

February 2017

**Northside Multiple Myeloma Support Group Meeting
February 4, 2017**

Meeting Notes

New members –

Roger was diagnosed June 2016. It was the first time he had heard of Myeloma. He had nosebleeds, pain, and swollen legs. When his doctor told him that he had cancer, he asked his doctor to leave the room and come back in with a better approach! He is considering a transplant, but does not have a caregiver.

Marc was diagnosed four years ago with high risk smoldering MM. He had to learn what an M-spike was! He is on Revlimid and the plasma cells in his bone marrow went from 40% to zero.

Willette “chased” a diagnosis for a year and a half. She is on Rev/Vel/dex and got diabetes from the dex. She had a transplant in December and has peripheral neuropathy. She is having GI side effects and lost a lot of weight.

Dirk was diagnosed last fall after losing seven inches in height. He had 15 compression fractures and 14 kyphoplasty procedures in two sessions. Those procedures, along with radiation, have reduced his pain level. He is planning on a transplant, but needs to gain weight and strength before starting that process.

Dr. Sohl and Kathy McNatt visited from Northside BMT. Dr. Sohl gave an overview of myeloma and it was good to hear a synopsis from a new point of view. The bone marrow is the factory for red blood cells, white blood cells, and platelets. The reds, whites, and platelets all have a purpose and they all start from immature stem cells in the bone marrow. The white blood cells are the body's army to fight infection. Within the white blood cells are the plasma cells to fight infection. They leave the bone marrow and go to the site of the infection. At the site, they secrete immunoglobulins that tag the infection for other cells to attack. Myeloma (MM) is a cancer of the white blood cells and plasma cells. When a person has Myeloma, they lose the line of defense against infections that the white blood cells provide. We don't know why MM happens. There are a few toxins that are known, such as Agent Orange, but 98% of patients are not exposed to the known toxins. Cancer cells don't know how to perform their assigned function and divide faster than normal cells. In the bone marrow, excess plasma cells push out other cells which results in anemia from the lack of red blood cells. The cancerous plasma cells secrete abnormal proteins that are hard to process through the kidneys and cause problems there. The abnormal plasma cells also secrete inflammation markers that impact the bones causing lots of fractures. If a patient presents with one or more of the markers, then the MM may be caught before serious damage is done. The first step is to assess the MM with bone marrow biopsy, blood counts, check bones, and kidney status. These base measurements are used to track progress throughout treatment. The first decision is if the patient is eligible for a transplant. This is based on general fitness, age less than 80, and any other health conditions, such as heart or lung problems. Induction therapy starts first, with a goal of reducing the MM by 50% or more. Revlimid/Velcade/dex is most common with good results since a three-drug

combination is better than two drugs. After 4-6 rounds of treatment, the transplant process hits the MM harder with a high dose of chemo, which has shown to give a longer survival. The high dose chemo during transplant kills all stem cells, but stem cells are re-introduced from the harvested cells to re-grow the bone marrow. Ten years ago, a transplant was done and that was it. Now maintenance is used to retain the remission for longer periods. A transplant can give remission for 2-3 years, but with maintenance, remission may last 4-5 years and maybe longer. Years ago, there were few options on relapse, but now there are many choices for treatment. For many years, melphalan was the only chemo used during transplant and about 30-40% of patients obtained a complete remission (CR). Now is time to try to improve the outcome for transplant patients. Some centers are using four drugs over 5-6 days prior to transplant to get CR up to 40-70%. In the bone marrow, lymphocytes attack abnormal plasma cells. But with myeloma, the lymphocytes are not strong enough to control the cancer. One option is to extract the lymphocytes and activate them to increase their numbers and re-introduce them with the stem cells, after the melphalan. Only Northside and Johns Hopkins are doing this trial to use the immune system against MM during the transplant process. Over the years, there has been very little change in the transplant process, so now it is time to work to improve results.

With relapsed MM, there are many new options for treatment. Consideration should be given to evaluate side effects from previous treatments and the patient's general health status. A combination of multiple types of drugs will attack the MM on several levels to get it back under control.

