

## May 2013 Meeting News – Both Groups Included

### Southside Multiple Myeloma Support Group Meeting – May 25, 2013

Doris brought the meeting to order.

Our meeting in June will feature Nancy Bruno, the new Regional IMF Director who will share information about her new role and Sheketha Cannon, a representative from Well Care, a health insurance that offers free supplemental health and dental insurance for those enrolled in Medicare.

This month's meeting featured a workshop for Care Givers and Patients. **Joe**, MS, Health **Educator** and care giver, led the group of caregivers; and **Alice Mullins, MS, LCSW**, Winship, led a group for patients. There was lots of discussion and sharing among members regarding issues unique to them as caregivers (or patients). The meeting was held at the Ben Hill Recreation Center and was well attended with 24 present.

Support group members were offered information to help provide guidance as they work through challenges of Multiple Myeloma. Mr. Brown shared ... **a caregiver's primary responsibility is to care for one's self first**. He said in a recent workshop on caregiving that "before we proceed to care for our loved ones, **We Should Put on our Personal Oxygen Masks First**." He then provided some **ABCs of Care Giving**:

- A.** We should "check in" with ourselves in the form of a self-inventory.
- B.** We check all aspects of our well-being, i.e. physical, emotional, social, and spiritual.
- C.** We should be on the lookout for stressful warning signs and take frequent emotional time outs.
- D.** We should make a list of our individual and/or personal needs.
- E.** We should identify all of our support resources: family, friends, neighbors, professionals, and community organizations.
- F.** If needed, we should seek professional help for self-care and confidentiality.
- G.** We should take care of our health, i.e. concentrate on preventive care, get annual health examinations, and take any needed or required medications as scheduled.
- H.** We should engage in positive health behaviors, by eating healthy nutritious diets, getting sufficient rest on a daily basis, practice relaxation techniques daily, and engage in humorous activities where possible.
- I.** We should not engage in unhealthy coping activities such as smoking, drinking alcohol, over eating non-nutritional foods, excessive shopping, and gambling.
- J.** We should guard our social well-being; maintain our social routines and activities as much as possible, schedule regular times to socialize with friends and families, find new ways to enjoy leisure activities, and attend caregivers support groups.
- K.** Avoid common barriers to caring for one's self. Statements such as: I don't have time to take care of myself; it's not me who needs help, I'm the healthy one; others will think I am selfish and irresponsible; I'd never forgive myself if something happened while I was out enjoying a morning or an evening of relaxation/entertainment; I'm strong, I don't need to take breaks or have "me time"; I have to take care of all of the household responsibilities or they will not get done; and I hate asking other people for their help. Following these ABCs can help ensure you are able to provide the assistance needed to provide the care needed by the patient. The workshop was informative and very interactive.

**Member Update:** Andrew, Arthur and Gerald, and their caregivers, need your prayers and support as they are each experiencing health challenges. They welcome cards, visits, and calls.

### **Announcements, Upcoming Teleconferences, Workshops and Seminars**

On July 11th The International Myeloma Foundation Presents Myeloma Updates 2013 Post **ASCO/EHA/IMWG with Brian Duire, MD**. Learn more about current trends in myeloma treatment and research with this update from three major medical meetings held in June 2013. Dr. Brian G.M. Durie will explain what's new and exciting from the American Society of Clinical Oncology (ASCO), the European Hematology Association (EHA), and the International Myeloma Working Group Summit (IMWG).

Also, on Thursday, June 20th The International Myeloma Foundation Presents: Living Well with Myeloma Teleconference Series -- **The Advantages of Good Nutrition - The Living Well with Myeloma** Teleconference Series. Speaker: Angela Hummel MS, RD, CSO, LDN. If you miss it, the conference will be available at [www.replay.myeloma.org](http://www.replay.myeloma.org) .

The **Leukemia & Lymphoma Society (LLS)** has connected to retailers to make shopping **rewarding** to shoppers. The retailers on the LLS site have agreed to donate a percentage of what you purchase to the funding of blood cancer therapies that are saving lives every day. From cruise vacations and wines to jewelry and sports gear, you'll find unique gift ideas that are perfect for any occasion that calls for a celebration! Check out this list of retailers and start shopping! Every purchase you make with the retailers at [www.lls.org/specialoffers](http://www.lls.org/specialoffers) will help save lives not someday, but today.

