May 2018

# Northside Multiple Myeloma Support Group Meeting
# May 5, 2018

## Business and News

Thank you to Jim M. who led the meeting. A nutritionist will be the guest speaker at the June meeting. Please note that the last meeting at the current location will be on June 2nd. A new location at another church very close to our current location has been confirmed for meetings beginning with the July 7th meeting. More detailed information on the new location will be provided soon.

Guest Speaker
Thank you to Dr. Harvey, Director Phase 1 Clinical Trials and Pharmacist at Emory, who joined the meeting to collaborate with us. Dr. Harvey explained that Multiple Myeloma (MM) options are growing with continually better options. Clinical trials (CT) provide care through research and are the means to get new treatment options to patients. We are very grateful to the patients who participate in CTs and many of our group members have been a part of CTs. Dr. Harvey was complimentary of the group and mentioned that he has been impressed with our organization and knowledge; and our interactions with each other that are very important from an advocacy perspective. The discussion was very interactive, and the group had many questions which Dr. Harvey answered, as follows:

Q: Please comment on the cost to patients who participate in CTs. I have not participated in a Phase 2 CT that I wanted to join due to the cost. These costs are in the form of insurance co-pays and the cost of the drug itself.
A: Cancer CTs are different from other types of CTs. A main difference is the out of pocket cost to cancer patients who participate in CTs. Costs to the patient may include insurance co-pays, drug costs, transportation, and parking. Sometimes these costs are covered but not always. If you cannot afford to participate in a CT you are urged to contact the drug company and your medical team for support. There are co-pay assistance and grants programs that can help. This issue has been raised with the FDA, with requests to lower drug prices, but historically the regulatory agencies have never managed drug prices, only safety.
Q: Why are some patients paid to participate in a CT and not others?
A: Healthy volunteers in CTs may be paid for their time. Cancer patients who participate in CTs are seen as vulnerable participants and there is a historical fear that paying them to participate may be seen as a form of coercion, so it is a matter of research ethics. Some drug companies will pay MM patients who participate in their CTs.
Q: What can a patient expect from a MM treatment coverage perspective when moving from private insurance to Medicare?

A: It depends on the Part B supplemental insurance that is selected. The coverage is often similar or better. The median age of a MM patient is 67, so most MM patients are already on Medicare.
Q: Please comment on CAR-T trials. What is the CAR-T process?
A: MM is a good disease for T-cell therapy because the B-cell maturation antigen (BCMA) is only made by MM cells. A MM cell was a normal B-cell that went rogue and it should be no different for the body to fight than any other virus. The body should recognize the rogue cell and kill it. The process: 1) Collect t-cells, 2) Teach the cells to target a certain protein, 3) Grow the cells in a culture, freeze, and send to patient, 4) The patient receives chemotherapy to get rid of cells that would challenge the new cells that will be introduced (i.e. make the environment more favorable), 5) Return the treated cells to the patient to fight the disease. The initial goal is to get the "soldier" cells to populate for the initial onslaught of the rogue cells, and then to act as a police force to guard against a return of the rogue cells. Cheri L. who had plasmacytomas and bone involvement commented that her experience with this type of treatment was positive. Side effects included fever and low blood pressure. The painful lesions on her head and skull (plasmacytomas) were gone after a week and she achieved remission in three weeks, which she thought would take months. Cheri was hospitalized for two weeks for monitoring, which included neurological testing. She said that her experience was generally better than she expected and that the side effects were not too bad for her. Dr. Harvey mentioned that there have been some severe side effects for some patients including fevers, agitation, and a depletion of good B-cells that fight bacterial infections. IVIG and antibiotics are used for supportive care when receiving this treatment.
Q: How many patients have received CAR-T treatment at Emory?
A: Currently, Emory has treated four MM patients (fifth in process) by taking their own T-cells, re-engineering, and applying the cells back to the patient. There have been approximately 50 Lymphoma and Leukemia patients who have received this treatment at Emory. The treatment is very new but appears to be promising. The CAR-T approach originated from not for profit academic centers, not drug companies, the same way that the stem cell transplant (SCT) approach originated.
Q: What are the criteria for receiving the CAR-T treatment?
A: The patient must be in good general health. To prepare, the patient must be able to have a period of time where no treatment is applied for an extended time. This treatment is not for everyone but there is no age limitation.
Q: Ideally, how would this treatment be used in conjunction with other available MM treatments?
A: Ideally the goal is for CAR-T to replace all other treatments. The long-term surveillance strategy appears promising.
Q: How do you know if the treatment is successful?
A: Initially, the patient is followed for months after the treatment. Side effects and the disease are measured early and often. The patient continues to be monitored for an extended time after the initial monitoring period.
Q: Is CAR-T treatment used as a first line treatment?
A: No. It is being used at any time after multiple treatments have been tried and failed.
Q: Does CAR-T treatment work for high-risk translocation and relapsed patients? Is the

