

February 2016 Northside Meeting

New Members

Donna was diagnosed with MM in September 2015. She completed Revlimid, Velcade, and Dex (RVD) induction therapy with great results and was in the process of preparing for a stem cell transplant (SCT) when she was diagnosed with kidney cancer in early February 2016. She is currently holding off on the SCT in order to have the kidney cancer treated, and then expects to resume plans for a SCT. Donna mentioned that her MM diagnosis was resultant of having a CAT scan performed for a kidney stone. **Bill** and his wife **Marilyn** also attended the meeting for the first time. Bill was diagnosed with MM in early October 2015. He explained that he had a virus that lasted 4 months. His feet felt numb and he went to a neurologist who tested his blood for proteins and found that he was producing antibodies that affected his nerves. He was diagnosed at Stage 1 and has no bone or kidney involvement. He has a SCT at Emory Winship scheduled for late February.

Business

Joe B. and **Tom L.** co-hosted the meeting. March is Myeloma Action Month, so please spread the word! As the world becomes more aware of MM it benefits us all. Brochures, pins, and posters were provided at the meeting to help spread the word. Posters can be hung in places that you gather within your community such as churches, schools, work, restaurants, pharmacies, shops, etc.

Discussion & Updates

There was some news related to members who could not attend the meeting. **Mary** is recuperating from a broken pelvis as a result of a fall. **Kappa** also had a fall and has had surgery for lesions in her neck. She has begun treatment with Daratumumab and is doing OK. **Virgil** and **Earnestine** are also working through a variety of health-related issues. Please keep these group members in your thoughts and prayers. **Loretta** mentioned that she had become anemic and over the past few weeks she has received 3 pints of blood and iron infusions (on different days) and feels great now. Before the transfusions she had been feeling weak and short of breath but after the transfusions there was an almost immediate change in the way she felt. She is currently on no MM drugs and her next treatment is pending as she prepares for the Senior Olympics. **Joseph** was in remission for six months but then lab tests detected progression and he has just started taking Dex, Ninlaro, and Revlimid. There was discussion about the recently approved drug, Ninlaro (the first and only oral proteasome inhibitor to treat MM). Trials have shown that Ninlaro works as a single agent however it has not been approved by the FDA to use singularly, but rather only in conjunction with Dex and Revlimid. There are group members who are affected by this. **Lory** mentioned that her doctor wanted her to begin Ninlaro as a single agent and she is waiting for her insurance company to approve. Lory said that she may need to combine Ninlaro with another drug in order to get the insurance company approval but she is not sure yet. **Jim** mentioned that his doctor wants him to start taking Ninlaro with Dex only, not Revlimid because he is allergic to Revlimid so his doctor is trying to get the approval for his special case. It was mentioned that Ninlaro is very expensive. **Monique** said that she was denied Ninlaro by her insurance, Medicare Part D. Someone mentioned that you can contact the manufacturer, Takeda, and they can help you get approved for the first month when taken as a three drug regimen (with Dex and Revlimid). There was discussion regarding the differences in handling by various insurance companies, **John** is two years out from a SCT and is getting re-vaccinated. He had heard that prior to getting vaccinations he should halt his use of Revlimid for two months but his doctor said that was not necessary. John got various vaccines and he noticed that each time he was vaccinated he felt weak afterward. He got a live virus MMR (measles, mumps, and rubella) vaccine and passed out. He went to the ER and was found to have low blood pressure and dehydration. He was released but the next day he had a fever and went back to the ER. It was discovered that he had an immune system crash and his WBC count was critically low. He was given infusions and IV antibodies and he is better now. He wanted to warn the group to be careful when getting live virus vaccinations. It was discussed that different facilities have different protocols for receiving live virus vaccinations post SCT. Some facilities maintain that it is OK to have the live MMR vaccines two years after a SCT, but never a shingles vaccine, and other facilities state no live virus vaccinations should be received. Beware of this and be sure to research for yourself. Someone suggested that getting the vaccines one at a time is gentler on your body. There is a vast difference of opinion in the medical world on this topic, so please beware and make informed decisions based upon your research, understanding, and knowledge. **Barbara** began Daratumumab as a single agent in September 2015 which worked for the first two months but then stopped working. She has pain in her thigh and her last PET scan showed new lesions and her right thigh and left hip may have fractures. She did not have bone involvement prior to this and her orthopedic surgeon suggested having a rod placed in her bone. Once she has the rod placed Barbara plans to try Daratumumab and Pomalidomide together. Some other group members mentioned that they have had rods placed in their bones. **Libba** has rods in both arms and mentioned that it has been no problem at all and does not hurt. **Sandy** has a rod in her Femur to strengthen the bone. The advice on this topic was just to be prepared at the airport when going through security. **Jan** asked the group if anyone has heard of anyone having their diaphragm affected from MM and/or

