

## June 2015 Northside Meeting Notes

### Business & Announcements

**Joe** led the meeting. The **July meeting** has been changed to **Saturday, July 11**, due to the Fourth of July holiday. The group voted for this **one-time change**. A representative from a well-known pharmaceutical company will join the July meeting and provide food from Panera Bread. Note the following local event that will occur prior to the July meeting (provided by **Carolyn**): The Georgia Chapter of The Leukemia & Lymphoma Society will hold a **free** education event to blood cancer patients, family members and caregivers. Topics covered will include: advances in blood cancer research, survivorship, the impact of healthy eating, integrative therapies, and local and national resources. The event will be held on Saturday, June 27, 2015 8:00 am to 3:30 pm at the Cobb Galleria Centre / 22 Galleria Parkway / Atlanta, Georgia 30339 Pre-registration for this free program is required. [CLICK HERE TO REGISTER ONLINE](#) Register by phone: 404-720-7838

### New Members

**David** and his wife **Linda** attended the meeting for the first time. David was diagnosed with multiple myeloma (MM) last December during an annual physical. Soon after, he got pneumonia and was admitted to Piedmont hospital for 16 days. He began chemotherapy at that same time. David has harvested stem cells at Emory and is scheduled for an autologous stem cell transplants (**ASCT**) on **July 15<sup>th</sup>**.

### Guest

Thank you to **Mariam Gilmer, Certified Yoga Instructor**, who kicked off the meeting with a respectful greeting of “Namaste”, and then a very well-received invigorating, yet also relaxing chair yoga session (performed while seated). All of the exercises can also be performed standing if preferred. Meriam explained that practicing yoga regularly can lead to an all-over basic health improvement for body, mind and spirit. Miriam’s contact information is: website: yogawithmariam.com / email: [mgilmer@bgilmer.com](mailto:mgilmer@bgilmer.com) / phone: 404-939-4342 Namaste!

**Meeting Discussions** After the yoga session the group took time to catch up with each other and discuss progress, issues, and offer helpful tips. **Anne** spoke of her husband **Joe**, who recently passed saying that he did very well for almost 5 years and the group support helped; Joe appreciated the group for the good information that was shared. **Sandy** was diagnosed with smoldering myeloma in 1989, a state she maintained for 5 years before progression. In 1994, began chemotherapy with the older style treatment and dosages. She has taken Thalidomide and has severe neuropathy that is not helped with drugs. She has survived MM for nearly 26 years! **Sandy** reported that **Earnestine** had double pneumonia months ago which caused her kidneys to fail resulting in a need to do regular dialysis. She is doing better and has begun dialysis at home. **Ed** was diagnosed with smoldering myeloma during an annual physical 5 years ago. He maintained a smoldering state for 4 years and then progressed. He did 4 cycles of Revlimid, Velcade and Dex (**RVD**) earlier this year and is scheduled to harvest stem cells on June 15, and then have an **ASCT on July 1st**. **Milton** was diagnosed in January 2007. He had an ASCT in 2010 and was off treatment for 3 years. Last December he began a clinical trial (CT) with Dr. Lonial that uses Revlimid and Dex and it is working. **John** had an ASCT a year ago and has obtained a stringent complete remission. He mentioned that he has used Velcade and Revlimid and has neuropathy. **Mary** was diagnosed in 2002 and had an ASCT that same year which resulted in remission for 6-7 years. She is now on Cytoxan, Velcade, and Dex and is stable. **Dave** had an ASCT approximately 3.5 years ago. He had been taking Revlimid as maintenance but his counts were low and he has discontinued the Revlimid for a while but is being monitored. **George** had an ASCT about 7 years ago and was maintenance free afterward. Then he began to have lower back pain and lesions were discovered and tests showed MM progression. He began Revlimid and Dex about 6 weeks ago and his most recent test results show no MM markers. George explained that the Revlimid has caused fatigue and cramps and he plans to reduce the dosage soon hoping to reduce side effects. **Nancy** was diagnosed with MM about 3 years ago and she explained that a SCT is not an option for her because she also has CLL and had that about 15 years before being diagnosed with MM. She had been taking RVD but has discontinued the Velcade. She mentioned that Revlimid has diuretic side effects. **Libby** was diagnosed with MM in June 2007. She had shoulder pain and had to have the

humerus bone in her shoulder replaced. Surgery, radiation, and chemotherapy resulted in a 3 year remission, and then relapsed and had more chemotherapy and an ASCT about 1.5 years ago. She currently in remission, taking 5 mg Revlimid and 4 mg Dex daily, and feels good but with some neuropathy. **Sylvia's** sister was diagnosed 7-8 years ago and attained a remission for 2 years with RVD. She is currently recovering from pneumonia, and on IV antibiotics and plans to begin chemotherapy again soon. **Jim** reminded the group that post-SCT your body may respond to drugs differently than before the transplant due to a different/new immune system. **John** mentioned that his initial oncologist has a dog that was diagnosed with MM 3 years ago. The doctor treated the dog with Thalidomide and the dog is doing OK. **Mary** mentioned that she also knows of someone who had a dog with MM. There were a few questions asked and responded to by various members:

Q: Has anyone else had feelings of what seems like a gall bladder attack or issues with gall bladder?

A: No one had but recommendations were to have it checked

Q: If a lesion is present does it feel like a constant pain, no pain, or pain sometimes?

A: Can be all of the above

Q: Does anyone consult with multiple doctors in different networks, locations, etc. simultaneously? For example, going to Emory for a SCT only but maintaining a different doctor for other maintenance, tests, etc.?

A: Yes, and MM doctors are usually willing to cooperate this way. It is also important to have doctors who specialize in MM.

Q: When on chemotherapy I was feeling fine, but when I stopped chemotherapy my legs became wobbly, I was not able to balance as well, etc. Currently taking Lyrica for neuropathy and using a walking stick for support. Has this happened to others?

A: Yes, neuropathy in feet can affect the functioning of legs. It may subside depending on the drug that caused the neuropathy and the dosage and duration of the drug taken.

Q: Is neuropathy reversible?

A: It can be sometimes once treatment dosage is reduced or treatment is stopped. It can take some time to feel the change after discontinuing treatment, however. It also depends on the drug that has caused the neuropathy. For example, it is possible that neuropathy due to Velcade use can eventually go away, but it is not the case with some other drugs.

Q: Does anyone have good advice for the caregiver for the 2-3month period post-transplant?

A: Have backup caregiver(s) to help give the caregiver some free time. Sometimes the facility performing the SCT can provide names of people to call to help. Have an outlet for any frustrations (whatever works for you). Learn to let go and remember that sometimes drugs and not feeling well can temporarily change a person's personality. Maintain a sense of humor as much as possible and try to take one day at a time, remembering that this is a temporary situation.

Submitted by Wendy



## Southside Multiple Myeloma Support Group

### Meeting Minutes June 2015

The meeting was opened with a silent pray and was led by Gail. There was one new member, **Carl**, who was invited by **Selina**.

During the July meeting we will use an IMF MM education video as a platform for discussion.

We were saddened with the loss of our long time member **Loretta R.** who passed away June 19<sup>th</sup> We also celebrated the life of long time IMF speaker, resource person, and MM patient advocate, Mike Katz, who lost his battle with MM after 22 years.

The agenda for the day was a Member's Roundtable of **Open topics**. **Debra Thompson (DT)**, Oncology Nurse with the VA Hospital for over 20 years, and Southside MM Support Group facilitator was present to participate in discussions.

**New Member: Carl** was diagnosed with MM in 2011 and had a Stem Cell Transplant (SCT) in 2013. The symptoms Carl recognized included frequent nausea. He started to have nonspecific pain in his left arm which lasted for over a year. Carl worked in construction, and attributed the initial pain to his physically demanding work in construction. While helping a family member move, he pulled a muscle. Fast forward 2 years -- Carl was rear-ended in a car accident on the interstate. He received a message from the hospital on his phone left at 3-4:00 in the morning – “they think it is cancer”. Carl subsequently had chemotherapy, and radiation. He currently has a rod in his right arm, a rod in his right leg, and a rod in his left ankle – all due to myeloma. Carl had not been to a doctor in many years and had no health insurance. He was diagnosed at Grady, and will soon begin treatment at Emory Winship Cancer institute.

**Debra:** Carl can be a great advocate for others, using his experiences. By the time many cancer patients get to the doctor, it's in a later stage – more challenging to treat. It is recommended that we all get general physical exam at least once a year. Be in tune with your body. **Early detection is key.** For example, with regular screenings for colorectal cancer, polyps can be removed before they progress to cancer. Early diagnosis of the Myeloma may have resulted in less damage to Carl's arm and leg bones.

**Question:** My doctors told me I would have to be on this treatment for the rest of my life. What are others doing for their health – I have heard about people living for 10 – 20 years with myeloma. I am currently on Revlimid/Velcade/Dexamethasone, Acyclovir, and Zometa.

