

# **MM Fighters! Support Group Meeting**

## **July 25, 2020**

### **Virtual Meeting**

The MM Fighters first July meeting in some time was well attended, with members from as far as Colorado joining us this month. Amazing how our ability to assist others can be amplified during this time of so many challenges! Again, we thank the IMF for their generosity in making the GoToMeeting app available for our use.

#### **Thoughts For The Month**

Some thoughts to help all of us gain the right perspective during these trying times...

- Life is like riding a bicycle. To keep your balance, you must keep moving.
- You can't go back and change the beginning, but you can start where you are and change the ending.

#### **Speakers**

**Josh Epworth**, Dr. Libby's PA at the SCCA, was our speaker this month, covering **Multiple Myeloma By The Numbers**, a look at the most common blood tests that Multiple Myeloma patients run into and what they can tell us.

Josh started off with some general guidance to help patients gain a firm footing when comparing lab results:

- Be sure to look at the units of each test, as these can vary between facilities.
- Understand YOUR normal, not what is normal for healthy people.
- Understand the trend of your labs over time. Do not worry over one lab result.
- The three most important organs for cancer patients:
  - o Heart – moves the medication around the body
  - o Liver – turns on the medication
  - o Kidneys – extracts medication from your body
- The ANC (Absolute Neutrophil Count) is the key to understanding if your body is well prepared to fight against infection. Neutrophils are the most common type of white blood cell and are utilized against bacteria.
- Doctors usually ask for MM specific blood test once a month (at the most) as this provides the most up to date information, not archival information.

Josh also shared some key takeaways regarding common tests associated with MM:

#### **Serum Free Light Chains**

- Remember it is the ratio between Kappa and Lambda that is key. One will increase, the other decrease, depending upon your disease.

- If both increase, it could be a sign of kidney problems not being able to excrete the light chains.

#### Immunoglobulins

- There are 5 types of immunoglobulins, with G usually being the most important for MM.
- In most cases these are not used for diagnosis or to measure response.

#### Serum Protein Electrophoresis (SPEP) or M Spike

- Be careful...this test is often labeled differently at different institutions.

Attached to this email is a pdf copy of Josh's presentation. Please refer to this for more details.

A few members also sent in questions for Josh, and the questions and his responses follow:

- What are your thoughts on MRD tests and how do you think the results could help MM patients?

MRD testing is a very useful tool for a pair of reasons:

1. If a patient has been on maintenance for 2-3 years and achieved and remains in a stringent complete remission at the end of that period then MRD negativity could be used to determine if a reduction or discontinuation of maintenance is warranted.
2. It is also a very useful tool for determining the response of a study medication/regimen. With a study we want to know if an approach is successful we also want to know *how* successful it is. One approach is to determine the median PFS. This can take years. MRD negativity can act as a proxy for PFS.

- Some patients do their best to avoid all sugar and alcohol. How do these, in moderation, impact our tests, or more importantly, our health?

1. A good diet is always a benefit for anyone regardless of whether they have cancer or not. There is a feeling, that has been around for years, that because cancer feeds off of sugar that to reduce sugar intake will "starve" the cancer. There is little randomized control study evidence that this is true. Please bear in mind that the body converts all food into sugar (glucose). I have seen some anecdotal episodes that support a control of sugar and alcohol to improve issues with peripheral neuropathy, but again, this has not been widely studied. Overall a healthy diet will produce a healthy body that can better tolerate the burdens of chemotherapy and transplant.

- What tests should be conducted if a patient only has Free Light Chains, but no M Spike? Twice a year PET CT's or bone marrow biopsies?

1. A patient with a free light chain only disease (meaning she has, for example, an elevated Kappa free light chain and a suppressed Lambda free light chains but no M-spike) would need, in theory, monthly free light chains (SFLC – serum free

- light chains) but no serum protein electrophoresis (SPEP – also called M-spike) tests. That said, many providers still test for both SPEP and SFLC because they do not want to miss if the patient *start* generating an M-spike (although this is pretty rare).
2. For an oligosecretory (where the low level of markers in the blood are not reflective of the level of disease in marrow) or non-secretory (no markers in blood) twice per year imaging with leapfrogging PET CT then 6 months later a BM MRI and then 6 months later another PET CT and so on is a very good approach for monitoring the disease. A lot of providers like the leapfrog approach of imaging (PET then MRI) because it minimizes the exposure to radiation that occurs with a PET.

## **Patient Roundtable**

There were more discussions regarding Darzalex, comparing the newly released injections with the IV, which was released earlier.

- Questions were asked about the comparative effectiveness of each. The clinical trials seemed to indicate that the injection was perhaps a bit more effective than the IV, but remember, each patient reacts to drugs differently, so your results may vary.
- More patients in Seattle are starting to use the Darzalex Fastpro (injection) with good results. There are a couple of patients that have experienced severe headaches after getting the injection, but up until now no other side effects have been reported.
- Speaking to MM patients at a leading facility in Utah, they have yet to start receiving the Darzalex Fastpro. Another example of how truly fortunate we are to be in Seattle, where the SCCA and Swedish have such strong relationships with pharmaceutical firms and are on the leading edge of Multiple Myeloma treatment!

Grocery shopping during the COVID 19 troubles was also a popular topic. Some hints from members included:

- Many grocery stores are offering home delivery or hands off pick up/curbside pick up.
- Many ask for tips for those delivering the groceries, but Safeway's delivery is no charge if you provide them with a 4 hour delivery window.
- Myers has no extra charge for curbside pick up.
- Most of these stores also keep a record of your prior orders, making it easier for you to select commonly ordered items.

The 7<sup>th</sup> Defeat Myeloma Fundraiser was held (virtually) last month, and in two weeks MM Fighters raised/donated close to \$5,000! Thanks to all those who contributed, as well as to Mimi and Judy who offered their fine handicrafts (a scarf and a quilt) as raffle prizes!

### **A More Somber Note**

Harold Alsop, a member since 2009, passed away on July 25th. He had been facing several health challenges.

### **Next **MM Fighters!** Meeting:**

**Saturday, August 22<sup>nd</sup>, 2020 – 10AM – Noon – Dr. Sibel Blau, Northwest Medical Specialities, Oncologist and Caregiver – “The Essence of Being the Invisible Half – Challenges of Being a Caregiver” VIRTUAL MEETING**