

## July 2008 Meeting News – New Members

There were no new members at the meeting this month.

### Business & Other Information

**Joe** led the meeting. It was sadly noted that we have lost two group members. The group acknowledged the passing of **Joe**, who was a very active group member. **Joe** was 83 and diagnosed with multiple myeloma eight years ago. Services are planned for some time in August. Also, **Daisy** passed away in early July. **Daisy**, who had bone cancer, was a member of the Southside group. Our thoughts and condolences are extended to their loved ones.

### Member Updates & Collaboration

**Sandy** reported on some members who were not present. **Carl**, who began a clinical trial in May, is continuing with the trial, but results are unknown at this time. **Carl's** wife, **Dee** recently had successful shoulder surgery. **Andy** reported that **Mike** is currently in a holding pattern, getting blood tests every 1-2 weeks, but under no treatment at this time; waiting to decide on the next treatment. **Suzanne** who has had smoldering myeloma for about 4-1/2 years is considering a combination of Revlimid, Velcade, and Dex as induction therapy. She had some questions about Velcade, such as how long the infusion takes, and side effects. Someone mentioned that the actual Velcade infusion is only for six seconds, but there is a one hour saline infusion and lab work that accommodates each Velcade infusion, so plan on approximately three hours for the entire session. Side effects mentioned from various group members included: fatigue, nausea, fever, neuropathy, and loss of appetite. The side effects mentioned varied greatly by different individuals, with some mentioning experiencing no apparent adverse side effects. **Ginny** has just completed the second round of a Phase 1 clinical trial at Emory called SNS-032, which is a kinase inhibitor. **Ginny** did not have good results after the first round and second round results are pending. **Ginny** is receiving the highest dose of the drug in the trial, and explained that she receives the therapy at Emory on three successive Tuesdays; then gets a week off. A typical schedule for her is: Tuesday – spend twelve hours at Emory / Wednesday – do nothing (there is much fatigue) / Thursday – start feeling better / Friday – usually feels good. On another topic, **Ginny** mentioned a new Emory site, <http://cancerquest.org/> where there will be a multiple myeloma link in the future (it is in process). **Latain** reported that she just completed her one year post stem cell transplant checkup and is waiting for the results. She is on no maintenance therapy and feels good. **Dale** took the advice of another group member and got a baseline bone scan. Recent follow up scans show good results. **Dale** has had Restless Leg Syndrome (RLS) for a while, but the RLS and cramps have become much worse recently. **Dale** met with a neurologist who thought that he may be over-medicated. **Dale** has tried reducing some of his medication to experiment, however no improvement has been noticed. **Jim** was in remission for 2-1/2 years, but when recent immunoglobulin tests showed potential activity he stopped taking Revlimid and Dex in order to collect stem cells. **Jim** was unable to collect enough stem cells two years ago, however he was able to collect enough (8 million) stem cells recently, using a new drug in trial at Emory, which reports a 90% collection rate. The trial actually does not currently include myeloma patients; however **Jim** was allowed the agent as a “compassion case”. In conjunction with the regular mobilization injections, the new drug was administered (injected) at his home, and the drug helps to keep the stem cells available. **Jim** also reported that he recently began experiencing vertigo, cold sweats, dizziness, and some hearing loss. After a series of tests a small tumor was found on the inside of his skull.

**Jim** made it a point to explain to the group that in less than a week he was able to have a complete diagnosis and a plan for beginning treatment because he asked for faster appointments than what he was initially offered. Otherwise, it would have been weeks or longer before he would have had a complete diagnosis and treatment plan. His point was that it pays to be very demanding (i.e. polite, but firm) when your quality of life is affected. **Jim** had been taking 2 MG Dex 4 times a day to reduce inflammation. It is possible that coming off of the Dex is what allowed the lesion in his skull to be detected. **Jim** made it a point to explain that even if your myeloma test results appear to be very good, don't ever rule out myeloma if something is not quite right. **Jim** noted that his recent myeloma test results still look better now than when he was initially diagnosed at Stage 1. **Dori** commented that if you are unable to get an appointment in a timely manner, try going to the organization's Practice Administrator level to get what you want. **Nancy** had been taking 200 MG of Thalidomide for nine months, but recently reduced the dose to 150 MG for the past two months since she began experiencing neuropathy. **Nancy** mentioned that the neuropathy seems to be mostly in the form of numbness in her left foot, and that she has increased her walking regime, which has helped. **Andy** mentioned that if the symptoms are asymmetric, then it may be a nerve or muscle problem and suggested also checking for other causes to be certain. **Wanda** also reported experiencing numbness and tingling in her feet. **Wanda** is currently taking Revlimid, but has taken Velcade and Dex previously. **Ray** mentioned that he has taken Alpha Lipoic Acid to help with neuropathy with success. **Ray** found neuropathy relief with alpha lipoic acid in the past when he was on Velcade and Dex, and currently while on Thalidomide. Alpha lipoic acid can be found in drug stores and health food stores, and someone mentioned there may be more information on the Dana Farber website, which has a list of supplements to take or not take with cancer treatments. Various group members have also found neuropathy relief using drugs such as Lyrica and Neurontin. There was some other discussion about Emory now scheduling appointments; they are no longer operating on a first come, first serve basis. Also there was some discussion surrounding bone marrow aspiration – both with and without conscious sedation. No one recommended going through the procedure without sedation, however a driver is required to do so. Another discussion was about the local stem cell transplant units; if any were better than others. Mostly Emory and Northside were discussed and in general the group seemed to feel that both were very good.

**Correction** – In the June 2008 newsletter, it was noted that **Doris** had received a stem cell transplant. Doris has not had a transplant. Doris had provided an update on Michelle, who had a transplant and is doing well.

**Submitted by Wendy**