

SW Florida K I T Connection

For Myositis "Managers" along the Gulf Coast

We Care, So Come And Share

Acupuncture: Is It for You?

Several of us heard one of our KIT members, Herb Schley, (IBM) speak at TMA's 2009 conference. He described his experience with acupuncture. So we asked him to share this same presentation with our KIT. No one, least of all Herb, would say that acupuncture (and some of the associated Chinese herbs and other treatments) are a *cure* for IBM. What he did say is that since he's been receiving regular acupuncture treatments, he has not had any falls and in fact, some of his muscles have actually increased in size. This is certainly food for thought!

Following Herb, Dr. Brenda Yanofsky, a local Chinese trained doctor presented some additional perspectives on acupuncture and Eastern medicines. Again, there certainly was no promise that these alternatives are a cure for IBM or any other myositis disease. These two presentations simply offered some possible alternatives that patients who are not responding to standard drug therapies, may want to consider. Many of us came away with a greater appreciation for Chinese medicine.

We also heard a presentation by Walt Barket from AMGEN (who very kindly paid for our lunch) and who told us about a new osteoporosis drug that may help some of us with bone density issues.

News of what happened at our February 6, 2010 meeting
56 people attended and we welcomed five first time attendees!
Next Meeting Saturday, May 1, 2010

KIT Happenings! **Meeting Announcements** **included the following:**

We were saddened to hear of the death of our member, Grace Bryce (PM). We will miss her smiling face!

On December 19th Barb and Marianne presented a check for \$200 to the Sarasota Hospital Foundation. They generously provide our meeting room each quarter and this was our KIT's way to say "Thank You".

On December 12th, 23 members and family attended our second annual Holiday Lunch. It was held at LeRoy Selmon's in Sarasota. We enjoyed the meal and the gift exchange. (We invited LeRoy to join us but he was unable to come; maybe next year...)

Several members have been making an effort to Keep In Touch with some of our lapsed or never-seen members. We shared information about those we've been able to contact. Anyone can do this! If you have a copy of the member list and contact information, reach out and call or e-mail a member. You and they will be glad you did!

We currently have 123 people on our KIT membership list. The good news is that our family is growing. The challenge is to keep in touch!

Teams Forming to Help Run Our KIT – Join One Now!

The week before our meeting, nine of us got together on a conference call to talk about how we can involve more people in the activities of our KIT. There were many great suggestions but the best and most eagerly agreed to, is to form teams that will help in all the aspects of running our KIT.

At the meeting we asked members to sign up for one of eight teams. Those who signed up will get an e-mail inviting them to connect with each other and begin working on their area of interest. If you would like to join one of these teams, please contact Marianne. Teams are:

- Meeting Refreshments
- Meeting Logistics
- Sunshine (keeping in touch)
- Publicity
- Fundraising
- Parties
- Speakers
- Gifts and doorprizes

In addition, another team was suggested; one to investigate how to get airports and airlines to comply with ADA. Since this is not a KIT issue per se, we won't make this a KIT team but if you are interested in this subject, contact Marianne and she'll put you in touch with like-minded members.

News of what happened at our February 6, 2010 meeting
(Continued)

**A New Breakout Group
At the Meeting**

Sometimes you just have to try something to find out if it's going to work. That's the case of a breakout group that met at this meeting. Actually, we did try this once before but it's been a while since we had a breakout for our caregivers and partners.

Again, on our conference call to discuss how to make our KIT more effective, there was lively discussion about whether or not, when we have our breakouts by disease, our partners and caregivers want to be with the patients, or to go into a group of their own.

Some of the discussion involved the feelings on both sides, that having your partner present might inhibit your willingness to speak frankly about some of the issues you face. In addition, caregivers might be unwilling to open up and speak to what they are feeling and experiencing.

So, thanks to the leadership of Jim Kahl (partner to Judy who has IBM) a group of about 12 had a lively discussion on Saturday. We will make this a regular part of our meetings going forward. Partners and caregivers should be assured that they may choose at any time to either join their patient partner, or to join the caregiver group. Thank you again to Jim and all who participated in this effort. It's a whole new way we are Keeping In Touch!

Horse Racing for Myositis

You may know that there are now two racehorses who are racing for YOU! Myositis Miracle and Stop Myositis are two young thoroughbreds that are beginning their racing career this year. Myositis Miracle has already run in two races and though he hasn't won yet, he seems to be to those who know, a very promising horse.

Both horses' owners have pledged a percentage of their winnings to TMA. How exciting and promising!

