

Myositis Support Group

Monthly Meeting Summary November 13, 2013

- **Ground rules:** This group is a supportive environment where you can learn about myositis from one another. Each person's experience with myositis is unique. Therefore, it is not a forum for providing specific medical advice; this is best done in consultation with your own physician. Confidentiality is essential. Although members may share what they heard or learned with others outside the group, please try to remember not to identify the speaker. It is important to consider time when individuals are speaking, as we wish to give all who choose to share an opportunity to do so.
- **Next month's meeting will be on December 11th.** We will be celebrating and having our annual **Holiday Party**. We will be discussing members' plans and how to manage what can be a stressful time of year. This will be a pot luck event, so if you would like to bring a dish or paper goods, please let me know as soon as possible.
- **Please remember** to visit our website for summaries that have been added. On our home page, you will also find links to summaries from support groups of other chronic illnesses, such as lupus and rheumatoid arthritis, that you may find interesting and helpful. This is a new addition, so that our patients may benefit from the wealth of information contained in these summaries:
www.hss.edu/myositisgroup
- Best wishes to those members who have recently experienced physical setbacks and for those planning to have surgery in the near future. We wish you a speedy recovery and hope to see you back at group soon!
- Congratulations and best wishes to members who are celebrating weddings, births, and other joyous events

Meeting Summary

Members who attended TMA's patient conference presented on topics of most relevance and interest. The Myositis Association celebrated their 20th anniversary, and they had a record 400 attendees!

Many of the presentations are available online, and the links to these will be provided in the summary. In order to help with this, Katie, one of our KIT representatives demonstrated how to log on and to go to the various presentations. You may view these summaries by logging directly onto:

<http://www.myositis.org/your-myositis-community/annual-patient-conference's>

Please note: If you have trouble getting onto the websites directly, you can try to log on to TMA's site:

- www.myositis.org
- On the right sidebar, go to **Annual Patient Conference**.
- Scroll down and you should be able to click onto presentations of interest to you.

One of our KIT representatives was part of a patient advisory group to offer suggestions on how TMA might better serve the needs of people with myositis. In addition, she attended the session co-led by Marianne Moyer, Board of Directors, TMA and Charlia Sanchez, TMA Staff Member on "Successful Support Groups." Again, you may view highlights from this excellent discussion on: <http://www.myositis.org/your-myositis-community/annual-patient-conference's>

Two other members discussed their interest in presentations by Dr. Frederick W. Miller and Dr. Steven Greenberg:

Frederick W. Miller, M.D., Ph.D, Chief, Environmental Autoimmunity Group, Office of Clinical Research, NIEHS, National Institutes of Health, presented: "Twenty Years Later- Progress in Understanding Myositis." Members said that what they found most interesting was that there are two components to autoimmune disease; there is the genetic piece but also there is a trigger- which can sometimes be environmental. Some of the topics covered in Dr. Miller's presentation were:

- Major Advances in Myositis
- Better Recognition of Myositis and New Diagnostic Assessment Tools
- Possible Environmental Triggers of Myositis
- The Broad Spectrum of Myositis
- Different Problems and Treatment Responses for Different Types of Myositis
- New Treatment Options and Understanding the Need for More Aggressive Therapy
- TMA's Major Impact on Myositis

For more on this presentation, you may log onto:

http://www.myositis.org/storage/documents/2013_conference_presentations/TMA_20_years_later_2013_final.pdf

He is also lead investigator of several trials for myositis patients related to environmental triggers and exposure to agents during military service. More can be learned by logging onto:

http://niams.nih.gov/Research/Studies_Seeking_Patients/default.asp

An area of great interest to those with IBM was a new “breakthrough therapy” * (please see below for definition) and clinical trials underway using BYM338 (bimagrumab) and led by Novartis. This presentation was by Dr. Steven Greenberg, neurologist at Brigham and Women’s Hospital, Boston, MA.

Novartis conducted a small clinical trial of 14 patients approximately two years ago. Patients were given a single dose of BYM338 intravenously. BYM338 is an experimental molecule that was tested to see if muscle atrophy could be reduced. The size of the quadriceps muscle was measured prior to giving the injection and then eight weeks after, using various methods of measurement to

Though results of the study have not yet been published, the initial results appear to be positive “in a certain way” (Greenberg) and demonstrated that muscles could be enlarged, especially in the quadriceps.

