ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

May 4, 2019

Thank you to **Nancy and Jeannie** who co-hosted the meeting. We wished Nancy a happy birthday and thanked her for her continuous support and dedication to the group!
An IMF Patient and Family Seminar is scheduled for September 6-7 in Charlotte, NC. Details at: https://www.myeloma.org/events/2019-patient-family-seminar-charlotte-nc
When you order from Amazon, if you use the **https://smile.amazon.com/** link to place your orders, a charitable donation will be made to our Atlanta Area Multiple Myeloma Support Group (AAMMSG). The group is also receiving donations from Facebook.
The AAMMSG website has been re-designed: http://www.mmsg.org/ and Nancy is looking for volunteer(s) to help post information to the site (announcements, photos, programs, etc.) so that we can begin using the site more actively rather than relying on email.

New Members
The group welcomed three new members. **Samantha** was diagnosed last June after experiencing broken ribs. She is being treated with an RVD (Revlimid/Velcade/Dex) regimen and is planning to have a stem cell transplant. **Belinda** was diagnosed in February. She is also being treated with RVD and is planning for a stem cell transplant. **Kay** was diagnosed in 2016. She has had a stem cell transplant and is doing well. She was also treated with Pomalyst, Dex, and Daratumumab for one year. She explained that her case is high risk due to a t*(11;14) translocation.*

Guest Speaker
Thank you to **Dr. Harvey**, Director of Phase 1 Clinical Trials and Pharmacist at Winship Cancer Institute of Emory University, who joined the group to talk about new clinical trials (CT), treatments, and answer questions. Dr. Harvey works with patients who are getting a drug for the very first time that it is being used in humans. Dr. Harvey began by mentioning how continually amazed he is by the great support that the multiple myeloma (MM) community has for patients and caregivers, and that MM therapies are getting much better. He also mentioned that he feels that MM is following a path that a pediatric cancer, Acute Lymphocytic Leukemia (ALL), which is a cancer that also affects adults has taken. Asking the right questions at the right time, and getting patients with ALL to participate in CTs, took a disease that was fatal in the 1970s to a 95% cure rate. ALL, as a cancer type, is not that different biologically from MM, as they are both B cell malignancies. The therapy that is now used for kids with ALL is a very long and multiple drug approach. Dr. Harvey explained that we have an induction therapy for MM (often RVD). The three drugs used in the induction regimen all work differently to kill plasma cells. Then many patients will have a stem cell collection and transplant, and then go on to maintenance. This is starting to resemble ALL therapy.
There are a variety of new approaches for MM treatment, and the immune system is getting a lot of attention currently. CAR T-cell therapy can be very intensive. It is a therapy where the patient has their cells collected. Then those cells get sent to a processing facility, where they

are taught to go after what's foreign, the cancer, i.e. the rogue plasma cells. They're taught to go after a specific protein called BCMA (B cell maturation antigen), which is unique to the myeloma cell. Another new approach for MM treatment uses drugs that build a bridge between the immune system and the plasma cell, which are called Bispecific T cell engagers (BiTE). Trials are in process for these approaches that are promising but come with some side effects. There are side effects of a ramped up immune system, which means you can get fuzzy thinking and confusion, fevers, diarrhea, and liver damage. When these therapies work very well, they can deplete your B cells, which results in continued risk of infection. You don't make any normal immunoglobulin for a long time and so you will need IVIG supplementation for a while. Another drug called Venetoclax targets the t(11;14) translocation pathway and blocks it, is in CTs for MM and is promising. Other areas of drug development are for maintenance drugs that work, are affordable, and are tolerable for a long time, similar to a blood pressure or cholesterol medication.
Dr. Harvey is very hopeful for the future, because 1) there are people who are really advocating for new drugs and better therapies, and 2) there are people willing to participate in CTs, because that's how we get new drugs. We don't get new drugs unless people participate in CTs.

