



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

November, 2013 Edition

November 2, 2013 Meeting

We had 35 Attendees; One First-timer and partner!

Please note there are other documents following this newsletter. Don't miss them; they include notes from the conference, recipes from the November meeting and other information of interest!

November meeting is 'our usual' and 'not so usual'!

It was a rainy day along I-75 but 35 brave souls showed up and enjoyed a lunch from our 'next-door neighbor' Geckos and also some home-made treats (see **Recipes** following this newsletter). We welcomed a new member, **Sue Prive** (IBM) and her husband **Wayne** and welcomed some of our northern friends who are returning to the sunny south.

Our presenters for the day were those who attended TMA's annual patient conference in Louisville last month. Addie Paul started out with what seemed to be an unusual way to start his 'report'. He performed a magic trick that reminded us that Veteran's Day is coming. He then told us about the sessions he and June attended. The first was about how to assess your ability to continue to drive. He then volunteered to research what the Florida laws and policies are and the details of his research are later in this newsletter; look for "**Driving Adaptations and Rehabilitation Services in Florida**". (Thanks so much Addie). He attended the session on Veterans' benefits and there will be more information on that very soon when TMA adds this information to its website. There was a Falls Recovery session that actually talked about personal airbags (if you are going to fall backward and your head has its own 'inflatable cushion, that could be a great thing!) He reflected on how the med students of today seem to be trained in all the medical 'stuff' but not in the 'art' of patient care. (Many of us can attest to that!)

June Paul spoke about a session she found valuable; computer access to information about myositis. She also appreciated Dr. Lisa Christopher-Stine who spoke about the importance of having faith, being positive and treating the whole body, not just the myositis. She stressed that it is important that the muscles get adequate oxygen (ie through exercise). She spoke to the value of a healthy diet; one low in carbs, high in protein and that avoids as much as possible, processed foods and artificial sweeteners.

Ray Lesoine reported that he enjoyed the streaming video of the Novartis presentation.

Marianne's presentation is summarized on the page following this newsletter, entitled "**Marianne's notes from 2013 TMA Patient conference; Louisville KY**".

In addition to our presenting what we observed at the conference, we also talked about what we would like to see in the 2014 conference. Most of our points had already been made but our suggestions include: Repeat the patient panel (see a summary of that following the newsletter!), it would help to have presenters' pictures in the program and then following their bio information, a cross-reference to their sessions. The end-of-day breakouts need facilitators. The computer presentation would have been more valuable if there was either a 'lab' with several stations or laptops or if participants were invited to bring their tablets, laptops, etc. Closed captioning would be a nice touch for the 'hard of hearing'.

For more on the Patient Panel, see the pages following this newsletter, entitled "**Patient Panel**".

Holiday Party Planning

Our KIT's holiday party is scheduled for **Saturday, December 7 at noon at the University Country Club**. You should have already received the invitation with a request to RSVP by December 3, to the Carneales or Karen Jacobs. Let Marianne know if you didn't see the invitation! Since we've had such fun with our previous gift exchanges, we invite you to participate in this OPTIONAL activity. Bring a wrapped gift worth no more than \$20 and each person who brings a gift, may then take a gift. Ho ho ho!

February 1, 2014; Our Next KIT Meeting

Another tradition; at this meeting we will feature a presentation that is of interest to not only myositis patients and their families but also to our friends and neighbors as well. The topic for this meeting will be Caregiving but it's not the 'same old: same old'. You know what we mean; a lecture on what to do or not do to keep your sanity while you help your loved one. Well, this will be an interactive, entertaining and thought-provoking session with no judgments; no lists of what you HAVE to do or NOT do. Just another way to look at the greatest heroes any of us know! And because we hope to welcome back many of our members who have summered 'up north', we'll again move to our alternate location; Mixon's Fruit Farm in Bradenton. They treated us well for the past two years so we'll return for more of their hospitality and yummy food. Watch for your invitation to the meeting around January 1. (Hard to believe we are talking about 2014 already!)

Our KIT Again Shone at the Conference...

Since a 20th Anniversary is a big milestone, TMA produced a 20-year scrapbook to commemorate the occasion. A special section on KITs reflected on how these groups have grown and prospered across the country. At our August KIT meeting, we voted to take \$250 from our KIT's checking account to purchase a full-page ad. It included the picture taken at last year's conference and some meaningful text reflecting our KIT's philosophy and efforts. There were also lots of pictures from our KIT. The scrapbook was provided to all conference attendees and those who bought ads. Come to the February meeting if you didn't get your copy in November. And thank YOU to Rose Ryan for designing our great-looking page!

