

MM Fighters! Support Group Meeting
November 19th, 2022
Virtual Meeting

As happens at least once a year, our scheduled speaker had last minute complications and we had to go in search of a replacement speaker. Thankfully, Dr. Cowan at the FHCC was able to find TWO speakers for us, pharmacists **Ashley Chen** and **Omar Marzouk** from the FHCC. They presented a wonderful talk on **Managing Myeloma Treatments**, not only outlining the potential side effects, but also providing methods to alleviate many of these challenges.

Thought for the Month

Every strike brings me closer to the next home run.

We all face challenges and setbacks dealing with this disease, but with a positive attitude and determination, we know that our next “home run” is that much closer.

Presentation

Ashely and Omar started off with a quick look at Multiple Myeloma, and focused on the goal of controlling the disease while avoiding complications from the multi-drug treatments needed to reach this goal.

After reviewing a timeline of new Myeloma treatments and how this has accelerated greatly in the last several years, Ashley looked at the many factors that need to be considered when selecting the correct treatment for each patient. She then outlined the drugs that they would be discussing and Omar delved into each one, considering the most common side effects as well as ways to overcome or minimize such problems. The drugs and side effects that were discussed included the following (please see slides and the video link for more details).

Proteasome Inhibitors (Velcade, Carfilzomib)
Immunomodulating Agents (Revlimid, Pomalyst)
Managing Diarrhea and Constipation
Steroids
Selinexor
Venetoclax
Tumor Lysis Syndrome
Monoclonal Antibodies (Daratumumab, Isotuximab, Elotuzumab)
Blen-rep (Belanatumab)
Teclistimab
Managing Nausea

Regarding cramps, Ashley and Omar suggested coconut water as well as apple juice or pickle juice.

A great presentation and some helpful direction for combating future side effects!

Patient Roundtable

There was a quick presentation of next year's first few speakers and their topics, and this is a strong start to the new year. As everyone likes to make yearly goals in January, we will be inspired with Exercise and how it can help us, and then continue the inspiration with the latest breakthroughs from ASH (Association of American Hematologists). Dr. Banerjee will return to present the second part of his talk in March focusing on improving the Patient Experience, followed by Dr, Namburi from Swedish who will discuss Bone Health....and there is more to come!

2023 1st Quarter (+) Speakers

1/28/23 – **Kenny Capps** – Throwing Bones – **Exercise and Myeloma**

2/25/23 – **Dr. Mary Kwok** – FHCC – **Best of ASH**

3/25/23 – **Dr. Banerjee** – **Patient Experience – Part 2**

4/22/23 – **Dr. Namburi** – Swedish – **Bone Health**

Lynn, a new member, gave us an update on her progress since being diagnosed in 2018.

Mary, also a new member, has been recently diagnosed and was being a bit overwhelmed by the influx of information, etc. The meeting seemed to help relieve some of the pressure, and we want to remind her that we are all here to help!

Sam recently moved into the Olympia area and is searching for potential care options outside of Kaiser. Several other members who are also situated outside the immediate Seattle area provided their insights into being treated at the SCCA/Swedish, the travel involved, etc.

Una, having completed TWO stem cell transplants back-to-back is going to be celebrating with an upcoming trip to Ireland!

Else spent last week out East getting a second opinion regarding stem cell transplants and will be continuing her quest for answers with the SCCA and Mayo. Frustration is growing over the FHCC changing their policy, no longer harvesting and holding stem cells for later transplant.

Tim provided the group with a summary of what he has discovered regarding Parkinsonism as an outcome of some Car-T treatments. A few isolated cases have been discovered and written about, and is something that should be kept in mind.

Bud, after Covid, pneumonia and heart problems, is once again feeling good and ready to get back on his bi-specific clinical trial.

Noel is considering his options now that time for a stem cell transplant is approaching.

Next MM Fighters! Meetings:

Caregivers Meeting – Saturday, December 3rd, 2022 – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

NEXT VIRTUAL MEETING – Saturday, January 28th, 2023 – Exercise and Myeloma – Kenny Capps from **Throwing Bones** – 10AM – 12:30 PM – **Virtual Meeting**