Dr. Harvey answered many questions for us, as follows:

Q: Are there any plans to eventually just be able to take a patient's stem cells, clean them to make them healthy again, and then reinsert them as a therapy for newly diagnosed patients? **A:** Challenges for a therapy like that include: the inability to collect all of the malignant plasma cells (the ones left behind can cause problems later), and MM cells can mutate. MRD shows that we're getting close to these very low levels, but we've got to get to zero for a therapy like this to work, and zero is a hard number to get to as that last MM cell can be very difficult to find and destroy. Dr. Lonial is very much in favor of lots of drugs early with this same concept in mind of knocking everything out we can and minimizing the likelihood of these cells surviving and continuing to do harm.

Q: I am taking both Pomalyst and Daratumumab and having problems with Pomalyst. Does Pomalyst help the Daratumumab work better? **A:** Yes, Pomalyst helps in many ways. We know that Pomalyst helps Daratumumab "see" the MM cells and cuts the attachment so that Daratumumab can kill the MM cells. Many drugs work in different ways and that is why we treat with multiple drugs simultaneously, as they really make each other work better. For example, Dex is a drug that makes other drugs work better. Remember: "*Dex is like bacon, it makes everything better*". Although Daratumumab works well as a single agent, it probably will not be used as a single agent for much longer.

Q: How soon will Daratumumab be available to be injected under the skin?
A: It is expected later this year in Q3 or Q4. Note: the first dose will probably always be a long infusion.

Q: I have been in remission for 4 years and am currently on 10 mg Revlimid and get Zometa. I'm in menopause and a side effect of Revlimid has been severe hot flashes. Do you have recommendations? **A:** Continue with Zometa for one more year if there are no lesions. Work with your doctor to try a Revlimid dose reduction to see if that helps; the longer that you can continue with Revlimid, the better.

Q: I have been taking Revlimid, playing tennis, and getting muscle cramps. Mustard and vinegar have been beneficial in helping with the cramps. Are there other natural remedies? **A:** Cramps can be related to calcium and potassium levels. Keeping well hydrated and having a good diet can help. People used to use quinine to help with cramps, which is in tonic water.

Q: Are there any known supplements that are good for MM? **A:** Regulated supplements such as Vitamin B, B6, and fish oil are OK, although we don't know if they work to help with MM; we only know that they are not harmful. Herbal supplements that are not regulated and don't follow good manufacturing practices are not recommended. Generally, be cautious about supplements and let your medical team know about all supplements that you are taking. If you feel like the supplements are helping you and your medical team is aware and approves, then OK, continue. More important than taking supplements is a healthy lifestyle, diet, good quality sleep, exercise, minimal alcohol consumption, etc.

Q: Does Emory work with nutritionists to find healthy, natural solutions to cure cancer versus drugs that are toxic? **A:** Yes, but there are so many variables in diet, that it is very hard to maintain control of the studies.

Q: At diagnosis, I was treated with RVD, which worked great, but when preparing for a stem cell transplant heart damage was discovered (likely from the Velcade). If I relapse, will I be able to take Velcade again? How handicapped am I by not being able to tolerate Velcade? Does this reduce my future treatment options? **A:** Whether or not you can use Velcade again depends on things such as the seriousness of the problem at the time, whether or not the problem has improved, and the risk factors. Understanding your total cardiovascular function is important. You may be able to use Velcade at a low dose later. If you are not able to use Velcade again, there are many other drug options to consider. I recommend avoiding Carfilzomib because it is known to result in heart issues for some patients.

Q: How far away are we from having each patient's DNA tested in order to be able to derive a customized therapy for each individual? **A:** In some high-risk cases we are already doing this. It will probably be anywhere from two to five years away for understanding what that DNA makeup looks like for each patient and then carefully deciding what drugs can best serve that individual.

Q: When a patient needs to get a DNA profile to get customized therapies, what are the diagnostic tests required? **A:** We can get a lot of data from a bone marrow biopsy and a flow cytometry test. Each time you have a bone marrow biopsy done, be sure to request that Fluorescent in situ hybridization (FISH) is done. That tells exactly what the driving DNA changes are, since over time the MM may change.

Q: What are the benefits of cannabis with THC for a MM patient? Does it help with neuropathy? **A:** Lots of cancer patients use this therapy to help with nausea, and appetite, but don't know if it helps with neuropathy.

