

MM Fighters! Support Group Meeting
September 24th , 2022
Virtual Meeting

Our speaker this month was Dr. Nicole Bates from the Fred Hutch/SCCA addressing an important topic, the **Physcosocial Issues of Myeloma for Patients and Care Partners**. We have had a long search for a presenter to address these key topics for Myeloma patients, care partners and their support community, and were fortunate to discover Dr. Bates.

Thought for the Month

Vitality shows in not only the ability to persist, but in the ability to start over.

This seems to exemplify the path that Myeloma patients and care partners travel...persisting through side effects and treatment ups and down, and when a relapse strikes, the ability to start the cycle over again. Our support group, family and friends play a vital role throughout these cycles, so keep your support network strong!

Presentation

After an introduction of psychosocial oncology (which addresses the emotional stress and concerns associated with cancer), Dr. Bates outlined the staff at the SCCA that is trained in supporting patients and care partners, as many do not realize the extent of the assistance available there and at other institutions. These include

Social Workers – advises regarding practical resources – charitable support, transportation, mental health.

Psychiatrists – A MD that can prescribe medication, psycho-therapy

Patient Navigator – helps patients navigate the often unfriendly medical system

Spiritual Care

Psychologists – provides psycho-therapy

Integrative Medicine – Acupressure, Holistic Medicine, Palliative Care

Dr. Bates also reviewed the many quality of life issues that face patients and care partners during their Myeloma journey, and how these priorities can change over time. Examining the cancer ecosystem that surrounds each patient team, she reviewed different impacts on the ability to cope with cancer.

An interesting series of slides followed, where Dr. Bates described how everyone tends to regress when undergoing stress, and how this impacts the roles and attitudes of the patients and their support members. She examined how roles can change between care partners and patients, as well as the struggles both face as they strive to return to “normal” after a cancer diagnosis and/or relapse.

Dr. Bates next discussed the struggles associated with the return of cancer, as well as the special challenges faced by those patients that face Myeloma without a full time care partner.

The roller coaster journey associated with Myeloma puts a great deal of stress on patients and care partners alike, and the presentation wrapped up with a detailed slide of different mechanisms that couples can employ to help overcome these barriers to communication and support.

Dr. Bates slides are attached to today's email, and there is also a link to a video of her presentation.

Patient Roundtable

The Board had a meeting a month ago and came to the decision to keep our meetings virtual. Our membership has expanded during the pandemic, and it has also spread out throughout the state and into other states, and we want to keep providing support for our "far flung" members. In addition, virtual meetings make it easier to recruit quality speakers that we need to keep us ahead of the Myeloma curve.

Last but not least, our former meeting place has changed many requirements for using their facilities, and it is not possible for us to meet there going forward. We will continue to look for opportunities to gather in person, but at this time our support group meetings will remain virtual.

Chris will be sending along a survey from DePaul's School of Nursing which will cover Values and Preferences for Myeloma patients and their care partners. Dr. Tariman has worked with the MM Fighters in the past, so supporting his efforts by answering this questionnaire would be greatly appreciated.

Erica shared a tip she learned from the Dana Farber Institute regarding minimizing the impact of neuropathy when on Velcade. The doctors there provide hydration first (at least 500 ml, but usually a liter) and then give the Velcade shot. In addition, they split the associated Dex dose into two days. Seems to be working!

Eve and Don are moving to the Denver area next month and will be missed! But they plan on keeping in touch with our meetings, so we will still have the pleasure of their company.

Kathryn is on her second week of treatment and seems to be handling the side effects well.

Mary is getting "her butt kicked" by KPD, but with her usually determination she is soldiering on! Best of luck!

Jon has started on CyborD to help prepare him for a second stem cell transplant. All is going well so far, and his numbers are responding.

After both clinical trials he was aiming for suspended their acceptance of new patients, Chris went with the 4th treatment he had lined up – Venetoclax, Velcade and Dex. The first week was extremely rough, but the side effects have since improved.

Jerry has started on his DRD treatments and is doing well...as well as planning a cruise in Europe this fall!

Else is deep into her Dara-RVd treatment and her numbers are responding well. But she now faces a decision about whether to stay with maintenance or head into a Stem Cell transplant. With no long-term data investigating the benefits of one over the other, she is again facing a tough decision.

Shelia has been experiencing bone pain for a while, and recently had her femur snap which put her in the hospital for a stay. She is doing better but still facing challenges.

A new member, Tracy, joined the meeting. Newly diagnosed, she has already undergone hip and spinal surgery due to the impact of Myeloma before it was discovered. Sitting is still very uncomfortable, and a good discussion on the benefits of seeing a Physical Therapist to help build back the needed “cushion” followed.

Ruth has been looking into the affordability of home healthcare for those who require it, and has discovered that although it is supposedly covered by Medicare, this is only true if the provider is “Medicare Approved”. And there seems to be no such provider in the greater Seattle area. She has been busy investigating this and speaking with State representatives, and will keep us updated on what she discovers.

Brian bounced back from his Stem Cell transplant and returned to work after a month, once again proving the vitality of youth!

Yolanda is preparing for a stem cell transplant down the line, sorting out all the challenges with living outside the Seattle area, etc.

Michele shared some of the challenges that have again come her way, but she is coping well with whatever seems to be thrown at her. Impressive vitality!

Next MM Fighters! Meetings:

Caregivers Meeting – October 1st, 2022 – 10 – 11:30 AM Contact mmfighters.caregivers@gmail.com for more information – **Virtual Meeting**

NEXT VIRTUAL MEETING – October 22nd – Dr. Andrew Cowan – SCCA –
Immunotherapy Advances – 10AM – 12:30 PM – **Virtual Meeting**