

May 2008 Meeting News – New Members

The group welcomed **Thina**. Thina was diagnosed with smoldering myeloma in March 2008 after being monitored for four years with MGUS. She is currently holding off from taking any drugs and is interested in homeopathic options. Thina is considering stem cell collection and has visited the Northside BMT unit and is also interested in finding out about other doctors for additional opinions and options. The group mentioned **Vinnie's** use of curcumin and various doctors and locations including Dr. Lonial (top researcher at Emory), the Myeloma Institute at Little Rock, Arkansas (known to be aggressive), The Huntsman Foundation in Salt Lake City, Dana Farber Institute (Drs. Anderson (retiring) and Paul Richardson), phone consultation with Dr. Durie of the IMF, and M.D. Anderson's clinical trial using curcumin.

Business & Other Information

Nancy led the meeting. *There is a possibility that the July meeting will be moved or cancelled* because it falls on July 5th (during the July 4th weekend). Feedback is welcome on this decision. The group will decide in the June meeting, so stay tuned!

It was also noted that the ACS is sponsoring many local "Relay for Life" events, as it regularly does this time of year.

Member Updates & Collaboration

Bill who is partaking in a clinical trial was absent from the meeting but provided some information - he is not getting good results yet, but plans to continue. **Ginny** has left the LBH clinical trial and is considering either the Immunomedics trial, or a different trial that opens the third week in May (a drawback to this trial is that it requires a long 12-hour day each week on site, in this case at Emory). **Nancy** reported that her husband, **Mike** is experiencing low blood counts and is currently getting blood and platelets. The low counts have further delayed stem cell harvesting, but is rescheduled for the very near future. **Al** mentioned that his father will be getting a blood transfusion due to anemia and asked if anyone has experienced any adverse issues associated with blood transfusions. Several in the group responded that they have not had any problems with blood transfusions. **Jim** mentioned the importance of getting a good doctor to "watch your bones", which is not automatically done. Even though Jim has remained in remission for some time, and has been on Aredia every three months, he recently found out that he had a fracture in his back after he experienced some pain after coughing and had it checked. Jim expressed the importance of getting skeletal surveys regularly. **Dale** reported that he is considering intravenous immunoglobulin (IVIg) therapy to assist his immune system, and asked if anyone in the group had used this before. It was noted that **Suzanne**, who has smoldering myeloma, reported in the January 2008 meeting that she planned to begin the therapy. **Dale** also informed the group of a side effect that he has experienced with Revlimid - he was on Revlimid for over a year before getting a rash. The rash was relieved with a cream that he obtained from his pharmacist. **Earl** is no longer taking Thalidomide due to neuropathy (even at 25 MG) and has switched to Revlimid, which he likes better. Earl is in the process of scheduling kyphoplasty surgery to repair 3 – 4 compression fractures in his back. Earl found a doctor at Pinnacle Orthopaedics to perform the surgery through the IMF. **Jim** reminded the group that just because your numbers appear good in blood tests, you should still get a 24-hour urine test at some regular interval since myeloma can clone itself, and begin presenting in other ways. This is something that should be discussed and planned with your

doctor. **Raisa**, who is in the process of preparing for a stem cell transplant at Emory, reported that she is anemic, which is likely due to gastrointestinal problems that she has been experiencing. **Raisa** is now going through a series of tests, which has delayed the stem cell transplant. **Marilyn**, who has smoldering myeloma, reported that her test results remain stable and she continues without any treatment at this time. **Latain** reported doing well and continues without any treatment other than Zometa.

There was some discussion about the IMF-sponsored "Myeloma Manager", an interactive spreadsheet available on the IMF website that can be used to track your personal test results. Many in the group are now using this spreadsheet and have provided positive feedback – it is highly recommended. **Jim** noted that he did not find built-in liver function functionality but he was able to add that information separately. There was also some discussion about harvesting stem cells and the amount required to be able to transplant. It was noted that if the bone marrow becomes damaged, it is much harder to mobilize stem cells for collection, and there is no way to predict how much you will be able to harvest. **Dana**, who had a successful stem cell transplant in 2001, attempted collection again in 2006 (two years ago). The use of Neupogen did not get his cells mobilized enough, so he tried another mobilization agent, which was in trial at the time. **Dana** was in the hospital for 3-4 days, but barely collected 2 million stem cells. **Mary** had a successful stem cell transplant in 2002 with only 3 million stem cells and had another 3 million frozen.

At a separate time, **Doris** provided an update from the Southside Group's April meeting, held at the new location at the Macy's Corporate Room at Greenbriar Mall; and for which all members were present. Two guest speakers attended this meeting:

- 1) **Mitchell**, a social worker from the VA Hospital spoke to the group, and also provides assistance to one of the group members.
- 2) **Ms. Marie**, a counselor for Fulton County, provided information about available services and assistance. **Ms. Marie** is the mother of one of the group members, **Jameca**. Ms. Marie will attend the next meeting to answer questions that were not answered in the April meeting due to time constraints. Member updates are as follows: **Mitchell** is in the hospital for a transplant. **William** is partaking in a clinical trial and has been in and out of the hospital. **Lonnie** was in the hospital but is now at home. **Authur** has been ill, and the group is waiting to get an update on his condition from family members. **Jameca** is getting additional testing for some problems that she's been experiencing.

Submitted by Wendy