MM Fighters! Support Group Meeting February 26, 2022 Virtual Meeting

We had another well-attended meeting, which is to be expected as the presentation was "Best of ASH" (American Society of Hematologists), one of the perennial favorites. We had a new speaker this year, Dr. Mary Kwok from the SCCA, and she approached this topic in a bit of different manner, focusing on 5 major abstracts that she felt were key for the Myeloma community. By focusing on the details of these key clinical trials, Dr. Kwok gave the members a broader understanding of all aspects of these trials, something that will help us all when it comes time to consider the benefits of different trials.

Thought For The Month

Fight for things that you care about, but do it in a way that will lead others to join you.

Fortune does favor the bold, and you'll never know what you are capable of if you don't try.

These two quotes are especially important at this time of year, as March is Myeloma Awareness Month (also known as Myeloma Action Month). This is an important time to focus on supporting the many existing efforts to educate others about Multiple Myeloma, while also undertaking a few initiatives of our own. By perhaps taking a small step outside your comfort zone, and finding ways to make your appeal attractive to others, you can help make a difference not only for yourself, but also for the tens of thousands of Myeloma patients worldwide.

Please see my email from Monday which illustrated a few simple ways each patient or caregiver can make a difference for the Myeloma community. The email message is briefly summarized below:

- In my letter, I mentioned three actions, supported by the IMF (International Myeloma Foundation) to spread awareness of MM:
 - Share some Myeloma facts from the list in the email on social media.
 - Send your doctor the letter about the warning signs of MM, which can others avoid needless suffering before an accurate diagnosis can be made, and
 - write your local paper, encouraging them to announce this month as Myeloma Awareness month (we already have received a proclamation from the WA governor to this effect – see image attached to this email).
- In addition, sign ups have just begun for the Defeat Myeloma 5K/1 Mile fundraiser, which will be held on Sunday, June 6th at Magnuson Park in

Seattle. This is the 10th year of this fundraiser, which has so far donated over \$1,000,000 to Myeloma research at the Fred Hutch. As we all benefit from new and effective treatments, your efforts to support this research can pay huge dividends for us all going forward.

- There are several ways you can support this important fundraiser:
 - Donate to the MMFighters team to show that our group values Myeloma research.
 - Register to join the Walk/Run on the 26th of June FREE to all Myeloma patients, \$35 for other adults.
 - Create your own team to fundraise, and watch friends support your efforts!
 - Donate to the team of another fundraiser there are a number already created!
 - Any amount can help!

Speaker

Dr Kwok began her presentation by explaining that she was focusing on what she considered 5 major abstracts (results from clinical trials) that she believes will have great impact on initial induction therapy as well as in treating Relapse/Refractory Myeloma.

Dr. Kwok sought to explore key criteria for induction therapy, reviewing the various therapies currently available, then examining the "standard of care" for both standard and high risk patients. At this time, the standard of care is a three drug treatment, but two abstracts Dr. Kwok reviewed showed surprisingly strong results from the use of 4 drug treatment therapies, the **GRIFFIN** trial and the **MASTER** trial.

The **GRIFFIN** trial examined the results of an important quadruplet therapy, adding Daratumumab to the standard RVd (Revlimid, Velcade and Dex). After introducing the treatment plan, Dr. Kwok took us through the patient profiles, cytogenetics, trial results to date (which interestingly have deepened over time), ending with a look at the MRD status for these patients. She also reviewed the various side effects that resulted from this trial, paying attention to the severity of those that more commonly impact patients. She ended with a review of these findings, as well as a short list of other things to consider when reviewing such a trial.

This thorough approach was repeated for the **MASTER** trial, another quadruplet therapy that is gaining prominence – Dara with KRd (Revlimid, Dex, with Kyprolis replacing Velcade).

While the results were also quite impressive, what stood out in this trial was that they also took a detailed look at MRD negativity not only by trial phase but also by **HRCA** (high risk cytogenetic abnormalities). MRD (Minimum Residual Disease) results were examined in patients with 0, 1 and 2+ HRCAs, looking at how these groups responded over time. While more trials are needed in order to confirm

these findings, trial results suggest that for those patients with lower risk Myeloma (0-1 HRCA), there is a possibility of using MRD surveillance as an alterative to lengthy maintenance therapy.

Dr. Kwok next looked at therapies for Refractory/Relapsed patients, taking us through two trials for **bi-specific anti-bodies (BITEs).** (Bi-Specifics are man-made antibodies with two receptors, one that attaches to the Myeloma cell and the other that latches on to the patient's T-cell, bringing them together so that the T-cell can eliminate the Myeloma.)

