# MM Fighters! Support Group Meeting March 25th, 2023 Virtual Meeting

**Dr. Banerjee** from the UW/FHCC returned to our group to continue his series on improving the Patient Experience with **Part 2 – Why Are There So Many Pills?** Dr. Benerjee has his focus squarely on how to help patients deal with the challenges that Myeloma as well as the related treatments throw our way. In his presentation, Dr. Banerjee reviewed avoiding infections, blood clot prevention and our old nemesis, Dex. He then spent a great length of time answering questions on all sorts of Myeloma related topics.

Please view the video link below or the look at the slides (attached to the email):

#### **Video Link:**

https://drive.google.com/file/d/1DqsAlZ6J1B088nvr3JLQvlWN NSXH9fa/view?usp=share link

# Thought for the Month

Everything negative – pressure, challenges – is all an opportunity for me to rise.

Sometimes, especially when one realizes that your Myeloma is relapsing, each of us needs a reminder like the above to kick us back into gear. This helps me to focus on the positive and keep my mind on the goal...staying around to celebrate the discovery of a cure!

During these last days of Myeloma Month, there are some simple ways to help bring awareness to our disease!

### **Defeat Myeloma**

This fundraiser for the Fred Hutch's Myeloma research will take place on Sunday, June 25<sup>th</sup> at Magnuson Park in Seattle. Donations to this cause help fund grassroots research, making it possible to prove concepts and attract larger grants to fund clinical trials.

- Sign up or donate at <u>www.defeatmyeloma.org!</u>
- Support the IMF (International Myeloma Foundation) Health Tree, the LLS (Leukemia and Lymphoma Society, the MMRF (Multiple Myeloma Research Foundation) or the other worthy organizations that are helping lead the fight against Myeloma!

## **Patient Roundtable**

Suzanne P. from that chilly country to the north is not feeling great but is still hanging on. Her second stem cell transplant lasted longer than her first, and wants to encourage everyone facing challenges to just keep up the fight....

Michele M. is doing well and has found that acupuncture has helped her with her struggles with neuropathy. Others have found that this procedure does make a difference, and it is offered at both Swedish and the FHCC. Just make sure that your acupuncturist has experience dealing with cancer patients!

Chris B. has found that his Venetoclax/Velcade combination has lost a good bit of its efficacy, and now is examining treatment options. Car-T and Bispecifics are both possibilities.

Andrea D. said that Sean has been having nausea issues since his stem cell transplant but working with the doctors to overcome this. Getting a new PET scan to check on progress...

Car-T updates: Annie T. is 3 months post Car-T infusion and getting energy back, slowly expanding her activities and starting PT. Still dealing with gut challenges from before the therapy, hoping a gastroenterologist will be able to find a solution. Also needs to be re-vaccinated (again!) which will start in a month.

Jon J. left the hospital after the initial week+ required stay and doing quite well. No real challenges after his infusion of Car-T cells, but the treatment team jumped on any sign of side effects very quickly.

Dorothy H. is doing well after her treatment for bile duct cancer. CT scan shows that the tumors have not returned, but now suffering a bit after getting 9 vaccinations at once!

Bud H. is back on his Regn5848 clinical trial after a few set backs, and his bone marrow cancer burden has fallen from 90+% to 34%! His is also looking forward to having his jaw reconstructed after his struggles with ONJ (osteonecrosis of the Jaw). He and his wife are also back participating in shooting competitions.

Tim R. reports that Ellen is doing well on Dara and remains in remission, and her Parkison treatments are also proving effective.

Cheryl V. is doing well and hiking monthly with Team Survivors NW. She is also looking forward to being a volunteer hiking guide!

Brenda C. attended a great seminar on World Cancer Day that even featured Dr. Cowan! She thanked the leader of the group (focusing on black women who have breast cancer) and during the discussion, volunteered to give a brief talk to that group about Myeloma. She ended up having a great time and learning even more about MM! Our Myeloma Action Month Poster Lady!

**Next MM Fighters! Meetings:** 

**Caregivers Meeting** – **Saturday, April 1**<sup>st</sup> – **10 – 11:30 AM** Contact mmfighters.caregivers@gmail.com for more information – Virtual Meeting

**Local In-Person Seminar – IMF** (International Myeloma Foundation) **Family Workshop – Saturday, April 22** – 8:30 AM – 3:30 PM - Daybreak Star Indian Cultural Center 5011 Bernie Whitebear Way, Seattle

NEXT VIRTUAL MEETING – Saturday, May 20th – Myeloma 101 All Questions Myeloma – Dr. Sarah Lee – UW/FHCC– 10AM – 12:30 PM – Virtual Meeting