Q – Does Velcade given subcutaneously (sub-Q) have less side effects? **A** – Yes, most people are getting Velcade sub-Q to reduce side effects.

Q – Why is Cytoxan now being used? **A** – Cytoxan is an older drug, but is still very effective. Cytoxan/Vel/dex vs. Rev/Vel/dex is giving about the same results and is a good alternative if problems with Revlimid.

Q – Should Ninlaro be given instead of Velcade? **A** – Ninlaro has been shown to have less peripheral neuropathy than Velcade.

Q – What is the difference between auto and allo transplants? **A** – An allo transplant (stem cells from a donor) is higher risk. For an allo transplant, 15% are not alive at one year. For an auto transplant, no one had died at Northside in several years. An allo transplant creates a new immune system that can destroy the cancer, but there is the challenge of graft-vs-host disease. After a transplant relapse, determine the success of previous treatments. If relapse occurs within one year of transplant, there is no point in a second transplant. In that case, an allo transplant could be considered. There are also the new mono-clonal antibodies that use the immune system to attack the myeloma cells. Used in combination with Revlimid, an immune booster, the results are very good.

Q – What about a patient with low blood counts? **A** - Wait 60 – 120 days and do a bone marrow biopsy to see the level of MM. If normal, stay on low dose Revlimid, which can go down to 2.5 mg. Lower doses are shown to still be beneficial. Try other medications.

Q – Is the goal to get to MRD-negative? **A** – There are two types of MRD tests: NGS: next generation sequencing and NCF: next generation flow, which is used by more centers and is less expensive. Both require a bone marrow biopsy.

Q – I have never had a MRD test. Will that be a problem in tracking my disease? **A** – You can get an MRD test at any time in your treatment. MRD may not change treatment decisions at this time, but it may give an expected remission. MRD-negative is showing an average of six years before relapse.

Q – If a patient is high risk, does it matter if they are in complete remission? **A** – Yes, a deeper response will do better, but high risk patients need to be followed closer and with more aggressive treatment.

Q – Does a bone marrow biopsy hit spots where there is no Myeloma? **A**– Myeloma is patchy. We used to do two biopsies at once, but that is hard on the patient. With MRD, it is a more sensitive test so we just need to get one cell. They are working on a MRD blood test.

**Southside Multiple Myeloma Support Group Meeting
Saturday, February 25, 2017**

Meeting Notes

Doris called the meeting to order and led the group in a moment of silence. There were 14 members present.

We welcomed one new member, Marian who reported she is doing well. She was diagnosed in 2013 then was treated through 2014, and has been in remission for one and a half years. She is currently not on any medication. Marian was diagnosed after severe back pain and was treated at Northside's Georgia Cancer Care in Fayetteville. She says she had a brother who also was treated for a blood/bone disease in 1990 and required routine blood transfusions; they were never sure of his diagnosis. Another younger brother also has multiple myeloma. There were seven children in the family and she and her brothers were the youngest. They moved to a home that her father built for the family in New Jersey; older siblings did not live in the home or were not there long term. She suspects there may have been environmental contaminants that may have influenced the development myeloma for her, her two brothers...or is it genetics? Because of her brothers' experiences, she was encouraged to get screening which resulted in early diagnosis of MM.

Our Speaker for March will be Victoria Collier, Certified Elder Law Attorney, who will address the following topics: Paying for Long Term Care, Don't Go Broke in a Nursing Home, Estate Planning & Elder Law and more. Bring your questions.

Business: Gail- Caregiver Forum and Appreciation event, Saturday, May 20, 2017 8:30 am— 12:45 pm. A nice lunch will be provided -- as well as lots of great resources for Myeloma Caregivers and patients. Register Early!!! Space is limited to first 60 Caregivers and Patients. The event will be held at the Atlanta Metropolitan State College, 1630 Metropolitan Parkway SW, Building 800, Atlanta, Georgia 30310. Registration is free but required. Takeda and LLS are co-sponsors for this event. Everyone with their address in our data base should

have received the Save the Date Flyer. You can register on line at <http://tinyurl.com/caregiver2017> or call Tricia Hernandez at 404-720-7838.