Q: Does Emory promote the use of CBD for cancer patients? **A:** CBD is not regulated, and a regulated, medical grade of CBD is currently being worked on. Emory has no official position on CBD but the palliative care group will discuss with patients. The palliative care group is starting a randomized trial for pain and symptom (i.e. sleep, depression, nausea) management and is system-based, versus cancer-based.

Q: Is it normal for any type of drug, not just MM drugs, for the body to become resistant to the drug over time? A: Yes

Q: I have achieved a partial remission and I'm not on any maintenance drugs. How high should my paraprotein level get before treating? **A:** There is no absolute number, and it depends on a lot of things when considering when to begin treatment: how the patient feels, CRAB criteria (what is the total MM burden), and how fast the paraprotein is increasing - the trajectory is important as it shows how aggressive the cancer is.

Q: When a patient is on a drug that is working for a long time and experiences a slight progression, then gets off the initial drug and on a different drug, can they ever successfully go back to the initial drug? **A:** When progression occurs, the assumption is that the MM has changed and then it is no longer going to respond in the same way that it did previously. Generally you can go back to the initial drug successfully: a) if you were using the drug as a single agent, then partner it with another drug, and b) if you were using the drug with another drug, then replace the other drug with a different drug.

Q: Does Emory have statistics on MM drug progression? **A:** Yes, and the biggest change has been with RVD being used as an induction therapy, more MM patients are living longer, particularly those patients who got RVD and then followed with a stem cell transplant.

Q: For those who have exhausted most options, what is next? **A:** We are developing new IMiDs, which are immunomodulatory drugs and continue to provide promise. There are many drugs and combinations of drugs for relapsed and refractory MM. It depends on what the patient has received up to that point, and what we believe will still be effective. We still also use conventional chemotherapy sometimes.

Q: Are you finding any resistance from insurance companies with some of the therapies that you want to bring in despite them being trialed and approved? **A:** I'm not the best person to answer that because my focus is on CTs, but my observation is that it has not been much of a challenge when we've taken data from trial to publications and recommended use for a patient. It may require a few phone calls, but in general, it's not been a huge problem.

Q: Is there CRISPR updates as treatment for MM? **A:** CRISPR is a single gene editing approach and is very promising. This approach where you can edit the gene that is driving myeloma to stop it is amazing. There are two primary patent holders for CRISPR technology, Harvard and University of CA, and they fought in court over who had the exclusive rights to a lot of the technology and the fight continues. A lot of the research is happening in China, because China doesn't follow our patent laws. How to operationalize CRISPR into therapy to use the approach in humans is still very murky. For example, gene editing in animals can actually cause cancer. Research is being conducted and it is still a minimum of 3-4 years away for us to use due to the potential negative outcomes and the regulatory requirements to be put into clinical medicine. There are no CTs in the US at this time.

Q: What is happening with Cancer Moonshot, Biden's cancer initiative, is funding still available? **A:** That funding went into a number of aspects of cancer care. One is making sure that trials that we are conducting are reflective of the population. There is money going into academic universities through granting mechanisms to understand how cancer cells use certain amino acids, and how we might be able to alter that such that they're more likely to die. There are other types of cell therapies that are being funded by Moonshot. Another area is research to use

natural killer cells, which we all have, to fight cancer. The program and funding is nonpartisan and it hasn't died. The change from a democrat to republican president has not affected the moonshot funding. Over time, this administration has had a reduction in funding the National Cancer Institute, their budget was cut, and some of us are going to Capitol Hill in September to try to reverse that trend. We're here for patients and patients get better because of better therapies, and better therapies come from research.
Submitted by Wendy R.

Southside Myeloma Support Group

May 25, 2019

The meeting opened with a moment of silence led by Doris. Doris reported that Pat C. is continuing to heal after her third SCT transplant and is doing well.

Next meeting: June 22, 2019. Topics - Developing Your Survivorship Cancer Plan and Members' Choice.

Many in the group attended the Pat's Myeloma School for Survivorship, which was co-sponsored by the Leukemia and Lymphoma Society (LLS). There was a consensus that there was lots of great information and resources during the two-day event. Some thought it was too long. Others were fine with the two-day design. They shared information from selected workshops on survivorship for patients, financing cancer care, and learning about additional resources.

