



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

February, 2015 Edition

February 7, 2015 Meeting

We had 58 in attendance, including four new members and
A former member of TMA's Board Dannie Haines and her husband, Howard.
There are two, one-page attachments at the end of this newsletter.

Highlights of our February Meeting

Our presenter, Dr. Amy Wood spoke to us about "How to Deal with a Chronic Disease in a Fast-Moving World". And the topic certainly got put to the test before the meeting even started. Just 48 hours before the meeting was set to begin, we were told by Mixon's that a tornado had torn the roof off the meeting room we were scheduled to use! We must be living right because instead of what could have been a mad scramble to find another venue and notify everyone, we were able to move our meeting about 50 yards to Mixon's outdoor wedding pavilion. We didn't have the use of audio-visual equipment and we had to light some gas heaters to take off the morning chill but the meeting went on as planned and we are most grateful to Mixon's staff that really scrambled to help us have our usual wonderful meeting. By the way, a few folks suggested that we use this outdoor pavilion more often. That's probably not going to happen; it's substantially more expensive and just think what it would have been like if the rain and wind we experienced a few days later had occurred on the day of our meeting! Brrr.

As a result of this presentation, a few of us thought it would be a good idea to get a little more mileage from it. See below for the topic of our next meeting in May! It doesn't matter if you were in attendance at the February meeting or not. You will still be able to benefit from the exercise we have designed to help us all to better deal with our myositis (and that does go for both patients and their care partners!)

It was a true pleasure to welcome four new members to our KIT. They are **Donna W** who has DM and lives in Palmetto, **Sandy T** who also has DM and lives in Englewood, **Don L** who has IBM and lives in Englewood and **Anna K** from Naples who has DM. For a 'rare' disease, we sure seem to be getting a lot of new members! In addition, in just the four days since our meeting, I've been contacted by two new additional members, **Steve V** who has IBM and **Neil J** who has H-IBM (that's Heredity IBM). How wonderful that our KIT continues to be a beacon of light and positivity in the lives of SW FL myositis families!

Our Next Meeting, May 2, 2015

In May, we return to our usual meeting place, the Sarasota Hospital HealthFit facility on Clark Road in Sarasota. Our topic will be based on one of Dr. Amy's questions, #5 "What can you discard to clear your mind and life?" The meeting will be led by one of our KIT's co-leaders, Rose Ryan, a licensed psychotherapist. Here's what we are thinking...

It's likely that each of us has something we are carrying around that is unnecessarily weighing us down. Your item(s) might be intangible; feeling sorry about something you think you should have done, or done better. It might be fear of something or anger at something over which you have no control. If so, plan to write it/them on a piece of paper and we'll help you look at it from other perspectives, shred and discard it at the meeting.

It could be something tangible like a cane or walker you no longer use and have been meaning to take to Goodwill. It might be an item of clothing like Amy mentioned; not worn in over a year but that you think might someday fit you again. How about a book you thought was great but just haven't found the right person to pass it along to? If there is someone at the meeting who would like to take your discarded item, it will be great (recycle, reuse, and reduce!) If there are no takers, we have a volunteer who will take all 'discards' to the nearest Goodwill Donation Center!

These actions of clearing intangible or tangible items that are weighing us down will be open for discussion, as we explore how to help ourselves and each other to better cope with our myositis and other challenges. Join us for this opportunity to clear up and discard some of the 'clutter' in our lives.

Potluck March 21

When a Quarterly KIT Meeting is not Enough

Because some of us want to be with our KIT family more than once a quarter, we agreed to schedule a lunch about half way between our regular meetings. Our next one will be on Saturday, March 21 at the home of Ray and Camille Lesoine. An e-mail invitation went out on February 8 and contained all the details plus directions to Lesoine's. If you haven't RSVPed yet, please do.

TMA's 2015 Patient Conference Returns to Orlando

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. The deadline for early conference registration at the discounted rate of \$165 is May 31. The special room rate at the hotel will only be good through August 9. We hope to see you there.

