

January 2009 Meeting News – New / Guest Members

There were no new members at the meeting this month however **Arthur** joined the group as a guest member from the Southside group, where he has been a member since February 2008. Arthur was diagnosed with myeloma in July 2007. He had surgery a week after diagnosis to remove a tumor from his arm and a metal rod was inserted at that time. Arthur currently sees an oncologist who is in an independent practice in Atlanta. His doctor has prescribed Alkaron and Prednisone, which he takes five consecutive days a month. Arthur has also obtained a second opinion from Dr. Lonial at Emory who suggested that adding Thalidomide to the mix may also be beneficial. Arthur also receives Zometa on a monthly basis.

Business & Other Information

Nancy led the meeting. Approximately 35 members were present. A sign up sheet is available at the meeting for members to provide refreshments for future meetings. Nancy brought the recently printed brochures for the members to review. She wants to express appreciation to Bequeath Printing (770-458-1111) for the professional handling of this project. The brochure colors turned out great with a dogwood banner across the top. The brochure holders are now available for distribution of the new brochures in various public areas such as clinics, hospitals, doctor's offices, etc. Some group members have volunteered to assist in getting these brochures available in pertinent areas where the information can be of the most benefit. Watch for them in these locations: Emory, Grady, GA Cancer in Snellville, Eastside Hematology, VA Hospital, NW GA Oncology, Kaiser.

Member Updates & Collaboration

Sandy reported that **Raphael** was not doing well and has begun treatment with a drug called Bendamustine. **Jeanette** reported that **Ginny** is doing well, but is currently sick with a cold and so did not attend this meeting. **Doris** reported that the Southside group's members are doing well. **Shemeka** reported that her father is working with Northside in the process of identifying possible sibling donor matches in preparation of an allogeneic (donor) stem cell transplant. Shemeka mentioned that there is a 25% chance of a sibling match. There was some discussion about the risks of this type of transplant as well as mention of the Matched Unrelated Donor (MUD) option for finding a potential donor. Also during the discussion mention was made of a recently FDA approved agent for stem cell mobilization called Mozobil (also known as Plerixafor). This drug was in clinical trials under the code AMD3100 for stem cell mobilization.

Monique reported that she had planned to begin a Phase 1 clinical trial, but she was not accepted into the trial due to the type of myeloma that she has. Instead, Monique is currently taking Velcade and Dex and has had some radiation to her arm as a result of a lesion and fracture. She is preparing for a second stem cell transplant; her first stem cell transplant was approximately four years ago. **Carolyn** has been consulting with Dana Farber about having an in-patient stem cell transplant at one of their facilities. Carolyn mentioned that she has been impressed with the coordination assistance that she has received from both Emory and Dana Farber so that she will be able to prepare for the stem cell transplant locally (at Emory) including chemotherapy and harvesting locally for shipment to Dana Farber where the actual transplant will be performed, and where she will be able to stay as an in-patient. **Milton**, who was diagnosed with myeloma in January 2007 is preparing for a stem cell harvest and possibly a stem cell transplant. **Harland** announced that he has achieved remission with a

treatment of Velcade and Revlimid. It took several months for the counts to reduce to remission levels, but he is feeling great about this achievement.

Drew reported that he relapsed in February 2008 after having a single stem cell transplant in October 2006. Drew recently had a mini stem cell transplant using stem cells left over from his original stem cell transplant after a half-dose of Melphalan. Drew mentioned that it is too early to tell if this approach has worked, however early results appear positive. Drew also mentioned that prior to the mini stem cell transplant he had tried a few different agents and noted that the approach seemed to be to begin at a relatively high dose, then decrease if possible. He suggested that it might be better to start at a lower dose in order to try to better tolerate the agent then increase the dose if necessary. **Karyn** has been taking Thalidomide, Velcade and Dex in preparation for a stem cell transplant at Emory in mid-January. Karyn said that she has had a couple of trips to the emergency room in the past month due to side effects of drugs. She also said that the kidney dialysis that she recently began is working and she also mentioned that myeloma patients are not eligible for kidney transplants. Nancy Bruno noted that some group members have found that once their myeloma becomes better managed then their kidney function becomes restored. The group specifically mentioned member **Tim** who would be a good person for Karyn to consult with on this subject

Submitted by Wendy