



Our Second Annual Myositis Awareness Celebration;

**Our KIT Sponsored TWO Myositis Awareness Events!
What a Wonderful Whirlwind Weekend it Was!**

Symposium for Medical Professionals in SW FL

On Thursday, May 4, local medical professionals had an opportunity to enhance their awareness and knowledge about diagnosing and treating myositis diseases. They were invited to a two-hour presentation led by our KIT’s good friend, Dr. Rossitza Chichkova. Doctors enjoyed a nice dinner and were entitled to two Continuing Medical Education units. We reserved the banquet room at the Ranch Grill in E. Bradenton and while we didn’t fill the room, there were 15 doctors who did attend. It was interesting to note that there were at least two retired doctors who just wanted to keep active and one med student who was just curious. Medical disciplines including pain management, pediatrics and general practice were present.

Four of our KIT’s leaders were present as well and we located ourselves around the room to better expose the doctors to informed and articulate myositis patients. This proved to be an exceptional opportunity for us to expand even further, their awareness of our diseases. For example, one pain management specialist was very curious about what kinds of pain we experience and when it occurs. Another appreciated the opportunity to see what DM calcinosis looks like and how it affects the patient. One wanted to know more about the standard doses for myositis medications. Others were interested in how patients appear to go into remission. There was even one question about if stem cells will become a viable treatment option.



Dr. Chichkova did a marvelous job of fielding the questions and covering a wide range of issues which included encouraging doctors to contact and join TMA and to direct patients to their local KIT. We distributed a large number of TMA publications including a hot-off-the-press Physicians’ Guide, Myositis 101, disease and KIT brochures, wristbands, magnets and tablets.

Rose, Dr Chichkova , Barbara. Donna, Linda, Marianne

Three home IG vendors set up displays and explained how their companies provide infusions in the patient's home. They were: HomeIG RX, MedPro and a new one, Biologics.

The bottom line here is that while there were only 15 doctors present (plus the staff of the Manatee Medical Society), this event must be considered a success. We raised awareness where it has the opportunity to do some real good...in the medical community. Before this event, the average time it takes a patient to get an accurate myositis diagnosis is 3.5 years after seeing up to five doctors. Hopefully in SW Florida, that time will get shorter!

The list of attending doctors is at the end of this newsletter. If you invited one of them, please say "thanks!"

And it must be said, this event was made possible by the money we raised last September during the Sarasota Community Foundation's Giving Challenge. We do not yet have all the costs incurred for the postage, CME application, dinner, giveaways and event but it will probably be less than \$5,000. Our KIT's leaders believe this was money well spent!

...And then it was OUR Turn!

Saturday, May 6 at the Ranch Grill, in East Bradenton

We had 65 in attendance, including 2 'first timers' and 33 'friends and family'

Once again, we had to reserve a new venue for this meeting. We knew the meeting would be well-attended and it was. We knew we'd need lots of good food for the crowd and it was. What we didn't know is if the space and technology would be sufficient and ...it wasn't. More on that later.

In keeping with the tradition, we began last year for our KIT's myositis awareness event to be tied to our regular KIT meeting, we again asked our members to invite friends and/or family who want to raise their myositis awareness. Clearly, that part of the plan was a huge success.

We wanted to deliver a presentation that would be of interest to all types of patients and guests and again, we were successful. Dr. Chichkova spoke about how she and the doctors Thursday evening were able to exchange information about myositis diseases. She let us know that she emphasized how she encouraged them to work together as a team to treat us and to not just attribute all our health issues to our myositis.

The second half of our meeting (that was not filmed), was an open invitation to KIT members and their partners to speak about what their lives are like, living with myositis. Here are a couple of the most moving comments and some follow-up. The follow-up acknowledges that in the true spirit of 'keeping in touch' and caring and sharing, our members were quick to recommend or comment on possible solutions for issues of concern to patients.

An IBM patient acknowledged that the challenges of IBM are certainly frustrating and getting more so every day. But she especially misses the confident use of her hands. The inability to securely grasp something is actually kind of scary (think about a cup of hot coffee or a large glass jar or even a child's hand.) There are probably many sources for exercise gloves but we can always count on good old Amazon (and of course, Amazon Smile so TMA gets a donation). Search for Traction Exercise Glove and choose your size. It appears from the ad that each glove is \$29.95 (I guess some people only need one...?) It comes with rubber bands which force your fingers down toward your palm to re-teach your hands to grasp.

