

MM Fighters! Support Group Meeting
November 14, 2020
Virtual Meeting

Due to a last minute emergency, our scheduled presenter was not able to speak to our group. We were fortunate to have Dr. Libby from the SCCA “appear out of the mist in our hour of need” to take over and answer All Questions Myeloma that were thrown his way. A well-attended and informative meeting, and special thanks again to Dr. Libby!

In addition, we do need to thank the IMF (International Myeloma Foundation) for allowing us to use their GoToMeeting app for our virtual meetings!

Thoughts For The Month

After my sudden flare up of side effects last month, I once again woke up to the fact that with Multiple Myeloma, anything can happen...you can't fight it, but need to learn to always roll with the punches. This led to this month's thoughts....

- Embrace the glorious mess that you are.

- Difficult roads often lead to beautiful destinations.

Speaker

Dr. Edward Libby, from the SCCA and UW, spoke to our group this month, fielding “**All Questions – Myeloma**”, one of our most popular and well attended presentations. This year did not disappoint!

Dr. Libby began with some slides reviewing what a BiTE is (Bi-specific T-Cell Engager) and how they operate.

- The key is the Bi-, which means that this man-made medication is formulated with two “arms”
 - o one of which is attracted to a specific protein on the surface of the myeloma cell (such as BCMA) and
 - o the other which draws in the body's T-cells, which kills outside intruders.
- By bringing these two cells together, it enhances the T-cells ability to locate and attack the myeloma cells.

He also introduced two clinical trials which will soon be beginning at the SCCA.

Teclitumab (which hopefully will be getting a new name) which is undergoing Phases 1/2 trials focusing on safety and tolerability. The trial is interestingly split into three arms, each which targets highly treated patients.

Arm 1 – Those who have relapsed after being treated with 3 lines of treatment
Arm 2 – Patients that have relapsed after treatment to all available drugs
Arm 3 – Patients who have already undergone treatment with a BCMA targeted therapy (most likely a Car-T cell therapy) – this will be a smaller group.

They have targeted such heavily treated patients since these patients are running out of options, and as there are already a good number of impressive treatments available to newly diagnosed patients.

Protocol 64007957 – Also undergoing Phase 1/2 trials, this BiTE will be investigating whether IV or sub-coetaneous injections are more effective and tolerable, in addition to the overall safety and tolerability of the BiTE. The possibility and treatment of cytokine release syndrome is also a focus of this trial.

Dr. Libby then turned to questions from the group:

The literature that I have read states that the average survival rate for Myeloma patients is 5 years. With all the progress, new drugs and patients living longer, is this accurate?

Dr. Libby said that there is a good deal of information out there, and a lot of it is old, so those figures might have come from older sources. He currently uses 7-10 years as an average, and other doctors use longer average survival spreads.

Part of the reason this is lower than hoped for is because 1 out of 3 patients have bad markers (17p deletions, etc.) and these markers tend to make treatment much more difficult, so survival in such cases is usually shorter in duration.

In addition, when patients are not able to have a myeloma expert treat their disease, or at least advise their oncologist, survival is also shorter. And those that have poor access to treatment, or are diagnosed late, also impact the average survival estimates.

Any advice on how to help improve the effectiveness of our treatments?

- Take your medications on time, and in the correct dosage.
- If you are taking any supplements, discuss these with your doctor, as many can have an impact on your medications. For example, green tea has been shown to inactivate Revlimid.
- Take notes on any side effects and report them to your doctor.
- Read about your disease so that you can better discuss various decisions with your oncologist.

Is there anything we can do to help improve one strength? I am involved with low load competitive shooting...should I be concerned?

- There are many fine and effective medications to deal with the ravages of myeloma on bones. Be sure to discuss options with your oncologist.
- Low load shooting will have minimal impact of your bones, and should be okay.
- Larger guns are of much more of a concern.
- In myeloma, the disease not only causes holes but also causes bones to become thin, thus weakening them.
- Dr. Libby is most concerned with impact to the spine.
- Spinal compression caused by lifting heavy loads, or jumping down from height can create major spinal cord trauma.
- In addition, severe twisting of the spine is likely to cause thin bones to crack or compress.

What are the pros and cons of harvesting stem cells now, but postponing a stem cell transplant until a later date?

- There is no problem with collecting stem cells and postponing a transplant, but stem cell transplants have been shown to delay the return of myeloma vs. remaining on maintenance for most people). And in many cases, it seems that the first remission is often times the longest, and a transplant would help extend it.
- However, this decision needs to be made between you and your oncologist, so be sure to discuss this in detail before making a decision.

Are there any ways to help fight neuropathy?

- Dr. Libby believes that this is one area of myeloma care that needs to have a lot more focus. Velcade is one of the major contributors.
- In some case getting off the medication can help in the long term.
- Exercise, massages and even acupuncture have been shown to help. But treat it early.
- If all else fails, then switch medications if the neuropathy is getting bad.

Are all the myeloma clones a patient has produced by one clone, or do they have various origins?

- One clone produces all the others.
- An average patient can have 5-7 clones at one time.
- As treatment proceeds, one or more clone is usually eliminated, but others become more prominent and new mutations can be formed.

Is there a standard of care for smoldering myeloma?

- The standard of care is not to treat smoldering myeloma until it becomes “full blown” myeloma.
- However, there are two types of smoldering myeloma, high risk and “standard risk”

- High risk smoldering myeloma should be identified and watched very carefully, as even in the smoldering state it can cause significant bone and kidney damage.
- There are some trials going on to determine the impact of early treatment of smoldering myeloma, but there are no definite result yet.

Is immunotherapy more effective with Myeloma than with other cancers?

- Immunotherapy is not as effective with Multiple Myeloma, and proven to be more effective when battling several other cancers.
- There are immunotherapy drugs that have cured other cancers, including some very nasty ones. That is why great hope has been put in this treatment.

Questions that were not addressed by Dr. Libby during our meeting will be answered in a separate mailing to the group.

Patient Roundtable

Several new patients introduced themselves as well as commented on their journey so far. They seem to be doing well!

***If your computer's microphone is not working, please be sure to mute your computer and call in on your phone. That way you still have the video picture on the computer but you also have the audio on the phone (don't forget to mute!)

Next MM Fighters! Meeting:

Saturday, January 23rd, 2021 – 10AM – Noon – TBD VIRTUAL MEETING

The group will be taking a break during December and will start meetings again in January. Notices will be sent out with details after Christmas.