

## August 2011 Meeting News

### **New Members**

The group welcomed 4 new members this month. **Elizabeth (Libba)** was diagnosed in June 2007. She thought her rotator cuff was torn due to pain in her shoulder. Her doctor found that her humerus bone was destroyed, but correct the situation using bone cement and a rod. She did have radiation, but no chemo. The pain returned a year later and she needed surgery. After a couple months, the pain returned and her orthopedic surgeon referred her to an Oncologist who confirmed the diagnosis. She was treated with Revlimid, Velcade, and Dex for 2 months and achieved remission. She did experience pneumonia and grade 4 neuropathy. She harvested stem cells 2 years ago. **Lizabeth** was diagnosed in June 2011. Her hemoglobin was fluctuating but no broken bones. She was referred to an Oncologist who performed a bone survey, urine test, and biopsy. It was noted that she was diagnosed with Carcinoid cancer 6 years ago. (Carcinoid cancer is a tumor in the intestines that can look like a polyp and can spread to lungs, liver, or heart). **Kenmond** was diagnosed June 16, 2011 after having back problems for five years. Bloodwork and a bone marrow test confirmed diagnosis. He is currently on Velcade and Dex. **Robert** was diagnosed in February 2011 after several misdiagnosis of back problems. His doctor was concerned after 3 epidural shots which resulted in him not being able to walk. He also had 4 fractured vertebrae. He was referred to an Oncologist who made the diagnosis and started treatment of Velcade twice a week. He was originally on Revlimid but stopped due to blood clots. He does plan to harvest stem cells. He has tried several medicines for the pain and says that Lyrica keeps him awake.

### Business and Other information

**Nancy** led the meeting and 57 members were present. Joe pointed out that this was the largest group without a guest speaker! Nancy spoke about the email survey and said she has received responses indicating that open group discussion is the most popular. The **MMRF Race for Research** will be on Saturday November 12, 2011 at Piedmont Park. Carolyn leads the committee for the Race and is asking all members to consider their employers or other companies for sponsorships. A company can donate \$500 and have name and logo printed on the MMRF t-shirts that are given to all participants. It was also discussed having long sleeve shirts available for sale. A handout was distributed regarding a conference call on August 25, 2011 from 4-5 pm (pacific time) The speaker is Timothy Tyler, Pharm D. The discussion will be “Drug Interactions and Contraindications for Multiple Myeloma” To join the conference, Dial In at 1-866-393-4674. Conference ID: 89197249. A pamphlet was given out about a Symposium for Survivors after Bone Marrow or Stem Cell Transplant. It will take place September 10 & 11, 2011 in Atlanta at the Sheraton Atlanta Hotel. Details at [bmtinfonet.org/atlanta2011](http://bmtinfonet.org/atlanta2011) or 888-597-7674.

Some news articles were given out and the synopsis are as follows:

(1) **“Onyx Pharmaceuticals and MMRF launch Cafilzomib Expanded Access Program”** The Carfilzomib Myeloma Access Program (C-MAP) will include eligible patients with relapsed and refractory Multiple Myeloma. This expanded program would make medicine being evaluated in clinical trials, available to patients with no treatment alternatives available.

(2) John's Hopkins is studying "**Bortezomib and Thalidomide as a steroid free regime.**" There are results showing significant anti- multiple myeloma activity, permitting development of a steroid free regime. The study is in Phase 2, which analyzes toxicity and efficacy as first line treatment. Peripheral Neuropathy was resolved in 80% of patients tested and a survival rate was 74%.

(3) "**Complete Response correlates with long term progression free and overall survival in elderly myeloma**" This study analyzed 1,175 patients at the Hematology Division at the University of Torino in Italy. The study has proven that, with certain treatments, patients have achieved a complete response in overall survival; versus progression of specific treatments. Results were noted in patients over 75 years old.

### Updates

**Virgil** says he is doing well. He has been taking Lyrica; six pills a day for two years. **Chaz** states that he is feeling good. He is still on chemo treatments, consisting of Revlimid and Dex. **Sandy** had an update on **Bill**. He was in the hospital after complaints of back pain. He was treated with Cytoxin, Velcade, and Dex. He is home now, but very weak and dehydrated.

Submitted by Lana