

September 2008 Meeting News – New Members

There were four new members at the meeting this month. **Carolyn** was diagnosed with myeloma in March 2008 after initially being diagnosed with MGUS in July 2007. She began taking Velcade and Doxil in March, but has experienced severe neuropathy, so has currently halted myeloma treatment while she tries to get the neuropathy under control. **Milton** was diagnosed with myeloma in January 2007 after being misdiagnosed with osteoporosis. Milton experienced severe back pain and an orthopedic surgeon discovered a plasmacytoma on his 8th vertebrae. He was admitted to the hospital and had radiation treatment. He is currently taking Thalidomide and is considering a stem cell transplant. **Roslyn** was diagnosed with myeloma in June 2008 via a MRI. Prior to the diagnosis Roslyn had MRSA. Roslyn is preparing for a stem cell transplant, and noted that she is having difficulty understanding lab results. Several in the group reminded us all ask our doctors a lot of questions about anything that we do not understand. **Pattie** was experiencing many different problems beginning in March 2006 – her ribs and back hurt and she was treated for shingles. She kept feeling worse. She went through a lot of tests and was finally diagnosed with myeloma in February 2007. She has many bone lesions, resulting in actual holes in her bones, and has had many radiation treatments. She began taking Thalidomide and Dex, and is in remission now, and preparing for a stem cell transplant at Emory, for which she has already harvested stem cells with enough for multiple transplants.

Guest Speakers

In preparation for the Multiple Myeloma Research Foundation (MMRF) Race for Research on Sunday, **October 26th**, **Amelia Lewis** from the MMRF presented information to the group about the race and how the funds help advance myeloma research. Kathy Giusti, a myeloma patient, has served as the President of the MMRF since 1996, the same year she was diagnosed. The mission of the MMRF is to “accelerate the search for a cure for multiple myeloma” by funding the best research. The MMRF operates with only 7% overhead, with 93% of funding going directly to research. The MMRF also sponsors a patient navigator program, helping match patients to trials; and a patient advocate program.

Business & Other Information

Nancy led the meeting. Approximately 33 members were present.

In support of the upcoming MMRF Race for Research, **Nancy** created a shared website for both the AAMMSG and Southside Multiple Myeloma Support Groups. This link can be forwarded to your family, friends, colleagues, etc. for easy online donations: www.active.com/donate/atlanta08/aammsg

Per Nancy, “Please tell your family and friends what an exciting time this is for Myeloma research and some of the great results that we are getting. This is an important time to keep the research going for all of us.” The groups’ goal is **\$10,000**, and the AAMMSG group voted to contribute \$500. Group T-shirts will be available at the next meeting. Short-sleeved shirts are \$10 and long-sleeved are \$20. This year’s **American Society of Hematology** (ASH) conference will be held from December 6-9 in San Francisco. **Emory** is in the process of becoming designated as an official “cancer center” facility. A final visit by the government is planned in September to finalize the process.

It is sadly noted that we have lost several group members/affiliates. The group acknowledged the passing of **Lou**, whose daughter **Dori** is a respected member of our community. Lou lived in Florida, and while most of the group had not personally met Lou,

many felt like they knew him due to Dori's frequent contributions. Also acknowledged in the meeting was the passing of **Roseanne**, author and myeloma patient, who was a guest speaker in our January 2007 meeting. She is the author of "Cancer Etiquette: What to Say, What to Do, When Someone You Know or Love has Cancer". The group also learned of the passing of **Jim** from a brain aneurysm. He was always a very active meeting contributor who had been present in our September meeting, providing helpful advice as he often did (as noted in the Member Updates below). Our sincere condolences are extended to the loved ones of these individuals.

Member Updates & Collaboration

Inge mentioned that she will soon begin a low dose Thalidomide treatment. **Pattie** has a persistently painful tongue and dry mouth and asked if anyone else in the group has experienced anything similar or can recommend a remedy. Another group member mentioned that lozenges and aloe gel are soothing. **Jim** mentioned that he had recently been in the hospital for a week due to anemia. Jim is on a regimen of a combination of Velcade, Revlimid, and Dex and his creatinine levels have been fluctuating, which was first noticed by him, rather than his doctor. Jim reminded everyone to keep copies of lab reports, and to ask the important questions. – "the numbers on the reports help explain why you feel the way you do". Jim also explained that a soft mass was found in his chest, which was radiated, and his doctor planned further radiation on a T11 fracture, but he was warned by his radiologist to hold off on the T11 radiation if he planned to have kyphoplasty surgery. Otherwise, the bone would not be able to be repaired. The bone can be radiated after the kyphoplasty surgery is complete if necessary. Jim's input to the group will be missed.

In a separate communication, **Doris**, from the Southside Support Group, provided the following information from the group's August 23rd meeting:

- 10 a.m. to 12:00 p.m. Kate Boyer from Leukemia and Lymphoma Society spoke about finances, Lymphoma Society and also about Binding Site/Rudi Hrcic, MD Technical Director-Freelite.
- We talked about MMRF Patient and Care giver Symposium which was held on September the 5th, 2008. We had four people to attend this program.
- We announced that September 20, 2008 will be a Shop For A Cause, at all Macy's stores.
- October 11th, 2008, will be the Light the Night Walk at 5:30pm at Centennial Olympic Park.. The Leukemia and Lymphoma Society's nationwide evening walk to increase awareness of blood cancers. Andrew Jackson will also be honored at the event.
- Deborah Thompson an Infusion Nurse will be the guest speaker from the VA Hospital on September 27th.
- Venell Stafford an Oncology nurse from the VA Hospital will be the guest speaker October 25th, 2008.

Submitted by Wendy