

June 2011 Meeting News

New Members

The group welcomed **Cappa** who was diagnosed in December 2007, after a year of unresolved jaw pain. When a plasmacytoma was found on her jaw, she was referred to Emory Winship. She had a transplant at Emory and obtained a partial remission. She is now on low dose Revlimid (5 mg). The group also welcomed **Robert and his wife, Sara**. Robert was diagnosed with MM this past March after two years with MGUS. He is now on Rev/Vel/Dex and dealing with the side effects.

Business & Other Information

Prior to the meeting, the **AAMMSG Board of Directors** held a meeting to review financial and planning issues. Your Board members are: Nancy, Joe, Jeanette, Tom, Andy, Mary, and Hector. The Board reviewed financial status and expected expenses. There was also extended discussion of standing committees and program planning. The group committees are: Outreach, Refreshments, Programs, Greeter, News and Notes, Non-Meeting Activities. From the discussion about programs and activities, it was determined that a survey should be prepared and distributed to members for opinions and feedback. The survey will ask for ranking of preferred programs and solicit comments on other activities.

Speakers

Mariam leads the yoga sessions that exercises in our meeting room immediately before our gathering and other times during the week. She has extensive experience with yoga which can help everyone. She led the group in a session of “chair yoga” with stretching movements while sitting in a chair. We learned that common shallow breathing uses only one third of the lungs. She helped us to stretch our arms and legs and breath deep to bring more oxygen to muscles and all cells. Yoga encourages inner focus for a more peaceful state of mind and better health.

Ashley Howze from Emory Winship brought informational brochures to the meeting. She was there to answer questions about Winship Foundation and the strategy. Winship was started by Robert Woodruff and is named after his mother, who died from cancer. Two years ago, Winship became the first and only cancer center in Georgia designated by the National Cancer Institute (NCI) as a comprehensive cancer center. They work with federal and state government to reach out to patients and doctors around the state to improve treatment and survival. Ashley noted that Winship has 13 defined programs for cancer research and Multiple Myeloma is in a program by itself. When donations to Emory Winship are designated for Myeloma research, they go to a fund set aside for Dr. Lonial to use at his discretion for research and treatment projects. The group was reminded to make families aware if we wish to have donations made in our memory to the Winship Myeloma research team. The business development team will be working to put the Winship name in front of more Atlanta residents and raise awareness of this world class institute in our own back yard. There will be the first Celebration of Success on October 15, which will include a 5K race and other activities. More information will be provided to our group. Someone also asked if there are Winship logo items available for us to help with awareness. Ashley said that she will explore expanding the logo inventory and update us.

Carolyn has connected with the Cleveland Clinic 4th Angel program to offer mentors to cancer patients and their caregivers. The program is in need of more caregivers, as well as patient mentors. Here is the information: The 4th Angel Mentoring Program is a survivorship program launched by The Scott Hamilton CARES Initiative that provides free and confidential telephone or e-mail support to cancer patients and their caregivers. Trained mentors, who are cancer survivors themselves or have been a caregiver to a cancer patient, offer guidance and support. The program ensures that participants are paired (matched) based on similar characteristics including gender, age, cancer diagnosis, and treatment type. Opportunities are also available for cancer survivors and their

caregivers to volunteer as mentors. Contact Jamie Kabat BSN, MSN, 4th Angel Program Coordinator, 216-445-8734 or 866-520-3197, www.4thangel.org

Updates & Collaboration

Jerry said that he is on a clinical trial with HuLac. After three rounds, his counts are in the normal range, but is dealing with constant fatigue. **Anita** is taking Vironostat with Rev/Vel/Dex and has full remission. Her liver enzyme was elevated and she had to take a break to give her liver time to recover. She was asking about maintenance protocols. Nancy noted that she has received walkers and canes from the family of a deceased patient and they are available to anyone who can use them. There is also a collection of other medical supplies.

Submitted by Nancy