

**MM Fighters! Support Group Meeting**  
**January 22, 2022**  
**Virtual Meeting**

We had an “overflow” crowd for the first meeting of the year, making it one of our best attended since Covid came along. It was great to see so many members, both veteran and new, and to be able to catch up on the past two months since our last meeting.

**Thought For The Month**

**When one door closes, another opens; but we often look so long and so regretfully upon the closed door that we do not see the one that has opened for us.**

**Speaker**

**Josh Epworth**, PA at the **SCCA**, spoke to us on Care and Coordination in Myeloma care, reviewing the advantages of improved coordination in care as well as what some of the challenges are that both institutions and patients face.

Some of the more common obstacles that patients face include

- insurance, especially at the beginning of treatment
- affording care – (fortunately there are many resources to assist)
- Mistrust created by miscommunication
- Multiple providers
- Language
- Coordination with facilities
- Staffing

After reviewing the assets to coordinated care, which are many, Josh reviewed many of the barriers as well as potential solutions to these problems, most of which could be addressed by correcting inadequate resources or ineffective teams.

Josh then introduced three co-presenters, key members of the SCCA patient support network

•**Chloe Siu**, PharmD, BCPS, BCOP: Hematology/Oncology Clinical Pharmacist

•**Sophia Khim**: Support Staff Supervisor | Team Coordinators: Hematology/Heme Malignancies

•**Patrick Evans**, BSN, RN: Nurse Manager Hematology/HemeMalig

With this all-star line up, Josh asked for questions and concerns that patients and caregivers might have about care and coordination, including challenges that they might have faced in recent months at SCCA. These were mostly handled off line so that the discussions could be free flowing, but a couple of interesting topics included:

**M4 clinic** – Josh explained more about the M4 clinic, how 3 PAs will be seeing patients that are currently in remission, freeing up the oncologists to see and treat those patients that are more at risk from active Myeloma. Every patient will still see their oncologist every few months, and once their remission ends, they will go back to being treated full time by their oncologist.

There are currently approximately 110 patients in the M4 clinic. While none are currently Smoldering MM patients, there is a strong possibility that SMM patients will also be included in the M4 clinic.

Also, when M4 patients have questions regarding treatments, etc. they should refer these to their oncologist, as they are still watching over their patients.

**Phone Tree** – this is simply the number that patients call to reach their oncologists, and the system gives them a list of the oncologists and their extensions (for Dr. Cowan, please press 1, for Dr. Kwok, please press 2, etc.).

**MyChart** – One patient suggested that as the support teams have yet to see the screens that the patients are looking at, that their training should include this so that they are better prepared to understand what patients are experiencing.

**Infusion Wait Time** – One patient shared her frustrations with the long wait time for medications to be ordered during infusions, sometimes resulting in 2 hour waits (such as for Carfilzomib). Chloe went through the process that the each drug order must go through, which can be even longer on extremely busy days or at peak times for treatments. The cost of these drugs, as well as the possibility that a patient might not be able to be treated that day prevents the pharmacist from preparing these infusions beforehand.

In addition, redoing blood pressure, temperature, etc. is standard operating procedure before infusions, even if you had just seen your oncologist and had your vitals taken. This is because patients can experience sudden changes, and the nurses want to protect the patients in case they have had a sudden setback.

**Incorrect Procedure** – One member discovered that she had been scheduled for a procedure that she had no idea was needed. Shortly before the scheduled date she reached out to her provider for confirmation and discovered that this was not something that he had ordered. She expressed her concern regarding how something like this had been scheduled, and how this could have been overlooked

by so many. Josh and Patrick both expressed their great surprise that this could occur, and said that they would track down the cause in order to eliminate a repeat.

**Bone Marrow Biopsy (BMB)**– Another member had a concern about communication before BMB, as well as the ability for patients to feel comfortable during the procedure. There has been a change in the offerings regarding levels of sedation during a BMB, but it seems that this was not communicated to patients beforehand. Once on the table being prepped for the BMB, the patient was told of his choices, none of which were the combinations that he had previously used and greatly preferred. He ended up going through a very painful procedure, especially due to a requested extra extraction from deeper in his pelvis, and left him rather angry about the situation.