**Welcome to our Newest
KIT Members!**

Our KIT has continued to grow, adding at least three or four new members each quarter. This is amazing and gratifying.

They find us in all kinds of wonderful ways; from TMA's website, from their doctors, from word of mouth and from our blurbs in the local papers. Whatever works...we are glad they found us and hope they find our group to be helpful and supportive in whatever they need. Please keep in touch!

First, welcome to our newest members. They are: Dennis Platt (IBM) who, with his partner, Pearl Colton, attended our meeting. They live in The Villages. Kim Gates (DM) lives in Ave Maria and she too attended our February meeting. Linda Mulrooney (DM/PM) was not able to attend but who hopes to in May, and lives right here in Bradenton!

**Caregivers Come Up With
Practical Hints**

After our caregiver/partners met, they offered two suggestions that may help others.

One big challenge for caregivers is helping their myositis partner to get up after a fall. (Marianne's note: I was blessed to have John who is strong enough to lift me and actually carry me around.) But if the caregiver is a lady or even a gent who is just not strong enough to lift his lady, what are they to do?

There are two phone calls you may want to make. One is to your local Hospice. It is suggested that you call them before there is a need, to first find out if they do this and secondly to set up that you can call them in an emergency. Then if there is a fall, they can send out someone to help.

The other is that you can call 9-1-1. When they ask the nature of your emergency, tell them you need public assistance or lift assistance and they will send two firefighters to help.

These sound like great ideas and you may want to check into what is available in your area.

**Next Meeting
Saturday, May 1, 2010**

We've invited a pulmonologist and expert in sleep disorders to speak at our May meeting. More info will be forthcoming when he confirms.

TMA: A Very Good Thing!

At our meeting as always, Barb did a great job of reminding us of what TMA is doing. She also encouraged everyone who either is not a member, or who has not renewed their membership, to please go on line and join or rejoin.

Marianne is working with TMA to discover which of our KIT members, are currently TMA members. While it is not strictly a requirement for KIT members to belong to TMA, it certainly does make sense.

For example, the Outlook newsletter is full of information relevant to PM, DM and IBM patients. (There is also now a special section for Juvenile Myositis patients). For \$15 per year you receive this newsletter and if you upgrade to \$35, you can receive it via e-mail.

In addition, TMA is going to start some regular pod-casts to have dialogue regarding new therapies, drugs etc. And these podcasts will only be open to members.

TMA has provided over \$3,000,000 in grant money to help researchers find new and more successful ways to treat our diseases.

I realize that our records are a bit incomplete, especially for our KIT members who maintain two residences. You may be shown as a TMA member of your northern KIT and not ours. I hope to get this straightened out soon.

TMA: A Very Good Thing! (continued)

The staff of TMA works very hard to provide KITs and individuals with whatever they need to cope with myositis. Please help them continue their good work by joining or renewing your membership. Just go to www.myositis.org or call Marianne on 941-794-8350 for an application.

TMA's Annual Patient Conference

September 23-25 in St. Louis

The following is taken from the mailer that will soon be sent to TMA members. Please consider attending this event that is essentially a Mega-KIT meeting!

Research explained. Friendships forged.

Research is the focus of TMA's 2010 Annual Patient Conference. Each day, the Conference will have a theme identifying the focus of that day's program. The Conference will present the search for better treatments and a cure for myositis. It will also focus on practical day-to-day adaptations that those living with myositis make to maintain balance in their lives and pursue their goals and aspirations.

This year's Conference is unique because, for the first time ever, the entire 20-member TMA Medical Advisory Board will be in attendance, sharing their

expertise with patients and caregivers. Conference sessions are interactive and questions encouraged. This is an event designed to present patients and their caregivers with an opportunity to hear from those most knowledgeable about myositis and to provide answers to your questions. If you can meet us in St. Louis this September, you will be rewarded with information that will enhance your ability to manage your disease, and you will form friendships with others who are experiencing many of the same challenges.

To make the Conference affordable, we are packing everything into 3 days and have negotiated with the Hilton at the Ballpark a room rate of \$99 per night for Conference attendees. The \$125 Conference registration fee covers all Conference meals and materials.

Hilton St. Louis at the Ballpark

1 South Broadway
St. Louis, MO 63102
TMA Group Room Rate: \$99.
Rate applies 9/22 - 9/26/10.
Phone: 314-421-1776
Toll-Free: 800-HILTONS
www.hiltonstlouis.com

To register for the conference; go to www.myositis.org or call 1-800-821-7356.