

MM Fighters! Support Group Meeting

September 26, 2020

Virtual Meeting

The MM Fighters' were visited by Kelly Cox of the IMF (International Myeloma Foundation), the kind provider of our GoToMeeting app. The IMF, for those of you who may not be aware, is perhaps the top patient oriented Myeloma organization in the US, supporter of most of the patient support groups nation-wide (160 and counting!), and the provider of a great deal of myeloma related information on their website, www.myeloma.org.

Thoughts For The Month

This month's thought is something we all discover during our journey with MM

If everything was perfect, you would never learn and you would never grow

Let's be sure to take advantage of this opportunity to find ways to develop ourselves and better the lives of those around us.

Speaker

Our speaker this month, from the SCCA and UW, was **Dr. Ata Moshiri**, a dermatologist and dermatopathologist. His presentation focused on "**Skin Care Basics and How to Care For Your Skin**".

Below are some of the highlights from his talk, along with a few qualifiers regarding some terms he used.

1 in 5 people in the US get skin cancer during their lifetime

- 40% of the white population, and 5% of those with darker pigmented skin
- DELAY IN DIAGNOSIS is a huge problem!! Be Vigilant!
 - o Basal cell carcinoma is most common for those with white skin
 - o Squamous cell carcinoma is more common for those with more pigmented skin
- Transplant patients have 10x the risk of developing skin cancer
 - o **IMPORTANT!!!** From a dermatologist's point of view, "transplant" refers to solid organ transplant (liver, kidney, etc.), as they are treated with huge quantities of immunosuppressant drugs.
 - o While stem cell transplants patients, and those who are immunosuppressed due to our treatment for MM, also face risks of increased likelihood of skin cancer, the risk is less, but as of yet unstudied.
- There is a list of risk factors for basal cell carcinoma, and for each of the types of skin cancer, in the slides

- If you have moles that grow or change shape later on in life (like now!) these are probably NOT moles and should be checked.
- Squamous cell carcinoma is found more often in African, Asian and Latin populations
 - It is especially deadly to those who have undergone **solid organ transplants** (65X baseline population)
 - While on the skin squamous cell carcinoma is fairly easily treated, but once it gets under the skin, it become much more serious.
- Those who have had burns over large parts of their bodies need to be extra careful, for squamous cell carcinoma often appears in these areas.

Melanoma – the cause of most skin cancer related deaths

- The death rate from melanoma has risen steadily over the years
 - 1930 – 1 per every 1500 people
 - 1980 – 1 per every 250 people
 - 1993 – 1 per every 100 people
 - 2010 – 1 per every 50 people
- Longer life spans, better diagnosis, more sun burns are some of the many reasons
- **IMPORTANT:** In slide #22, the **MM** stands for **Melanoma**
- Mole like structures that change in color, shape or border are important to look into...might be melanoma
- AVOID indoor tanning – does not provide UVB protection, terrible for skin
- Heredity also plays a part in melanoma – if you have a family history of this disease, your risk goes way up

General Note: Never get a sun burn or a deep tan – too much harmful UV light

- The Pacific Northwest has one of the highest percentages of Melanoma in the US – people here are much more careless regarding the effects of the sun due to our cloud cover.
- Use sunscreen when you go out – the higher the number the better. But at least 30 SPF.

Dr. Moshiri's presentation is attached to today's email.

Patient Roundtable

Jean has asked her online Darzalex FastPro group if they have been experiencing headaches like a few of our members have. To date only 2 have responded that they have. We hope for an update next month.

There was a good deal of discussion on the benefits of massage to help minimize the effects of neuropathy, as well as the benefits of daily walks. One member, Donna, has been seeing a Reflexologist to help with her neuropathy and has experienced some very positive results. (Reflexology is the application of pressure to areas of the feet or hands. The theory behind this practice is that areas of the foot

correspond to organs and systems of the body, and the applied pressure helps your internal systems.)

For those of you who are interested, the Reflexologist is Sue Gaughenbaugh and she can be reached at 425-890-5155.

For those on Carfilzomib, many occasionally experience chills a day or two after infusion. While it is recommended to take Tylenol before and after the infusion to offset this effect, this does not always work. Cheryl has had success eliminating her chills by adding Pepcid A/C to her Tylenol (doctor recommended!). Be sure to check with your oncologist before adding any supplements or additives! Always best to make sure that these additions do not interfere with your other medications!

One member has found that her M Spike has started to increase, and even at relatively low levels the PET scan found bone lesions in several part of her body. Remember that Myeloma often attacks our bones and/or creates lesions, and that even at early stages this disease could be establishing itself in various parts of the body. It is always a good idea to get a complete picture when myeloma starts to return, and scans often play an important role in establishing this new reality.

Naoko suggested a book for those of us who are interested in fighting your myeloma via the food we eat. The book is titled "Eat To Beat Disease" by William W. Li, MD. It's written based on new science of how your body heals itself and how your body is designed to fight disease. Li is a physician-scientist and talks about the anatomy of human bodies and how foods and what foods can help our bodies heal and beat disease based on evidence. He even discusses how red wine is good for you, and beer can also be a benefit!

Bud, who is waiting for the Corona virus to subside so that he can have some teeth implants to replace the teeth removed while battling jaw necrosis, has been dreaming about returning to his favorite restaurants...a list he was kind enough to share.

1. Kosta's: Mukilteo: Anything on the menu, especially the gyro for lunch
2. Wally's: Des Moines; salmon and steak
3. Conto's: Lake Stevens; ribs with balsamic barbecue sauce
4. Mandarin Kitchen: Des Moines; beef chow fun

Remember! The virus is still running wild out there, and we all need to take precautions in order to stay healthy! A study has found that those who ate at restaurants these days have a much higher possibility for catching the virus....so for all of us...please be careful!

Next MM Fighters! Meeting:

Saturday, October 24th, 2020 – 10AM – Noon – Dr. Andrew Cowan, UW/SCCA – “Immunotherapy, CAR-T Cells and Other Cutting Edge Treatments” VIRTUAL MEETING

Saturday, November 14th, 2020 – 10AM – Noon – Rachel Douglas, Physical Therapist, SCCA – “The Benefits of Physical Therapy for Myeloma Patients” VIRTUAL MEETING