**TMA Annual Patient Conference in Reno Nevada
September 4-7, 2014
Peppermill Resort, Spa and Casino**

Put this into your planner, I-pad, tablet, or whatever you use to keep track of your busy schedules! Room rates are just \$85, parking is free, there's free shuttle service from the airport and the resort looks lovely!

What's Happening with our KIT's 20 for 20 Campaigns?

Our KIT as always stepped up to the plate in TMA's latest fundraising campaign that was called "20 for 20". We asked 20 friends or family members to donate \$20 to TMA. It was amazing how many of our friends just handed over a \$20 bill when we asked. TMA is still tallying up the totals and will send them to each participant but our KIT can be proud that we were a big part of the \$17,000 raised by 85 members. (I think we had about 15 participants!)

Keeping In Touch With Our Members

We were greatly saddened to hear that Ray Pearl, June's husband, caregiver and all-around nice guy has left this earth. Our KIT expressed our sympathies and received a thank you note from June. We hope she will soon return to our meetings.

Barb Kluding's second grandchild, Ellie arrived on this earth, Friday, November 8. Congratulations to the happy family! Now little Collin has a playmate!

Rose Ryan and Stephanie Mossman had a great visit to Ireland and dined with a KIT friend of ours, Deirdre Merrigan.

We pray that Sue Corning's mom is resting well and that her family is okay in these challenging days.

Sandy Rocha's friend, Sandy Valdez is undergoing rotator cuff surgery this month. Here's hoping she's well enough to drive to our February meeting!

For these and ALL our KIT family, please remember them in your prayers and if you have a spare moment, call or e-mail them to let them know you care. If you have news about yourself or others in our family, please let Marianne know so we can all "Keep In Touch"!

OK so this isn't the most fun topic out there...

Sometimes I get inquiries about the darnedest things. Recently a member asked how to go about donating their body to science. Let's face it; we all want to do whatever we can to help myositis research and short of donating a million dollars to TMA's research fund, we're hard pressed to find ways to help not only current patients but those who will get myositis in the future. So Joanne Carnevale offered to research this question and here's her message on what she found. Keep this info or toss it; it's up to you. It's just provided here as something to consider... (Big Thank YOU to Joanne!)

I went to the website – old.med.ufl.edu/anatbd/usprograms.html. It was very easy to navigate and very informative in providing all the answers to your probable questions. When you first go to the website the states are listed alphabetically with their appropriate information and contacts.

I clicked on Florida. The main office is located at the University of Florida in Gainesville and there are two branch offices one at the University of Miami and one at the University of Central Florida college of Medicine in Orlando. Mailing addresses, telephone numbers and emails are listed for easy contact.

Their mission is to supply anatomical materials for teaching and research programs in Florida.

General information: The donor or surviving relative must make arrangements with a local funeral home, crematory or mortuary and pay for 1) preliminary embalming 2) transportation to the board at the University of Florida in Gainesville. They cannot accept bodies if 1) an autopsy has been done 2) death was caused by a crushing injury 3) the individual had sepsis, extreme obesity, or a highly contagious disease (such as hepatitis or AIDS). There is no age limit. The board will not issue any reports in regard to the cause of death or any other findings. If family wants this they should have an autopsy done.

There is a page of instructions to persons interested in donating their bodies.

- 1) Two copies of dedication form should be signed in the presence of 2 witnesses. This is legal and no will is needed.
- 2) One original dedication form is sent to the board in Gainesville – address on site. The other copy is to be retained in personal files.
- 3) Copies of the “Instruction to Survivors” should be given to relatives or whomever will be in charge of arrangements.
- 4) You may want to make arrangements now with your funeral director to save your relatives from this task.
- 5) The board cannot remove or store tissues for eye banks or other agencies that collect for transplantation so if you want this you need to speak with your doctor.
- 6) Ordinarily after being used in research the body will be cremated. If the survivors wish to receive the ashes they must send a written request with the dedication form or at the time the body is transported. If there is no request then the board will dispose of the cremains by spreading them over the waters of the Gulf of Mexico. If cremation is not wanted, the board needs to be notified at the time of transportation. The body can be turned over to the funeral home for burial at the family’s expense.

The dedication Form is on the website. Print two copies; one to send in and one to keep for your record. The Instruction sheet for survivors is also on the website.

There is a donor assistance fund info on the website, which allows for a reimbursement of up to \$650. For those who do not use computers the phone number 800-727-0700 has a free referral service.