treatment. Jan's brother had a SCT a year ago and has experienced shortness of breath before and after the SCT, but it was discovered at his one year SCT checkup that his lung capacity was reduced by half and was affected by a nerve in the spine. No one at the meeting had heard of anything like this before. **John** mentioned that since he has been on Revlimid (5 mg) he has noticed that it seems to be affecting his brain function and he has experienced episodes of temporary confusion and wondered if others had experienced the same. Others in the group have experienced general short-term memory loss and thought process functionality related to MM drugs and pain medications and sometimes stress and fatigue. The term "chemobrain" was mentioned as we know that is a real condition. It was mentioned that all drugs can cause a chemical imbalance that affects the brain function. Someone mentioned that they heard of a doctor that was on Revlimid and she experienced dementia symptoms. When she stopped using Revlimid the symptoms went away. **Alvinia** suggested using a diary to record medications, diet, sleep schedules, etc. to share with your doctors to help them see the big picture when you are experiencing side effects from drug use. **Libba** and **Tom** mentioned the importance of staying hydrated and that being dehydrated can affect so much, especially when taking drugs. This led to a general discussion regarding the necessity of taking care of your total health, not just the MM. Eat nourishing foods, stay hydrated by drinking a lot of water, and move! **Jeannie** reminded the group to maintain all checkups for both patients and caregivers. **Marilyn** asked the group if they thought that it was helpful to consult with an oncology psychiatrist. Many members responded that yes, they have had good experiences and found them helpful. **Donna** mentioned that she has received some good assistance by talking to a nurse practitioner available through her insurance EAP plan. Someone else mentioned that for those who go to Emory, the doctors there can write a referral for you to see Dr. Bear, who is very nice and very helpful. **Libba** mentioned the IMF (myeloma.org) as a great resource and someone mentioned that they had the IMF hotline phone number programmed into their phone. Also someone mentioned the January 11, 2011 Myeloma Beacon article that addressed hyperbolic treatment pre SCT harvesting as a way to multiply the output. **Joseph** mentioned that he had a great experience when working with both Northside and Emory doctors recently. He was very impressed with how the doctors coordinated and worked together to help him. The communication was very good and he is very pleased with the results. **Helen** mentioned how fortunate we are to be in this location while treating MM!!

Submitted by Wendy R

Southside Multiple Myeloma Support Group

February 2016

Doris welcomed the group and led the group in prayer. There were 17 present. We welcomed one new member, **Evelyn**, who was diagnosed with MM and also learned she had kidney failure in 2011. She says she is doing well; but will go in for an MRI to determine the source of pain in her shoulder and clavicle and an MRCP designed to determine if gallstones are lodged in ducts surrounding the gallbladder. She has dialysis 3 days each week. **Falomi's** mother, **Jeanette**, was in attendance. She was visiting Atlanta from Wisconsin and she and her granddaughter came to spend time with the group. (Falomi was a beloved member who passed away a few years ago). We heard from **Elizabeth** via email. She had been in Emory Hospital for a month and was in rehabilitation and doing better. She was very sick with a respiratory ailment, and sepsis; she had chemo around the clock for 5 days and was visited by Dr. Lonial daily. She says she misses the group and welcomes your prayers and positive energy.

Speaker: Nancy Bruno - Regional Director, IMF Support Groups. The Mission of the International Myeloma Foundation (IMF) is to improve the quality of life of myeloma patients while working toward prevention and a cure. This is done through research, education, support and advocacy. **Topic:** "Living Longer with Myeloma" – **A Patient Checklist:** How to be safer as you live longer. With patients living longer with myeloma it is important to have a Care plan with your doctor. **Review any ongoing maintenance and supportive care measures.** **Ask:** Is maintenance needed and/or helping? Are there downsides of the maintenance therapy? Has there been any impact on blood counts, neuropathy or bones? *Consider an initial option of dose reduction, if needed.*

Watch your white blood cell counts, hemoglobin, and platelets. Reduced levels of white blood cells are of particular concern because of increased susceptibility of infections. Hidden infection in sinuses, teeth, kidney, and bladder areas can go undetected. **PET/CT** scanning can reveal small areas of infections in sinuses or soft tissues areas, which may require attention. **Be aware of ongoing use of Steroids**—they are helpful when combined with other drugs to arrest Myeloma; but long-term use can be harmful. Having a **frank discussion with your doctor about when to stop steroids (Dex).** **Be aware that blood-sugar** levels can increase and then turn into full-blown diabetes. **Cataracts** can develop requiring surgery. Can the dosage or frequency of use be reduced?