efficacy of the treatment understood with all of the variations?
A: There is not enough world-wide information known yet. We are just defining more sub-types now and there is an evolving understanding of the treatment for low and high-risk patients. We currently are primarily concerned with not over or under treating anyone.
Q: What is CRISPR?
A: It is an acronym – Clustered Regulator Interspaced Short Palindromic Repeats. CRISPR is a genetic editing and profiling approach being researched. There are a lot of ways to use this evolving technology. One way is to find ways to accelerate the death of cancer cells or to re-engineer cancer cells so that they do not create the protein that helps cancer cells live. We may find ways to be able to do this with or without drugs. There is a lot of genetic data that is still not understood.
Q: Does chromosome 13 and 14 deletion usually go together?
A: It can occur, but generally does not.
Q: Will we get to a point when we can target specific MM mutations and treat with targeted therapies?
A: Yes, and we can currently do this already with some other types of cancer. With MM there are a lot of variations which are still not fully understood.
Q: Is there a cure for MM?
A: Yes, it is possible. In the meantime, it can be treated as a chronic disease. For example, for other conditions (i.e. high blood pressure, high cholesterol, etc.) we administer drugs to control the condition, rather than cure. With MM we need to be able to better tolerate the side effects of the drugs that control the condition
Q: Will we ever treat MM before we actually get sick with a full diagnosis of MM?
A: We know that smoldering MM is more likely to progress. We also know that a condition of MGUS is too early to treat because only 3% of MGUS patients progress to a MM diagnosis. There are drugs that are known to be well tolerated when there is a low amount of disease which could be used to treat the disease, i.e. such as an early surveillance strategy.
Q: What are some of the CTs that show promising results?
A: There are many. 1) CAR-T, 2) cellular therapies, 3) Daratumumab and immunotherapy, 4) targeted therapies, 5) new “IMiDS”, 6) Selinexor (tough to tolerate).
Q: I’ve been on Revlimid for maintenance for 8 years. When should I stop?
A: The standard response is that you should stay on the drug until it no longer works for you. The same standard response is the same for CTs.
Q: Why would someone stop a CT?
A: There are several reasons such as: 1) the patient withdrawals consent, 2) either the patient or the medical team does not want the patient to continue, 3) the drug is not working for the patient.
Q: Is Daratumumab a maintenance option post SCT?
A: Yes, Daratumumab is an immunotherapy and there is a study being conducted for subcutaneous administration.
Q: What is known about the new Shingles vaccine?
A: The new Shingles vaccine is a non-live vaccine. Be sure to ask your doctor if and when you should receive this vaccine. Vaccines are not effective when given just after a SCT because B and T cells are needed to make the vaccine work, and these cells are

depleted during a SCT.

Submitted by Wendy R.

## Southside Multiple Myeloma Support Group Meeting
## May 26, 2018

Doris opened the meeting with a moment of silence.

