

**September 2017**

**Northside Multiple Myeloma Support Group Meeting  
September 9, 2017**

**The September meeting was our annual luncheon, a special time to get together and visit with our friends in the group. The luncheon was held at The 57<sup>th</sup> Fighter Group Restaurant in Chamblee, next to the Peachtree-DeKalb airport. We celebrated the 20<sup>th</sup> anniversary of the Atlanta MM Support Group. Cathy and Andy Lebkuecher founded it in August of 1997. Cathy was diagnosed with MM and had a bone marrow transplant, not stem cells! When diagnosed, she had lost several inches in height and had severe back pain, but was a strong and energetic person who wanted to make a difference. Andy tells us that the first meeting had only six people there, so we have come a long way! Cathy passed away in December 2006 and Nancy took leadership of the group in January 2007. We are all so grateful for Cathy's vision and drive to help MM patients in Atlanta. She also helped Doris Morgan start the Southside group in 2006, which continues as another tribute to Cathy's legacy.**

**Our speaker at the luncheon was Deborah Cook, Clinical Nurse Educator for Takeda. She spoke about survivorship and shared her personal stories. Survivorship starts from the day someone is diagnosed with cancer until the end of his or her life. At this time, there are 15 million survivors from all cancers. That number is expected to grow to 20 million by 2024. For those diagnosed with Myeloma, we are fortunate to have so many options for relapse. There are so many new drugs in the pipeline. This brings hope to so many families. But survivorship is not just about the treatment. It is also**

about those factors that have changed since the diagnosis: physical, psychological, social, work, intimacy, spiritual, etc. These changes affect the overall quality of life. It affects the ability to function on an acceptable level. Discuss these issues with your family and your doctors. Communication is critical. Do not be afraid to get anti-depressants for a short period to get up and be your best advocate. There are short term and long term effects that need to be discussed. Patients should get a Care Plan from their healthcare team. CMS will require it soon for all survivors. Search for “Cancer Survivor Care Plan” to find suggestions on how to make a plan. You are in charge of your wellness!!

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### **Southside Multiple Myeloma Support Group**

**September 23, 2017**

Doris opened the meeting with a moment of silence. There were 19 persons present. We had one new member, Bernard. He attended the meeting with his wife of 37 years, Mirian. Bernard is a good friend to Doris' son. They both had many questions for the group.

**Patient Updates:** Doris provided an update on patients who were not present. Sandy is doing better with pain management for her back. She still is not able to get out much.

Pat C. has had a relapse after 11 years in remission and is on no treatment.

Alma's niece has been very ill and has been in and out of intensive care over the past several months.

**Vermell has had family health challenges.**

**Dorothy C. was hospitalized with heart issues.**

**Harold is doing well at rehab facility. Please keep all of these members in and their families your thoughts and prayers.**

**Bernard was diagnosed with stage 3 Multiple myeloma. He had problems with his kidneys, which led him to have further test. He will begin treatment this week with Dr. Carr at Piedmont/Fayetteville Cancer Specialists. Though this facility is convenient for visits, he was encouraged to seek a second opinion and/or collaborative treatment with Myeloma specialists locally, since we do have that resource. Specialists in Myeloma, not just cancers, are more likely to be current on new drugs, regimens, side effects, clinical trials, etc. Bernard said that they had tried to get an appointment with a member of the Emory myeloma team, but has not been successful yet.**

**Those present briefly shared their myeloma journey for Bernard's benefit.**

**Kimberly was diagnosed in 2008 and had a Stem Cell Transplant (SCT) at Northside Hospital. She was announced in Stringent Complete Remission (sCR). She is currently on no medications. She did not tolerate Revlimid (Rev) well—and is being treated by Georgia Cancer Specialists.**

**There was a discussion about the process of a SCT to help allay any fears and respond to concerns from Bernard and Mirian. People have had many different experiences during their SCT as expected. Vermell (nurse practitioner) shared that experiences are based on the physical condition of the patient. She shared that infections can be the greatest cause of death in cancer, further**

underscoring the need to pay attention to potential sources of infection, including handwashing.