Marianne's notes from 2013 TMA Patient conference; Louisville KY

Board meeting with members: How to get more info to our local docs? Why not try fundraising like Rotary; pledge over time. Add a comedy act to conference. Shorten sessions to one hour. Repeat more sessions. Liked the 7PM sessions. Need more caregiver support. How about a fun evening reception? Include photos of MAB and Board in program so we can be identified. Can we expand KITs to other countries? Can we schedule times for meeting with MAB docs? Provide more info on local tourist attractions. Start each morning with an optional prayer meeting.

Chronic Disease in a fast moving world; great presentation on dealing with stress of disease; may pay to have speaker come to a KIT meeting so we can all benefit.

Diagnosing and prescribing meds for myositis: Difficult to balance treating inflammation and autoimmune system. Thymus gland is involved in autoimmunity. Your system is pretty much developed by age 8-9. Autoimmune diseases tend to run in families. Distance from equator tends to indicate likelihood of autoimmune disease; more distance, less disease. (This is a correction thanks to Addie; I had the relationship backwards!) AI diseases 9x more common in women may be due to estrogen. Gets better in pregnancy, worse after delivery but after menopause, male/female ratios equal out. One doc doubts any diagnosis of PM after age 50, may be more likely to be IBM. PM not likely to cause pain. DM and IBM do.

DM: Calcinosis a result of active inflammation of muscle. Hard to remove; best to prevent by keeping DM under control with anti-inflammatories.

Dysphagia: If you have an I-Pad, ask your therapist to get ISwallow app and use to exercise your swallowing muscles.

Environmental issues: Myositis results from exposure to some environmental factors for people with a genetic disposition. Need more studies re which factors: silica, solvents, smoking, UV, gluten, infections, vaccines, hormones, agent orange, etc.

Interstitial Lung Disease (ILD): If you have ILD, it's not likely you have IBM. ILD is another autoimmune system disease; system is attacking alveoli. If there is a choice, Cell-cept is better than Methotrexate to treat the myositis. Exercise does help keep lung capacity. So does pulmonary therapy.

Medical Panel: Dr Greenburg is developing a blood test to diagnose IBM. Dr Raju is working on a new drug to replace prednisone. Dr Christopher Stine is looking into correlation between heart, calcinosis and arteriosclerosis. Dr Shoeman researching blood vessel walls in damaged DM tissue. Dr Maillard is developing a resource for PTs. Dr Ascherman is researching lung issues. Dr Shoeman says if you have calcinosis, treat the underlying myositis first.

Next Year's Conference: Reno Nevada, Peppermill resort. \$85 per day with free parking. Dates are September 4-7.

PM and DM treatment: Be aware that while muscles are inflamed, they are being damaged and this creates scar tissue which does not have normal capability and therefore exhibits weakness. PM and DM patients should get regular cancer screenings.

Shingles Vaccine: surprised to learn that even on my current meds (12 pred, 50 imuran, 20 methotrexate and 100 IVIG) I should get the shot. See PDF article as separate document, from Rheumatologist with backup info. Re flu

shot, don't get 'pre-emptive' extra dose of prednisone before. All myositis patients recommended to get flu shot (other family members too). Dr. Oddis suggests we get not only flu but pneumonia shots.

Veterans with myositis: Great info and soon will be on TMA's website. Caregivers living with a disabled vet may now be eligible to be paid up to \$1,000 per month. Described Tri-Card. If you have a purple heart, and low income, enrollment may be free. You may be assigned a medical home team of a LPN, pharmacist, nutritionist and social worker. You can have secure e-mail messaging to your team. Vets should register and enroll even if they don't need services at this time. In an emergency you can be taken to a civilian hospital, stabilized and then transferred to a VA hospital. ACA should not change anything in a vet's treatment. One vet said he did get VA to pay for his power chair to have lift capability.

Just using this white space to add some notes of interest!

Use that computer for GOOD!

Don't forget that as you shop this holiday season, many of us use on-line retailers. If you shop through GoodShop you can make a painless donation to TMA. Before you go directly to LL Bean or some other on-line store, go to www.goodshop.com . You will be asked what charity you are shopping for. Enter The Myositis Association. Then enter the store you where you want to shop then shop as you normally would. The store donates between .5% and as much as 7% of the value of your purchase to TMA. Painless to you and it helps our cause.

Facebook for SW FL KIT

Also, many of our members and their family have been visiting our SW Florida Myositis KIT Facebook page. The conversations have been interesting and informative. If you would like to share what's happening in your life, have a question or wish to comment on another's posting, feel free. It's just one more way we are "Keeping in Touch". Be a friend of our KIT!

