

MM Fighters! Support Group Meeting
March 27, 2021
Virtual Meeting

A good turnout this month to learn about MRD (Minimum Residual Disease, or Measureable Residual Disease) from **Mark Schliekelmann** of Adaptive Biotechnologies, the first company to have their **MRD** tests approved for broad use by oncologists, hematologists, hospitals and clinics in the US.

We do need to thank the IMF (International Myeloma Foundation) for allowing us to use their Zoom app for our support group meetings. The IMF recently made the change to Zoom, and thanks to their training for Mari and I, the meeting went off without a hitch (well....more or less!).

Thought For The Month

Remember to always keep a positive attitude, which helps both yourself and your caregiver, in order to shine even brighter....

Nothing can dim the light that shines from within.

Speaker

Mark Schliekelman, Oncology Medical Science Liaison at Adaptive Biotechnologies (a Seattle based firm!) educated us the variety of MRD tests, as well as how these tests can help both patient and physicians.

MRD testing covers several more sensitive tests than those commonly employed to detect levels of myeloma in a patient, being able to identify one myeloma cell out of 10,000 (or up to 1 in 1,000,000, depending on the test that is being used). Unfortunately, there is no standard set for these tests yet, but hopefully the FDA will establish more guidelines soon.

Effectively used in a few other cancers, MRD testing is still in its infancy in myeloma. While a MRD negative test (no cancer cells found in 1,000,000) shows a very deep remission (great news!), doctors are not 100% positive how to best apply the test result. It does show the depth of remission, but does not tell you anything about the length of remission, so repeated tests over time are required to track the progress of the disease. But as the test becomes more commonly employed in clinical trials and by oncologists and hematologists, better guidelines will be created.

Adaptive's MRD test is based on Next Generation Sequencing (molecular or DNA assessment), and it helps determine the myeloma burden you are faced with as well as the types plasma mutations (17p-, 11:14, etc.) that you have. This test is carried out from the results of a bone marrow biopsy.

While Adaptive is also working on a test for myeloma that can be done from the results of a blood draw, this is currently not possible due to the nature of our disease. Myeloma tends to be found mainly in the bone marrow, and there is no known consistent correlation between the amount of myeloma in your blood and that found in your marrow.

Unfortunately, as Adaptive's test focuses on a narrow band of DNA, it can not be used to help determine if other members of your family be pre-disposed to developing myeloma.

Mark's presentation is attached to today's email, along with several handouts (in pdf format) from Adaptive Biotechnologies. I think that you will find the MRD Fact Sheet and the Adaptive Assist Brochure to be helpful.

Patient Roundtable

Some great news was announced on Friday – the first CAR-T cell (chimeric antigen receptor T-cell) therapy for multiple myeloma was approved by the FDA! Abecma, or ide-cel, is a product from Bristol Myers Squibb and bluebird bio, inc. A variety of CAR-Ts are in clinical trials, and most have shown great promise over a period of 1-2 years for patients that have become refractory to at least 4 myeloma treatments. While there is still work that needs to be done in order to extend the effectiveness of these treatments, having the FDA approve a CAR-T cell therapy is a huge step forward!

Several members of the Stem Cell Transplant team checked in, and despite a variety of challenges, all were doing well. Erica, almost three weeks into her treatment, was in very good spirits and walking 2-3 miles a day – quite impressive for any of us that have gone through a transplant! If others are considering a stem cell transplant, or are preparing to undergo such a procedure, and would like to gain some first hand knowledge of what to expect, as well as become part of an extremely supportive group of patients, please drop me a line and I will make introductions.

The group discussed if they were changing their behavior now that they had received the COVID vaccines. While understandably pleased, most were continuing their same cautious behavior (masks, social distancing, hand washing) but perhaps venturing out more. As many doctors and experts recommend, this is the correct behavior until herd immunity (between 70-80% of the population is inoculated) is reached. It is certainly not easy, but as we have lasted this long, we can all hold on a bit longer!

For those who have run into intestinal challenges while taking Revlimid or other chemo drugs, a couple of patients recommended Heather's Tummy Fiber, which is an organic prebiotic Acacia Senegal fiber (and tasteless!). (Prebiotics are "food" for the healthy bacteria in your lower gut.) If you want to start taking this, be sure to

mention it to your oncologist, just as you should do with any new supplement or medication, so that they are aware of any potential complications that may arise.

A member had started taking Carfilzomib and had experienced some chills after his infusion. Cheryl's oncologist suggested trying Tylenol and Pepcid A/C before the infusion, as this seems to help lower and/or eliminate the chills. Other patients also found that this had been effective.

Next MM Fighters! Meeting:

To important meetings coming up!

NOTE DATE CHANGE!! Saturday, May 1st, 2021 – 10AM – Noon – Dr. William Bensinger, Swedish, Best of ASH (American Society of Hematologists) VIRTUAL MEETING (We will be using Zoom – details to follow)

Saturday, May 22nd, 2021 – 10AM – Noon Dr. Damian Green, UW/SCCA?Fred Hutch, CAR-T cels and Immunotherapy – Virtual Meeting

Sunday, June 27th 2021, Defeat Myeloma Virtual Walk Run – fundraiser to support myeloma research at Fred Hutch.

October 9th, 2021 – IMF Regional Workshop for Washington State – details will follow!