Larry was diagnosed with myeloma in 2012 after a car accident. He is being treated at Emory Winship by Dr. Kaufman. He stressed the importance of staying as active as possible. He is being treated with Daratumumab, with infusion once a month. He also takes Rev (oral) 25 mg. 21 days on 7 days off in each 28-day cycle.

Alma was diagnosed in June 2006, had a SCT in 2008. She has participated in a Dara clinical trial, and is now on Dara, Pomalyst and aspirin.

Glenda was diagnosed in 2015, had a SCT in 2015 and is still in remission. She is on maintenance therapy of Rev- 10 mg and monthly Zometa.

Doris was diagnosed in 2004, started treatment with Thalidomide, and harvested cells 13 years ago. She selected not to have a SCT. She is now on Rev – 14 on/14 off in 28 day cycle and Dexamethasone (Dex) - 8 mg.

Gail was diagnosed in 2008 after having severe back pain over several months. She went through 4 cycles of Velcade/Rev/Dex, was able to harvest cells, and had SCT in 2008. Following SCT, she was in near complete remission for almost seven years. She is now on a 28-day cycle of Ninlaro (oral), Pomalyst (oral), 325 mg aspirin, Gabapentin/Neurontin for Peripheral neuropathy (PN), Acyclovir (to prevent shingles) and pain medication. She is being treated at Emory Winship.

Portia attends most meetings as a friend and supporter. She is a caregiver by profession and by choice.

Selina was diagnosed in 2009, and had a SCT. She was on maintenance for 4-5 years – participated in a clinical trial with Rev. The trial had three arms – Rev, Rev and Dex, and tandem transplants (back to back transplants). She is being treated at Northside. She has had dosage reduced with Rev several times due to

side effects,

In general, the group said to attend an orientation for SCT. If one is not offered, ask for a one to one detailed orientation, write down questions and concerns before your appointment, and ask the doctor and healthcare team about any concerns. Mentally and actively prepare for medical appointments, and continue to communicate with primary care doctor and any other specialists you might have.

Members in this group are at all stages in their treatment.

Deborah (nurse consultant for Group) talked about the importance of Advocacy. Pay attention and get involved where you can. Two things to look at include pre-existing conditions and placing caps on treatment costs. Families are losing savings, houses, etc. with private insurers. Bernard said he is glad to meet everyone and glad to know he is not alone.

- FDA closed down clinical trial. The CAR-T approach to therapy for MM – masking immune T-cells allowed the T-cells to attack, not just MM, but also critical normal tissues, including lung, liver, thyroid, and heart, unacceptable toxicity. Three Novartis keytruda (pembrolizumab) trials were stopped due to unexpected deaths. These are PD-1/PD-L1 inhibitors combined with Imids (Revlimid, Pomalidomide). A hold was placed on 5 Celgene clinical trials. A partial hold was placed on trials with PD-1 inhibitor, Opdivo (nivolumab) by Bristol-Myers Squibb. Any patients on these trials should review next steps with provider. Immune system for MM is different from that of melanoma – huge success with keytruda. This is major setback in research for patients and drugs.

- Hurricane Harvey – Houston. Cancer- causing impact. More than 2 dozen

Superfund sites and 40 petroleum and chemical plants increased levels of cancer-causing agent benzene. Benzene linked to MM causation for over 50 years.

- IMWG – Consensus on success of ASCT in upfront therapy. Unfortunately, many MM patients in US do not opt for transplant. US must work harder to store cells for later use; MRD negative is superior in remission duration.

Questions – should this group continue therapy; prior therapies influence what next therapy works better. High risk patients do better with Elotuzumab. Dara+ Rev or Dara + Velcade – and low dose dex; Cost of MM therapy is ongoing concern.

Closing comment came from Alma. *“Be helpful when you see a person without a smile. Give them yours.”*

*Respectfully submitted by Gail M.*

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.