ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

September 12, 2020

Introduction & News

Thank you to **Nancy B**, IMF Regional Director - Support Groups, who hosted the virtual meeting, with approximately 35 attendees. Nancy gave a brief presentation, and then we welcomed two new members and had an open discussion with updates from our members. **Dr. Harvey** from **Emory** will join us in our **October** meeting, and in our **November** meeting we will break into separate patient and caregiver sessions. Please note that you can view prior newsletters at our support group website: http://www.mmsg.org/

Presentation

September is blood cancer awareness month. Multiple Myeloma (MM) is a bone marrow cancer and is the second most common blood cancer. The International Myeloma Foundation (IMF) provides free resources to help both patients and families, and a toll-free hotline (800)452-2873. The IMF's mission is to improve quality of life for MM patients, while working towards prevention and a cure. Cure is a word that's associated with immune therapy, and what's happening with the Iceland project, i.e. to detect MM early, and treat it before it progresses, to knock it down and keep it under control. There is a lot of research being conducted. **Nancy** reviewed pages from the IMF website (myeloma.org), a great resource for staying informed for all patients and caregivers. Information about recent FDA-approved treatments is available at the website. For example, Kyprolis in combination with Darzalex and Dex was recently approved for relapsed or refractory MM. The IMF has a global reach and contains information from doctors who collaborate with each other from a world-wide perspective. Some highlights from the IMF website include blogs from Dr. Durie, Chairman of the board for the IMF and a co-founder, including COVID and MM treatment, information from the International Myeloma Working Group (IMWG), and Dr. Durie's highlighted summary from a recent two-day virtual IMWG meeting. There will be a **free, virtual, two-hour IMF-sponsored Patient & Family seminar on Oct 3rd** at 10AM ET. Register for this event **here**. Topics include clinical trials (CT) with new drugs and new combinations, treatment options for frontline, early relapse, and multiple relapse patients, recent FDA-approved drugs, and worldwide COVID updates. In preparation for attending the virtual seminar and/or replaying the event, review the Patient Handbook and booklets on new drugs, Sarclisa and Xpovio. All of this information can be found and downloaded for free at myeloma.org. It is recommended to also have on hand a summary of the classes of MM drugs, described in the chart below. Note: When the name of a drug appears in parenthesis in the chart, it means that the drug is FDA- approved.

Updates & Discussion

We welcomed new members, **Cheryl S.** and her husband, **Paul**, and **Kevin W.** who all joined the group for the first time. **Cheryl S.** was recently diagnosed in July. She is being treated with Revlimid, Dara, Velcade, and Dex and after just one round her numbers are much better. She is working with both Emory and Dana Farber and deciding whether to proceed to stem cell transplant (SCT) now or wait. Emory is encouraging her to proceed with SCT now, but Dana Farber suggests waiting. Regardless, she will harvest stem cells early. Her risk level is standard and she has no bone pain, no renal or bone issues, normal PET scan results, and is getting Zometa monthly. **Nancy** mentioned that SCT can stop bone destruction and pain from MM and most patients in the group have had SCT at various times in their

