

Northside Meeting Notes - October 2014

New Members

The group welcomed **Don** and his wife **Carolyn** (who also attended the September luncheon). Don was diagnosed in August 2014 and was initially thought to have a heart problem until a large tumor was found behind his heart. Don has had radiation treatments to minimize the plasmacytoma and is also currently in his 2nd round of Velcade, Revlimid, and Dex. **Tom** and his sister **Jan**, (who also attended the September luncheon) were at the meeting. Tom is in the construction business and had some hip pain which he thought might be sciatica before being diagnosed in June 2014. He is currently being treated at Northside in Canton and is nearing his 4th and final round of Velcade, Revlimid, and Dex with good results. When the final round of chemotherapy is complete Tom plans to have a stem cell transplant at Northside in Dunwoody and is looking for a place to stay close to the facility during that time. **Mary Lou** and her husband **Nelson** are from NC and friends of Lori and Ed, who met when Mary Lou was first diagnosed in September 2010. At the time of diagnosis Mary Lou had some hip pain and bloodwork displayed an M-spike, so she was referred to an oncologist. She has had a stem cell transplant at Duke and mentioned that she has not had any disease symptoms, only side effects from treatments. **Sandy** also attended the meeting for the first time. Sandy was diagnosed in May 2013 after increased protein levels were found during an annual physical. She had four rounds of RVD at Emory, and then had a stem cell transplant at Mayo in Rochester, MN. Sandy explained that she chose Mayo for a second opinion and her transplant site because she was impressed with her doctor, Dr. Morie Getz, who also treated her mother after an amyloidosis diagnosis in 1998.

Business & Announcements

Tom and **Joe** co-hosted the meeting. After meeting the new members, future meeting agendas for the remainder this year were discussed. In the **November meeting** Joan Giblin, Director of Emory Winship Survivorship Program, will attend to discuss staying fit. The **December meeting** is traditionally a combination of member updates and a holiday “potluck” celebration where everyone is invited to bring their favorite potluck dish to share! The group also traditionally donates toys to Children’s Hospital of Atlanta to brighten the holidays for children who are in the hospital during the December holiday season; and everyone is invited to bring a new, unwrapped toy to donate. Additional information will be available in the November meeting.

Meeting Discussions

The **October meeting** broke into separate meetings between patients and caregivers. **Don** graciously led the caregiver session with the topic being stress – how to recognize, reduce, and cope with stress in the caregiver role. It is extremely important to be able to recognize stress because sometimes it is not at all visible until something happens after a person has become weakened from it. It is necessary for everyone to be able to take some time in each day to do the things that you enjoy and that help to reduce stress levels and rid the body of the stress hormones that are produced

and that can cause damage. These stress relieving activities can vary greatly between individuals, but some highlights of the recommendations include, 1) don't isolate yourself or withdraw from social situations - remain socially active, 2) incorporate meditation into your day, which can help you stay focused when the need arises and enable you to become aware earlier of signs of stress 3) incorporate physical movement to take care of your body, and 4) maintain a sense of humor, which can help reduce worry and anxiety. Try to incorporate each of these things daily, even if only for a few minutes a day, so that they become habits that occur naturally for you. This is good general advice for everyone.

Carolyn led the patient session and they discussed various topics during the discussion. There were several questions about stem cell transplant. Patients who had completed transplants shared their experiences with those who were preparing for that part of their journey.

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Southside Multiple Myeloma Support Group Meeting – Meeting Minutes October 25, 2014

Gail opened the meeting with an explanation of the many benefits of deep breathing and led the group in deep breathing techniques and brief chair exercises for range of motion.

Doris introduced **Bria** who was present representing the Leukemia and Lymphoma Society (LLS), to share experiences of “Light the Night”, and to thank the group for their participation. We were successful in making financial contributions – Bridgett and Montine participated in the walk. **Bria** brought beautiful T-shirts for all group members and stayed for the entire meeting.

Updates

Luncheon: The November 22, 2014 meeting will be held at Pascal Brothers Restaurant located: 180 Northside Dr. SW, Atlanta, GA 30313 Phone: (404) 525-2023). **Special time 11:00 am.** This annual luncheon is sponsored by **Millennium Pharmaceuticals**. In addition to presentations by Millennium, we will have a brief discussion on Combating Depression and Stress reduction during the Holiday Season. Morehouse School of Medicine Department of Psychiatry representatives will lead the discussion. Planning for **2015 Calendar** schedule will be led by a Committee comprised of **Doris, Gail, Paulette, Debra, and Vermell**. The **December meeting** will be held on the 27th at our usual location on the second floor of Macys’ Department Store in the Greenbriar Mall beginning at the usual 10:00 am time. **December Meeting Topic:** Group discussion on Support Group Agenda for 2015.

