

MM Fighters! Support Group Meeting
January 23, 2021
Virtual Meeting

Happy New Year! We had a great turnout for the first meeting of the new year, and an informative speaker to help us kick off 2021! Rachel Douglas, PT, helped us better understand the challenges caused by cancers and their treatments, as well as providing us with some guidelines to help us overcome these challenges.

During this long drawn out absence from each other, we need to be especially thankful to the generosity of the IMF (International Myeloma Foundation) for allowing us to use their GoToMeeting app for our virtual meetings!

Thoughts For The Month

As with many challenges in life, good things happen once you accept what has happened and discover ways to make the best of your situation...therefore

Life is not about waiting for the storm to pass, it is about learning to dance in the rain.

Speaker

Rachel Douglas, PT, MPT, LMT from the SCCA, spoke to our group this month regarding “**Multiple Myeloma and Physical Therapy**”, with thoughts on how we can all take better care of ourselves by keeping moving.

Many things have changed in cancer care, including the view of bed rest. Previously, it was thought best for patients to rest often and for longer periods of time. However, research has shown that for each day of rest, it can take up to several days of activity to build back muscle loss.

Physical activity, at low to moderate levels of intensity, helps build energy as well as muscle tone and strength, lessen stress, improve attitude, better control weight management and brighten moods.

However, when you begin any physical activities, be sure to do so slowly and under the direction of a PT or other experienced exercise professional.

There are multiple sources to encourage and guide physical activity – care teams, Physical Therapists, athletic trainers, etc.

- **IMPORTANT!!!** Make sure that they have experience dealing with cancer patients!!!

- Just as with oncologists that lack detailed knowledge of treating myeloma, inexperienced physical therapists can end up causing more damage.
- For those in more remote locations, or without an experienced PT nearby, one face-to-face meeting with a cancer-knowledgeable PT, followed by tele-visits as required, can help guide your program.
- These more experienced PTs can also contact your local PTs in order to help guide their treatment.

A helpful chart was provided detailing blood counts (platelets, white/red cells and hemoglobin) and corresponding recommended activity levels.

Posture has also proven to be important for long term health and quality of life. Several pages of guidelines and suggestions are included in the presentation.

Rachel also gave us three pages of exercises that help to combat the effects of neuropathy in your lower limbs.

- At this time, there are no known exercises that can overcome neuropathy.
- However, by building muscles and improving balance and flexibility, patients have been able to combat many of the effects of neuropathy, leading to better outcomes.
- Remember that exercise programs should strive to cover the following areas – cardio, strength/balance, stretching/posture.

Attached to today's email is a pdf copy of Rachel's presentation. At the end of her presentation, Rachel has provided her email address in case any member has a question.

Patient Roundtable

Several new patients introduced themselves as well as commented on their journey so far. Discussions centered around upcoming stem cell transplants.

Our membership gained 30 new members in the past year, while unfortunately losing 5. Patients found our group through a number of avenues, including the web (our website and the IMF), doctor/nurse recommendations, social workers as well as at the suggestion of current members. It has proven beneficial to the myeloma community that we have such a wide array of avenues to our group!

Discussions that attracted a lot of comments included stem cell transplant options (Swedish vs. SCCA, melphalan vs. BEAM) as well as side effects and efficacy of different treatments, especially Darzalex and Polmalyst.

Marilyn suggested that people check out the Greenwood Senior Center's online educational opportunities at <https://www.phinneycenter.org/gsc/>. She has been impressed with their offerings!

Dave brought up his struggles with back pain and several members related experiences with similar challenges and what worked for them. From pain patches to exercise, rest and acupuncture, as well as seeing pain specialists, there are a lot of options out there. Be sure to discuss with your oncologists first! And again, make sure the acupuncturist has experience with cancer patients!!!

Ablation was another procedure that many members have in common. The techniques associated with this procedure have advanced greatly in recent years, and the results seemed to have improved as well.

Next MM Fighters! Meeting:

Two important and informative meetings are scheduled for the next two months! Best sure to put these dates and times on your calendar!

Saturday, February 27th, 2021 – 10AM – Noon – Dr. Bensinger (Swedish), Best of ASH VIRTUAL MEETING (On GoToMeeting)

Saturday, March 27th, 2021 – 10AM – Noon – Michael Schliekelmann (Adaptive Biotechnologies), MRD VIRTUAL MEETING (We will be switching to Zoom for future meetings – details to follow)