able to detect an increase in his muscle mass but at this point that progress seems to have stopped. He has hopes to be invited to participate in the next stage of the trial. The title of this section "Trials and Tribulations..." is a reflection of the fact that it's not easy to be a trial participant. While your travel and expenses are often compensated, there is no way to compensate you for the stress you are likely to experience. Just ask **Barb** and **Matt** about a monthly drive to Miami or **Augie** about monthly flights to Ohio! Still and all, we all know that it is only through the efforts of researchers that there will be any progress toward diagnosing and treating myositis diseases.

Our KIT's Financial Status

You may remember that in September, our KIT participated in a fundraiser sponsored and largely funded by the Patterson Foundation and the Sarasota Community Foundation. In just 24 hours we raised (and received matching funds) of over \$30,000. This money was split between TMA and our KIT. We specified that our part would go for several initiatives; helping to fund some of our members' attendance at TMA's conference, developing and implementing our livestream process and delivering myositis awareness events, both for local medical professionals and for our KIT and their families and friends.

To date, we have spent the following:

\$986.43 for the Livestream equipment

\$2,566.32 for the Medical Symposium

\$817.22 for the KIT Myositis Awareness event (lunch was sponsored by Home IGRx)

We have not yet spent any of the money for our member's financial aid to attend the conference because TMA has agreed to bill us after the conference. We had anticipated spending approximately \$4,000. However, several of our recipients have withdrawn from attending and so at this time, we expect to only spend about \$2,000. Since we had budgeted at least \$10,000 for these 'scholarships', we will hold onto this money and use it for the same purpose next year. It is likely that the conference will be held somewhere east of the Mississippi so this should make it more attractive for our members to plan to attend.

As a final financial note, we initially set up a monthly 50/50 in order to raise some funds to enable us to invite and pay for speakers like **Drs. Ytterburg** and **Oddis**. With the balance we currently have, it would appear that 50/50s are no longer necessary but they are fun. We will therefore continue them at each meeting. The only difference is that since so many of our members have been extremely generous to give back their winnings, we are providing another way for them to 'give back'. If they wish to specify how that money will be used, we will honor their request. For example, the money could go to our KIT's scholarship fund, to speakers or to be given to TMA's Research fund. If the money is not designated, it will simply be added to the KIT treasury to be spent as needed.

In Closing...

By the time the meeting ended, it was actually difficult to leave. It had been an amazing day, surrounded by our KIT family and being able to reflect on our ten years of showing what a 'support group' is all about. Here's to ten times ten more years of our wonderful KIT family!

Dysphagia Presentation

Diana Juble-Delgado, M.S., CCC-SLP
Phone: 813-974-8171
E-mail: julbedd@usf.edu

Mary Pyfrom, M.S., CCC-SLP, MT-BC
Phone 813-974-7563
E-mail: marypyfrom@usf.edu

They made the initial point that there are many issues around dysphagia. And regardless of the patient's type of dysphagia, it can be defined as any impairment in the structure or function of your swallowing. There are numerous different treatments and they will each address various stages of your swallow.

Oral Stage symptoms can include or be characterized by:

- Decreased lip closure
- Food sitting in the mouth
- Difficulty moving food from the front to the back of the mouth
- Increased chewing time

Pharyngeal Stage

- Nasal regurgitation
- Inability to trigger a swallow
- Aspiration (could be coughing and choking or silent)
- Residue left in the throat
- Feeling of food stuck in the throat (even if it's not really there)

Esophageal Stage

- Dysfunction of peristalsis
- More feelings of food stuck
- Heart burn (reflux)
- Dry mouth

Aggravating factors of reflux

- Take precautions like avoiding spicy, greasy foods
- Don't overfill on liquids making you feel full
- Don't exercise on a full stomach

What to expect from a speech language pathologist evaluation:

Observational and Instrumental stages like a Barium swallow study or a fiber-optic endoscopy

Treatment options will definitely be individualized based on your evaluation!

Strategies you may be asked to employ include:

- Eating more slowly
- Taking smaller bites
- Not talking with food in your mouth (see, your mom did know best)
- Alternate solid and liquid intake
- Sit upright to eat

Both ladies said they would be happy to see any of us who feel we'd like to know more about our own swallowing issues.

One indicator of possible need for an evaluation would be to look at the Reflux Symptom Index (RSI). I was unable to print the form but go to this link. <http://www.ucdvoice.org/laryngopharyngeal-reflux/>



Members
Linda and Don Broughton



Audreyanna Malone



Speakers :
Mary Pyfram
Diana Juble-Delgado



Augie and Leslie DeAugustinis

Thank you to our Friends and Sponsors

The sponsor banner features a central green-bordered box with the text "Thank you to our Friends and Sponsors" in a green, italicized font. Below this box are seven logos arranged in two rows. The top row includes Kroger Specialty Infusion, MedPro Rx (A Diplomat Company), Home IGRx Specialty Infusion Services, and STAND AID. The bottom row includes Mallinckrodt Pharmaceuticals, EZ-STEP (with a logo and the tagline "SAFETY • STABILITY • SECURITY"), RITA B LAMERE MEMORIAL FOUNDATION, and NuFACTOR Specialty Pharmacy.