

**MM Fighters! Support Group Meeting**  
**February 27, 2021**  
**Virtual Meeting**

Despite a last minute glitch caused by Dr. Bensinger's emergency operation (a back problem caused by a fall – he is doing well and recovering slowly), **Ami Batchelder**, Dr. Bensinger's PA, stepped into the breach! Thank you, Ami! Dr. Bensinger, once he has recovered, will present his "Best of ASH" to the group (see announcement below – **NOTE NEW DATE!!**).

We also need to thank the IMF (International Myeloma Foundation) for allowing us to use their GoToMeeting app for our virtual meetings! **Please note** that the IMF is switching to using the **ZOOM app** for all their meetings, so starting in March, our meeting will take place on ZOOM. More information will be sent out shortly.

**Thought For The Month**

A great thought for both our lives and our treatment is

**Those who don't believe in magic will never find it.**

You can never tell what will happen, so keep that positive mental attitude!

**Speaker**

**Ami Batchelder, PA at Swedish**, helped educate us on "How to Prepare for Your Appointments in a Changing World".

With the changes that Covid has brought to the world at large, Amy feels that the world will not go back to the way it was, so virtual meetings with doctors will continue to be available and a popular option. Benefits of virtual meetings include

- helping people with hearing challenges,
- enabling the doctors see more patients,
- allowing family members who are far away to join meetings,
- avoiding travel and expenses for patients

Prepare for each meeting with a focus of what your situation is/what you want to know. Keep your list of questions to manageable levels – 20 questions will never be answered in one appointment. Concentrate on the most important details for right now - what's my future plan, what stage am I, lab questions, a new diagnosis, etc.

For bone marrow transplants, both Melphalan and BEAM have been around for many years, and have been used by different doctors for different reasons during this time. BEAM is a cocktail of drugs, and is more toxic than Melphalan, and therefore requires hospitalization during the procedure.

Interestingly, there has never been a study regarding which is more effective. Therefore, Dr. Bensinger and Swedish Hospital are conducting a clinical trial of 100 patients to determine if there is a difference in these two treatments.

Many people are concerned regarding what information from your other doctors you should share with your oncologists. Ami suggests that any time you have a new diagnosis, or start on new medications or supplements, this information would be of interest to your oncologists.

For those who would like to contact Ami with questions, her email address is [ami.batchelder@swedish.org](mailto:ami.batchelder@swedish.org).

Ami's presentation is attached to today's email.

### **Patient Roundtable**

Several members have undergone a stem cell transplant recently, are in the midst of one, or are planning on undergoing a transplant soon. To provide support as well as exchange experiences and suggestions, these members have formed a Transplant Team! If any other members have a transplant in your future, or would like to support these members as they tackle this challenge, please let me know and I will put you in touch with them. They are having a virtual get together this Saturday.

People also asked if there was an age limit on stem cell transplants. This seems to be a moving target, based on the health of a patient, their response to treatment and the doctor's opinion/experiences. While the mid-70's was seen as an upper limit 5 years ago, that is no longer the case.

Bob told us of his trials and tribulations with back pain, and how, after many discussions and several false starts, he believes that he is on the right track. Bob is in CA these days, and it is great to learn that he has found a top notch cancer center there in City of Hope. It is great to know there are so many wonderful treatment centers spread out across the US.

Bill discussed some sobering news on Saturday. As he has gone through all the available myeloma treatments, and is not able to participate in clinical trials, he has decided to stop treatments and start undergoing palliative care. With his aim focused on quality of life, this choice, while disturbing for his friends, dovetails with his desires.

But on a bright note, two days after the meeting, a new Myeloma drug, Pepaxto (melflufen) was approved by the FDA. Remember to keep a positive outlook on things, as you never know what will happen next!

Chris has started acupuncture to battle his neuropathy, and had some positive things to relate regarding his experiences. The acupuncturist also encouraged acupressure, or stimulating massage, as another tool to overcome, or at least relieve some of the symptoms of neuropathy. Several members enthusiastically endorsed massage, as well as reflexology, in addition to acupuncture, as beneficial in their efforts to overcome the effects of neuropathy. As with all treatments, remember that the outcomes are best if started early!

An email with information on acupuncture will be sent out later this week, including what the scope of their practice is in WA, acupuncturists that have experience with cancer patients, as well as helpful questions to ask your acupuncturist to make sure they are familiar with the challenges faced by cancer patients.

One patient mentioned that they were considering a port to use when drawing blood for labs, having infusions, etc., but were concerned regarding the procedure. Several members who had opted for ports were more than pleased with their decisions. Despite receiving a larger dressing each time, the advantages of avoiding numerous pokes at a vein, faster blood draws and a simple procedure to install the port (30 minute with local anesthesia (or something stronger if you want)) are great benefits over the long run. A drawing of a port as well as an image after the operation are attached to today's email.

**Next MM Fighters! Meeting:**

A lot is going on in the next several months!

**Saturday, March 27<sup>th</sup>, 2021 – 10AM – Noon – Michael Schliekelmann (Adaptive Biotechnologies), MRD VIRTUAL MEETING (We will be switching to Zoom for future meetings – details to follow)**

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

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

**October 9<sup>th</sup>, 2021 – IMF Regional Workshop for Washington State** – details will follow!