

## **April 2008 Meeting News – New Members**

The group welcomed five new members this month - **Al, John, Harland,** and **Brian and Martha. Harland** was diagnosed with myeloma in December 2007 when a high protein level was discovered. He is participating in a clinical trial at Emory and is currently on a Velcade, Revlimid, and Dex mix, and experiencing neuropathy in his legs. Because of the neuropathy side effects, he plans to lower his Velcade dosage. **Harland** has harvested stem cells for a possible stem cell transplant, and is considering a tandem transplant. **Brian and Martha** also attended for the first time. **Brian** was diagnosed in April 2007. Symptoms included severe leg pain, high fever, and he was found to be hypercalcemic, with an abnormal hemoglobin range. **Brian** has since had two stem cell transplants – one in September 2007 and a second in December 2007. **John** was diagnosed with myeloma in February 2007. **John** went to Northside Hospital in great pain and he was sent home. He was in such pain that he returned to the hospital the next day and was diagnosed with renal failure and placed on dialysis for a week. A gall bladder infection and another infection were also found, and he was in the hospital for three months. John is currently on Velcade, which he began three months ago, and has also taken Thalidomide previously. **Al** attended the meeting for his father, who is 87 years old. **Al's** father, who is also diabetic, was diagnosed with myeloma last summer when abnormal blood counts were noticed. He has tried Thalidomide, which was not tolerated well. **Andy** mentioned that Melphalan may be a good option if a stem cell transplant is not planned. (Note: Melphalan damages bone marrow and can not be taken in excess if you intend to have a stem cell transplant at some point).

## **Business & Other Information**

**Nancy** led the meeting. **Nancy** is working to finalize the new group brochure. The purpose of the brochure is to help spread information to myeloma patients, and the plan is to place the brochure in waiting rooms of various doctor's offices, clinics, etc. where patients will be able to locate them. Please bring any other recommendations of where these brochures can be placed to **Nancy** and/or the group meeting to help spread the word. **Mary** reported that there are two new CDs in the library from the dental presentation held in January. **Joe's** daughter has volunteered to help with a new group website. **Pat** reported that the Southside group has moved to the Macy's building on Greenbriar Parkway, on the second floor. This new location provides better parking facilities. Six Southside group members attended the recent local IMF Patient and Family Seminar, (many were new members), and all reported that the seminar was valuable. In a separate phone call **Doris** mentioned that very good feedback was provided on the caregiver portion of the seminar as well. **Andy** reminded the group that there is a new IMF-sponsored "Myeloma Manager" interactive spreadsheet available on the IMF website that can be used to track your personal test results. The program can be downloaded, the data is stored locally (i.e. where only you can access it); and the program will calculate, measure, and compare your data for you. An email address support means is also included. **Bill** also mentioned that the data is stored in encrypted format. **Andy** recommended that everyone try this valuable complimentary program.

## **Member Updates & Collaboration**

**Sandy** provided an update on some group members that were not present at the meeting. **Carl** is near the six month point beyond the second of two stem cell transplants, and his protein and plasma cell counts have both become elevated. **Carl** plans to discuss this with Dr. Hefner and possibly consult with Dr. Durie as well. **Sandy** has also been trying to

contact **Mary** who has moved. **Nancy** reported that her husband, **Mike** is recuperating in the hospital from double pneumonia. He is doing much better, but the pneumonia has delayed the stem cell mobilization and collection in preparation for a transplant, and in the mean time, the cancer is active again, so additional chemotherapy will be required before proceeding with mobilization. **Dale** reported that he is doing well after a bout of pneumonia in December, and then again two months later. He was in the hospital for a week during the second bout, when E coli bacteria was also detected. **Bill** recently began a new clinical trial, and just completed the last chemotherapy treatment. In theory, no dramatic results are expected, but the protocol should slow disease progression with minimal side effects. **Bill** reported being sick the first day (which he said is “typical” with any therapy for him) and some sleepiness, because the protocol includes Benadryl; with no other side effects noted. He is hoping for one month “on”, and then three months “off” the protocol. **Norma**, who continues to take Revlimid after partaking in one of the first clinical trials, has remained in a complete remission for approximately five years. **Norma** reports that she has experienced no adverse side effects from the Revlimid. **Norma** mentioned that with previous therapies she tried, she always experienced a good and quick response, but without lasting effects; even if remission was achieved it did not last long. When her husband **Glen** asked Dr. Lonial if she can be considered “cured”, he responded that it is unknown because there is “no cure on record”. **Nancy** reported that her husband, **David** is doing well on Revlimid and Dex, although the Dex is “taking a toll”, even though it is considered a low dose (20 MG/week). **David’s** myeloma is of the nonsecretory type, so it is hard to measure; but his freelite levels are normal, he gets periodic PET scans, and his clavicle is healing.