During the financing cancer care session, attendees learned more about what LLS provides. Several were able to take advantage of the one-time $100 offer for myeloma patients by just calling and identifying yourself as a myeloma patient. The group was reminded that organizations like LLS can run out of funds as they did about three years ago. Some also learned about the once a year funding offered by the Patient Access Network Foundation. (PANF). Every hospital should have a social worker or advocate who can help patients and families apply for different grants. It is important to know the resources available and to use those resources, not to stress unnecessarily about paying for cancer care. Another session that members learned from was the physical therapy session – with presenters from Emory. Many myeloma patients have concerns and issues with movement based on bone involvement from myeloma. This team received high praise from those who attended. Caregivers are a crucial part of optimal patient outcomes. Whether you, as a caregiver, are a spouse, child(ren), or family member, you must practice self-care. Other sessions that people gained from included clinical trials, immunotherapy, and stem cell transplants in myeloma. The consensus was that it was a meeting with time well spent.

Each year, our Support Group makes a donation to IMF, LLS, and MMRF to support their activities. This is how funds from some of our fundraising activities are used. We could never repay what they provide for us, but we can express our gratitude for their programs. Members of

the group contributed an additional $125 to add to the original amount for a total of $275 for the Support Group treasury. Gloria shared that she learned that myeloma could be one the most expensive cancers – as a chronic disease – to treat.

Jameca addressed the group and shared that after a discussion with Doris, she decided she would be taking a break from attending Support Group meetings to use her talents in other pursuits. She will not be leaving the myeloma world but has an interest in the fundraising side of activities. Jameca was the youngest of our members at diagnosis of her myeloma in 2003 at age 28. She has been in remission since 2004, and on no medications for myeloma since that time. She hoped that she had made some meaningful contributions during her time with the group. Members assured her that they were very appreciative of all she had done and wished her well in whatever she decided to do. Jameca has brought many activities to the group, the latest of which was the Belk department store ticket sales.

Our April speaker from Takeda was unable to attend. We will get her rescheduled. Her topic was to include the importance of each cancer survivor having a cancer plan. Before Elizabeth Carter comes to speak, we should all get a head start on creating our own Cancer Plans. The Plan would include important dates and treatments during your journey, some strategies for wellness and stress control, and would help to identify whether subsequent signs and symptoms might be related to your cancer (e.g., secondary cancers). Vermell will provide us with a template of a Cancer Plan to get started.

Deborah shared that she had invited a speaker, Hazel Jackson, MD to come to speak about palliative care. She was unable to come due to a family circumstance. The discipline of Palliative Care continues to be misunderstood by both professionals and patients and families. We will get Dr. Jackson on our schedule at her earliest convenience.

The Group was encouraged to read their newsletter each month. Of particular note in the June 2019 newsletter was speaker/pharmacist Dr. Harvey from Emory at the northside Support Group meeting. There are a series of important questions with responses in that newsletter. We reviewed of few of those topics.

Announcements/Resources/Upcoming Meetings

- **Light the Night** – the annual LLS awareness and fundraising event will take place this year on October 5 at Piedmont Park. Cynthia and Alma talked about what a beautiful event it is for the entire family. Look for more details to come.
- **CONQUER** – Cancer and Obesity. About 40% of cancers are associated with obesity. The NCI has identified about 13 cancers that show increased risk with obesity, including breast, endometrial, gall bladder, and multiple myeloma.
- **LLS – Who Gives to the Caregiver?** Archived—ready for viewing. https://www.lls.org/patient-education-webcasts/who-gives-care-to-the-caregiver. For a copy of the transcript and the slides, call (800) 955-4572. Also, Car-T Cell Therapy in children and adults (Jan 2019) available for viewing.
- **IMF –** Amazon donates 0.5% of all purchases you make to the IMF when: You shop at smile.amazon.com, AND You designate the International Myeloma Foundation as your preferred charity. All donations are made at no added cost to you! It's that simple

- **Free rides to doctor visits**. Patients seeking the free rides can coordinate with the American Cancer Society by calling 800-227-2345 or visiting www.cancer.org. ACS will then use the Lyft Concierge service to arrange a ride

Respectfully submitted, *Gail*

Respectfully submitted, Gail