SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly November, 2014 Edition

November 1, 2014 Meeting

We had 42 in attendance, including three new couples and
TMA's Board Chair, Augie DiAugistinis and his lovely wife, Leslie!

Highlights of our November 1 Meeting

This was one jam-packed meeting. Here are the highlights and where applicable, we refer you to a website where you can get more information. Hold onto your seats, this will be a whirlwind of a ride!

Before we reviewed what we learned at the conference, we welcomed Jennifer Hall who works with the Sarasota Hospital system as a Certified Driver Rehabilitation Specialist. Her presentation reviewed what a CDRS does once a person has a doctor's order, a license and is seizure free. There is a two-part process that evaluates the driver clinically and behind the wheel. The fees run from $150 to $750 (depending on how long the evaluation lasts) and are not covered by insurance. She showed us some adaptive devices and provided some handouts. To find a CDRS near you, visit www.aded.net or call 866-672-9466.

We also welcomed three ladies from TeamTommy Foundation who spoke about how Tommy, brother and husband to two of them, died from complications of DM and ILD. Their foundation was started to provide financial help for those with myositis. They also hold several awareness and fundraising events during the year. As an example, they brought with them their "Guns and Hoses" 2015 calendars (Tommy was a Sheriff's deputy.) Please consider supporting them and if you are in financial need (like to attend the conference, pay for your meds or travel to Hopkins) go to their website for the application forms. They are simple and straightforward. Their site is www.teamtommyfoundation.org.

There weren't too many of us who attended TMA's conference so we only had a few 'reports' on what we learned there. Patches created a detailed report on the IBM sessions she attended and she shared this during the IBM breakout. Barb reported that the DM sessions reminded her that ointments are the best way to deliver meds to a DM patient and to stay hydrated! Marianne said the PM sessions seemed to be indicating that we are still learning about these diseases and that we should all continue to monitor trustworthy information sources like TMA's website. (www.myositis.org). She learned that a bit of antibiotic cream on the nostril openings can help when taking an airplane flight. She also heard another recommendation that if you haven't had the myositis antibody tests (MSA and MAA), you might want to ask your doctor about them. They may tell you more about your disease.

Ray and Judy participated in the on-line streaming videos and said they learned a lot. Others reported that since the conference, they've accessed the various presentations and slides. If you haven't yet done that, please do and remember that past conferences are also available. Go to www.myositis.org and from the homepage, click on 2014 Conference, session presentations. Then you can pick which ones to access and maybe even share with your doctor(s)!

We were lucky enough to be on the mailing list for the NYC KIT which also reviewed the conference at their recent meetings. Nutrition, Veterans issues, and many other subjects were covered. Again, if you are interested, go to TMA's website!

We welcomed several new faces to our meeting and KIT. Pat and Ron joined us because Pat, while undiagnosed at this time, has been told she probably has myositis. Her doctors are still testing her. And boy, does she now have more information for HIM! Jim (IBM) and Donna drove up from Ft Myers and we are glad they did. Steve (IBM) and Bridget may be unique within our KIT; he has IBM and now her doctors think she may have it too. She is still being tested. Rare disease? Hmmm.

TMA's 2015 Patient Conference Returns to Orlando

In case you haven't heard, yes, once again the conference will be at the Caribe Royale from Thursday September 10 through Sunday, September 13, 2015. TMA and the hotel are already taking reservations so visit TMA's website and register. It's not too early if you are looking for a room to accommodate your myositis needs.

Also, we share newsletters with other support groups and so our KIT agreed that we'd like to spearhead contacting the other Florida groups (formed or forming) to consider how we might help TMA and also be welcoming to our myositis friends from around the world. More on this later!

Keeping In Touch With Our Members

As always, we circulated cards for members unable to attend for health or other reasons. They include one that made us very sad. Chris Parsons, one of our founding members, passed away just before this meeting. His IBM and complications just got to be too much for him. We send our sincere condolences to Laura. We also signed cards to Sandi who continues to battle broken bones, as does Nancy G, care partner to Joan. Best wishes to Karen who is caring for her ailing mom. Please let us know if you hear of any of our members whose day would be brightened by receiving a card from us!

Doctor Referrals

We continue to develop our list of doctors you recommend. It doesn't matter if they are treating your Myositis or other issues. I often get calls from members or newly diagnosed patients asking if I can recommend a doctor in their area. TMA keeps a list of doctors, but there's nothing like a *local, personal* recommendation. If you'd like a copy of the list, please contact Marianne. Our list just helped one of our members who was able to connect with Dr. Chichkova for some improved treatment of her myositis. That's what support groups are all about! Don't forget to recommend doctors that you may travel to see at places like Mayo, Hopkins or other sites!

Myositis Awareness got lots of help from our KIT members!

In September, more than 35 of our group's members wore their WinPin which allowed them to count the number of people who asked them about myositis. We had a contest for both patients and our care partners to see who could get the most 'clicks' on their electronic pin. The pictures below show our awesome Patient Winner, Patches, who registered over 300 on her pin. The other picture is Augie presenting the prize for Most Clicks by a Care Partner, for Judy and Jim's daughter in law, Jo Ann who had 157 clicks. Not bad! All in all, we had over 700 clicks between us and I have a feeling the clicking isn't over! Remember that Myositis Awareness in not just a day; it's every day!

Speaking of Myositis Awareness, we distributed to all present, some of the materials recently sent to us by TMA. Wrist bands, a new magazine called "Advocacy" and the Physician's Guide to Myositis are all tools we can use to continue to raise awareness. Thank you to TMA for these materials.

