



Meeting Saturday, August 4, 2018
The 11th Anniversary of our first KIT Meeting
42 people attended



As we again gathered in the Goodwill Community room, members were happy to see that **Bob Goldberg**, TMA's executive director was present. It was an honor to have him attend our KIT meeting in the last month of his service to TMA. (He's retiring on September 30.) We also welcomed guests: **Rachel Rivlin** and her husband **Manuel Goldberg** from the local CMT Branch (more on this later.) And in addition to one of our speakers, **Juanita Jubia** from Briova Infusion services, two other infusion providers, **Connie Ramos** from Diplomat and **April Agnew** from Kroger were present to help us celebrate our KIT's 11th Anniversary.

Safely Surfing without even Getting Wet

Linda Sabatino, a member of our KIT who retired recently from the IT world, offered us some tips and guidelines for when we surf the web. Let's face it; it's become second nature that when we need to learn something we go to the internet: "Just Google it". And while it's easy to find answers, it's often hard to find the RIGHT answers and that's what Linda's presentation was about. She explained Viruses, Malware, Worms, and other computer problems. She reminded us to look for https instead of http at the beginning of a website's address. And she especially reminded us that we should be super cautious about putting our personal information and credit card numbers on any website or in any e-mail we don't recognize or that contacts us first. Just because the e-mail logo looks just like the Bank of America does not mean it's legitimate.

We have attached Linda's slide presentation and list of links to this e-mail so you can review her cautions yourself. Just remember, not everyone out there is as honest as you are!

Anniversary Celebration



While lunch doesn't usually warrant a newsletter section of its own, this time it's worth it. Your KIT leaders made the sacrifice of tasting six proposed cakes to help us decide how to best celebrate our 11th anniversary. It was not a unanimous decision but we chose a key-lime and coconut creation that we thought was the perfect summer cake. There was of course, one holdout for chocolate. We might have listened more closely to her. Three

people actually commented on their survey sheet that they wanted chocolate! Let the people be heard! Next year the cake will be chocolate and for the meetings between now and next August, our volunteer dessert crew knows what is expected of them. C-H-O-C-O-L-A-T-E!

Not All IVIG Infusion Companies are Alike

We heard from **Juanita Jubia**, representative of a new (to us) infusion company, Briova. While most of us know something about IVIG, some of us aren't familiar with all the companies that provide it as a home infusion.

Juanita shared with us an interesting statistic that I don't think we've heard before. That is that Briova, like other companies will apply to your insurance company for coverage of this expensive treatment. What Briova is most proud however, of is their record of 86% turnovers in refused coverage. It's nice to know they will fight for the patient!

We will add Briova and also Kroger, represented by **April Agnew** who attended the meeting to our KIT's list of preferred providers. It's nice that these companies come to our meetings to get to know us as *people*, not just patients or numbers. **Connie Ramos** from Diplomat was also with us, inviting us to visit their display at the conference.

Fall Frolic Set for Saturday, October 13

We look forward to again gathering for an afternoon of socializing and great food at one of our quarterly pot-luck events. Please plan to come to the Lesoine's for this opportunity to gather with your KIT family for a purely social time. An invitation and directions will be in your e-mail inbox a few weeks before the event. We'll ask you to RSVP to **Camille Lesoine**.

Conference News and Scholarship Announcements

TMA's 2018 Annual Patient Conference will be September 6-9, 2018 at the Louisville Marriott Downtown. Nine of our KIT members and companions will attend compliments of our KIT's being the recipient of money from both the 2016 and 2018 Giving Challenges.

Another Conference Item – The Reception

Since our members voted that the word that first comes to mind or that best describes our group is "Supportive", we will use our KIT's display at the reception to show how we find ways to support our members. A mock-up of the display was available at the meeting and will feature three areas: first is Fundraising or how we turned the picture of **PacMan** into a \$500 grant for our KIT. Another panel will show how through determination and hard work, we've been able to finally livestream our meetings to members unable to attend. Finally we have a picture of our new, proposed van transport service...more on this later in this newsletter.

One Last Conference Item – Dinner Friday!

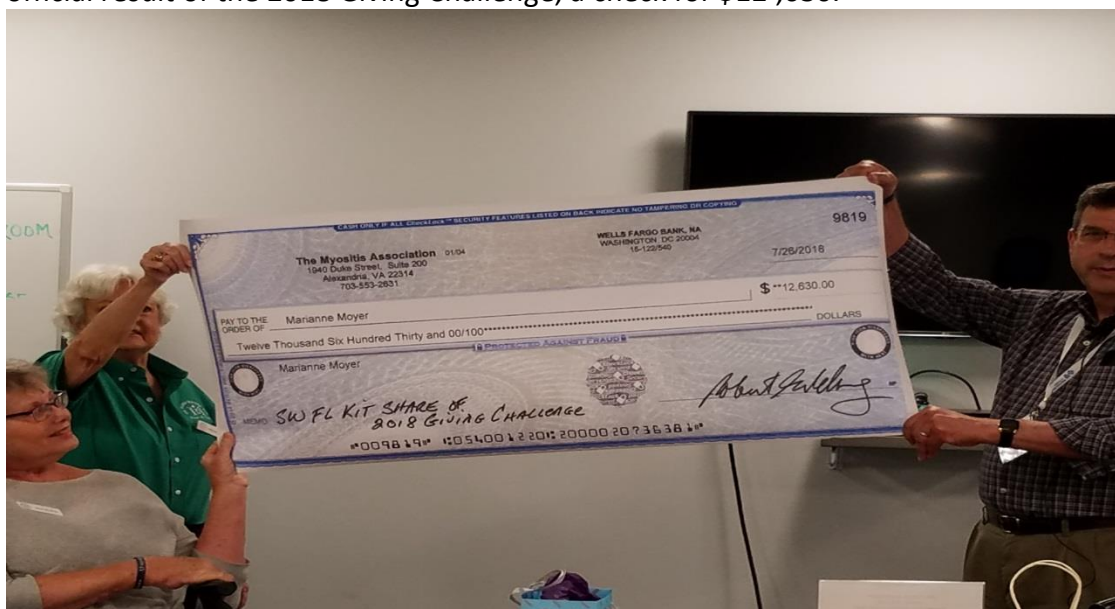
All KIT members who will be attending the conference are invited to join us for a casual dinner at the Porch Restaurant, there in the Marriott. The reservation is for 15 of us because that's how many we know are coming. If you are attending and are not on a scholarship, please contact Marianne if you want to be added to the reservation. Dinner will be at 6:30 p.m., right after we close down our KIT display at the reception.

