

MM Fighters! Support Group Meeting
June 26, 2021
Virtual Meeting

Josh Epworth from the **SCCA** was our presenter this month, helping us to better understand why certain tests for Multiple Myeloma are used and what the differences are between these tests. In his role as a PA for Dr. Libby, Josh has developed the ability to explain complex ideas in an easy to understand manner, and the members came away with a much clearer understanding of why Myeloma patients undergo such a battery of tests.

Thought For The Month

In the past few months, three active members of the MM Fighters – Dennis Bock, Bill Matson and Ed Moore, passed away. In their honor we had a few moments of silence to remember these gentlemen and to better understand the saying

The best thing to hold onto in life is each other.

Fortunately, members passing does not happen often within our group, but it is important to remember those who have helped pave the way for each of us. All three were active during our in person meetings, and touched many of our lives. Remember – don't live in fear, but celebrate the lives of these members, as well as what they brought to our group and others during their journey.

Speaker

Josh Epworth's presentation focused on the tests that Myeloma patients routinely undergo, splitting them in to 4 groups – Blood tests, Urine Tests, Imaging and Bone Marrow tests.

BLOOD

Josh listed the various blood tests that are commonly seen, and provided a brief explanation of each:

CBC – helps determine the correct levels of treatment by monitoring the blood counts – count are rising (myeloma usually diminishing) or counts are falling (myeloma returning).

BMP – watch the Creatinine levels, this also helps determine the level of treatment (to ease the strain on the Kidneys).

Liver – These two tests are the same, and give a picture of how the liver is operating and filtering certain impurities out of the blood. Also helps indicate if there is damage to the kidney.

SPEP – monitors Gama and abnormal proteins – indicates level of M Spike.

SFLC – Watches Free Light Chains and whether they are binding to Heavy Light Chains.

URINE

24HOUR TEST – A pain for many, but is able to identify the different types of proteins that are excreted into the bloodstream and then into the kidneys, including Bence-Jones.

IMAGING

A great summary of the different imaging tests doctors can order, and what they do well, and not so well. These tests help monitor bone damage, presence, proliferation and activity of Myeloma.

X-RAYS – Good for getting a view of larger lesions and fractures, but misses many of the smaller masses and bone problems.

MRI – Very good at finding small masses and determining the difference between Smoldering MM and Active MM. However, can not determine level of activity of the Myeloma.

PET/CT – One of the best tests to determine the levels of MM. Effective at detecting the location of disease as well as the activity levels, and can even differentiate between arthritis and MM activity.

HS (WBLDCT – Whole Body Low Dose CT) Newest scan for Myeloma, devised at Mayo Clinic for covering the whole body, uses CT equipment, so good for those locations without PET access. Does not require contrast, so easier on kidneys. However, needs special training for the staff, and is not as sensitive as PET.

MARROW – Looks at two parts of the bone marrow

- Aspirate – the fluid interior, where MM activity usually occurs
- Marrow – core sample and bone (outside of bone – what cells are present, their behavior)

Examines 4 levels of sedation for BMB

Hematopathy – counting of the abnormal cells (% of abnormal cells) – helps determine the baseline of the disease.

Flow Cytometry – collected cells are stained and passed individually through a light. How the stained cell responds determines what types of cells they are. Usually used after treatment or transplant to determine level of disease in marrow.

Cytogenetics – helps discover the type of disease – high risk usually seen as having 17p-, 1q, 4:14, 14:16, 14:20...

Next Generation Sequencing – uses the unique DNA sequence (not complete DNA sequence, but specific portions found to indicate MM) of your MM to determine the level of presence. This specific region is called the CDR3.

There is a lot of discussion regarding MRD (using NGS and FC above) but little clear idea what the results mean, and how this can guide treatment. One doctor states that it is best not to give any test unless there is a plan on how to use the results. This is difficult with MRD testing, as a MRD- result does not necessarily mean a long remission (such as with some Car-T cell patients), and a MRD+ test does not necessarily indicate the disease coming back quickly. There is still a lot to learn, but these tests are being used in many clinical trials, and follow up can definitely provide answers going forward.

All these tests are used to give the doctors and patients a picture of the diagnosis, treatment and durability of the response.

Josh's slides are attached to the email.

Patient Roundtable

Questions for Josh:

Bone Marrow Biopsies will always look somewhat different as our Myeloma is always mutating (it is very unstable).

It is rare, but one can have a M Spike but still be MRD-...

Maintenance is defined as the decrease in frequency or dose level of your medication, or the elimination of one or more medication (if taking a triplet).

Is having IGG Lambda worse than IGG Kappa disease? This statement is based on a 10 year old article, and many things have changed since then. However, this could

have been due to something associated with the Lambda. Amliodosis is also more often associated with IGG Lambda disease. More studies will help resolve this issue.

Josh also covered many questions regarding the upcoming retirement of Dr. Libby. His current patients will be assigned to different myeloma experts, but this does not mean that you are “stuck” there. If you find that your assigned oncologist does not work for you, you may request a change.

Josh will also be heading up the Maintenance and Monitoring Team. This group will cover patients for Dr. Lee and Kwok who are in maintenance - the monitoring cycle will be 3-4 consecutive appointments with Josh, then one with the Myeloma expert: repeat. If you have questions, please reach out to Josh.

Lots of positive news from our members this month!

- Connie has not been on maintenance for 11 years! Had one relapse, but is going strong!
- Sharon has been on maintenance for 3 yrs, and has just determined the time in now to stop her maintenance!
- Other members are being able to drop Dex from their maintenance doses!
- Cheryl has very high anti-body counts after her 2 Covid vaccines, which is great news after hearing that a couple of others had less stellar results. Hope for all of us, especially once a third dose for immune compromised patients is approved.
- Several recent transplant patients have bounced back from challenges and are going strong, walking, biking and travelling!
- Others are taking advantage of their good health to plan vacations, both locally and internationally. Life is slowly returning to normal...but still be cautious! The Delta variant is proving to be quite nasty, even to those with vaccines.

A recent member, David, will be heading to transplant around January. He also suggested two books for patients by Dr. Jerome Groopman – “How Doctors Think” and “Your Medical Mind”

Jaw necrosis popped up as a concern. The SCCA has a dentist on staff for consultation and treatments, and Dr. Alice Chen from Inspired Dentistry in Renton, formerly at the SCCA, was recommended as another option.

Team Survivors is an organization for women cancer patients/survivors that offers many online and in-person physical activities, such as hiking, yoga, and more. Great reviews, and a fantastic option to help stay active, especially since the YMCA LiveStrong program is not active currently.

One suggestion for newer patients. Some have dropped out of a meeting as they feel that the information was not suitable, or was too difficult to understand. We have all been in this situation before. However, repeated exposure to information is the

easiest way to absorb and understand it. Stay with the program, then read the notes and review the slides the following week. If you still have questions, bring them up at the next Patient Roundtable, or head to the following sites where lots of easy to understand information can be found:

- MM Fighters Website (www.mmfighters.com) – Look under Resources
- The IMF (www.myeloma-org)
- The LLS (Leukemia and Lymphoma Society) – www.lls.org
- Health Tree (Myeloma Crowd) – www-myelomacrowd.org

Next MM Fighters! Meeting:

Saturday, August 28th, 2021 – 10 AM – Non – Tony and Sibel Blau – What does the progress in Covid-19 pandemic mean for Multiple Myeloma patients? – Virtual Meeting

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