



## Meeting Saturday, February 2, 2019

**52 people attended**

### **Including nine first-time Patients and their Care-Partners**

It's crazy that the sign on our meeting room wall says that the room can hold 200 people. They would have to all be standing shoulder to shoulder because with just 52 of us, the room was packed. And it was okay! The energy and camaraderie in the room was a physical thing; snowbirds returning and 'regulars' sharing holiday stories and first-timers being welcomed to our family. Add to that, Dr. Chung, a great speaker and the day was definitely a success!

We welcomed **Danny Blair** (PM), wife **Sloan** and parents **Kathy** and **Fred**. **Lisa** and **Shaun Chang** have an eight year old with DM and came to learn about it. **Stanford Erickson** (IBM) and wife **Nancy** attended from Vero Beach. **Miriam Gurowsky** has not yet been diagnosed but wanted to come to learn about what she might have. **Warren McHenry** (IBM) and wife **Cheryl** found us at the last minute. **Nancy Nilles** (PM/IBM) also got in just under the wire. **Lorraine Pierce**, (PM) was amazed to find she and the Blairs who live in the same development, have something in common; PM! **Frank Rettinger** (IBM) and **John Scanlon** (IBM) rounded out our nine first time patients! We've said it before—is this really such a rare disease?

By the way, with these new folks, our KIT list now includes 162 names of patients or caregivers. And that doesn't count a separate list we keep of friends like KIT leaders and TMA staff!

A final note on our first-time attendees...we usually try to capture a quick photo of each for our scrapbook but at this meeting it appears that no one thought of it. It would be great at future meetings if someone would pull out their cellphone and snap a couple pics for us...

### **Dr. Tae Chung – Psychiatrist**



Johns Hopkins Myositis Center has a wealth of superior medical experts where many of us have received treatment. Dr. Chung is no exception. His presentation had something for everyone, even our caregiver/partners. His slides were concise and understandable. He has provided them to me and they are available to any member who e-mails me for a copy. It's 46 slides on a >1500 Kb file so I didn't want to crash anyone's inbox if they don't want it. Following, I've included my notes from his talk.

A Physiatrist (fizz ee at' trist) is a doctor who specializes in helping patients to better function. He distinguished between being impaired, having a disability or being handicapped—these are not the same things! If some part of you exhibits functional impairment, he works to find therapeutic help, including PT or exercise. He pointed out that it's important to identify a PT or OT who understands things like your Functional Index and how to treat you. He suggested that if you want to find a Physiatrist, more information can be found in the AAPMR (American Association of PM&R) website: <https://www.aapmr.org/about-physiatry/about-physical-medicine-rehabilitation>. I looked in a recent Sarasota Physician's guide and there are no Physiatrists listed. The closest I could find was a couple doctors advertising they practice "functional medicine". (We need to look into this.)

Then he talked about that word we all love; exercise. It can actually be a serious medical intervention and includes endurance, cardio and resistance work. To that end, he spent some time on walking and how even with a myositis disease, there are ways to prolong our ability to walk safely. An ankle brace, walker or even cane/walking stick can all help keep a patient mobile and out of a wheelchair. The message about canes is that they provide a sensory input for stability and are not for weight-bearing. Patients should not resist using a cane out of misplaced desire to appear 'able'. A Physiatrist can help evaluate not only your ability to walk but also your gait. They will also take into account your desired level of activity (do you really want to train for a marathon or do you just want to be able to do the grocery shopping?)

What is needed to 'prescribe' exercise is a:

- Accurate and objective measure of muscle strength
- Types of exercise should be well defined
- Standardized way of "dosing" the amount of exercise

Many of us were surprised when he said that there is a guideline in using more or less weight or intensity versus more or fewer repetitions.