The Atlanta Alumnae Chapter of Delta Sigma Theta Sorority will have its annual Health Fair on April 22nd at Greenbriar Mall from 10:00 am to 2:00pm. We need volunteers to pass out literature and share Myeloma information with the public. Lunch from Chick-fil-a will be provided to those at the table at lunch time. If you are interested in volunteering for any amount of time between 10-2:00 please contact Doris at 404-346-7213. Deborah also announced that the Atlanta Alumnae chapter of Delta Sigma Theta Sorority will honor Shirley Caesar at its Celebration of Women: "Saluting Women Who Have Risen to the Challenges of Our Changing World" Celebration of Women Awards Luncheon and Silent Auction on April 8, 2017, 11:30 A.M. Renaissance Concourse Atlanta Airport Hotel, One Hartsfield Centre Parkway Tickets @\$70 Self- Parking - \$3. Contact Deborah if interested at dat1stvicepres@gmail.com

Gail shared an article from the AJC on Cancer Treatment Centers of America (CTCA, AJC 2/23/2017). CTCA has appealed to legislators once again to allow more Georgia patients to come to the for-profit, cancer-only 'destination hospital.' Georgia Hospitals are against this because CTCA is allowed to cherry pick patients with great insurance – leaving other hospitals to shoulder expenses of those who are uninsured or underinsured. Some records show that CTCA has 83% (versus 28 % for other hospitals) of patients who had high paying private insurance. CTCA has been open in Newnan since 2008, and received an exemption to the state's Certificate of Need (CON), based on their proposal as destination hospital, that would draw more than 65 percent of its patients from out of state – to help control costs. In 2015, CTCA employed more than 24 lobbyists to wine and dine legislators to help change the law (AJC, 9/10/2015). It failed. Georgia Hospital Association asks that CTCA go through same process as other hospitals if they want a rule change.

Member Updates

Meriel reports she is doing very well and is still in remission. She was diagnosed in 2004, and given 3-5 years to live, but I am still here!" Her dosage for Revlimid was reduced from 25 to 15 mg.

Kimberly and her husband John were both present –both have been sick with some upper respiratory problem - some version of the flu. They have been caring for a 6 month old which may be a contributing factor. Kimberly reported she had her 4 month check and is still in stringent complete remissions. She says she is still anemic and raised a question about the possible relationship between her persistent anemia/sickle cell anemia (C—trait) and maybe the Stem Cell Transplant or the myeloma itself. Kimberly says she was told in high school she had the sickle cell C-trait and she was anemic. She questions if her myeloma was in her system when she was very young and presented as a symptom via anemia. She will raise question with Dr. Kaufman. An additional note is that the "science" for sickle cell disease has advanced – medication can help with the sickled cells, and survivorship and quality of life have been much improved.

Larry reported he is recovering from pneumonia and sepsis; he was hospitalized for more than 2 weeks with these life-threatening health issues. He said Karen, his wife, had urged him to go

to the emergency room, call the doctor but he refused. Larry's current treatment regimen includes Daratumumab/Darzalex, Dex and Revlimid 21 days on 7 days off (may be 25mg). Larry's message is to have symptoms evaluated as soon as soon as you notice something different and "*listen to your wife*" when she tells you to go to the doctor.

Vermell, our oncology nurse consultant, commented on how serious and life threatening these conditions can be independent of each other. She commented both pneumonia and sepsis are extremely dangerous and can be fatal.

Deborah, nurse practitioner and oncology nurse with VA, recommends annual exams for all. She reported that she was having joint pain and reported to her primary doctor. Tests revealed she had Vitamin D deficiency. She was prescribed high dose Vitamin D treatment for 2-3 months. Debra reported she no longer has joint pains. *Note: The IMF recommends Multiple Myeloma patients get tested for Vitamin D deficiency and treated if needed.*

Gail suggested we should have someone come to speak on Vitamin D. There is a research project at Morehouse School of Medicine focusing on the benefits of Vitamin D and possible links with diseases such as hypertension.