Dr. Greenberg emphasized that BYM338 is not a cure and is not yet considered treatment for IBM, even though it has received approval by the FDA as a breakthrough therapy.* It remains in the experimental stages. Dr. Greenberg’s discussion can be viewed on:

<http://www.youtube.com/watch?v=zMnj3scBisE>

*”**Breakthrough therapy** designation is a process designated to expedite the development and review of drugs that are intended to treat a serious condition and preliminary evidence indicates that drug may demonstrate substantial improvement over available therapy on a clinically significant endpoint (s).”
(www.fda.gov)

At the conference, one of our group members moderated a discussion on entitlements and compensated disability for veterans on two occasions. Joining him were Dean Carver, who specializes in benefits through the Veterans’ Administration (VA) and the Director of Prosthetics, Stanley Kerr, at the VA in Louisville, Kentucky. It was learned that many veterans are entitled to benefits through the VA. In fact, there are some specifics regarding the definition of a veteran and “having served time in the military” and that those who were in the reserve may also be eligible. It was also stated that a veteran might qualify for disability if it can be proven that myositis was related to your having served in the military. There is research underway investigating this possible connection at the National Institutes for Health, under Dr. Frederick W. Miller (mentioned above).

One of our members enjoyed the presentation by Renee Lantner on **Nutrition and Myositis**, which discussed:

- Eating healthy in general
- Nutritional abnormalities in chronic disease
- Specific supplements and diets related to myositis

This presentation can be found online at:

http://www.myositis.org/storage/documents/2013_conference_presentations/TMArevised916.pdf

and also found presentations by psychologist, Amy Wood, Psy.D., helpful and inspiring. Dr. Wood discussed 10 principles and then exercises that may help with managing emotions. Two examples found in the presentation are:

- What small change can you make to take better care of yourself?
Exercise: Make the most of your resources
- What can you do to reward yourself and others?
Exercise: Set and maintain health limits

Her complete presentation can be found online at:

http://www.myositis.org/storage/documents/2013_conference_presentations/maac_powerpoint.pdf

Following the discussion about the conference, members discussed issues relating to how myositis has placed limits on their lives: being unable to continue working, difficulty in getting around, and not knowing how you will feel from one day to the next- making it difficult to plan. Another area of concern was the recent restrictions placed on certain pain medications, such as oxycontin. Members shared how changing to other pain medication has been difficult for them and not as effective. We discussed the possible benefit of seeking help from pain management experts.

CLOSING REMARKS

Many thanks to our members for presenting on your areas of interest at the conference and for bringing the conference back to us. It was clear that there was a great deal of excitement generated at the conference and that more is happening in myositis research than ever before. Our presenters expressed, as others have done in the past, that it is not only the presentations that they find valuable but meeting so many others who share their experience. There is true meaning in the connections that are made and the stories that are shared.

Wishing all continued strength,
Suzan



Photo Courtesy of Tom T.

CONNECT WITH YOUR FELLOW GROUP MEMBERS!

At meetings, group attendees may ask for updates on members they haven't seen in awhile or on members who regularly attend and are missing a group. We also wonder about members who receive the monthly newsletter but are unable to attend. We want to connect members of the group with each other. If you would like to communicate with others in our group to let us know how you're doing, please call or email me with a special thought, update on your health, or inspiring story. Some group members have already asked me to tell the group hello or read an update, which is a great way to keep in touch when you can't attend a meeting.

*****LET YOUR DOCTOR KNOW ABOUT OUR GROUP!**

Every person with myositis needs a support network that includes other myositis patients. Help us to reach out to others in our area with myositis by sending me your doctor's contact information. I will send a letter and flyer announcing our group to your medical providers so that they can inform other myositis patients about our group. *We already have the contact information for many doctors in our area and several members have taken flyers for their doctors. Please contact me if you would like to participate!*

GROUP DETAILS:

Contact Me with Your Ideas for Speakers and Meeting Topics: We want to provide meeting topics and speakers that are most interesting and important to you. Your assistance in finding guest speakers for our group is appreciated. Please contact Suzan if you know anyone who might make a good guest speaker or have a particular topic suggestion. Or, if there is a topic or guest speaker from the past that you would like the group to repeat, please contact Suzan. *Even if you aren't able to come to our meetings, we value your participation with the group and welcome any ideas you have on guest speakers.*

To contact Suzan, Group Coordinator: I will be checking e-mail and voicemail twice a week and will get back to you as soon as possible within the following day. Phone number: **212.774.7623**; email address is: **fischbeins@hss.edu** **If you have an urgent need, please contact Roberta Horton, at 212-606-1033.

Upcoming Meetings in 2013 – WEDNESDAYS (except where otherwise noted):

The Myositis Support Group will be meeting on the **SECOND WEDNESDAY OF EVERY MONTH (except where otherwise noted)**, from 6-8 PM in Conference Room A at Hospital for Special Surgery, 535 East 70th Street in Manhattan.

Mark your calendars for the following meeting dates in 2013: In 2013, we will continue to hold our monthly meeting schedule on Wednesday evenings during the second week of the month in Conference Room A. Group meetings will occur on: January 9th, February 13th, March 13th, April 10th, May 8th, June 12th, July 10th, **Sunday, August 4th- annual luncheon**, September 11th, October 9th, November 13th, and December 11th.