treatments. But some have decided not to have a SCT and many have done well with drugs only. **Sandy B.** has been a MM patient for 31 years and has not had a SCT. Sandy's son in law was diagnosed in 2013 and joined a clinical trial (CT) and had a six-year remission. He relapsed in 2019 and had a SCT then, and now is using Pomalyst for maintenance. **Cheryl** asked if anyone has had a bad taste in their mouths from drugs, specifically Dara or Revlimid. **Lory M.** responded that during induction treatment she lost her taste completely, but her body adjusted after the first round of drugs. **Kevin W**. was diagnosed two years ago at age 56, and has high risk MM. Kevin began treatment with Velcade, Revlimid, and Dex, and then had a stem cell transplant (SCT). He has continued treatment with **Daratumumab, Pomalyst, and Dex** and he explained that his paraprotein level is increasing and has joined the group to learn more about potential next steps and treatment options. He also wanted to learn more about the signs that other group members observed when they were coming out of remission. **Jim M.** mentioned that his kappa and gamma ratio became out of line when he was coming out of remission. **Lory M.** said that she began to relapse also after two years of treatment and her paraprotein level was much higher than Kevin's is currently, but she did not experience any symptoms. **Nancy** mentioned that there is a lot of flexibility with combinations and dosages of drugs that can be administered just once or short-term for a boost. **Joe H.** reported that he was diagnosed four years ago and just learned two weeks ago that his diagnosis was changed from low risk to high risk due to a 17 p deletion, which recently presented in a bone marrow biopsy. The 17p deletion had never presented in prior bone marrow biopsies. He had a SCT four years ago but did not achieve remission. He has been on Revlimid, Ninlaro, and Dex for the past three years. **Dave O.** was diagnosed nine years ago and had a SCT after induction that did not help; his paraprotein level was the same after the SCT as it was just before the SCT. **Nancy Y.** had two (tandem) SCTs four months apart in 2009 and is doing well**. Pat C**. has also had two SCTs. There was some discussion about Blenrep, an immune therapy drug and side effects. It causes blurry vision and the FDA requires the patient to visit an optometrist for an eye exam every time before the drug is administered. **Mary Lou S.** mentioned that she knows someone that is taking Blenrep and he experienced corneal problems and very impaired vision for a while where he could not read, and his vision was very blurry. But that has all been rectified now after a couple of months. He had to see an ophthalmologist before each treatment, but he is thrilled with the results so far. Someone called in from NYC and mentioned that her husband had been getting tested regularly and the test results looked fine. Then, a recent full body MRI showed MM all over his body. She mentioned that her husband was on Dex, Pomalyst, and Ninlaro, and now has also started Elotuzumab. Her husband is very weak now. His progression was rapid and his doctor tried to get him on a Car-T CT but he was not accepted. She feels like the doctor is top-notch but is also challenged with this case. **Nancy B.** mentioned that non-secretory MM can be challenging and requires more frequent bone marrow biopsies to track. A few people mentioned a flu shot CT that is being conducted at Emory and there were several questions in the chat that were discussed:

Q: Are COVID vaccines being developed with "non-live" components, so that MM patients will be able to receive them (Wendy R.)?

A: **Nancy B.** responded: We do not know, check with your doctor before getting any vaccine. Also, check with the IMF hotline.

Q: Does everyone diagnosed with MM always have smoldering myeloma?

A: **Nancy B.** responded: No, but they always have MGUS (per Dr. Durie), which is diagnosed by protein in urine

Q: Does the Shingrix Shingles vaccination protect MM patients from getting Shingles?

A: **Nancy B.** responded: Per Dr. Durie, the two-part Shingrix vaccination will protect you, but it is advised that if you are on active treatment (including maintenance treatment), you should continue with

Acyclovir (since this has not been fully tested yet). If you are in remission and not being treated, it will protect you.

Q: Is there anyone in the group that is a non-secretory? (Ian)

A: **Jim M.** mentioned that Libba is non-secretory

Q: For those of you who have taken Kyprolis, what cardiac precautions were taken before you started that drug? (Mary Lou S.)

A: Someone responded that they did a total cardio workup before starting Kyprolis

Q: Has anyone tried CBD under guidance of their doctor, like medical marijuana or CBD that the doctor helped him get? (Ian)

A: **Lory M.** described her personal experience and acknowledged that everyone is different. She went to a palliative care doctor at Emory because she was having sleep issues and restless legs, so taking Revlimid made worse. The doctor prescribed CBD. She is not sure if it worked; it seemed helpful sometimes but not at all other times. She stopped taking it after an acute pancreatitis attack for which no cause was determined, as well as some additional research that she did which concerned her. **Nancy B.** mentioned that medical marijuana can help some patients with pain, appetite, and to sleep better and longer.

