

November 2008 Meeting News – New Members

There were two new members at the meeting this month. **Karyn** was diagnosed with myeloma in mid-October. Karyn was experiencing fatigue and flu-like symptoms and tests revealed that she was in the midst of renal failure. She was in the hospital for five days for plasmapheresis and received five transfusions during that time. She is planning to begin home dialysis. Other tests detected no lesions and Karyn is starting her second round of Velcade and Dex; and plans to consult with Dr. Bashey at Northside in preparation of a stem cell transplant. **Frank** was also diagnosed with myeloma in mid-October. Frank was experiencing some fatigue and low white and red blood counts and high protein levels were discovered during a physical exam. Frank was referred to a hematologist, and had a full body scan with good results relative to bone, but a PET scan identified a tumor. Frank is currently deciding on treatment and is consulting with the Mayo Clinic in Jacksonville. He is expecting a two month treatment in preparation for a stem cell transplant. **Andy** suggested that a phone consultation with Dr. Durie from the IMF could also help with the treatment decision.

Business & Other Information

Nancy led the meeting. Approximately 34 members were present. The group raised over \$5,000 in the MMRF Race for Research, which was held in October. Thanks to everyone who supported this important event. During our December meeting we will have a potluck gala. All members are welcome to bring a dish to share – either hot or cold; heavy hors' d'oeuvres and desserts have been a big hit in the past. Also, during the holiday gala the group traditionally collects toys to donate to children with cancer at Egleston Children's Hospital. Please bring a new, unwrapped toy to the December meeting.

Member Updates & Collaboration

Mary reported that **Ginny** has had a serious adverse reaction to her current treatment and has been hospitalized in the Neurology ICU at Emory. Ginny is very sick with low energy and she is not allowed to have visitors or phone calls. If you wish to contact Ginny, please send cards to her home address and/or send email. **Sharon** notified the group of an experience that she recently had after ordering a steak at a local restaurant. Her hemoglobin suddenly dropped and she needed two blood transfusions due to food poisoning, which caused hemolysis. Sharon warned the group to be careful of ordering steaks prepared with spice rubs. It turns out that when spice rubs are used they can mask the taste of old beef. In summary, be careful when eating out. Although Sharon's white blood count was already low, this could have happened to anyone. **Karyn** has been feeling jittery while on Dex and Velcade. Many in the group recognized that the culprit was likely the Dex making her feel this way and offered suggestions such as not taking the Dex all at once in one day, but rather taking a couple of pills at a time scattered throughout the day. It was also suggested that to prevent nausea while on Dex to take the pills with something like ice cream, pudding, etc. **Inge** is currently on Velcade and Dex. She had problems tolerating the Dex and so her doctor has reduced the dosage. **Roslyn** is doing well on Revlimid and Dex. Roslyn asked the group if they had any suggestions for preparation for traveling outside the USA. It was noted that there are laws in some other countries that will not allow narcotics, or may be very strict about carrying narcotics, so find out ahead of time what the rules are if you plan to carry narcotics. Depending on the laws, you may be able to bring a note from a doctor explaining what the medication is for and why you are carrying it. Also, if your

immune system is compromised, wear a mask and use hand sanitizer. **Suzanne**, who initially had smoldering myeloma for four years, began treatment for the first time in October using Revlimid, Dex, and Velcade in preparation for a stem cell harvest. **Rick** reported doing well after single stem cell transplant approximately 2-1/2 years ago. Rick is not currently taking any myeloma drugs, but does receive Zometa on a regular schedule. **Latain** is also doing well post stem cell transplant and is not taking any myeloma drugs, but receives Zometa. Latain mentioned that she recently had Shingles, and is just recovering from that. **Sharon** mentioned that patients on Velcade are susceptible to getting Shingles and that some doctors will use an antiviral agent, such as Acyclovir to prevent Shingles while the patient is on Velcade. **Gwen** reported being off medication for one year and doing well. **Carter** reported that his myeloma has progressed slightly and he is trying to improve it with Revlimid. **Helen** reported that her husband **Jim's** myeloma seems to have plateaued, but he is experiencing bad pain in his neck, which they don't think is myeloma related. Jim has been on Revlimid and low-dose Dex for over a year and is continuing with that regimen. **Vinnie** reported that his myeloma numbers look good. **Shemeka** reported that her father who lives in Hawaii is planning for an allogeneic (donor) stem cell transplant and has consulted with Atlanta area clinics - Emory and Northside so far. **Andy** mentioned that Dana Farber and Seattle would also be good places to consult with for this type of stem cell transplant. **Monique's** myeloma has relapsed and she plans to begin a Phase 1 clinical trial in mid-November using Revlimid, Dex, and HuLuc63. **Bill** mentioned that he also began that regimen about two months ago and has had good and fast results. Bill said that after the first round he had an adverse reaction (which he said is typical for him), but otherwise he has done well. **Sandy** reported that she just had an MRI for some thigh and leg pain and she is waiting for the results. Sandy has been in remission since 2004 and was diagnosed with myeloma 19 years ago. **Mike** was diagnosed with myeloma 10 years ago. His most recent treatment was in April when he was on Velcade and Cytosan and obtained a partial remission. Mike's myeloma is of the non secretory type and is difficult to monitor. Mike said that the disease has been improving with no current intervention. **Carolyn** reported that she also has the non secretory type of myeloma and stopped treatment in July and her disease is also improving. She attributes the good results to eating organically, water aerobics, and a positive attitude. Carolyn also mentioned that she had previously taken Doxil and had experienced black blisters, neuropathy, and other skin problems while on the Doxil. **Sharon** mentioned that she was also unable to tolerate Doxil; however she was under the impression that most who tried Doxil tolerated it well. There was some discussion surrounding why some patient's test results may show a large amount of plasma cells in the bone marrow, and yet the patient does not experience bone problems. It was explained that it is possible to have such strong bone on the outside, that even when the marrow is compromised, the myeloma will not necessarily be able to attack and harm the bone due to the bone's strength. A way to test bone strength is by having a bone density test.

Submitted by Wendy