TMA moves the conference around the country each year in an effort to enable the most people to attend via driving. They don't get any closer than this for us so if you've been meaning to attend a conference and aren't sure this is the one, think about whether you can travel over 1,000 miles to next year's offering.

Keeping In Touch With...Doctors

We continue to develop our list of doctors you recommend. It doesn't matter if they are treating your Myositis or other conditions. Don't forget to recommend doctors that you travel to see at places like Hopkins or other sites! If you'd like a copy of the list, contact Marianne. Also, please be sure to share with all your medical professionals a copy of TMA's recently released booklet "A Physician's Guide to Myositis". We've handed them out at our last two meetings and still have a few on hand. Contact Marianne if you'd like one. Or go to www.myositis.org to order one or to download the PDF version.

Our Annual Holiday Lunch was GREAT

Our December get together was our annual Holiday lunch on Saturday, December 6 at Carrabbas in St. Petersburg. 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 February meeting. Thank you to all who participated and a special thank you to Bernie and Joanne for arranging the event!

Wear Your Colors With Pride!

Donna DeFant has again ordered KIT logo shirts for us and has delivered them to those who placed orders in November. We still have a few left. Since we are likely to have a big turnout for TMA's conference in Orlando, it would be neat to again take a group picture of us 'wearing our colors'! Contact Donna on doozerdona@verizon.net or 941-749-1778.

TMA News - Member Survey

TMA has recently posted on their website the results of the member survey conducted last fall. Here is the link: <http://www.myositis.org/about-tma/2014-member-survey> As a result of this survey, TMA's board is working to improve the services and information provided to members. Watch for more news about this initiative!

Don't Forget – Clip and save this:

TMA Annual Patient Conference

When: Thursday, September 10-Sunday September 13, 2015

Where: Caribe Royale Hotel in Orlando FL

Contact: TMA to register for conference www.myositis.org and Caribe Royale 1-888-258-7501 or www.thecaribeorlando.com

Costs: Hotel suite \$109, Villa \$169. Conference \$165

Deadlines for discount registration: Aug 9 for hotel, May 31 for conference early-bird registration!

Myositis Medical Symposium Scheduled For September 11

As in past years, TMA's Medical Advisory Board will be hosting a symposium during the annual conference. It is open to physicians only, who are interested in learning more about our diseases. It will be from about 10 a.m. to 3:30 p.m. and will cover a wide variety of topics (way too technical for me to list here). If you would like for TMA to invite one of your doctors, please ask your doctor if they are interested and then provide their contact information to tma@myositis.org

KIT Dinner at the Conference

Donna DeFant is organizing dinner for our KIT members and their partners, for one evening at the Caribe Royale. We haven't picked the evening yet because we are awaiting word from TMA on whether or not there will be any kind of evening special event for the general conference population. I will send a separate e-mail with specifics when I have them. You will RSVP to Donna and seating will probably be limited to about 30 in the private dining area. Watch your e-mail for the invitation!

Florida KIT Members Volunteering at the Conference

Camille Lesoine is finding out what "herding cats" feels like. She is in contact with the other KITs in Florida, either existing 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! To find out about what we are planning or to offer input, please contact Camille at lesoinefamily@aol.com.

TMA Live Discussions on Various Topics

There have been and will be many more live discussions that members may follow online or reference after the session (they may also want to print some of the info for their doctors.) Go to TMA's Home Page, click on Explore Research, click on live discussions. Prior to a session, you may submit your questions which will be answered 'live' during the discussion.

Upcoming:

In Search of the Right Diagnosis by Dr. Alan Pestronk on Monday, Feb 23, 2015 at 7:00 p.m.

Lung Disease and Myositis by Dr. Dana Ascherman on Monday, March 9, 2015 at 3:00 p.m.

Recent session:

Skin Care for Myositis by Dr. Ruth Ann Vleugels (not just for DM patients)

TMA Research Grant Money Triples in 2015!