One very satisfied IBMer said she wore hers while sleeping, riding in the car and while watching television. It helped her ability to grasp. (As always with this kind of recommendation: ask your doctor before using.)

Someone had a different IBM-hand issue and that's that he's finding it increasingly difficult to maneuver the mouse on his computer. He already uses voice-recognition software. Several people spoke up to recommend once again, Amazon for "hands-free, computer mouse". They aren't inexpensive but there are several models available.



Pulling on a pair of support socks/stockings is a difficulty several people described. Again, our group was quick to point out sources for readily available compression sock applicators: Amazon and many medical equipment suppliers. In fact the Doctor Leonard's Catalog not only has the sock-"puller-onner" but they also offer zip-up compression socks with no pulling needed! <http://www.drleonards.com/>

A partner of an IBM patient mentioned the challenge of her not being able to close her eyes. And a few of us could relate; the muscles affected by IBM sometimes work in the darnedest ways and when it affects the eyes, patients find they have to wear a mask to sleep or even tape shut their eyelids. Needless to say, many kinds of lubricating eye-drops are also a handy item to have.

While it was a part of Dr. Chichkova's presentation earlier, one tip that may have been missed by some of us is that she highly recommends that we create some sort of complete record of our health issues; not just those directly associated with our myositis. We want to encourage our medical team to look at us as a whole being; not just a myositis patient who happens to come in for a colonoscopy or eye exam. It can be a daunting task to address how to make, maintain, keep and use this kind of record but it's an important one.

After the meeting, one of our 'friends' was asked what he thought of the day. He replied that while he has been witness to his loved one's long-time battle with myositis and has seen the changes she's experienced over the years, he was amazed to see all the various stages of our members' conditions. And he was very heartened to see the positive support shared by everyone there.

That sums up the Southwest Florida Myositis KIT's 2017 Myositis Awareness Events. We experienced a wide range of people's unawareness to semi-awareness. We handed out valuable materials that we know will soon find their way into doctors', nurses' and other medical professionals' offices. We are lucky to have received, hot off the press, the latest version of the Physician's Guide to Myositis. We shared them with the doctors at our symposium, our members and even our families and friends who were asked to take them to their doctors. Here's a fun anecdote about the Guide. Recently Dr. Dana Aschermann, Chair of TMA's Medical Advisory Board saw a new myositis patient and the first thing she did was hand him the Guide and ask him to read it! How could she have known he was partially responsible for its content? That's what we call raising awareness! Now how are we going to top that next year?

BTW, as we said above, we are still processing bills from these two events. They cost a bit less than we expected and our KIT is solvent and ready to engage in new and exciting awareness efforts. After all, Myositis Awareness is not just for the Merry Month of May!

One factor that helped us is that a new vendor but an old and dear friend, Susan Artabasy and her boss, Susan Pearring who are now with HomeIG Rx, sponsored our lunch. We are most thankful for their help.

Now, About This New Technology...

The Fab Five is falling all over themselves apologizing for the lack of sound in our transmission of the May 6 meeting. Sometimes it's the little things that really get you and that's what happened that day. To make a long story short, the microphone was disconnected from the system. So none of our remote participants could hear us and those who went online to view the presentation afterwards were just as unlucky.

But here's a really interesting question! Why didn't one of you who were online real-time, use the question/comment feature and just type: "Hey dummies, there isn't any sound!"? We promise to try not to make this kind of mistake on future programs but if we do, we ask, beg, entreat you to use the system to let us know what you are experiencing. Then we can plug in the darned cable or whatever is wrong and everyone is happy!

Summer Potluck Barbecue, Saturday, June 24 at 1 p.m. at the Lesoine's

As I type this I'm humming "Summertime, summertime, sum, sum, summertime" (by the Jamies.) It's pretty much always summertime herein SW Florida but now it's official and it's time to celebrate. The KIT will furnish beverages, burgers and dogs. We'll ask for a 'free will offering' to cover their cost. Everything else will be pot luck so when you call or e-mail Camille with your rsvp, please let her know what you will be bringing; side dish, buns, condiments or dessert. The invitation to which you may reply will be in your inbox around June 3. Watch for it and plan to join us.

