

MM Fighters! Support Group Meeting
March 16 ,2024
Virtual Meeting

Barb Regis, from the UW/FHCC, joined us last weekend to discuss the challenges and rewards of Survivorship. It was a wide ranging presentation, and it brought forth some interesting discussions.

For those of you who would like to watch this presentation, or perhaps rewatch it to review some of the key points, the video link, along with the following Q&A, can be found at the bottom of the accompanying email. A copy of Barb's slides is also attached.

Thought for the Month

Few will have the greatness to bend history, but each of us can work to change a small portion of the events.

A positive thought for all of us, especially as we are in Myeloma Month.

There are opportunities out there for meaningful action this month:

- Some organizations are making a big effort to promote awareness of MM this month, and they offer many ways to join in:
 - o Visit the IMF's effort at www.myelomaactionmonth.org to learn more!
- Many organizations are involved in supporting patients and caregivers and/or funding research, such as the IMF (International Myeloma Foundation), the LLS (Leukemia and Lymphoma Society), the MMRF (Multiple Myeloma Research Foundation) or HealthTree.
- Sign up for All4Cure or SparkCures.
- Attend **the IMF seminar in Seattle on March 23rd** (Westin Seattle) to learn more about MM and meet many other patients and caregivers in person.
- You can join a local effort
 - o Let your care team know about the MM Fighter and how it benefits patients and caregivers.
 - o Join Defeat Myeloma, a fundraiser that supports MM research at the Fred Hutch. www.defeatmyeloma.org.

More information on these activities will follow!

Patient Roundtable

On a somber note, MM Fighter Sean Donalty passed away last month after complications following a Bispecific treatment. Sean had been fighting his high risk

disease, and while the treatment was initially effective, complications proved to be too much for him. His sister and family were by his side at the end.

Sarah, an MM Fighter for many years, was diagnosed with MM at the age of 22! She is still going strong, and gave us a brief presentation of her journey to found and run the Defeat Myeloma fund raiser.

Shawn M. joined for the first time to report that her husband is 6 months out from his Stem Cell Transplant and doing well.

Linda M. was able to wean off of her pain medications and although there is still a struggle with some pain, she is feeling better than she has in a long time. She also reports that all the numbers from her labs were “between the goal posts”!

Connie C. is going to be starting IVIG soon and was worrying about side effects. A couple of members were able to share their experiences with this infusion, which normally goes pretty smoothly. However, there are several medications that are given in conjunction with the IVIG that sometimes do cause side effects. (Please see the note on Beer’s list below.) Hopefully all will go well.

Mary R. made it to CO to help her daughter with her wedding dress shopping in preparation for the upcoming nuptials...a wonderful time for all, and a perfect dress was found! Mary is yet to begin maintenance treatments..

Mary also brought Beer’s list to the group’s attention, a list of drug interactions and potential side effects that patients should be aware of. This information can be found at www.pharmacyquality.com.

Also, we have an updated list of MM related terms and definitions posted on our website under Resources. This is especially helpful for newly diagnosed patients to help them get quickly up to speed on commonly used expressions they will hear during presentations and from their care team.

Please see Barb’s presentation for more information on the Survivorship clinic at Fred Hutch. There is a lot of support available that is not commonly known by many patients.

Jan G. is doing pretty well, and is currently on a chemo break as he prepare to have his stem cells harvested for an upcoming SCT. There are still a few challenges that may delay this process a bit, but overall things are looking good.

Ferid M. is doing well with his treatments and feeling good, and is in the midst of deciding whether to go with the SCT....feeling pretty sure this will be his path, but still considering options. His daughters Amna and Adna want to thank the many people who wrote to them regarding their own decisions around SCT.

Karen B. returned safely to Alaska after her SCT transplant at the Fred Hutch, and is feeling good as well, and she is even walking for up to an hour a day. A bone marrow biopsy is coming up soon, and she is hoping for great results. Karen is also pleased to announce that Spring will be coming to the chilly north, with temperatures already in the 20s and 30s.

Matt S. was diagnosed in October and in the hospital in November, but doing much better now, as he is engaged in a lot of walking and biking. He has light chain disease, which presents its own sets of challenges, but is expecting very good things from the Bone Marrow Biopsy that is coming up next month.

Laurie C. is looking forward to her 50th wedding anniversary that will soon be here! Congratulations on the great milestone!

Sherry B. was able to join the group again after several months of challenges. She was in the hospital twice late last year and spent 2 months recovering, and then Scott went in for knee surgery and had to quickly have a second one as the surgeon made an error selecting the apparatus that he used. Fortunately, he is also doing well! Sherry is also pleased that she can finally eat spaghetti sauce again!

Next MM Fighters! Meetings:

Caregivers Meeting – Saturday, April 6th – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

Living Alone With Myeloma – Saturday, April 6th – 9 AM – Contact heidolsen6308@gmail.com for more information – **Virtual Meeting**

Support Group Meeting – Saturday, April 6th – MGUS and Smoldering MM – Dr. Mary Kwok – UW/FHCC – 10AM – 12:30 PM – **HYBRID Meeting**