

Which highlight of our meeting is the most special?

- 63 people attended!
- 25 were newcomers!
- Bob Goldberg, Exec Dir of TMA was our special guest!
- Our two presenters were great!
- We learned new exercise moves!

Meeting Synopsis:

It was a bit scary at first; as we were setting up the room with our usual 50 chairs, and more and more people kept showing up at the registration table. (Kathy O'Connell and June Pearl did a magnificent job of getting them registered and making nametags.) Then Barb Kluding took pictures of them and all were welcomed into our winter meeting. It was a bit crowded but no one complained and we all managed to find a seat, have breakfast snacks and lunch and then participate in both the presentation by Bob Goldberg and also our Occupational Therapist, Jorda Redhead and two rehabilitation success stories, Laura Parsons (wife of member Chris Parsons) and Lydia Drelles, Jorda's client. Marianne even provided some comic relief by showing how pushing on balloons is another form of exercise. Attendees each got a thera-band and/or washcloth to use in resistance exercises. Some members brought cans of food to use as weights. (We then donated them to the local food bank; 63 pounds worth!)

What a fun, educational day!

Read all about our February 7, 2009 Meeting!
Our most well-attended meeting with 63 people; 26 were first-timers!
We are definitely Keeping in Touch!

Bob Goldberg's Updates on TMA

As Executive Director of TMA, Bob wears many hats. One is to oversee the daily operations of TMA as they advocate for Myositis patients, provide services and work with the medical community and politicians to increase awareness of our diseases. He also works to raise funds, both for TMA itself (we are a non-profit organization) and also for research into causes and treatments of Myositis.

Bob gave us an overview of services members can access, either via the website or by calling TMA's office in Washington, DC.

Our meeting attendees had a chance to ask questions and clarify their understanding of TMA.

One clear result that shows the benefit to having Bob speak, is that three attendees wrote checks right then, to join TMA. Way to go!!!

Bob commended our KIT for our fundraising efforts over the last two years; over \$10,000. While this is not the most ever raised by a KIT, it is the largest amount raised by just donations by members, their families and friends.

From our meeting, Bob left to visit with some generous donors who have given to TMA's general funds or to the Research Grant. We're grateful to have had time with him!

One Highlight we Love—Group Break-outs by Disease (this time, we had one for caregivers, too)

After Bob spoke, we asked the DM and PM groups to split out into separate rooms for disease-specific conversations. We are lucky to have had Sherry Schell who also led a group discussion about some of the issues facing caregivers of Myositis patients.

After we reconvened, we again enjoyed a lunch from Chick-fil-a who continues to provide a tasty and reasonable lunch for us.

Then we addressed Real-World Exercises and Therapy!

Jorda Redhead is an Occupational Therapist who attended our meeting last February with her client, Lydia Drelles. When Lydia heard that we were considering a speaker to address exercise, she immediately volunteered Jorda. When the two of them met about a year ago, Lydia had a list of several "things I want to be able to do" and she and Jorda set about making this happen. The result was amazing. Lydia's strength, balance and abilities were substantially increased, and are continuing to do so. The two of them demonstrated how some of the simplest moves can have a tremendous effect on muscles we thought were permanently restricted. Jorda also handed out a substantial document that detailed many of the exercises

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she demonstrated and they have used. (Copies are still available for those who could not attend; contact Marianne.)

Then Laura Parsons spoke to us about how she managed much of her own recovery from a serious accident some years ago. With major spinal damage, she had to cope with not only physical limitations but also the crushing experience of emotional damage. "Why me?" is something we've all probably said at one time or another. Yet this woman did not accept her limitations and began to create a workout routine and exercises that would bring her back almost to where she was before. In addition, she is cheerleader for her husband, Chris who has IBM. She knows what she is talking about! She demonstrated some simple stretching and resistance exercises that she has used; reminding us that progress may be slow but it is PROGRESS! Then we picked up our cans of food and she showed us exercises that not only used the cans as weights but also helped with range-of-motion. It seemed like almost everyone was participating and having a good time and that's what exercise should be about!

Then Marianne had everyone who could, blow up a balloon and she showed how her PT from Maryland had her find multiple ways to squeeze it; between her hands, legs, between thigh and chair, foot and floor, etc.

Other members also made suggestions like blowing up a balloon and filling it with sand, to use as a resistance ball. Another member is a big fan of a device called Power-Plate (it's expensive but helps with balance, strength and calorie burn). There was a lot of laughing and exchanging of ideas and that was the whole purpose of our presentations.

Thank you again to Jorda and Laura. Thanks also to King Pharmaceuticals who donated some thera-bands and DVDs.

Thanks also to everyone who donated canned food. Every bit we can donate to those in more need than we are, is a blessing!

Announcements
Welcome to our KIT!

We're grateful to all who came but special welcome to first-timers: Robin Bentley DM and sister Renee, Jeanne D'Albora DM, Don Klersy PM and wife Marge, Carol Lopez PM, Jan Marriott DM, Elaine Meyer IBM and husband Carl, Lynda O'Neil, wife of Kevin, Peter Ruffalo DM/PM and wife Jayleen, Herb Schley IBM and wife Delia, Debi Singer PM/DM, Julie Taylor DM and friend Robin, Russ Knight IBM and wife Marg, Steve Kelly IBM and wife Millie, Carolyn Gerow IBM, and Jim Hageman IBM and wife Marily.

(And since the meeting we've also found another new KIT member, Rex Corbin IBM. Did they tell us this is a RARE disease?

Next meeting of our KIT will be: Saturday, May 2, 10:30 to 3:30 at the Health-plex. Watch for your invitation around April 1!

Responses to our survey indicate you'd like a speaker to address either Assistive Aids or Pain Management. I'm working on finding someone that will be a good presenter on one of these topics. If you know someone, please contact Marianne via e-mail or phone.

Financially we are in great shape. There is about \$600 in our checking account which may come in handy if we have another large crowd at a future meeting. Health-Plex will charge us between \$200 and \$300 if we move to a larger room...not an issue yet but something we might have to address. Also, we will need to cover some of the Neurologist's expenses at the August meeting.

Fundraiser for KIT and TMA!

We have a great opportunity to do a little Fundraising! On Thursday, April 9 in Bradenton, there is a free band concert (popular, country, etc) at a local orange grove, Mixon's. They hold a special 50/50 drawing at the event and give ½ the money to whatever charity is there that day. April 9th it's our KIT. Watch your e-mail for details but if you are nearby, plan to come. It starts at 6PM, and is free though it's \$5 per car to park. Food and drink are available for purchase.

Best wishes to everyone in our KIT!
Let's Keep In Touch!