- High intensity (weight), with typically < 5 – 10 Reps is usually good for PM/DM patients
- Low intensity (weight), with typically > 15 to 20 Reps is usually good for IBM patients

He addressed the topic of 'muscle soreness' after exercise known as Delayed Onset Muscle Soreness. While in the past this may have been seen as contra-indicated for myositis patients, there now is no likely damage.

Many of us were able to ask specific questions that Dr. Chung was happy to answer, even recommending some changes in the equipment that a few of us were using. It was a very enlightening session and we're grateful to Dr. Chung for his time spent with us.

## Our Next KIT group Meeting Saturday, May 4, 2019

Members have told us that sometimes they would rather not have such structured meetings. So In May we are going to have minimal structure and almost no 'agenda'. But we will have some of that valuable information we usually take home from a meeting. This meeting is going to take a page from TMA's 2019 Conference theme: ***Who You Are Matters!*** What does this mean? You aren't 'just' a myositis patient or caregiver; you are someone special who manages to deal with a challenging disease that, before diagnosis, you'd never heard of. And YOU are managing. YOU are prevailing. YOU are a shining example of determination. So come to this meeting to tell us about YOU. Specifically, we'll have some questions we'll send in the meeting invitation that we'd like for you to consider. No one is expected to be a polished orator; just be yourself, one of our KIT family members telling us how you are doing. Think about what equipment and/or aids you use to get by and how they have helped you to adapt to your new normal. And caregivers; this is for you too! Now, if only Pacman could talk! A long time ago our KIT adopted the slogan: "We care, so come and share!" Let's *do* it!

### Medical Equipment Assistance Plan Underway!

At the meeting, Barb reminded members that the medical equipment assistance plan is in full swing, with so far only six members applying for and receiving \$100. This money may only be a drop in the bucket for what some of us have to spend, but our KIT believes that anything can help and that this is another way we let members know we care. So find that e-mail that you received (you didn't delete it, did you?) and send your application today. Purchases you made after January 1, 2018 are eligible. For more details, find the December 9, 2018 e-mail and attachment you received. The subject line of the e-mail was **Medical Equipment Assistance**.

### Magnets to help tell your story...



We all know how difficult it can be to explain our myositis to those who know and love us. It's even harder to explain to strangers. Some of us have expressed annoyance that as we park our car with a handicap hanger or tag in a handicapped parking space, there are people who have said unkind things about us not *looking* handicapped or disabled. We now are distributing to all who want one, a car magnet that looks like this. Contact Marianne or get one at each event upcoming.

## Keeping in Touch with Members

At the start of our meeting, we signed cards to mail to members who could use a little cheer. There were a lot of them this time. **Jean Rosenberg** had her gall bladder removed the day before the meeting and gee, she just didn't think she'd be up to coming! **Jo Randolph** is fine but we can't say the same for **George**, her husband. He fell and broke his shoulder. It's always difficult when the caregiver becomes the one needing care. **Sheila Vander Sanden** is trying to get used to a feeding tube—no more Cracker Barrel lunches for her, we're afraid. **Deb Santana** has one of those weird DM side issues; near blindness! The docs are treating it with what else—steroids. And did you notice **Rose Ryan's** eye at the meeting; swollen and red? She's not yet sure what it is but the docs say it may be related to her DM or medications. We still ache for **Linda Sabatino's** family, learning a new normal after her grandson died. And finally, one of our favorite KIT 'associate members', **Mary Marriott, Jan's** mother in law, died of complications from a fall. We will miss **Mary's** smile and spirit!

Please keep these and all KIT members in your prayers and thoughts. Also, remember that we had nine new myositis patients join us at the meeting. One had only been diagnosed a week before! The others had never experienced a support group meeting (especially one like ours). Think back when you were newly diagnosed or were venturing out for your first KIT meeting...

## May is Myositis Awareness Month

Because our KIT devoted time and effort during the Sarasota Community Foundation Giving Challenge, we have a bank balance that permits us to do unique and special things. In 2017 we sponsored a myositis awareness event for local medical professionals. This year we plan to do something similar.

