

MM Fighters! Support Group Meeting
August 22, 2020
Virtual Meeting

The MM Fighters' meeting was lucky enough to have members from California join us again this month, as well as several members of the Spokane Support Group drop in for the presentation. It is wonderful to be able to extend our support outside our metropolitan area and assist others. Once again, we thank the IMF for their generosity in making the GoToMeeting app available for our use.

Thoughts For The Month

Some thoughts that I have found to ring true during my myeloma journey...

Every day is not a success. Every year is not a success. You have to celebrate the good.

To succeed in life, you need three things: a wishbone, a backbone, and a funny bone.

Speaker

Dr. Sibel Blau, Medical Director at **Northwest Medical Specialists** (in addition to wearing numerous other hats!), was our speaker this month, covering **The Essence of Being The Hidden Half – The Challenges of Being a Caregiver**, an intriguing discussion comparing her roles as an oncologist and a caregiver, as well as insights into lessons she has learned as a caregiver to her husband, myeloma patient Dr. Tony Blau.

Dr. Blau began with a brief summary of Tony's diagnosis and first year as a myeloma patient, and then compared his journey with that of a caregiver. In addition to a description of what a caregiver goes through, Dr. Blau shared a national study outlining some of the many tasks that caregivers are faced with. She also compared the two worlds that she found herself in - that of an oncologist compared with a caregiver.

From her experiences, Dr. Blau shared several key lessons she picked up while dealing with Tony's myeloma.

1- Learn To Take One Step At A Time – and find time to take care of the caregiver.

2 – You Can Make Mistakes! – learn from them!

3 – Follow Your Instincts – you are often correct, no matter what others may be telling you.

4 – It Is A Marathon – Not A Sprint – take the long view, don't get caught up with “now”, as this disease evolves and changes, and so must you.

Dr. Blau also discussed the feeling of guilt that all caregivers must deal with from time to time....and reminded us that we are all humans, and must forgive ourselves for not doing everything correctly.

Dr. Blau's presentation ended on a high note, outlining a few goals for caregivers to help make the journey more enjoyable and less stressful, as well as the many good things that the myeloma community has to look forward to – numerous new therapies, advance research, data sharing platforms as well as Support Groups.

It was a very informative presentation, and the slides can be found attached to this month's email.

Patient Roundtable

Once more there were discussions regarding Darzalex, comparing the newly released injections with the IV, which was released earlier.

- More members are taking the injections, but 3 have experienced severe headaches after their injections. All three have decided to return to the IV, filling up the quiet time with reading, projects, etc.
- Those that have not experienced headaches are quite pleased with their results, and it will be interesting to follow these groups as their journey progresses. Darzalex has been able to deliver long lasting results to many patients, and we hope that our members are all able to enjoy similar outcomes!

Greg asked the group for some assistance to help a new myeloma patient to whom he has been introduced. This new patient is facing several challenges, and our members stepped up to assist.

- Bill and Janell both volunteered to speak with this patient.
- The group was reminded the MM Fighters' website has a great deal of information for newly diagnosed patients as well as those seeking more information, education or financial assistance.
- Myeloma non-profits, such as the MMRF, the Myeloma Crowd, the IMF and Patient Power, are always good sources of information.
- It was also suggested that the patients seek out resources, such as social workers, at the clinic where he is being treated.

The challenges of keeping an appetite during treatment was also discussed.

- Members shared techniques they used to overcome such challenges
 - o Eating small meals several times a day versus a few larger meals

- Experimenting with different foods to find what makes you the most comfortable, then sticking with these during the difficult times
- Covering your nose during meals if you find that the smell of food makes eating challenging. A cloth mask folded several times and strapped under your nose worked for me when my taste and sense of smell were in conflict.
- Speak with your oncologist/hematologist about effective nausea medicine that can help overcome appetite problems
- Find a spice or two that can help make food interesting again, especially for those who are experiencing a severely diminished sense of taste.
- **Do the members have any other suggestions? If you do, please share!**

Social distancing, and appropriate measures/distances was also a topic of discussion.

- Those undergoing treatment, as well as the older members of our group, need to be extra cautious regarding contact with others...in other words DO NOT go to the post office to mail numerous packages, Helen!
- The IMF web site has a number of videos under “Ask Dr. Durie” that address COVID-19 and myeloma patients. Those with questions should visit the site. Each video is about 3 minutes, and can be very helpful in clarifying matters.
- Listen to others, but remember each of us face our own unique situations. You need to do what works best for you.
- Take care of the patient first, then others in the household need to be careful of their exposure due to the possibility of the contagious nature of this disease.

Despite the disease we are challenged with, and the impact that various treatments can have on patients, member of the group continue to impress with their many activities!

- Else and Marilyn are both contributing columnists to the Myeloma Beacon
- Marilyn and Helen are both taking time to write op-ed pieces for the Seattle Times
- Helen, who is a young 88, has just completed a book that has been published
- Bud, who has also had to battle jaw necrosis, is still able to travel around the US as a Dedicated Ballistics Researcher and Theoretician (DABRAT). He and his wife also shoot cast bullet rifle competitions.

Hope that their efforts can inspire you!

Next MM Fighters! Meeting:

Saturday, September 26th, 2020– 10AM – Noon – Dr. Moshiri, Dermatologist at UW/SCCA – “Cancer Treatments and Skin Care” VIRTUAL MEETING