The group discussed some highlights from the IMF Patient and Family Seminar held locally last month:

- 1) An IMF nurse discussed drugs and their side affects and the importance of staying as active and hydrated as possible to counteract negative affects.
- 2) Michael Katz (IMF) presented, “How to Be a Better Patient”, which doesn’t necessarily mean a “cooperative” patient. Ask questions!!!
- 3) There is a helpful list of acronyms on the IMF site.
- 4) Dr. Hefner (Emory) discussed how stem cell transplants may be a “key element” for some patients.
- 5) It was noted that currently remission is achieved in 60-70% of patients. Ten years ago remission was achieved in only 20% of patients.
- 6) Gene therapy mapping to customize treatments has become very popular – to date, three myeloma markers have been identified.
- 7) Dr. Durie (IMF) spoke about Velcade and Revlimid as front line therapies, the decision process to have a stem cell transplant or not, the CRAB (Calcium, Renal (creatinine), Anemia (hemoglobin), and Bone lesions) criteria, and the increase in survival rates.
- 8) Dr. Lonial (Emory) presented different ways to view bone images for baselining and tracking, including images from PET scans, CAT scans, MRI, and X-rays. Also discussed was kyphoplasty surgery, and Osteonecrosis of the Jaw (ONJ).
- 9) Research in general is very aggressive, organized, and dynamic. Results are shared, with much collaboration.

**Harland** asked “how long does it take to recover from a stem cell transplant?” The group’s consensus was that it really depends on the individual; and that there are many in the group who have had stem cell transplants that could provide more details of their experiences.

**Rick** commented on his experience with kyphoplasty surgery in September 2005 to repair vertebral damage caused by myeloma. **Rick's** experience was excellent and he highly recommends it to anyone who is a good candidate for the procedure. It is done very quickly as an outpatient procedure and there is very little recovery time. There was some general discussion surrounding Procreit, which has been in the news a lot lately, with some reports of adverse reactions. **Andy** commented that reactions to the drug appear to be very personal, and that there are other similar drugs available, with a few currently in trial. Try searching the internet on "anemia drugs" for alternatives to consider if necessary. There was also some general discussion surrounding bisphosphonates, specifically Aredia and Zometa. Any bisphosphonates can cause kidney problems, but Zometa is considered to be rougher on the kidneys than Aredia. **Andy** mentioned that if there is no (or little) bone involvement, then less bisphosphonates might be in order. The current protocol is Aredia or Zometa every three months, however less may be sufficient, depending on the situation. **Jim** mentioned that the bisphosphonate dose is also based on creatinine levels. **Carter** mentioned that bisphosphonates may be given more frequently early on, and then begin to taper the frequency once stabilization occurs. Some group members shared experiences of "close calls" with drug interactions and reminded us to be aware, especially with the introductions of new drugs. **Bill** has a friend who recently changed medication without stopping use of the original medication before beginning the new, which resulted in a "near fatal" situation. **Glen** reported that his son was prescribed a "potentially fatal" drug combination that was caught by CVS pharmacy. It is extremely important to be especially careful when multiple doctors are prescribing medications. Be sure that all of your doctors and pharmacies are updated with all medications that you take in order to reduce risk.

**Submitted by Wendy**