

MM Fighters! Support Group Meeting
March 26, 2022
Virtual Meeting

This month's meeting allowed us to introduce a soon-to-be new member of the UW/Fred Hutch faculty, Dr. Rahul Banerjee, currently at the UCSF. A fairly young doctor who has already taken part in publishing 32+ papers, Dr. Banerjee's broad research background helped generate an interesting and informative presentation.

Thought For The Month

If you think you are too small to make a difference, then you have never spent a night with a mosquito.

Remember that all actions influence others, sometimes to an extent that is beyond our immediate level of awareness. This is important to remember during Myeloma Awareness Month, as well as Defeat Myeloma. Keep on reaching out...you will be surprised at the positive results!

During Myeloma Awareness Month, the MM Fighters were pretty active! Along with a WA State proclamation recognizing March as Myeloma Month, we had a great article in the Vashon Beachcomber paper (great going, Mary!), and an impressive article written by Michele and her oncologist placed in a medical newsletter for Wenatchee and North Central WA. Wonderful efforts!

Several MM Fighters also generously contributed to various fund raising teams who are participating in the Defeat Myeloma fundraiser, while others contacted their PCPs to help spread awareness of the warning signs of MM.

Please let me know what you have done so that we can celebrate your actions!

Speaker

Dr Banerjee focused on 4 major areas in his presentation – the complexity of determining the causes of many side effects (treatment or disease), and the causes and potential treatments for neuropathy, fatigue and “time toxicity.

Starting with a list of potential side effects that impact many Myeloma patients, Dr. Banerjee also examined the many unreported side effects that can plague patients, including Quality Of Life, financial challenges brought about by treatment and Long Term side effects that follow on from Short Term side effects. Dr. Banerjee strongly suggests that patients and caregivers are aware of these side effects and do not hesitate discussing them with their care team!

An interesting note is that increased levels of treatment does not always result in decreased quality of life. A great example is the positive impact of many triplet treatments over a double.

Fatigue is a very common side effect in Multiple Myeloma, often caused by inflammation and treatments, but not effectively treated by sleep. Because of the multiple causes, many times there needs to be a combination of solutions, and the slides give a good summary of many of these.

Dr. Banerjee also looked at fatigue caused by IMiD (Revlimid and Pomalyst) as well as steroid induced fatigue, and explores whether dose reduction or spacing out the doses is able to relieve some of the fatigue.

Neuropathy (pain, numbness, tingling or cramps in the hands and feet) was the next side effect addressed in the presentation, which is often brought about by Velcade and occasionally by Thalidomide and Revlimid. (Diabetes is yet another cause of neuropathy, and this side effect can worsen under Myeloma treatment.) Dr. Banerjee explored whether dosage had an impact on the severity of neuropathy, as well as various ways to treat this side effect, with the effectiveness varying depending upon the patient.

He has found little evidence that vitamins or supplements are effective against neuropathy, but has seen Vitamin D and Calcium together have some impact. Dr. Banerjee also stated that low Vitamin D has been associated with worse survival for many MM patients, especially Caucasians, so be sure to have your levels checked (especially in the Pacific Northwest).

In addition, there were a couple of warnings. While CB oils have proved to have some beneficial effect, other derivatives of marijuana have been found to have little impact. And Dr. Banerjee also warned MM patients to stay away from extra magnesium, as this can increase diarrhea, which is already a common side effect from several Myeloma drugs.

The last area examined was **Time Toxicity**, which most patients have experienced. During our care cycles there is a lot of waiting for labs, monitoring, waiting for drugs, etc. Dr. Banerjee came up with 8 suggestions to help minimize time wastage. Below are a few of the more interesting suggestions:

- For those taking PI (proteasome inhibitors such as Velcade), Dr. Banerjee suggests trying to get injections only once a week. No better long term results have been shown to come from twice weekly injections, and saving a day of travel and wait time adds to your Quality of Life.
- After the initial period, receiving Zometa once every three weeks has been shown to have the same results as monthly injections.

- As Car-T therapy becomes more common, the use of electronic devices for monitoring patients in the long term could save a lot of time and money.

Dr. Banerjee's slides can be found attached to the email, along with a link to the video of the presentation.

Patient Roundtable

Dexamethasone is often taken with Myeloma drugs as it has proven to enhance the effectiveness of these drugs, but it can also cause several side effects. One impact of too much Dex with older patients can be thinning of bones, and patients who have been on Dex for a long time should consider a Dexascan for the best picture of your bone density.

A large number of members have received the Evusheld injections, and for most there have been next to no side effects. One of the more worrying side effects has been a short term increase in blood pressure, which was mentioned by a couple of patients.

The MM Fighters have at least 3 members undergoing Stem Cell Transplants, so be sure to keep them in your thoughts! Una has emerged at the other end of hers and is doing wonderfully!

Travel seems to be on the agenda of many members, with people queuing up for trips to Hawaii, Europe (the south part, of course!), Boston, San Diego and Tucson. Travel safely! While not all of us can, or are willing to travel at this time, we can use others' travels to create bucket lists or to dream a bit.....

This month's meeting not only had people signing in from The Tri-Cities, Spokane and Idaho, but also from Canada, California and Florida! Glad that we are able to reach out and support so many!

Next MM Fighters! Meetings:

Caregivers Meeting – April 2nd, 2022 – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

NEW GROUP! Myeloma Families with Young Children! Contact Jen at erikson.jen@gmail.com for more information!

April 23rd, 2022 – Samantha Clark – Evergreen Health - Palliative Care and Hospice – 10AM – 12:30 PM – Virtual Meeting