Q: Has anyone noticed a difference in their number (e.g. paraprotein) after switching from Dara IV to Dara Sub-Q? I noticed the side effects are not anywhere near as bad as with the infusion – i.e. shortness of breath, tiredness and weakness is not there like it was with the infusion? Is it the same with others? (Dave O.)

A: **Jim M.** responded that he has nowhere near the amount of side effects that he had before, including less shortness of breath. **Jeff W.** said he has less shortness of breath with the Sub-Q version, and he did not experience other side effects with the infusion, so about the same for him. **Lory M.** said that she never had shortness of breath with the infusion, but she had headaches. Now, with the Sub-Q version she has no side effects. **Belinda C.** also said that she does not have any side effects with the Sub-Q version.

Submitted by Wendy R.

Everyone stay strong, stay safe, and stay home!

Southside Virtual MM Support Group

September 26, 2020

Next Month: We will hear the voices of patients and caregivers and have a review of recent webinars. We will also have an Update on our Light the Night activities. The question for this month is the same as last month's question, *"What are two things you know now that you wish you had known – wish someone had told you about when you were starting your MM Journey (lessons learned)?"*

The theme of the meeting was "Accentuate the positive – Counting Blessings…" **Doris** opened the meeting with a moment of silence. We welcomed several new members. **Willene** has been diagnosed with smoldering myeloma. She wants to learn as much as possible about the role of bone marrow and bone marrow transplants. We also welcomed **Arliss**, who was diagnosed in 2014. Arliss had an autologous stem cell transplant (ASCT); **Carolyn** has joined the meetings before. She was diagnosed in September 2019, and in June had a SCT. Her status is up and down, but she has a great support system, and is learning a lot; **Karen** is a member of the northside group and was diagnosed in October 2018. She recently completed one arm of a clinical trial with Dr. Nooka. She was on three medications – Dara-Vd [daratumumab (Darzalex), Velcade, and dex] over three months. The other arm of the trial included Dara, dex, and ixazomib (Ninlaro). This is followed by Dara, ixazomib (Ninlaro), and dex. Her numbers did go down while on the trial. She is eligible for a SCT as a low risk candidate.

Ajay Nooka, MD, MPH, was our speaker and his main topic was **Progress in myeloma for African American Patients.** Dr. Nooka opened with remarks emphasizing the importance of communication. Doctors should listen to patients. Patients must talk to their doctors. He also shared a personal note about himself. Dr. Nooka started from humble beginnings in India. His father was an obstetrician/gynecologist male physician in a very conservative country, so examining women required a very special sensitive skill. Dr. Nooka also shared pictures of his focused journey from India, to MD Anderson, to Emory Winship, and is now the Chair of the Myeloma Working Group at Emory. He has learned to be keenly aware of the need for good patient-provider communication throughout his journey.

His research interests include **therapeutic innovations**, **clinical outcomes** and **disparities** in healthcare outcomes and access to quality medical care. His research has focused on biological differences in blacks, whites, and others as well as differences in treatment. He looks at both new and relapsed patients. There should be the same care for everyone.

Dr. Nooka followed with the updated International Myeloma Working Group's (**IMWG**) recommendations for the diagnosis of myeloma. The disease starts with clones of myeloma cells that are not yet causing any trouble -- called **MGUS** (**m**onoclonal **g**ammopathy of **u**ndetermined **s**ignificance). The next indication of disease is **Smoldering Multiple Myeloma** (SMM) where there are more than 10% of abnormal plasma cells in the bone marrow or an M-spike of greater than 3 g/dL, and no evidence of organ damage, anemia, or bone lesions. Therefore, smoldering myeloma is **asymptomatic.**

Then we may start to see high calcium levels, or kidney failure… symptoms that are referred to as the **CRAB** criteria -- Too much **C**alcium in the blood or urine, **R**enal (kidney) failure, unexplained **A**nemia, and **B**one involvement. Everyone does not have the same risk of moving from asymptomatic to symptomatic disease, so for some, there is still "watchful waiting." Research in recent years shows that some treatment level may be beneficial to prevent the conversion to active disease.