The agenda for the May meeting was a check-in of patients, caregivers, and supporters. There was one new member, **Candace**. Candace was diagnosed in 2013 by her primary care physician during her annual physical exam – finding extra protein in her urine. She is being treated at the Atlanta Cancer Center, Jonesboro, GA. She started on a clinical trial 2-3 months ago.
**Evelyn** is scheduled for a PET scan and a bone marrow (BM) biopsy in July. She continues to take Zometa every three months.
**Geraldine** was diagnosed in 2012, and still has not had the transplant she was told she needs. She has discussed her dilemmas with the staff at Northside Hospital. They told her they could not performs the SCT until she has someone who will bring her and take her home each day for about 14 days. She was denied residence at the Hope House (American Cancer Society) because of the mileage requirement. She does not have a caregiver. The group strongly encouraged Geraldine to put her health first. The SCT could save her life. Some suggestions: Get social workers involved – from Northside and from Kaiser; inform staff that she will get a consult from Emory – see about having the transplant there. She must find her strong voice and provide a progress report at the June meeting. Meanwhile, she is on Kyprolis and pomalyst –not tolerating it well. She has been sick since January – being treated for the flu.
**Janice** was diagnosed in 2012 – and has gone through all the drugs. She is currently on Darzalex and pomalyst with good results so far. Insurance would not approve a "booster" drug because she did not display classic symptoms. Side effects of Darzalex include tiredness and itching. She spent 24 hours in the hospital for first and second treatment.
**Vena** was diagnosed in 2007 and was treated with the standard Velcade, revlimid, and Dex (VRd). She is currently in remission with her MM and continues to be monitored. Vena has been fighting an additional cancer over the past two years. She has been diagnosed with stage 4 lung cancer that has spread to her liver. Her sister has been a tremendous help, giving the injections she needed each morning to build up her white blood count. Vena has never smoked cigarettes, and vetted her boyfriends based on their smoking habits. Her work has included bus operator and in clothing stores. She has learned being treated for one cancer does not protect you from other cancers and there is a delicate balancing act for the drugs used in treatment. She is taking the drug Opdivo – and it has made a tremendous difference in her quality of life. Vena is being treated at Kaiser.

**Doris** was diagnosed in 2004, and a BM biopsy showed she had 30% myeloma cells. She was treated at Atlanta Oncology, and Dr. Collins, before going to Emory where she has been for more than 10 years. She was treated with Thalidomide, was in remission, and is now on Revlimid for maintenance.

We will soon update the website. Everyone please send any pictures you have from the past 2-3 years of Support Group activities. We do need to get consent forms from everyone to post their pictures on the website. Gail will look for a consent form on the IMF website.

We discussed the COMMpass study led by the MMRF. This is a landmark study on genomic and myeloma. Newly diagnosed MM patients were followed for eight years – participants were ages 27-93 years. Participants were 67% male and 16% African American. Some questions being answered by this study (which will advance personalized medicine) include: the role of transplants in treatment; the role of triplets vs doublets; and high-risk disease. Significant differences were identified between black and white MM patients with respect to mutation frequencies of key cancer genes. There will be a webinar on the COMMpass study in June.

**Announcements, Upcoming Events:**

· Complete surveys == for patients who have taken the drug Ninlaro[G1] . The company is the Endeavor research group. The incentive for completion of the survey is $150.00 Amazon gift card. https:www.research.net/r/MM_Pref_Survey_W1

· **LLS.** Patients and Caregivers may get one **FREE Nutrition consult**. Call 800.955.4572 and provide your contact information.

· **IMF. The importance of bone health in myeloma treatment**. Wednesday, June 20, 2018. Webinar. Replay now available at replay.myeloma.org and look for June 20.

· **IMF. Stand up to Cancer (SU2C).** A new myeloma project to model the MM study in Iceland where all residents of the country are participating. This study is for African Americans 45 and over with first degree relatives (mother, father, sister, brother) with MM. The study kicked off in April 2018. Stay tuned for more details.

· **Fourth Annual Homecoming Celebration**. Portia's church. Edgefield Baptist Church, 140 Church Street, Fayetteville, GA 30214. June 3, 1:00 – 5:00 PM. Music, jazz, gospel, jewelry…vendor space available. Bring chairs and tents. Portia's church has been extremely supportive of the Group and with donations. We have provided awareness materials during this event in the past.

· **Community Health Fair**. William Walker Recreation Center. Saturday, June 9, 10:00 – 2:00 PM. 2405 Fairburn Road, Atlanta, GA 30331

The **question for the day** was to discuss briefly a proteasome inhibitor. Dr. Durie has created a series of six short webinars on understanding proteasome inhibitors. They were created for physicians but are available to all. This series is part of the effort of the IMF (International Myeloma Foundation) to provide educational opportunities for physicians who are not myeloma specialists. You may find this series on the IMF website – www.myeloma.org

Respectfully submitted, Gail

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.