**Meals to Heal**, a patient- and caregiver-focused cancer nutrition resource, announced today that it is opening enrollment for a focus group designed to develop and refine its products and services to better meet the needs of people undergoing cancer treatment. The Company is recruiting volunteers in the 48 Continental United States (excluding Alaska and Hawaii) to receive a 5 day supply of nutritious lunch and dinner entrees delivered to their home, completely free of charge. In exchange, participants are asked to provide honest feedback and input on the meal service via a 1 hour phone discussion. There will be no subsequent obligations once the feedback is received. Interested cancer patients or caregivers can email [info@meals-to-heal.com](mailto:info@meals-to-heal.com) or call **888-721-1041**. Additional information on the focus group may also be found at <http://meals-to-heal.com/focus-group-offer/> Meals to Heal is a comprehensive cancer nutrition service providing home delivery of fresh, nutritious meals that are customized for cancer patients' unique needs as well as free cancer nutrition resources. The Company is founded on the premise that carefully balanced nutrition enhances the body's ability to fight the disease and better tolerate the treatments. More information may be found at <http://www.meals-to-heal.com>.

Respectfully submitted by Paulette

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### **Northside Atlanta Area Support Group May 2013 Meeting News**

#### **Business & Announcements**

**Tom and Joe** co-chaired the open discussion meeting. Approximately 30 people attended the

meeting and there were no new members. March proved to be a successful Myeloma Awareness month, and a group photo was taken with the proclamation plaque. Upcoming programs include: **June meeting** – Charise Gleason from Emory Winship will present to the group and answer your questions, so please have your questions ready for the post-presentation discussion. **July meeting - Tom**, a chemistry teacher for 35 years will lead a discussion on chemistry and how it relates to drug terminology. **Tom** also brought copies of a book to the meeting (now in our library), written by a friend of Latain's, which is a cookbook focused on cooking for cancer patients. Tom is looking for feedback on the book and can get additional copies as needed for the group if there is an interest. **Joe & Sandy** attended services for **Dolores** who recently passed.

### Discussion & Updates

**Earnestine** began a new treatment two weeks ago that includes Velcade, Dex, and Cytosan. Since she began her neuropathy has worsened, but otherwise she is doing well. She is also on Aranesp to increase red blood cell count. This led to further discussion on low red blood cell counts as several in the group have anemia, including **Robert**. Having anemia can lead to lightheadedness, dizziness, etc. and it is important to be careful when moving. Try to be slower, as sudden movement can cause an imbalance leading to falls. **Brenda** mentioned that when anything affects your equilibrium (i.e. medication, dehydration, illness, etc.) you need to remember to move more slowly and gradually. **Virgil** mentioned that he had a bad case of bronchitis earlier this year which caused him to black out and hit his head on a door. He does not remember anything for two weeks during that time and was in a rehab center for four weeks. He had to relearn how to walk and is using a cane now, but is otherwise well. Prior to this issue he had been taking Revlimid, but then was off the Revlimid for about six weeks. Since his counts remained good, even while off the Revlimid, his doctor lowered the dosage when he resumed. **Christine** explained that she had a stem cell transplant in June 2011 and her doctors expected a long remission, and she had been doing well on Revlimid as maintenance post stem cell transplant. She was hospitalized in January 2013 for low hemoglobin and oxygen levels with heavy breathing as a symptom. A bone marrow biopsy revealed 50% plasma cells and she learned then that she was no longer in remission. She is now taking a combination of Velcade, Revlimid, and Dex. Her blood counts fluctuate, but are beginning to look better and her M-spike is down. She is currently planning to take a break from Velcade since she has been experiencing neuropathy worse now than when she was previously on it before her stem cell transplant. When she resumes Velcade, she plans on a once a week schedule. **Anthony** had a stem cell transplant two years ago and is feeling great. He decided to stop maintenance therapy since he had experienced bad side effects from Revlimid, which he can't tolerate, when he initially tried it for maintenance; but is monitored every six months with a skeletal survey, blood work, and bone marrow check and is doing well. **Don** reported that his wife has had very good results from a clinical trial of Revlimid and Dex begun in October, but there are side effects including headaches, nausea, and digestive issues. It is hard to know when she will/won't feel good. **Suzanne** has been participating in a clinical trial with Carfilzomib and *Panobinostat* and reported that she is doing well but is very fatigued and has feelings of constant nausea. There were some updates provided for those who could not attend the meeting. Earnestine mentioned that she recently saw **Carolyn** and that Carolyn was doing better at that time and continuing with her current treatment. Someone also reported that **Bill** has been experiencing a lot of pain and fatigue due to side effects of his treatment and is currently getting fluids to help. **Bill** and **Jeannie** hope to attend the June meeting. There was also news from **Cheri**, 10 days post stem cell transplant. She is doing well and hopes to be at the June meeting. The experience was not as bad as she thought it would be.

There was some general discussion about the importance of bringing someone else to your doctor

appointments with you to help you remember things and stay better organized. Also, remember to check and double check your healthcare providers – doctors, nurses, pharmacies, etc. If something does not seem correct to you, then ask about it. And, remember to take care of your entire mind and body, not just the myeloma. Your psychological well-being has a tremendous impact on your overall health.

Submitted by Wendy

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