Current Studies at Emory with a focus on African Americans

In a SWOG (Southwest Oncology Group) study where patients with MGUS/Smoldering were simply observed, the U.S. Cooperative **Observational study**, less than 10% of the African American patients converted to active disease versus about 20% of white patients. Blacks tend to present at ages at least 5 years younger than whites with MGUS or SMM but take a longer time to convert to active disease. African Americans have less high-risk disease. In a study of 1,000 patients (N. Joseph), with 35% African Americans, there were no differences in blacks and whites before disease started to show (Progression Free Survival, PFS). African Americans seemed to do much better – and with improved access to care, they should have much better survival rates. **Each patient should know his/her risk status**. The risk for active disease depends upon test criteria set by the IMWG.

Dr. Nooka shared several complex ongoing studies going on in collaboration with other institutions. **A Genome Wide Scan of Multiple Myeloma in African Americans –** is biobanking MM precursor tissue samples in order to conduct a genome wide scan of MM in African Americans. For high-risk SMM patients, an additional study includes observing asymptomatic myeloma – using Revlimid versus observation-only for progression of disease. Another small study with **PVX-410** is to induce immunity against MM cells by selectively stimulating tumor-associated T cells. Dr. Nooka and others published an article in JAMA (2018) on the effect on SMM of a vaccine versus a vaccine plus Revlimid. Six dosages of a vaccine are delivered over a 10-week period. So far, there is a positive response to the vaccine, but is the response sustainable? There was no control arm, so no proof yet of sustainability. Another study showed that **transplant helps with a longer/deeper remission**. **Question:** So, if you are Smoldering, should you be treated? **Answer:** Everyone is not at the same risk. You should have a very detailed conversation with your doctor to understand your risk factors.
MRD (Minimal Residual disease). A 3-drug study, Dara, Rev, and Velcade produced a significant increase in the MRD-negative status over 16-18 months in African Americans. These were newly diagnosed, transplant-eligible patients. (Emory. UAB, Moffitt Cancer Center).

Future directions include: Dara/Rev vs Rev for patients with high risk smoldering myeloma (N.Joseph); Dara vs observation (Nooka); PVX-410 combination with lenalidomide and HDAC6 inhibitor (like Panobinostat). Studies are ongoing to determine why African Americans are not showing better survival based on presentation. Emory Winship has brought on several new myeloma specialists over the past 10 years, including Nooka, Kaufman, and Hoffmeister who will all contribute to this work. As usual, Dr. Nooka was full of lots of great information – and attendees were pre-warned not to try to absorb all the information at once.

More Research at Emory Winship

New research on treatment regimens: Antibody Drug Conjugates (ADC) in myeloma: Belantamab Mafodotin in Myeloma. The FDA approved this drug and the name is Blenrep. It attaches itself to a BCMA receptor, which is on most myeloma cells, to kill the cell. One must have had 3 or More Prior Lines of Treatment, are refractory to a Proteasome Inhibitor and an Immunomodulatory agent and have failed an Anti-CD38 Antibody (DREAMM 2).

We are not expected to understand all the science that goes with these studies. We should feel comforted in knowing that there is lots of exciting research going on to help curb the negative impact of myeloma on our lives.

Categories of Drugs and New Drugs in Trials

1. **Oral proteasome inhibitors** – Oprozomib, Marizomib (same as Velcade, Carfilzomib, and Ixazomib)
2. **ImiDs** (Immunomodulatory Drugs) - CC-220 (early in its testing, so far no long-term toxicity, can be an option soon. Alma is a participant in this trial), CC-92480 (Revlimid, Pomalidomide)
3. **HDAC Inhibitors** (Histone Deacetylase) – Ricolinostat (Panobinostat)
4. **Monoclonal Antibodies** – Isatuximab (Daratumumab, Elotuzumab)
5. **Novel MOAs** (Mechanism of Action) – Venetoclax (approved for use with translocation (11:14) – 15 % of MM), Selinexor/XPOVIO (when refractory to bortezomib, carfilzomib, lenalidomide, pomalidomide, and daratumumab)
6. **Immunotherapies**

Immune checkpoint inhibitors, Pembro-lizumab
CAR-T (Chimeric Antigen Receptor)
BiTEs (Bispecific T-cell Engager)
Belantamab (ADC)

To date, there have been 50 patients to undergo CAR-T cell therapy at Emory. Neurotoxicity is different in blacks and whites – there is less toxicity in blacks than whites.