Bob Goldberg Reflects...



We were happy to see **Bob Goldberg**; TMA's outgoing Executive Director at our meeting. He said a few words about some of the areas of TMA's work of which he is most proud. In his 16 years at TMA there have been many changes and a great deal of good news for myositis patients. Research dollars (over \$7 mil) have enabled researchers to conduct clinical trials all with an eye toward finding causes, treatments and a cure for myositis diseases. And research is the KEY to finding help for us. It's expensive and that's why you often hear TMA and KIT leaders asking you to consider donating for research, or including TMA in your estate plan.

Bob then presented the KIT with a 'big' check. In addition to a poster-sized one, we received the official result of the 2018 Giving Challenge, a check for \$12,630.



Special Guests Rachel Rivlin and Manuel Goldberg Talked about CMT



CMT stands for Charcot-Marie-Tooth Disease, a rare, genetic disease of the nerves that can cause patients to have muscle weakness, especially in their arms and legs. Does this sound a bit like IBM or other myopathy diseases? Cause and parthenogenesis are different but the effect on the patient is very similar.

After the Giving Challenge, **Marianne** researched some of the other groups participating in this fundraiser and ended up meeting **Rachel**, who leads the local CMT support group. One thing led to another and so at this KIT meeting, we proposed that the CMT and SW FL KIT combine resources to hold some sort of awareness event on or near the next National Rare Disease Awareness Day. We also will ask the Suncoast Center for Independent Living to join us. They'd be the perfect link between our two diseases. Our members present at the meeting agreed. Stay tuned for what develops. (Rare Disease Day is February 28, 2019.)

Update: Rachel invited us to their group meeting, held a week after ours, August 11. **Rose** and **Marianne** attended and heard more enthusiasm in response to **Rachel's** proposal for a joint awareness effort. Their meeting, like ours, had attendance by folks walking unaided to those in power chairs. Many wear leg braces. There is no known medication for any of the forms of CMT (there are about 14 types.)

Note that a copy of the proposal members received on August 4 is attached to this newsletter.

Speaking of Collaboration...

Barb presented information about the American Autoimmune Related Association (AARDA) having just opened a new center where autoimmune patients may go for accurate diagnoses and proper treatments. This Autoimmunity Institute has its hub at West Penn Hospital in Pittsburgh, PA. A dozen medical specialties will care for patients with the more than 100 autoimmune diseases. For more information visit: www.aarda.org

Finding Ways to be Supportive of our Members

We've asked a few members how the KIT could be helpful (supportive) in dealing with their everyday issues. While there have been many suggestions, it has been difficult to find a way that would benefit the most people for the most efficient use of our dollars.

One issue that has arisen several times is transportation. Some of our KIT members no longer drive; some are on incomes that limit their gasoline expenditures. Some have a friend or neighbor who drives them 'occasionally' but is not completely dependable.

By now you have received the special e-mail, sent August 18, outlining our KIT's desire to provide members with solutions to some of their transportation challenges. This help can be accessed in two ways. First, most counties in which our members live provide some sort of bus or van service for seniors or disabled people. There are usually some restrictions but the service is inexpensive; usually \$2 to \$5 each way. The second option is for members to call Doctors Transport, a reputable and reliable firm that will pick up and deliver members in all counties. For now we are asking that members limit trips to 25 miles round trip so that the KIT is not funding a ride to Jacksonville. This service is free to the KIT member and easily available.

In addition, we've heard KIT members say they wish they could attend KIT meetings but can't make the long drive or don't have the money for the gasoline. Doctors Transport has offered that if we can identify some people in a close-by area, they will pick up and deliver from some central point to the KIT meeting. When the meeting is over, they will pick you up at the Goodwill Center and take you back to the place where you started! Think how much easier it will be to travel with friends and not have to worry about I-75 or US 41 traffic! Remember that 'season' will be starting soon and our November meeting will be a great way to try out this idea.

You need to contact Marianne to let her know of your possible interest in this idea. We can't arrange for a central pick up point if we don't know who might want to use it!

Our Next Meeting – November 3, 2018

Join us as those who attended TMA's annual conference return to share what we learned there. While it's become easier to watch some sessions live or catch them online after the conference, it's always nice to hear our members' impressions of what they heard and saw.



Long-Range Planning – KIT Holiday Party December 1, 2018 at Lesoine's

That busy holiday season is fast approaching so it's time to be sure to put this date on your calendar. Each year **Camille, Ray** and **PacMan** outdo themselves decorating and setting beautiful tables for our group. Watch for the invitation e-mail sometime in November!



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