Alma –says she is doing well-she is on Daratumumab/Darzalex given slowly and Pomalyst (2 mg). She says larger doses of Pomalyst caused some breathing concerns. Alma is having tooth and jaw pain. Alma says she completed paper work to seek payment support for Daratumumab. She takes all her past lab tests to doctor's appointments in a notebook.

Janice is feeling good and in November 2016 was told she was in remission for the first time since her diagnosis. In January, she had some spiking but is not on treatment. Pomalyst gave her respiratory problems. She is scheduled for knee replacement in March. Janice reminded us that Geraldine lost her father and will go Jamaica to bury him this month.

Gloria-doing very well she and sees the benefits of having all of her doctors in one place and she follows her results through the patient portal. She also tries to eat right and exercise regularly.

Pat had her 3 month check is doing well; she is on only one medication - Zometa (quarterly); she is 11 years post-transplant and is in remission. She has some back pain- doctor says it is arthritis and she is scheduled for a bone scan to authenticate. Comment: regarding sepsis Pat says when having oral surgery be very careful.

Doris reported Harold fell and is rehabilitation at a facility on Butner Road. Harold has Parkinson's and MM. He welcomes visitors but call ahead as he is in regularly scheduled therapy. Call before visiting. Doris says she has accessed Celgene's Patient Assistance program to help her to pay for Revlimid.

Gail is doing well she says her insurer changed her pain medicine from oxytocin to Xtanzia. (We were told by health care provider (HCP) that Xtanzia is essentially a re-packaging of oxytocin to try to avoid the abuse and theft of the medication.) Her insurance company (United Health Care) announced they would no longer pay for the oxytocin and listed Xtanzia as a possible replacement. It has been hard to find but she finds it at Walgreens inside Piedmont Hospital. Gail is on 4mg Pomalyst, 3 mg Ninlaro and 4 mg Dexamethasone. Gail was recently diagnosed with Vitamin D deficiency and was placed on 50,000 IUs once per week for 8 weeks. She is going monthly for labs and has had some edema, back pain and breathing concerns.

Be sure to make regular visits to your primary care provider, even as you go through cancer treatment.

All should remember that there is assistance to pay for medications through patient assistance programs with the pharmaceutical companies (e.g., Celgene, Takeda), and through LLS. We have to seek out ways to help with the expensive cost of care.

March is Myeloma Action Month; Alma is coordinating these efforts. Our focus will be to get word out in churches, seven members pledged to provide information to their congregations. In addition, we will air a Myeloma radio interview on the Clark Atlanta-radio station. We encourage members to wear myeloma buttons and share information with those we meet.

Thanks to Gloria who helped sell most of the inventory of IMF hats, T-shirts, etc. This provided more revenue for our Support Group's treasury.

Announcements/Resources/Upcoming Meetings

- The Power ...and the fear of Knowing your Cancer Genome. Wisdom from Kathy Giusti, MMRF. Her bone marrow first analyzed in 1996 -- conducted FISH test, and determined to have t(4;14) which means parts of two chromosomes had switched (Translocated) places. This is a very aggressive form of MM. It also helps now to determine type of precision, targeted therapy to use. We must build knowledge by sharing data in same spirit as CoMMpass Study -- to get to a cure faster. Clinical Medicine, academia, biotech and pharmaceuticals must work as a team -- and partner with diagnostic companies and insurance companies to pay for tests. Share information through CoMMunity Gateway, MMRF.

Multiple Myeloma Classes of Drugs/Therapies:

1. Proteasome Inhibitors- *Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib (Today's answer)*

2. Immunomodulating - Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst

3. *Monoclonal Antibodies - Daratumumab/Darzalex; Elotuzumab/Empliciti

4. Histone Deacetylase - Panobinostat/Farydak.

*New agents - Farydak, Darzalex, Ninlaro, and Empliciti

Respectfully submitted by Paulette and 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.