A Request from the folks at Questcor

We are looking to identify dermatomyositis and polymyositis patients that have taken or currently take the drug ACTHAR. Questcor, one of our corporate supporters and manufacturer of the drug, is working on a project to document patients' experiences with ACTHAR. Please contact Charlia Sanchez at TMA Charlia@myositis.org so she can contact you directly regarding this opportunity.

Spending KIT money for GOOD!

I wrote two checks this week from our KIT account and both will raise awareness of myositis and help our KIT to continue our good works. The first was for \$200 for our (now) annual donation to Sarasota Hospital Foundation to thank them for providing our meeting space. A room like ours would normally cost over \$200 per meeting. We 'pay' nothing. This donation is to their charitable group which helps handicapped people learn the joy of art.

The second was for \$25 and I wrote it to a local Senior Center which is holding a free Health Fair for the community on November 20. Rose Ryan and Camille and Ray Lesoine will be there to share information about myositis and about the value of support groups. (And of course we will sign up anyone who has or knows someone who has myositis.) More on this after it happens!

Recipes from November KIT meeting

Delish Cranberry Sauce Dish

2 cans cranberry sauce (whole berry)
½ cup orange marmalade
2 Tablespoons raspberry preserves (seedless is best)
2/3 cup chopped pecans

Blend all ingredients together. If you prefer it 'crunchier', don't add the nuts until just before serving but ours on Saturday was made Friday night.

Light-as-a-feather Pumpkin Pie

Single pie crust
¼ cup chopped walnuts (optional)
1 envelope unflavored gelatin
½ cup brown sugar
½ tsp. salt
½ tsp. nutmeg
½ tsp. cinnamon
¼ tsp. ginger
1 ¼ cups evaporated milk
1 ¼ cups canned pumpkin
2 eggs, separated
¼ cup sugar
Whipped cream (from scratch or in a can or freezer container) (optional)

Prepare single pie crust by pressing walnuts into it and bake as directed. (I use Pillsbury roll-up). The nuts are optional but help keep the crust from getting soggy.

Put gelatin, brown sugar, salt and spices into saucepan. Stir in pumpkin, the two egg yolks and milk. Cook on low heat for 10 minutes. Remove from heat and cool.

When mixture is cool, beat 2 egg whites until stiff and add regular sugar. Fold into cooled pumpkin mixture. Pour into pie shell and chill till firm (at least 3 hours).

Optional serving is to omit the pie crust (and carbs) and just prepare the filling as a mousse. Spoon into individual serving dishes or just pour into a pretty bowl and spoon out amounts as desired.

And of course, topping with whipped cream is the way to make it really special!

Patient Advisory Panel – Wednesday 10/16/13

Twelve TMA members were asked to address questions about TMA. Here are brief notes of that session:

How well does TMA serve the community?

Nilda Conrad – TMA provides good support/information, happy with our support and resources

John Schell – good service for referrals and help with finding support

Katie Weyhrauch – website is good and informative, challenging to navigate at times but very resourceful and good for sharing/spreading the word about Myositis

Carolyn Ester – TMA provided good service for help starting new support groups

Ike Crase – has no contact for support groups and would like us to help expand in Iowa

Dennis Chada saw a disconnect between the website and the community forum; we need to have clearer distinctions. In St. Paul, MN he thinks the KIT should be more connected to TMA. Some of the support group members are not aware that they are part of the larger TMA organization.

John Schell – thinks we should encourage more use of the forum.

Mike Harper/John Schell – think the FB site has more engagement, more frequently visited but the forum has more quality content.

TMA Community Forum needs more staff/MAB engagement and the FB page should be more clearly defined as an open space for anything.

Bob: in Canada – considering building a support network through CHIR (comparable to NIH), asked by Barb Romaniuk

Patricia Mayer – potential leader for support group in Houston

Mike Harper – 50 miles from Indianapolis – talk to Jan Schuler about reviving group in Indiana

Major project of cleaning up support groups and promoting leadership

Suggestion: More outreach to the medical community from TMA – thru neurology/rheumatology/dermatology associations – Would like to see an increase in partnering with medical associations for physician education – common issue among panelists of not feeling connected to doctors.

Richard Stevenson – received a lot of calls from recently diagnosed patients who are not familiar with TMA – need to encourage newly diagnosed patients to join TMA

Support Group lists online do not list disease type or phone numbers. KIT leaders use that information to organize

RE: Support from MAB for meetings or for members to know who to reach out to based on same disease type.

