

Thanks to everyone who was able to attend our "KIT" meeting on May 12! The meeting was a big success, and somehow we escaped being impacted by the Rodeo Parade!

We started the meeting by remembering Harry Meekma, a long time member with IBM who passed away in December 2013. He was a dedicated attendee and we will all miss his upbeat attitude and wacky jokes!

Gary Tjader was given a big thanks for taking on a newsletter for our group, and this is also a reminder that if you have newsworthy info to share with our group between meetings you can email him at [gary@tjader.com](mailto:gary@tjader.com).

We watched a video from the Annual Myositis Conference in 2011 entitled "Exercise for all Levels", in which Dr. Ingrid Lundberg from the Karolinska Institute in Stockholm reviewed the studies her group has done on exercise in myositis types. While the numbers of patients in her groups were small, her studies were scientifically rigorous with good methodology. Her group was able to show that exercise improves function and strength in DM and PM patients without elevating CPK levels or harming muscles. Although she was not able to show such good results for the IBM patients in her study, she discussed a study in Australia that appeared to show such improvement for IBM. The main difference was that in the Australian study the exercises were done more frequently daily and over a longer period of time. Dr. Lundberg's video ends with a demonstration of the exercises that her research patients were doing, and if you'd like to see both her video and a demo of the exercises follow these steps:

Go to home page of TMA and notice the "In The Spotlight" heading; click on 'read more' under the topic "2014 Annual Patient Conference"; that leads to another page that says "2014 Annual Conference" requiring yet another click on "read more". On the page that highlights the upcoming 2014 conference there is a sidebar on the right that says PAST CONFERENCES, where you can find the 2011 conference in Las Vegas. Going to this page allows you to scroll through the topics (highlighted) covered in that conference, and you will find Dr. Lundberg listed as "Exercise for every level".

Our chapter currently has two members that are on the TMA Board of Directors, Carla Stevenson and John Suttle.

You might remember that John gave our group a talk on estate and tax planning two years ago and also talked at the conference in Las Vegas, just before joining the board. Today he talked about joining "The Legacy Society", which is a way of making sure part of your estate can go to TMA after your death. If a bequest is set up to come out of, for example, an IRA or other retirement income, there might be tax benefits to your estate while you continue to support TMA's research and support efforts. A brochure called "Planning for Our Future" is available to help you consider this more, if you are interested. Call [800-821-7356](tel:800-821-7356) and asked for information on TMA's Legacy Society.

Carla, wife of our co-leader Rich Stevenson, joined the board recently. She is excited about having our group support "Myositis Awareness Day" which is September 21 each year. Anything we can do as individuals or as a group to educate our friends, family,

medical staff or the public about myositis is welcome both on this day and on any day! Often our own family members have insufficient information about myositis, and we should consider asking them to attend the annual conference where a wealth of information is available in a short period of time. She also discussed the race horse, "Myositis Dan", a promising horse that helps to raise awareness about myositis when he races, just because of his name. When he wins, TMA gets half of the purse! The history of Myositis Dan can also be found on the TMA website.

Rich Stevenson brought our group up to date on the trials going on for the IBM drug, BYM338. There are two trial sites in California, one in Davis and one in Irvine. Getting accepted into the trial is very difficult as only a few people are being accepted at each location, and criteria for acceptance are very strict. For example, you have to be able to walk a certain distance in a certain amount of time, and there are restrictions on certain medications such as prednisone which is not to have been taken recently. Even if accepted, only 2/3 of the trial participants will get the drug itself, with 1/3 getting a strong dose, 1/3 a weaker dose and 1/3 getting placebo. To further frustrate the situation, it is unclear whether the research sites are still accepting candidates or even accepting positions on the wait list. The trials are ongoing in other states and worldwide, so it is likely that results might be available earlier in certain sites.

Finally, we brainstormed three main ideas on raising awareness about myositis in our communities. One idea is that each of us can share information which our local newspaper or bulletin boards about our meetings and about TMA. This could happen on or around Myositis Awareness Day or at any time that seems opportune. Many coffee shops and libraries have community bulletin boards where meetings can be posted. For the local newspapers, consider a small article telling your own story or the story of someone near to you who has been impacted by myositis.

Secondly, information packets for our doctors, health education centers or departments within medical clinics (such as rheumatology and/or neurology) should be made available to each member who wants them. Our national office is working on a new brochure for medical providers, and I have volunteered to assist in putting packets together when this becomes available.

Thirdly, members can hold fund raising events such as a picnics or events at restaurants, where fun and food can mix with education and awareness.

After lunch we broke into small groups, a perfect time to share information on current progress and symptoms, medications, side effects, care issues and experiences that might benefit others in the group.

Our next meeting will be on Saturday, November 1, at Eden Medical Center from 10a-3p as usual. We are grateful to Eden for making their conference center available, as it is centrally located for members from Fresno to Reno! Speaking of Reno, the Annual Conference will take place at the Peppermill Hotel and Casino in Reno from September 4-7. Conference registration rates are lower before May 31, so register soon! All the information needed and the agenda are on the TMA website!