Marianne reported that at TMA's board of directors' meeting in January, there was a vote to more than triple the usual budgeted amount for research into myositis diseases. We can all probably relate to a desire to see more research into the causes, treatments and eventual cure for our diseases. And we know that the research to find the answers to our questions is costly and takes a long time. This year however, TMA is the recipient of a very generous bequest from a TMA supporter who left instructions in her estate to provide for myositis research. The bottom line is that instead of our usual \$200,000 annual research allocation, this year TMA will be able to offer to researchers, \$750,000. What incredible generosity and forethought!

After Marianne's report, Donna DeFant, a Certified Financial Planner and one of our KIT's co-leaders, gave a brief overview of how someone's estate plan can include providing just this kind of support for TMA and other charities. It was a very easy to understand talk and apparently had some impact. One KIT member has already notified TMA that they have made a change in their IRA beneficiary. If you are interested in the handout Donna provided, it is at the very end of this newsletter. At least four families in our KIT have made this designation. Please consider joining them.

Dealing with Chronic Disease in a Fast-Moving World

Here are the ten questions Amy used to guide our discussion about how we can better deal with a chronic disease like Myositis, in this fast-moving world. I have added a couple *italicized* thoughts of mine that I wrote down as we reviewed these questions. There was a lot more that I noted but I don't want to overwhelm you with my thoughts. Let yours go and see what comes up for you...

1. From your childhood perspective, what is most incredible about this era and your life right now?
2. What small change can you make to take better care of yourself? *(I noted that I want to concentrate more on people and less on 'doing stuff')*.
3. Recall the last time you were 'in the flow' *(define that any way that works for you)*. What personal strengths came shining through?
4. How do you want to be described when you are gone? *If you are having trouble making a decision about something, consider what impact it might have on how you will be remembered.*
5. What can you discard to clear your mind and your life? *This is the one we will review at our May meeting. See the description of what we plan to do, earlier in this newsletter.*
6. What can you do to reward yourself and others?
7. What would your mentor do *(if you had one)*?
8. What limits can you set to protect yourself?
9. What are you most proud of?
10. What can you delegate to Something Greater?



This picture doesn't do justice to Amy but does show the beautiful outside setting we enjoyed for this meeting. Hooray for Mixon's ability to provide this venue!

Planned Giving to TMA - FAQs

What is the Legacy Society? It is a way for you to plan to give a portion of your estate to TMA upon your death.

Do I need a lawyer to change my will? No. Unless you want to...

Is there an EASIER way to do this? Go online to your life insurance policy beneficiary info. Where it says "change beneficiary" change the percentages from (for example) 100% to your kid(s) to 90% to your kid(s) and 10% to TMA. Any percentage split is okay.

Are there other ways? Do the same online change procedure with your IRA or other savings vehicle. Any percentage will help.

Can I leave stock to TMA? Yes. The advantage to you is if the stock (or other equity) has appreciated since you bought it, you don't have to pay capital gains tax and it will be out of your estate. You donate the equity and take a charitable deduction for its current value.

What if I need to hold onto my savings for my long term needs? Continue spending as you currently do and make this change anyway. If you spend every cent, that's fine. If there is money left over, TMA and future myositis patients will be grateful for your gift.

What if my circumstances change? You can make changes to these percentages, accounts or policies any time; changes cost you nothing.

Are there tax consequences? Yes; good ones. If your heirs inherit your IRA, they have to pay taxes on it but since TMA is a 501c3, IRA money transfers to TMA with no tax consequence to anyone!

Do I have to tell TMA of my plans? No. You may wish to go to the Legacy link on TMA's website and register with other members who have done so but it is not necessary. If you do, you do not have to provide specific amounts, account numbers or other private info.

Can I designate how my money will be used? Yes. If you want your money to go toward research (either general or to a specific myositis disease), you may indicate that by notifying TMA.

When can I do this? Anytime.

Where can I get more information? Visit TMA website www.myositis.org or call 800-821-7356.