Next KIT meeting, Saturday, August 5 and we are returning to HealthFit

First here's the news about the meeting and then our rationale for the venue choice. Our summer meeting will feature several special offerings to entice you to venture from your air-conditioned homes to your air conditioned cars to our air conditioned meeting room. And yes, in-between, you'll be cooking as you go from one to the other! Our presenter for the meeting comes to us highly recommended by member Jan Marriott who discovered **Diana Julbe-Delgado, M.S., CCC-SLP**, a Speech-Language Pathologist, Clinical Instructor at the University of South Florida and Interim Clinic Director - Speech Language Pathology. When we first considered her as a speaker, we were concerned that in our ten-years of meetings, we have twice heard presentations about dysphagia. But upon reflecting on when those presentations occurred (August,

2007 and August, 2013) it seemed like a good idea to look at this scary subject again. So, it doesn't matter if you experience dysphagia now or not; it's a real possibility for all of us and we should be aware of how to recognize and manage it. Please join us!

Speaking of August meetings, we will once again happily and thankfully celebrate our KIT's anniversary and this is a big one. We are TEN years old. And while Hallmark says that the 10th anniversary gift should be diamonds for a contemporary celebration, thankfully a more affordable alternative for a more traditional gift is tin or aluminum. We'll let you guess what kind of gift you should expect to receive on August 5. (And if you really want to stretch your imagination, try to guess what flavor of cake will be served!)

Fingers and toes are crossed as I type: The August 5 meeting will be available for real-time viewing (and the communication can be duplex!) For old telecom execs, in this case 'duplex' means two-way simultaneous communications, not a small cottage on the beach! If you are planning to watch, plan also to let us know you are there; just send a message, which can be as short as "Hi, this is Charlie."

Where can Our Growing KIT Meet???

Your KIT leaders, the Fab Five, are flummoxed! It's a good problem to have but not a good one to solve. The reason we held the May meeting at the Ranch Grill is that our previous meeting venues are not always adequate for our group. We polled our members at the May meeting and here's what you told us:

No comment about room	4
Positive comments	6
It's okay for a small group only	7
Didn't like it at all	11

Your KIT leaders think the Grill is "ok for a small group, or with rectangular tables" but "not ok because of bathrooms and poor AV/wi-fi capability, so we have to remove the Grill from our list of meeting venues. For a small-group, sit-down banquet it's fine. For a regular or large meeting with movement and handicap aids, it just doesn't qualify.

Here's the current bottom line: For our August and November meetings, we believe we are ok to continue meeting at the HealthFit. It's easy to get to, has parking and bathrooms for handicapped people and the next-door Chick-fil-a and Geckos provide easy food and drink provisioning. The room easily handles our projected 40-50 people, even with chairs and walkers.

For our February and May meetings, where we have been experiencing 60 or more attendees, it becomes more complicated. HealthFit is out. And sadly, after six years at Mixons, we can no longer fit into their room either. Plus, their outdoor pavilion that we used "the year of the February tornado" would probably be fine for a large group but they will not reserve it more than six weeks in advance and weddings and other big-bill parties get the first shot at Saturday dates.

Where does that leave us? For now, we're homeless for these two meetings. But fear not, there are some options we are examining and we'll keep everyone informed. An ideal spot will seat up to 100 (including those with walkers or scooters), would be inexpensive (free would be nice), should be easily reachable from I-75 and have plenty of handicapped parking and bathrooms. Our live-stream equipment must work with the room's system. Reasonable food and beverage provisions are also necessary. And since our KIT seems to be almost evenly split between north of Bradenton and south of Bradenton, AND we plan to continue meeting in the south (HealthFit) twice a year, it might make sense to consider avenue north of HealthFit.

It's a work in progress folks. Please be patient with us!

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

There are only a few days left till the early-bird deadline for Conference registration of \$225 per person. After May 31, it will cost you \$270 so get on line or mail that postcard ASAP. Go to myositis.org which already has the preliminary agenda of sessions posted. Be aware if you are a first-timer, (or even those of us who have attended many conferences), there is a tendency to try to spend every minute 'productively' in a session. Try to pace yourself and if you don't get to all the sessions you wanted to; remember the presenters' slides will be on TMA's website shortly after the conference ends. See you there!

Scholarship Winners are on Their Way to Conference!