**Debra and Gail:** Sometimes your goal changes. So part of your conversation with providers is “what is my treatment goal?” Sometimes your doctor's counsel is based on their perception of your participation in your treatment. As science of treatment advances, including new medications, your treatment plan might change. The important thing to remember is continuity of care – do not miss any appointments and take medication as prescribed.

**Question:** I am having problems with my remaining shoulder.

**Response:** You may be overcompensating with this arm since there is a pin in the other. Be careful about repetitive lifting – ask doctor what restrictions you have on physical activity based on your history. Physical therapy may be an option to help you address this. **Never suffer in silence** – if you need pain control, ask for it. Make no apologies. There are some studies that show that there are disparities in how pain medications are prescribed. You, your caretaker, and patient advocate should emphasize the need for something to address pain (or other issues). Every hospital should have a patient advocate – ask if you think you want to speak with one.

**Selina:** Has anyone else experienced muscle spasms in chest as a side effect of Revlimid? I am on 5 mg daily with no breaks. This has been happening for over a year. Adjustments have been made by provider, but it continues to happen. Each time, it lasts 15-20 minutes, and then it subsides. There is also pain in my shoulder, arm, and wrist. I have also been sweating profusely for over a year. I am also on pain medication.

**Discussion:** **Carl** is on 10 mg of Revlimid– **Patt** is on 15 mg – each is on 21 day cycle. There have been some side effects – unsure if it's the Revlimid. **Patt** has experienced a cough and cramps in hands (this could be arthritis?) Others have had varying rashes as side effects to Revlimid. **Debra** suggests call 911 the next if spasms occur again. That way, they can do an EKG that can be taken to provider. An EKG taken days after the event may not provide needed evidence. Some suggest tonic water for cramping in feet. Infusion of Velcade has also been related to cramping.

We should all have a working knowledge of possible side effects of medications we take. Use the print-out that comes from the pharmacy. Be cautious of information on the Internet, unless it comes from reliable sources. One resource that

most of us underutilize is the pharmacist. We mostly decline the offer when they ask us at the Pharmacy: **“Do you have questions for the pharmacist?”** Portia shared that CVS hosts a “Brown Bag Day” periodically, so the pharmacist can review all medications with clients (including non-prescription/Over the Counter (OTC) medicines, vitamin supplements, and herbal supplements). We have had challenges securing a pharmacist to speak at Support Group meetings. Debra volunteered to secure a pharmacist to speak and address some of these concerns.

Additional resources we underutilize include: The **American Cancer Society (ACS) – Road to Recovery** and other programs. Transportation from ACS depends on volunteers in a geographic area of need. Gail shared her experiences have been that volunteers have not been available when asked; Portia said that this is a role churches can help to address. Her church participates in Relay for Life each year and earmarks funds raised for their community.

#### **Additional Announcements/Information:**

- Supreme Court supported the Affordable Care Act (once again) – so 65 million Americans will not lose their insurance. Now attention must focus again on **cost of cancer drugs – and co-payments** which could still price some out of optimal treatment;
- IMF – Myeloma Updates 2015 – archived. Includes information on new drugs (including Elotuzumab, Daratumumab, Farydak/Panobinostat, and CAR-T); imaging as a part of routine care; revised staging of MM; personalized medicine, cost of drugs, and **“patients do need to be at the table”** – Brian Durie. Access via Youtube, SoundCloud, and [www.myeloma.com](http://www.myeloma.com).
- IMF – Oncology Nursing Society – “Evolving treatment paradigms: MM case studies” – presented at April 2015 conference. Great slides, shows actual lab results, IgG, IgA, biomarkers, genomics, and why they are important.
- LLS – Updates on Myeloma treatment and Side Effects Management. Archived webinar from June 17.
- IMF. Durie’s Blog. **Lift Veil on (Expensive) Genomics and focus on prevention.** *What causes myeloma? – How can we reduce toxicity exposure? How do we change our eating habits and other behaviors to reduce risks?*
- Mike Katz has transitioned. A true definition of the **“activated patient.”** Diagnosed with myeloma in 1993, Mike helped to shape the philosophy of IMF – and patient-centeredness. He helped to lower the dosage of dexamethasone (from 40 mg)...proposed study that showed that patients on lower dosage performed better...video-recorded interview with leading doctors and presented them at national and international conferences...helped establish the link between bisphosphonates and osteonecrosis of the jaw (ONJ)...in 2014 was awarded the partners in Progress Award from the American Society of Clinical Oncologists (ASCO).

Respectfully submitted by Gail and Paulette