

Southside Meeting Notes

The **Southside Multiple Myeloma Support Group** submitted notes from their April 25, 2009 meeting.

Announcements:

- 1) Emory Winship Cancer Institute 2009 Celebration of Living – The event will be held Saturday, June 20, 2009 from 8:00AM-1:00PM at Peachtree Road United Methodist Church, 3180 Peachtree Road NW, Atlanta, GA 30305. Registration is requested-register online at www.cancer.emory.edu under “Training & Education” or call 404-778-7777. All are encouraged to attend this informative and fun filled event.
- 2) The Leukemia and Lymphoma Financial Aid Program Changes information sheet was distributed to members. All are urged to be aware of the proposed changes which go into effect July 1, 2009.
- 3) Patient Questionnaire was provided for members who desire to be contacted by IMF regarding their treatment.
- 4) In July, Doris will represent the group at the IMF Support Group Leaders Conference, in Texas. She said two from the group could attend the meeting.

Members Status

- Gail stated that she was told April 1, 2009 that her status is near complete remission. She is doing fine but said she has some back pain and has lost 3 to 4 inches of height.
- Leo stated that he is experiencing amnesia when the medication was increased from 10mg to 15mg. He has back challenges and has lost about 4 inches in height.
- Lonnie stated that his counts are still down. No changes. He has been on his regiment for two and half years.
- Michelle said she has had two transplants and was in complete remission in January. She started taking medication in March. She feels a little fatigued. Her diagnosis date was December 10, 2007.
- Arthur stated he is one of the Jersey connections. He is in remission. He is feeling good. He also told the group about the patient and caregiver session that the AAMMSG group is having and encouraged everyone to attend.
- Marvin introduced himself and stated that he was diagnosed one year ago. He thought he had a pulled muscle in his back. It eventually got to where he was not able to walk. His spine had collapsed. Two months ago he stopped his medicine and was told that he is a good candidate for a bone transplant. He talked about the numbness he experienced in his hands and feet. He is taking herbal supplements to help with the neuropathy.
- Doris gave updates on the following members: William - he is doing well and he is in Louisville. Andrew told her they might have to amputate his leg. Sandy was diagnosed 19 years ago. She has stopped her medication while she is healing from some broken bones.

Speaker for April meeting - Lonnie - a group member. Topic- How to get information and how to use the information you receive. He encouraged members to read about MM and gather information to help understand the disease and treatment. He stated there are several good sources for information from the International Myeloma Foundation (IMF), Multiple Myeloma Research Foundation (MMRF), drug manufacturers, nurses, and others. He encouraged everyone to take charge of his or her own health and treatment. Ask questions about medications doctors prescribe, to understand the goal of the treatment,

what are the side effects, will this prepare you for a transplant, how long will it take for the drug to become effective, etc. You need to know your doctor's viewpoint or treatment philosophy. The group shared thoughts on this and concluded it is good to get information from many sources so you can make an informed decision about your healthcare.

Other comments:

Gail told the group to become knowledgeable about nutrition. Gail and Marvin will bring a list of supplements that have been proven helpful in treating neuropathy. Marvin will bring information on natural herbs his doctor recommended for him.

Deborah, Lonnie's nurse from the VA Hospital Oncology unit, stopped in to visit with the group and share in our meeting. She agreed to conduct a session to teach members to read lab values and to provide journals that will assist in keeping test results.

Speakers for upcoming meetings

May- The speaker may not be able to make the meeting is on Memorial Day Weekend. The speaker will notify Doris.

June- Dr. Heffner will be the speaker. Members were asked to come with questions.

Respectfully Submitted by Yvonne, Gail, and Paulette