The first trial, **MajesTEC** (featuring **Teclistamab**) focused on a BCMA targeted treatment (bringing in the T-cell with its CD-3 receptor). This off the shelf treatment has already gone through Phase 1 studies (safety) and was examining the correct dosing.

An impressive fact about this trial is such a strong overall response was generated by a single agent (60%+ compared with 30%+ for most other single agents). This result was obtained even with such a heavily pre-treated patient group. This is creating hope for even more impressive results once Teclistamab is combined with other agents.

The **MonumenTAL** trial (**Talquetamab**) is a bit different as it has a new target on the surface of the Myeloma cell – GPCR5D. This is good news, as it offers an alternative from the current abundance of BCMA targeted therapies. A drawback is this receptor is also found on skin and nail cells, which resulted in some unique side effects (skin rashes and nail disorders).

This therapy was again used on a heavily pre-treated group of patients, and ORR (overall response rate) was very high, 67-70%! While there are numerous side effects, the overall feeling is that this can also become an effective treatment for patients who have experienced multiple relapses.

The final trial reviewed was the **CARTITUDE-1**, examining the results of the Car-T cell therapy Ciltacabtagene Autoleucel, otherwise known as **Cilta-cel**. This trial has had some very impressive results, and should be the second Car-T cell therapy approved by the FDA in the near future....in fact it just was approved! Great news!

A few interesting points in this trial

- one is that again we are seeing the positive responses deepening over time.
- The second is that the trial allowed a patient to receive a bridging therapy while waiting for their Car-T cells to be manufactured, which is not always the case in trials.
- There are discussions with the FDA about considering the use of Car-T cells earlier in the treatment. It will be very interesting to see the response from newly diagnosed patients!

Dr. Kwok does a wonderful job reviewing the above trials in depth, and watching the presentation and the Q&A can help deepen your understanding of these important developments. **Please click on the video link in the email**.

Patient Roundtable

Jerry will soon be undergoing a **Stem Cell Transplant**, and several patients took him through an abbreviated trip of their first month or two after transplant, usually the most trying time. There were a wide variety of responses, which helped to highlight the fact that each of our journeys is very different. But understanding what can happen allows both patient and caregiver to prepare for a number of eventualities, most of which hopefully will not occur.

Covid, boosters and Evusheld anti-body treatment were important topics, especially in light of the recent announcement that the FDA recommended dose of Evusheld had just been doubled. Dr. Kwok suggests that you contact your oncologist or their staff for more details. However, as this announcement was just made on Friday, and stock of Evusheld is severely limited, a firm decision on how to proceed might take each institution a few days.

A number of **bicycle riders** were discovered hidden in our midst! Larry started off talking about his rides, and several others joined in with their routines. While most of us seem to walk for exercise, there are a number of ways to get similar benefits, and bicycling is just one of them. Find out what you enjoy, and go do it!

On a related note, methods for reducing **cramps** were also discussed. While lavender, coconut water and potassium enriched water were more "run of the mill" treatments, Larry swears by honey, tonic and pickle juice. He also suggests trying blackstrap molasses…at least there are choices!

Greenwood Senior Center has an impressive array of **online offerings for free**, and Marilyn strongly suggests that members check them out! Please visit www.phinneycenter.org/gsc/ for more details.

Susie, leader of the Tri-Cities Support Group, has a couple of members who are preparing to start **Car-T cell** treatments. Any members who have undergone this process and would like to help, please reach out to Susie at laranjowells@gmail.com.

There was a question regarding **visits to hospitals** during these trying times. Other members have visited friends in certain wards at the hospital, but went fully protected – vaccinated, boosted, double masked, gloves and a face shield. It was also suggested to call the nurses on that floor to understand if any restrictions on visits exist, and if they are encouraging certain practices in order to protect the patients.

Bud also suggested that calls or cards would be welcomed if a visit is not possible. There are many ways to reach out, and such "small" actions for people in the hospital do an incredible job if boosting spirits.

Suzanne has experienced an extremely itchy back after taking Daratumumab. Have other members had a similar experience?

Next MM Fighters! Meeting:

Caregivers Meeting – **February 5**th, 2022 – **10 – 11:30 AM** Contact mmfighters.caregivers@gmail.com for more information – Virtual Meeting

March 26th, 2022 - Dr. Banerjee -UCSF - Treatment Toxicities in Myeloma - 10AM - 12:30 PM - Virtual Meeting