

April 2009 Meeting News –

New Members

The group welcomed **Bernie** who was representing his wife, **Patty**, who was diagnosed with myeloma in May 2008, after kidney failure. A regimen of Revlimid and Velcade has begun, and a stem cell transplant is being considered.

Business & Other Information

Nancy led the meeting. Approximately 40 members were present. Mike and Nancy's son, Mark, held a party for cancer research at a club in Buckhead. The gathering at Andrews Upstairs was held to raise funds for the MMRF Race for Research. Nancy reported that everyone at the party had a good time and it was a success! In the May meeting the group will divide between patients and caregivers for separate discussions. **Joe** will lead the caregiver discussion. The group needs volunteer note takers for the patient sector of the May meeting; and also for the entire June and July meetings. Please contact **Nancy** and/or **Wendy** if you are available and can help take meeting notes during these months.

Member Updates & Collaboration

The group learned that one of our members, **John**, passed away last October. Our sincere condolences are extended to John's wife, **June**. **Nancy** provided updates on members who were not present at the meeting. **Janice** is participating in a CC4047 clinical trial at the Mayo Clinic in Jacksonville, FL, where she is on site on the first Saturday of each month. The agents consist of Pomalidomide (a derivative of Thalidomide), and low-dose Dex. Meeting members commented that this trial is expected to be available locally at Emory in the near future, and that research is showing that it appears that the side effects of Pomalidomide are much less than that of Revlimid. **Shameka** reported that no sibling donor match was found for her father, **George**, however they are still considering an allogeneic (donor) stem cell transplant. **David** commented that he has heard that there is an effort to try to get the graft-versus-host disease (notoriously associated with allogeneic transplants) to work to the advantage of the patient to fight myeloma cells with the mini allogeneic transplants. **Mike** is getting Procreit and is taking Revlimid every other week. Mike has low red blood counts and platelets and experiences much fatigue. **Raisa** who relapsed in June 2008 after a stem cell transplant is now taking a combination of Cytoxan, Velcade, and Prednisone, and is being treated at Emory. **Monique** had a second (non tandem) stem cell transplant a month ago and is doing very well. She was home after just 2-1/2 weeks and found the second transplant to be much easier than the first, which she had in 2004. **Earnestine** reported that she is doing well, and also heard from **Mary**, who is currently on Thalidomide, and is doing well, however is experiencing much fatigue. **Ginny** reported that the most recent clinical trial that she participated in did not help her. She is now taking a combination of five drugs including Revlimid, Velcade, Cytoxan, Dex, and Dynastat; with a complex schedule (i.e. some daily, others every other day, etc.). Round 1 of this combination resulted in a less rapidly escalating paraprotein level, and Ginny is just beginning Round 2. **Helen** reported that her husband, **Jim**, is continuing on Revlimid, but has currently dropped the Dex. Jim is also experimenting with over-the-counter Curcumin, with his doctor's allowance, but not necessarily recommendation. **Marilyn** who has smoldering myeloma is doing well. Her numbers are remaining stable and she continues to stay health conscious in order to strengthen her immune system. **David** reported that he is doing well. Since relapsing over two years ago he has taken Revlimid and Dex, and has

decreased the Dex dosage. David explained that he has experienced neutropenia and is using Neupogen injections to counteract the problem. **Sandy** reported that she recently fractured her foot bone, and stopped all maintenance drugs prior to surgery in late January. Sandy explained that this is her third fracture as a result of long-term steroid use. Sandy also mentioned that studies have confirmed that long-term Aredia and Zometa use can make bones brittle and also cause fractures. **Carolyn** has begun a Phase 2 clinical trial for HuLuc63. The trial combines Revlimid, Dex, and HuLuc63 agents. Carolyn explained that she spends all day on site one day a week, and takes Revlimid every day and Dex once a week. Additionally, Acyclovir (antiviral medication) and Bactrim (antibiotic) are a part of the mix. To date the only noticeable side effects appear to be from the Dex, along with low blood counts. Some group members suggested that Carolyn try spreading out the Dex throughout the day, rather than taking it all at once. Also, taking an over-the-counter antacid before taking the Dex can make a difference. **Bill** reported that he just completed this same trial that Carolyn has started and it appears that his numbers are down to close to a near complete remission. Bill reported that his numbers decreased the entire time - each week - throughout the trial. Bill is one of 21 who have completed this trial with Dr. Lonial. Bill mentioned that he was sick during the first week, which is typical for him, but once he adjusted to it there were not a lot of negative side effects. He also mentioned that the on-site time shortens over time. **Sharon** began a Phase 2 clinical trial for Carfilzomib in January. After two cycles her freelite count was down 65% and her paraprotein and IGA counts were down 35%. Right after she began the third cycle she became very anemic and needed blood transfusions. Sharon explained that Carfilzomib is a permanent protease inhibitor (unlike Velcade), and it takes a long time for blood counts to recover because cells need to regrow. There was much bone pain as a side effect of this drug but no new neuropathy was experienced. Sharon also suffered bone damage and broken ribs since she began the trial, and should have continued with Aredia. In hindsight Sharon realizes that she probably should not have been allowed into the study and encourages everyone to read and fully understand the associated consent forms and to “stay on top of things”! **Karyn** attended the meeting just 25 days after a stem cell transplant. Karyn explained that although she is doing well generally, she is feeling “quite run down”, and she is unable to eat solid food currently, due to a case of Esophagitis. Karyn acknowledged that she has had a “great caregiver” throughout the process and appreciates her husbands diligence. **Gail** reported that she had a stem cell transplant in December and that she has achieved a near complete remission. **David** reported that he is doing well since his second (non tandem) stem cell transplant two years ago. His first stem cell transplant was performed four years ago. David is not taking any maintenance drugs and his numbers are remaining low. **Carter** reported that he recently suffered a pathological break in his clavicle, and some additional lesions were discovered; resulting in a series of ten radiation treatments. While he was receiving radiation he stopped participating in the trial of Revlimid, Dex, and Velcade, which caused his numbers to rise. Carter is currently looking for a new trial in which to participate.

The group expressed appreciation to the patients who are on clinical trials for the future of MM treatment. There was some discussion about the definitions of clinical trial phases. From <http://www.nlm.nih.gov/services/ctphases.html>: “Clinical trials are conducted in a series of steps, called phases - each phase is designed to answer a separate research question. **Phase I:** Researchers test a new drug or treatment in a small group of people for the first time to evaluate its safety, determine a safe dosage range, and identify side effects. **Phase II:** The drug or treatment is given to a larger group of people to see if it is effective and to

further evaluate its safety. **Phase III:** The drug or treatment is given to large groups of people to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information that will allow the drug or treatment to be used safely. **Phase IV:** Studies are done after the drug or treatment has been marketed to gather information on the drug's effect in various populations and any side effects associated with long-term use.”

Submitted by Wendy