And thanks to the generosity of our families and friends, The Patterson Foundation and TMA, our KIT will be sending six of our members to San Diego with their hotel and conference expenses covered. As a result of our participation in the Giving Challenge last September, our KIT raised enough money to make these 'scholarships' available to some of our members. Our anonymous panel of judges reviewed the applications and awarded six members this awesome opportunity to not only learn from the experts more about their disease but also to connect with other patients and their families as well. Think of it as a KIT meeting on steroids!

Another Conference Opportunity and it's FREE!

Speaking of conferences, TMA is offering a wonderful opportunity to those who are not planning to attend the San Diego conference. On Saturday, June 3 at the University of Miami there will be a FREE half-day conference with sessions addressing research, IBM muscle biopsies, dysphagia, physical therapy and pulmonary complications. Since Barb Kluding has become such a fan of driving to Miami, she will be attending and we hope some other members will also consider this unique opportunity. It's free but you must register via TMA's website.

Keeping in Touch with Members

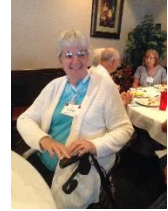
We received this response to the card we sent to Laura Parsons, congratulating her on her recent marriage (she lost her husband Chris to IBM-related issues several years ago,).

Thanks so much for the lovely card and best wishes to David and me. It came today, on my Birthday! AND, Saturday, I kept thinking of you and the SW FL KIT, especially the Derby Days that we spent in Sarasota meetings followed by great food and fellowship at Geckos. I couldn't help feeling emotional about the love and support we always received through the SW FL KIT meetings, fund raisers, the dinners at Conferences, etc. etc. etc. The reason I felt so much on Saturday was because you were thinking of me and wishing David and me, new energy and new life. How sweet is that!!?? To God Be the Glory! Love and Peace to all of you, Laura

Barb Kluding updated us on her 'trials and tribulations' with her clinical trial for DM. Trips to Miami aren't fun and the constant changes in scheduled treatments are stressing her and Matt! But she's hanging in there in hopes that what she's getting will help her and other patients in the future. Here's hoping! Notwithstanding her frustrations, please note that not all trials are run exactly the same. There are other trials that are currently recruiting especially DM and PM patients. If you have any interest in helping researchers to help us, please go to clinicaltrials.gov and look at the options for applying to be a participant.

Are they 'snowbirds' or 'northern visitors'? Who cares! They are KIT family members and we know that at least five of our KIT couples also alight somewhere up there in a northern KIT. This means more collaboration and more ways to learn from one another. Win, win! We'll see you when you return for our November meeting! Meanwhile be safe and well and know that we miss you.

Jo Randolph lives near the shores of Lake Okeechobee and was led to our KIT by TMA's new Programs Services Director, Ruthann Devine. Jo has IBM and before our meeting had not been able to talk with others who have her disease. She fit right in at our meeting and promised to return! It will be a long drive for her but we hope she'll think it's worth it.



Norm Eubank brings to three the number of men with IBM who reside in the small town of Parrish. If Parrish has a total population of 8,252 and three of them have IBM, is myositis such a rare disease? The three that we know about are Norm, Ray Lesoine and John Setzer. Well it IS rare to find three IBM neighbors who are all charming and sitting at the same table at a meeting. Let's hope the 'three musketeers' continue their adventures.

Doctors who attended the May 4 Symposium

Adler, Jonathan	MD	Koser Robert	MD
Brainard Karen	MD	Simmons Courtney	MD
Cartaya Bernard	MD	Singh Rishita	DO
Clulow Scott	DO	Sprenger Thomas	MD
D'Auria John	MD	Turalba Cornelius	MD
Hassan Ahmad	MD	Valenti James	DO
Jawitz Jack	MD	Yonker Richard	MD
Jefferies, John	MD		

Note that some of these doctors brought friends or relatives and we were not able to capture their names or professions. There were actually 21 non-KIT or non-staff attendees. Six will just have to remain mystery folks who now know more about myositis than they ever did before! If you see or know one of these doctors please thank them for attending. Then give them an oral exam about what they learned! (Just kidding; I'm in that kind of mood after typing all these pages!

In closing; if I forgot to include something in this newsletter that you expected to see, I apologize. As you can see from the preceding pages, it's been a busy time and I wanted to get this out to Linda to get to you before another day goes by. Bye!



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