Influenza Vaccine Trial at Emory

During the 2017-2018 flu season, there were 30,000 people hospitalized for the flu. Most were over the age of 65. Myeloma patients are at least 10 times more likely to have flu-like symptoms as the general population. Dr. Nooka asked that any Myeloma patients who had **not yet had their flu shot** for the year, consider joining a flu shot study. The purpose of this randomized study is to determine whether one dosage or multiple dosages of the vaccine over several months will better protect patients with blood disorders. The study is being carried out at Emory. 90 more (of 140) participants are needed by **December 15, 2020**. **Doris.** The consent form says you will not be responsible for any negative effects from participation in the study. Is this true? **Nooka**. This is standard language in consent forms for studies. An Emory committee, the IRB (Institutional Review Board), reviewed the study, and found there would be no excessive risks over benefits from participation in the study. The study has several layers of review, including the FDA.

The question for the week, was *"What are two things you know now that you wish you had known – wish someone had told you about when you were starting your MM Journey (lessons learned)?""* While time did not allow us to discuss the question in the meeting, **Sheryl** shared her thoughts via email prior to the meeting. She said," caregivers *should hear any conversations with the pharmacist, including when the patient is renewing/or refilling medications – and including when they are on a (clinical) trial."* Also, she said – *ask your loved one what makes them fearful. Open the lines of communication so the caregiver can be more prepared for what may come.* We will revisit this question in our next meeting.

Announcements/Resources/Upcoming Meetings

•Light the Night 2020 - Just one week left for Fundraising. Please thank your donors!

-IMF. Patient and Family Seminar. Available for replay at www.myeloma.org Susie Durie, Drs. Joe Michael and Craig Cole. Topics include Translational Genomics and Caregiver Support Services.

•IMF. Everybody Loves Raymond Fundraiser FREE – donations requested. October 23. 6:000 PM EST

•LLS. App for health Manager. Can track your side effects, medication, meal planning, questions for your doctor, and more. https://www.lls.org/health-manager?sfmc_id=217716154

•LLS. Navigating Clinical Trials as a Treatment Option. (Podcast). Dispelling myths. Finding one that may be right for you? https://marrowmasters.simplecast.com/episodes/clinicaltrials?utm_source=sfmc&utm_medium=email&utm_campaign=CTSC&utm_term=CTSC_Podcast_Episode&utm_id=70146&sfmc_id=217716154.

•The Power of **Vitamin D**. for Myeloma – for COVID-19. Get your Vitamin D levels checked. Bones, joints, heart health, immune system

•Study. **African American Caregivers over age 45.** Brain Health & Alzheimer's. $50 gift card. Saliva and finger prick blood samples from home. Taqiyya Alford Clinical Research Coordinator emory.ohicc@emory.edu. (404) 727-8421

•Georgia CORE. Seeking **Members for Georgia Cancer Survivorship Advisory Council**. https://www.georgiacancerinfo.org/cancer-news/georgia/gc3-survivorship-advocacy-council-looking-for-memb/714

•MMRF. Fall Awards. Robin Roberts and Kathy Giutsi. MC – Bonnie Hunt.

•Please Vote. Information Sheet Available.

•Advocacy – Two Bills: Increase Diversity in Clinical trials and require Medicaid to pay for Clinical trials therapy.

•Smart Patients. Cover topics including medications, side effects, treatment options, Medicare & MM, personal experiences, Clinical Trials, and more. www.smartpatients.com

Respectfully submitted, Gail