Dennis Chada – IBM, would like information on the question of exercise, experts appear to be split. Would like to see a peer-reviewed study of the effects/benefits (dis)advantages of exercise for IBM patients

Barb Romaniuk – some website improvements to include a higher level fact sheet provided for FAQ's put together by MAB, exercise, nutritional recommendations, items regarding prednisone taper. Would something put together with the MAB perspective on everyday tips for dealing with Myositis.

Debbie Risinger – would like consultations facilitated between MAB members and members' personal doctors

RE: Increased medical community relations

Suggestion: start educating physicians at med school/residency level

Bob: TMA has visiting professor series to create more awareness about Myositis for med school students

Katie W: encourage members to FW us info about their docs so that we can send information or put them on our mailing list. (Myositis monitor)

TMA Newsletters – OL, monitor, update (Barb Romaniuk/Nilda Conrad – never received OL)

Reminder to members that you are your best advocate!

Suggestions for OL: more personal stories, human interest pieces.

Debbie Risinger brought up the issue of print vs. online, Richard Stevenson shared idea of the option to opt out of print OL (note: but members don't know how to access online via MyTMA)

Stanley Prather – asked about TMA/MDA collaborations, sharing funds

Bob: competitive fundraising environment, possible opportunities to partner for specific programming but not in fundraising efforts

Suggestion: develop a fact sheet for website that has button for “print here”

What TMA is not doing that we should be doing or doing better:

Dennis Chada – caregiver discussion board on community forum

Barb R: Printable pages on website

Nilda Conrad: more timely feedback for calls and emails – uphold 24 hour response time

Katie Weyhrauch – clearer distinctions on website, in publications and videos etc, as to what is for patients and what is for doctors – we need to consider levels of understanding i.e. the dysphagia video was not simple enough to be understood by patients and offered no recommendations/tips for patients.

Patricia Mayers – getting handouts for all sessions for those that could not attend because there were so many good sessions happening simultaneously

#1 issue/improvements for TMA:

Barb R – providing more practical/daily tips for patients (online)

Don Parks – increased visibility of TMA

Mike Foley – spokesperson, face of Myositis, celebrity to draw attention

Mark Leonard: regarding the faces of Myositis idea (DM/PM only) Questcor may have an opportunity for Acthar patients to document their stories or experiences

Marianne Moyer: idea of videos at support groups, find and share video demonstrations or self-made remedies and solutions – to be shared on website

Mike Elliott: Questcor is currently optimizing their website and resources specifically for patient and physician use.

Suggestion: Expand physician outreach to docs that deal with spinals for those that deal with gripping issues (IBM)
Richard Stevenson – area of fundraising, suggested offering a type of training to help overcome the anxiety of asking others for donations. Campaign building – better at sending acknowledgments and notices, consider option to send notices/lists via email instead of mail.

NOTE: Go to TMA website and access 2013 conference sessions to see the presentation materials. There are slides and graphs that may or may not be clear to you but at least show you what was presented. In addition you can view the presentations that were videoed. Finally, there are still presentations from previous conferences as well.

Driving Assessment and Rehabilitation Services in Florida

Several driving assessment companies have been approved by The Florida Highway Safety Motor Vehicle Medical Review Board to do business in Florida. The one nearest us is in Orlando:

Adaptive Mobile Services
1000 Delany Avenue
Orlando, FL 32806
www.adaptivemobility.com
(407)426-8020

Why someone might be interested in an assessment:

Recent change in health status (Decline in mobility, significant hospitalization etc)
Family or physician questions your ability to drive safely
Accident history
Significant trauma
Recently diagnosed with a progressive disease
Influence possible future automotive liability issues

What is necessary for an assessment in State of Florida:

Valid drivers license or permit
Seizure free for six months
Physicians prescription, or an order from the Florida Medical Review Board

How to apply for an assessment:

Have physician complete a Medical Approval Form for Driving Evaluation)
Physician should have this form, or you may download it from
www.adaptivemobility.com
Complete "Client Information Form", also available at www.adaptivemobility.com
Contact Adaptive Mobile Services to schedule an appointment

Be mindful:

An Evaluation may cost several hundred dollars, and may not be covered by insurances
Should you fail the evaluation, the Florida Medical Review Board (FMRB) may be notified and your driving privileges revoked.
If the FMRB receives a complaint challenging your driving ability, they can demand you be evaluated, or risk losing your license. This challenge may come from a variety of sources, e.g. Police, License Examiner, Physician, Family Member, or a Concerned Citizen. (HSMV Form # 72190 is the form the complainant would use).

If we don't see you at the December 7 lunch, have a blessed holiday season. The greatest gift in my life is this KIT. Love to you all, Marianne