On Thursday, May 23, from 5:00 to 8:00 p.m., we will host Physical and Occupational Therapists in an event intended to raise their awareness of myositis and how myositis patients aren't like other clients they have. Dr. Chung agreed that one each of his Physical and Occupational Therapists will be available to conduct this symposium.

The event will be at the Gold Eagle Distributing Company in Lakewood Ranch. Since this symposium is targeted to therapists, KIT members are not expected to attend. Instead, after the event, our hope/plan is that we will have a plethora of therapists from whom to draw speakers for our meeting in August.

### **Our First Van Rider Survives the Experience!**

**Ruth Peto-Wieclaw** has been driving herself to our meetings for some time. When she heard about our new contract with Doctors Transport, she decided to give it a try. Talk about “Easy”. She called DT’s dispatch, told them where she lives and that she wanted a ride to the KIT meeting, and a ride back home. That morning they picked her up, dropped her off and in the afternoon, repeated the process. Our KIT paid the bill and that was it!

There is no question it would be more cost effective if we got three or four members (with or without walkers, wheelchairs or powerchairs) plus their caregivers, on the same trip. Ruth lives in Venice where we have many other members. Who else is up for riding in our KIT’s “Party Bus”? Just let Marianne know when you get our next meeting invitation. We’ll arrange for a common spot for all to be picked up and dropped off.

### **Don’t Be A Statistic!**

Our friends at the Suncoast Center for Independent Living have invited us to a seminar on how to prevent falls. The seminar is entitled “Living Safely at Home—Fall Prevention”. This talk, part of their lunch and learn series will be on Thursday, March 14 at noon and includes a free, healthy lunch from Panera. It will be held at the SCIL office, 3281 17<sup>th</sup> St (at Lockwood Ridge Rd) in Sarasota, FL, 34235. The session is free but reservations are required. RSVP to Margaret Ann at 941-351-9545, Ext. 110 or [outreach@scil4u.org](mailto:outreach@scil4u.org).

### **Save the Planet**

**Jane Hansen**, caregiver to Julian, her father, asked if we could put a little thought into using more recyclables for our meetings. She, like many of us was concerned that we put a lot of plastic into those trash barrels. So to make a long story short, with the May meeting we will start a new process to put recyclable plastics and paper into one trash barrel and everything else into the trash. It’s great when a member comes up with a new idea and helps us implement it quickly and easily. Thank you Jane, and thank you to **Donna DeFant** who agreed to take the recyclables home with her.

### **Holiday Party**

Yes, the holidays seem like a long time ago (really only a couple months) but we’d be remiss if we didn’t again thank **Camille and Ray Lesoine** plus Pacman, for hosting our annual party. The potluck as usual gave everyone many, many choices of fabulous, festive food. Thanks to all!

**Spring Fling Party**  
**Saturday, March 23, 1 p.m.**  
**(Where? At the Lesoines!)**

Watch for an invitation in your e-mail around the first of March. Remember to RSVP to Camille when you do. Start planning your potluck offering now!

**Special Door Prize**

Our KIT is blessed to have wonderful relationships with many vendors who supply goods and services to the myositis community. One very special guy, John Stocker was chatting with some of us at TMA's conference in September and mentioned he'd be willing to donate another E-Z Step Mobility Device as a door prize for our meeting. Needless to say we took him up on his offer and at the meeting we drew a special ticket that belonged to one of our first time attendees, Warren McHenry. This is the second time John has given us one of these wonderful canes and we thank him! This picture makes me look like I'm not happy—wrong. I think I was just hoping that everyone who needs an aid like this gets one—we don't want anyone to fall! If you are interested in purchasing one of these terrific canes, go to [www.ez-step.com](http://www.ez-step.com) to learn more. There is a 10% discount on the website. (And then you can apply for our KIT Medical Equipment Assistance too!)



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