

July 2010 Meeting News

Business & Other Information

Nancy led the meeting. Approximately 29 members attended; there were no new members attending the meeting this month. Nancy shared some news articles from the annual American Society of Clinical Oncology (ASCO) Conference held in June, relating to results from some of the latest research studies. Copies of articles were emailed to members in a separate communication along with notification of a free conference call on July 22. This call will cover the latest news with Dr. Lonial and provide an opportunity to ask questions. To register for the call, go to:

<http://www.cancereducation.com/cancersyspagesnb/a/mmr/m1005/index.cfm?rid=138>

or see the conference information at www.themmr.org

Of special interest, and discussed in the meeting were 1) the high response rates to the new medications, and 2) the low impact of side effects, 3) additional research on new drugs and new combinations. **Monique's** daughter-in-law has designed some high quality note cards for the group to purchase, with proceeds going toward myeloma research and the support group. **Mike** recently celebrated a birthday. In lieu of gifts for Mike, his family collected \$400, which was donated to the support group. *We thank these individuals for their generosity!*

Guest Speaker

Norma Heard, a nurse from Morehouse School of Medicine attended the meeting to discuss research that is being conducted by the school in partnership with the National Cancer Institute and the University of Alabama. The "iMAGE" study is being conducted in an effort to examine the causes of multiple myeloma. For more information, contact **Norma Heard**, RN, MS, Senior Nurse Coordinator, 404-756-8818, or **Jolita Wainwright**, Senior Research Coordinator, 404-756-1877.

Member Updates & Collaboration

Many members reported doing well! **Carolyn** is preparing to move to Arizona, and mentioned that she plans to retain her current doctor from Emory post move, and also consult with a local doctor. **Rick** obtained his four year post stem cell transplant results (at the 4-1/2 year point) and there is no sign of recurrence. **George, Marilyn, Sandy, and Latain** all reported doing well. **Latain** mentioned that her 100 day post stem cell check up is soon. **Earnestine** is considering a trial by Merck & Co, offered at Emory, in which the drug being tested is combined with Velcade. **Hector** reported having serious pain from neuropathy associated with Velcade, and was temporarily wheelchair bound. He is better now that he is off Velcade and has used many supplements as well in an effort to regain health, as he is preparing for a stem cell transplant currently scheduled for mid-July. **Bob** had a stem cell transplant in 2004, but now his numbers are elevating and he is considering options. Bob mentioned that he has tried Thalidomide, which resulted in clots in his legs and lungs. It was discovered that he has a blood clotting disorder called "Leiden Factor V", which is a hereditary condition, which all of his siblings also have. Bob also mentioned that his mother was diagnosed with myeloma 30 years prior to his diagnosis. **Milton** is recovering from surgery he had in May, and doing well. He plans to move forward with a stem cell transplant after his full recovery. **Jeanine** reported that she is doing well and recovering from a recent emergency hip replacement surgery, not related to MM. **Steve** has smoldering myeloma, but attended the meeting to gather information for his mother, who was recently diagnosed with myeloma. At the time of diagnosis, his mother had a lesion on her skull and compression fractures in her back. She has had kyphoplasty surgery to correct the back fractures and alleviate the pain. Steve mentioned that he has learned that a general oncologist, on average may have a patient base with approximately 2% myeloma patients. He goes to Suburban Hematology, where some of the doctors are from Emory, and their myeloma patient base consists of about 5%. There are other group members who go there as well. **Chuck** has begun the process for stem cell harvesting, in preparation of a stem cell transplant in the winter time, or after. **Rebecca** mentioned that she is planning for radiation therapy for an area in her head. **Gail** reminded everyone to stay well hydrated especially when undergoing treatment. If you don't keep yourself hydrated, your doctor may order it to be done for you, which could add an additional 2-3 hours to your treatment time. **Gail** also mentioned that she has been getting Aredia on a quarterly basis at Emory and recently learned that Emory has been using a generic version of the drug for about a year (just FYI). Various other topics were discussed, including: 1) Drug disposal - some drugs such as Revlimid and Thalidomide must be returned to the manufacturer for disposal; others can be removed

from their containers and mixed with an agent such as cat litter, then disposed; 2) myeloma and family members – several in the group disclosed that they have family members – such as aunts, mothers, and cousins who have also been afflicted with myeloma, although the disease is not considered to be hereditary.

Submitted by Wendy