MM Fighters! Support Group Meeting February 24,2024 Virtual Meeting

The group's first virtual meeting of the year was held this past weekend, and over 50 patients and caregivers joined us to listen to Dr. Rahul Banerjee review his selection of the Best of ASH (Association of American Hematologists). Splitting his presentation between the best options for patients that have been recently diagnosed and the latest developments in the Immunotherapy arena (CarT and Bispecifics), Dr. Banerjee covered a lot of ground.

For those of you who would like to watch his presentation, or perhaps rewatch it to review some of his points, the video link to his detailed discussion, along with the following Q&A, can be found at the bottom of the accompanying email.

Thought for the Month

Lead from the heart, not the head.

This should be a guiding thought as we enter March, which is Multiple Myeloma Month. With a number of organizations pushing awareness of MM, this is a great opportunity for each of us to help spread awareness of this disease, and for each of us to do our part to help work towards a cure.

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:
 - Visit the IMF's effort at <u>www.myelomaactionmonth.org</u> 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 (location to be determined) to learn more about MM and meet many other patients and caregivers in person.
- You can join a local effort
 - Let your care team know about the MM Fighter and how it benefits patients and caregivers.
 - 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

IF anyone is near the SLU House, one MM Fighter, Sean Donalty, is at the UW undergoing his introduction to bispecific therapy (Teclistamab). His wife Andrea would love a call or a visit. You can find their contact information in the MM Fighters roster.

Yolanda has had challenges trying to get her childhood vaccinations redone, as is required after Stem Cell Transplants. Many PCPs do not realize this, and smaller clinics seem to no longer carry vaccinations. Several MM Fighters had good suggestions on how to proceed, and we hope that this problem is solved quickly.

- You can call the Long Term Follow Up number at the Hutch for a suggested schedule of vaccinations.
- If you are having such troubles, speak with your Myeloma expert for guidance and support.

IVIG (intravenous IGG) is often required for severely immunocompromised patients after CarT and Bispecific treatments. However, guidelines regarding how these infusions impact other treatments are sometimes overlooked. Be sure to ask your care team for guidelines regarding how this infusion impacts your other upcoming treatments. Remember...there is no such thing as a dumb question!

Ferid's is thinking about the pros and cons of undergoing a Stem Cell Transplant, and Amna, his daughter/caregiver, is asking the group for their experiences surrounding this procedure. She would love to know the important questions you asked your care team and the transplant team, and as well as factors that helped you make the decision to undergo, postpone or refuse a SCT.

Else is doing well 1 year post transplant and is looking forward to becoming much more active once she receives her vaccinations.

Nigel is 120 days post SCT and enjoying life to its fullest with touch rugby, cycling and hopefully, soccer.

Edna attended her second meeting and is learning loads. She also wanted the group to know about her dance/movement based program to help older patients be healthy and active in a safe manner. She has been developing this program (The Art of Breathing and Healthy Movements) for over 45 years and is working with the UW and South Seattle Community College. For more information regarding free Zoom classes please contact Edna at ewajocentre@gmail.com.

Susie, the leader of the Tri-Cities MM Support Group, is still going strong. They meet monthly and are still building a stable patient base. They are looking forward to trying something new for their extended Defeat Myeloma event this year!

Michele just had a bone marrow biopsy and is hoping this one tells her she reached MRD-! Fingers crossed!!!

Ken is as healthy as ever and recently returned from a trip down under to New Zealand and Australia.

Eric is experiencing no challenges on his monthly Dara and looking forward to his upcoming retirement! He has great plans for RV travel and even has his care team's blessing to miss a treatment during a prolonged excursion.

Denny, splitting his time between Tucson and Seattle, has been proceeding well under the care of the VA.

Laurie has reached 11 years of being treated on Dara! This drug has done a wonderful job for many patients!

Next MM Fighters! Meetings:

Caregivers Meeting – **Saturday, March 2**nd – **10 – 11:30 AM** Contact <u>mmfighters.caregivers@gmail.com</u> for more information – Virtual Meeting

Living Alone With Myeloma – Saturday, March 2nd – 9 AM – Contact <u>heidiolsen6308@gmail.com</u> for more information – Virtual Meeting

Support Group Meeting – **Saturday, March 16**th – **Survivorship** – **Barbara Regis** – **UW/FHCC**– 10AM – 12:30 PM – Virtual Meeting