The good news is that MM patients are living longer. So it is important to always be alert to possible health issues that affect us as we age whether we have myeloma or not. Regular follow-up with your internist or primary care doctor, as well as any specialist whom you may have seen in the past are important parts of your health plan. Keep your own records -- hard copies or electronic copies -- so you will have them when and if you need them in the future. Normal monitoring for colon cancer is recommended as well as **annual whole body PET/CT is recommended** as it is an excellent way to monitor myeloma and can also detect hidden infections and detection of a secondary cancer.

Business

Gail completed an application for a grant to fund a Caregiver Symposium /Appreciation Event. The proposed event is scheduled for June 11th 8:30-2 pm at the InterContinental Hotel in Buckhead. We will have space a maximum of 120 participants. **Thank you Gail** for the time and effort you have put into preparing a proposal to bring this event to us. *We are looking for volunteers from all Support Groups to help us plan and execute this very important event.* **Doris** celebrated her birthday by having a fabulous party with guests donating to the International Myeloma Foundation on her behalf. So far this effort has earned **\$3,020.00. Congratulations and thank you Doris.**

March is Myeloma Action Month. IMF has changed the name to Myeloma Action Month to reflect educational and outreach activities that will be conducted to increase awareness in the community. Action will lead to even more awareness. To achieve this objective, the following activities are being planned by our group. Special thanks to Doris, Alma, Vermell, Paulette and especially Gail for the hard work planning and coordinating activities to develop strategies for this year's Myeloma Action Month. **Myeloma Television Interview: *It's a wrap!*** Lyn Vaughn, veteran CNN news anchor and current host of Fulton Government TV "HealthLine", interviewed **Kimberly, Joe and Nancy.** The interview focused on the disproportionate impact of Myeloma in the African American community, importance of regular annual visits to your primary physician and the importance of early detection. The Myeloma segment will be aired during the month of March from Fulton Government TV on Comcast Channel 21 in the county and on *Uverse* on channel 99 in the region. You can also live stream to watch it by connecting to www.fultoncountyga.gov/fultonlive.aspx at 5:30 and 8:30 pm. The program was dedicated to Lonnie Ward a MM long-time support group member. **Concerned Black Clergy:** On March 7th Vermell, and Tricia (LLS) presented information about Myeloma to representatives of the Concerned Black Clergy of Metro Atlanta. The message of early detection will be stressed and desire to connect with members from their congregations to participate in a Clergy Round Table. (It is our hope to work with the "ministers of health" in churches, Synagogues, Temples, and Masjids, to inform them of Myeloma and the importance of early detection). Also, to provide support, Doris, Kim, Alma and Nancy were in attendance. Vermell was honored by this group last year and has visited the meetings several times. At least two of their members passed away from Myeloma within the last three years (Rev. Arthur Lewis and Rev. Gerald Richardson); they were also members of our Myeloma support group. **Radio Interview:** On March 8th Alma, Doris, and Vermell participated in an interview on **WYZE Radio station 1480 AM.** The radio show is 30-minutes long and allowed listeners to call-in with questions. This is the second time our Support Group has participated in interviews on this station during Myeloma Month. **Church Bulletins:** Seven members agreed to work with their churches to have a short paragraph placed in church announcements/bulletins about Myeloma. Other members agreed to support them by visiting those churches to discuss Myeloma if asked.

Zika Virus: Bottom line from Dr. Durie is "Myeloma patients should definitely avoid traveling to Zika-affected areas! Even if pregnancy is not a consideration personally, it may be for other family members or friends, and the risk of Guillan Barré, the polio-like condition, is real!"

Announcements/Resources/Upcoming Meetings

- *International Myeloma Foundation (IMF) is reaching out to primary care doctors, lawmakers, and patients to raise awareness of the disease during the organization's 2016 Myeloma Action Month. Go to MAM.Myeloma.org and click on My Action Matters to download a letter to primary physicians to be aware of MM.
- MMRF - FREE Patient and Caregiver webinar "Understanding Next in Class Novel Therapies in Multiple Myeloma" March 23rd at 1:00PM EST
<http://www.cancereducation.com/cancersyspagesnb/a/mmr/m1602/register.htm> l
- IMF - Smart Patients is an online peer-to-peer program - community where patients and caregivers affected by complex illness learn from each other about treatments and challenges. Collectively, our experience is a vast and often untapped resource. <http://www.smartpatients.com/imf> .

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