Josh explained why there had been a change in sedation offerings but had no idea why this had not been communicated, especially to a patient that previously had requested one of the stronger options. Sophia said she would bring this up with the team.

One member said that she had copied down her requested medication from a past BMB report, and made sure that this was included each time she had a BMB. Another suggested that if you are uncomfortable and they have not prepared the procedure as expected, you do have the right to refuse undergoing it at that time. The situation will either be remedied or rescheduled for a time when things could be straightened out...both preferred outcomes.

Josh and the team will return **in June** to review progress on the above problems, and to quiz members on other areas that require attention.

**Dr. Grethlein – SCI (Swedish Cancer Institute)** – Dr. Grethlein took time from her Saturday to follow up on her email from earlier in the month. She reviewed her background and provided an update on how their search for Dr. Bensinger’s replacement was progressing (very well so far, and have interviewed several candidates). She feels that this position will be filled in around 4 months, as there are many considerations for Swedish as well as the appropriate candidate.

She also reviewed the situation at SCI regarding Evusheld anti-body treatment for fighting Covid, which is covered below.

## **Patient Roundtable**

**Covid, boosters and Evusheld** anti-body treatment were a large part of the discussions. Josh and Chloe stayed into our second hour to help answer questions, assisted by both Randy and Tony, two doctors that we were fortunate enough to have join our discussions.

Byron started the ball rolling with his review of the Evusheld antibody treatment he had been recommended by his hematologist, and during our call at least two members were contacted by the SCCA to arrange their treatments. This treatment is meant for those immuno-compromised patients that are not responding to the Covid shots in order to give them protection. This treatment can last 4-6 months, and takes the place of your Covid vaccine.

Links to articles from Byron regarding Evusheld are below and are in the email

<https://www.cnn.com/2021/12/24/health/prevent-covid-19-evusheld/index.html>

<https://www.fda.gov/news-events/press-announcements/coronavirus-covid-19-update-fda-authorizes-new-long-acting-monoclonal-antibodies-pre-exposure>

This treatment is in short supply everywhere, and if you would like to get it, you must contact your oncologist. Both the SCCA and SCI have been very straight forward that this is in high demand/short supply, so sign up early!

Randy and Michele gave us a brief explanation on the process they went through to **claim disability** after Michele's stem cell transplant (SCT). Randy was also kind enough to create a short document that guides patients through the steps on Medicare's website for your to get the required forms. A SCT is considered a basis for disability for at least one year, and if you begin to work again before that time, the government will stop the support with no penalties. Review the attached document and let me know if you have questions.

Treatments for **neuropathy** were also a focus of discussions. This seems to impact a good number of patients, especially those on Velcade. The best remedy for neuropathy is never to get it, so watch for early signs of numbness, pain, tingling, etc. in your hands and feet and bring these to your oncologist's attention. Dose reduction as well as changing of drugs can be discussed.

In addition, there are a number of ways to treat this condition, although effectiveness varies by patient, and several different treatments used in conjunction are usually the most effective. Methods mentioned by our members include the following, but be sure to discuss these with your doctor.

- Exercise, especially walking (physical therapists can be helpful in creating a program for those severely impacted or unsteady)
- Acupuncture (the SCCA has a list of acupunctures approved for treating cancer patients, as well as questions to ask to ensure any acupuncturist understands your challenges)
- Pain relief – different treatments including Methadone, Lyrica, Gabapentin, Duloxetine (Cymbalta)
- Massage and acupressure
- Creams such as Fibro and Somba (800-225-3963)

- Vitamin B6

**Next MM Fighters! Meeting:**

Caregivers Meeting – February 5<sup>th</sup>, 2022 – Contact  
[mmfighters.caregivers@gmail.com](mailto:mmfighters.caregivers@gmail.com) for more information – Virtual Meeting

February 26<sup>th</sup>, 2022 – Dr. Mary Kwok - Best Of ASH – 10AM – 12:30 PM – Virtual Meeting