Presentation/Discussion

During the meeting we used an LCD projector to demonstrate International Myeloma Foundation (IMF) resources available to all on the Internet. We viewed the two new videos on the role of Freelite and Hevylite assays in monitoring Myeloma – on the IMF website, www.myeloma.org. We also looked for clinical trials; specifically, we were seeking information on the Daratumumab, Pomalidomide-Dexamethasone regimen, being considered by Alma R. with Dr. Lonial. Unfortunately, we could not locate the study on the National Cancer Institute (NCI, National Institutes of Health) site, or www.clinicaltrials.gov, where all clinical trials should be listed. We also looked at the MMRF (Multiple Myeloma Research Foundation) website, and were unsuccessful on locating the study there. We did find a study on Daratumumab, Lenalidomide (Revlimid), and Dex. We distributed a recent brochure from IMF on POMALYST (pomalidomide) capsules. We need to research further for information on the specific study – and determine where explanations of clinical trials are available. The clinical trials in Georgia should also be listed at www.GeorgiaCore.org. **Georgia Cancer CORE** also receives its information from **NIH**. We will make use of archived teleconferences, including the Living Well with Myeloma series, Nutrition, and Complementary Medicine for increased information at future Support Group Meetings and to generate discussion.

Announcements:

IMF will sponsor **Gail** and 11 other Support Group leaders and representatives from across the country to attend the annual ASH (American Society for Hematology) Conference. The Conference will be in San Francisco in December 4th- 9th. IMF wants the patient to be front and center to observe first-hand all the worldwide Myeloma research --as the end-user of the research. She will have the new experiences – to twitter and blog from the Conference. Her twitter handle is @IMFgailMyeloma. Follow her, if you can. On January 10th, Emory Winship will host a meeting to report highlights from the ASH Conference. **Stay tuned for specific details of this meeting.** This is an annual effort that Emory Winship does to keep patients and caregivers informed of developments in MM research and reports on clinical trials. We will also have our Group meeting in January. The **“Management of Bone Disease”** teleconference was on Nov 13 and will be available for you to listen at www.replay.myeloma.org; **“Navigating the open enrollment period” webinar on November 18 @ 7PM** – www.myeloma.org. IMF recommends **flu shots for Myeloma patients**. There are special instructions for those with recent SCT (stem cell transplant) and those who could benefit from high dose vaccine—speak with your oncology provider.

New Member: Juan was invited to attend the meeting by a fellow military veteran, **Lonnie** While in treatment at the VA Cancer clinic Lonnie W. shared his experience with the SSMM Support Group Meetings. Seven months ago a golf size mass was identified in his chest; he was later diagnosed with lung cancer. He continues treatment at the VA. Even though Juan is a Lung Cancer Patient shared his story and appreciated opportunity to meet with other cancer patients to share

common experiences. Juan commented on the benefit of fellowship with like-minded people. Juan took MARTA, and traveled over two hours from DeKalb County, to attend this meeting.

Elizabeth attended LLS conference in New Orleans last month. The conference was blood conference for patients in Mississippi and Louisiana; she received a scholarship from LLS to attend meeting. Along with patients and care givers with other blood cancers, there were three tables of Myeloma patients. Doctors from Arkansas spoke about Myeloma. Elizabeth shared that there was a physician from Emory with an African American myeloma patient who had been in remission for more than 20 years. She said Arkansas boasted as one of the top hospitals for MM and is known for tandem transplants. **Elizabeth** is taking 2 mg Pomalyst (Pomalidomide) capsules -- will see doctor in a few weeks to determine effectiveness.

The Myeloma Phrase-for-the-Day was “How many types of remission are there for Myeloma?” The answer: **Remission can be defined as:** 1. Stringent complete remission/response; 2. Complete Remission; 3. Near complete remission; 4. Very good partial response (VGPR); and 5. Partial Response. The type of remission is based on serum & urine protein electrophoresis, free light chain assay and bone marrow test.

Respectfully Submitted by Paulette and Gail.