

MM Fighters! Support Group Meeting

January 25, 2020

Happy New Year to all the MM Fighters! Hope that your year has gotten off to a great beginning!

Our 1st meeting of the year was a bit of a mixed bag, thanks to my forgetting to bring along the projector! But the group forgave such an oversight, and our speaker, Ami Batchelder, was able to do a wonderful job without her PowerPoint, so we had a great meeting none-the-less!

Thought For The Month

I thought that we would start out with a couple of messages for the new year that seem quite applicable to myeloma patients:

Only I can change my life. No one can do it for me.

A diamond is a chunk of coal that did well under pressure.

We have a few additions to the MM Fighters Board:

Bill and Mimi have volunteered to be our Greeters for each meeting, an important position with the number of new patients we have been experiencing.

Roger and Kris have stepped back from the kitchen after a year plus of supplying us all with coffee and goodies. **Sherry and Scott** have been good enough to fill the important position of Kitchen Wrangler, and did a great job of keeping the caffeine flowing on Saturday!

Patient Roundtable

Revlimid and Dex were two “hot” topics this month, as a couple of patients were starting with one or both of these medications and the groups shared their experiences with these two drugs.

- They are still working for a number of MM Fighters, but Dex is far from a favorite! Lack of sleep for a night or two was common, but there have been some patients that have had no impact at all from this drug.
- Intestinal challenges were a common theme with Revlimid, as were various levels of neuropathy.
- A number of patients have been able to handle Revlimid for a good many years with no large increase in their M Spike, so it is an effective drug.
- Long term Dex usage has also impacted the vision of several people at the meeting, with blurry vision fairly common, and in the worst case, cataracts.

- Side effects depend on the person, their health, etc.

Another medication that was mentioned was Zometa, often used to strengthen bones that have been attacked and weakened by Myeloma.

- Two members at the meeting have experienced osteoporosis of the jaw due to the use of Zometa and have had to have parts of their jaws replaced. Not a common occurrence, but one needs to be watched for.
- When you on Zometa, you can not visit a dentist, so be sure to get all dental work done before taking this drug.
- While it is an effective drug, there are other options available. Be sure to discuss pros and cons with your doctor!

Exercise as a way to extend remission as well as feel better was again brought up.

- One member has started exercising at 70 and encouraged all to move more.
- LiveStrong at the YMCA and Survivors Northwest (for females only) are two great programs for those looking to get back to exercise.

Kathy had a word of warning for everyone. She had new slippers that caught on something a resulted in a slip....as well as a huge bruise up and down one leg. She ended up removing all area rugs to help ensure that did not happen again.

- Be careful, especially if you are experiencing neuropathy in your feet. Changes might need to be made to help avoid spills.....and sandals are probably not a good idea!

With participation in clinical trial increasing, another member had a warning about taking ANY drugs not supplied by the trial. Very often, if you take anything not given to you by the doctors running the trial, it can disqualify you from that trial.

Speakers

Ami Batchelder, AP-C from **Swedish**, joined us to speak about “How To Get The Most From Your Appointments”. Ami spoke to the group a few years ago, and has also worked with our Caregivers, so it was great to welcome her back.

Ami’s PowerPoint presentation is also attached to the email, but the highlights from her talk include:

- Be sure to bring along someone else when you meet with your doctors. A second set of ears is extremely beneficial. And TAKE NOTES!
- You can also ask the doctor if you can record the meeting in order to listen to it again later on.
- Sending the doctor a list of questions before your appointment can be a great help. Do try to focus and be concise...two pages of questions will never be covered in one meeting.

- If the doctor says something you do not understand, or uses unfamiliar terminology, ask for clarification, or for another example. This helps the doctor or PA to know that they need to dial down their language.
- Focus on myeloma. Do not bring up other topics, past illnesses, etc. Your time with the doctor is precious.
- Ask the right questions to the right people. Insurance, parking, etc. are not for doctors or PAs.
- Do your homework! Prepare for meetings!
- Know your blood work, details of your myeloma
 - o First question should be if you are stable or progressing
 - o Understand what your M spike and Light Chain are saying about your disease so that you can discuss
 - o Also, if a nurse or someone misreads your labs, you are able to at least question the findings, or discuss why you believe otherwise.
- Decision should be made with your doctor – not by them. Discuss options, pros and cons.
- You can ask the doctors what they would choose, but remember, they are not you.
- Clinical trials do not treat you like a guinea pig – their aim is to make good better.
- The lowest level treatment is always standard of care – that is the benchmark that they seek to improve upon.
- There are more eyes on you – nurses, doctors, providers, sponsors, pharmacists.....
- What you are doing will help other patients in the future, just like the medications that you are currently benefiting from were proven effective by other patients in earlier clinical trials.

Next MM Fighters! Meeting:

Saturday, February 22 – Dr. Bensinger – Best of ASH (American Society of Hematologists) 10AM - Noon Aldersgate United Methodist Church

Saturday, March 28th – Speaker TBD- 10AM – Noon Aldersgate United Methodist Church