Thanks also to Patches for not only raising awareness but funds as well. She collected for IBM research and to help our KIT's efforts. This was most welcome and shows what just a little effort can accomplish.

When a Quarterly KIT Meeting is not Enough

You may remember that some of us long to see our KIT family more than once a quarter. We agreed to schedule a lunch about half way between our regular meetings. So on September 20, seven of us met at a restaurant in North Port and enjoyed a nice lunch with plenty of social time. We will continue this experiment for a year, alternating sites to the north and south of our usual meeting area of Bradenton/Sarasota. Our next gathering will be in December so look at the article below for details. After the holidays, and our regular February meeting, our next lunch will be in April. Please plan to come; watch your e-mail for an invitation! And thank you to Camille and Bernie and Joanne for making this happen for us.

Let's Celebrate the Holidays Together

No matter which holiday you and your family celebrate, this certainly is the time for getting together with friends and family to spend time sharing our blessings! Thanks to Bernie and Joanne, we have a date, time and place for our annual Holiday lunch. It will be on **Saturday, December 6 at 12 noon**. It's about an hour north of our HealthFit meeting location but is an easy on and off from I-275. **RSVP to Joanne and Bernie by Saturday, November 15**. jcarnevale@tampabay.rr.com or 813-891-1885. We hope to see you there!

Carrabbas Italian Grill
3530 Tyrone Blvd N
St Petersburg FL 33710

This year instead of a gift exchange, we agreed at the November meeting that we'd give a gift to our KIT instead. We ask each lunch attendee who would normally purchase a $20 gift to exchange, to donate $20 to our KIT to help defray expenses of our upcoming February meeting. This is optional of course.

Our February, 2015 Meeting

As we have done in the past, our February meeting will move to a larger facility and will also feature a presentation of interest to all myositis patients and their care partners. So please plan to join us on **Saturday, February 7, 2015 at the Mixon Fruit Farm Conference Facility at *2525 27th Street East in Bradenton.*** Directions will be in the invitation I will send around January 1. For now, please put this date on your calendar because this will be a very special meeting. Our presenter will be Amy Wood, a psychologist who has presented at the last two TMA conferences. Instead of just talking to us, Amy will be talking with us. We will each have the opportunity to consider her topic: "Managing a Chronic Disease in this Fast-Paced World". Applicable to both patients and partners, her hands-on exercises can truly transform how we deal with myositis, if we will just consider our alternatives. Please plan to join us at this lovely facility (and then there's the ice cream bar…)

Because we will be covering Amy's expenses, we've embarked on some fundraising efforts. At our November meeting, our 50/50 drawing (thank you for making it a 100/0, John C) and several donations have put us in a position that will enable us to cover our increased costs. This also is why we eliminated the gift exchange at the Holiday Lunch. Plus we are hoping for some additional help from one of our IVIG vendors and TMA. It's wonderful when a plan comes together!

Wear Your Colors With Pride!

About four years ago, our KIT ordered shirts for ladies and men, with our KIT logo on the breast. Since then, we’ve added numerous new members and some of us have worn our shirts so much we need new ones. So Donna has offered to once again order them but you need to contact her. There is a minimum order and we haven’t yet reached it. Please e-mail or call her by December 6 so we can have your shirts delivered by the February meeting. Reach her on doozerdona@verizon.net or 941-749-1778.

We also now have the capability to charge your debit or credit card for the shirts or for donations. Thank you to Rose for getting a “Square” for this purpose! It really came in handy at the November meeting.

End of Year Donations

Many of us plan our charitable contributions for the end of the calendar year so that we can deduct them off our income taxes. In the case of our KIT, since we don’t file a tax return, this is a moot point. However, one tradition that we have maintained for the last five years is our KIT gives a donation to the Sarasota Memorial Hospital Foundation. (We don’t’ pay for our meeting room so this is our way of thanking them for making the facility available to us.) It is a tribute to the generosity of our KIT members that even as we face the challenges of raising money for OUR needs, we again voted to donate to the facility that has continued to provide us a safe, clean, accessible meeting location for all of our seven years (except for those February meetings in Bradenton!)

Some time ago, our KIT changed how we honor our members who have passed on. In the past, we sent a flower arrangement or plant. However, about a year ago, we changed to something we felt was more meaningful; a donation to TMA in the name of our fallen member. Again, even as we face the challenge of fundraising for OUR needs, we acknowledge the needs of the many; all our myositis family. And so, once again, our KIT donates to TMA in the name of Chris Parsons. Bless you for sharing your riches. I like the quote that sums this up: “From everyone who has been given much, much will be demanded; and from the one who has been entrusted with much, much more will be asked.” Thank you all.

Use Your computer for GOOD!

Don’t forget if you shop this holiday season using on-line retailers please do it through GoodShop. You will be making a donation to TMA. Before you go directly to an on-line store, go to www.goodshop.com. Enter TMA as your charity. Then enter the store you where you want to shop and shop as you normally would. The store donates as much as 7% of the value of your purchase to TMA. No cost to you.

Upcoming Events of Interest

Details elsewhere in this newsletter

Saturday, November 15, 2014	Deadline to RSVP for Holiday Lunch
Saturday December 6, 2014	KIT Holiday Lunch Carrabbas, Tyrone Blvd
Saturday, December 6, 2014	Deadline to order KIT shirts
Saturday, December 12, 2014	TeamTommy Pub Crawl www.teamtommy.org
Saturday, February 7, 2015	KIT meeting, Mixon Fruit Farm

That’s it for now; if we don’t see you before February, have a blessed holiday season with those you love and please **Keep in Touch**!

Marianne, Barb, Donna and Rose