

## October 2009 Meeting News

### New Members

The group welcomed **Lana** who attended the meeting for her father, **Hector**, who was diagnosed with myeloma in March 2009. Hector is 64 with no history of illness, and is a local doctor who did his residency with Dr. Hefner of Emory. Hector was diagnosed after experiencing a sharp pain in his shoulder at a firing range. Myeloma was discovered in his vertebrae. He is currently getting Zometa and doing well, and plans to attend the local MMRF Race for Research in November. **Rosemary** was diagnosed with myeloma in May 2009. Rosemary was living in Lewisville, TX at the time and began treatment there in June, but has since moved to the Atlanta area to be nearer to her daughter, Kathy. Rosemary was found to be anemic but nothing more was found by her regular doctor. She was sent to an oncologist who did a bone marrow biopsy and discovered myeloma. She is currently taking Velcade and Zometa. Rosemary discovered this group from an informational brochure in her doctor's office in Lawrenceville. **Lesley** was diagnosed with myeloma in July 2009 by her primary care physician. She is being treated at the Georgia Medical Center and is currently taking Doxil and Velcade. Lesley mentioned that she is experiencing some numbness in her hands and feet – probably from the Velcade. Lesley discovered this group from information on the internet.

### Business & Other Information

**Joe** led the meeting. Approximately 35 members were present. Guests from Proteolix, inventors of the drug Carfilzomib, will present at the next (November) meeting. At the December meeting we will have our traditional “potluck” holiday celebration. Everyone is invited to bring a favorite dish to share. **Jeanette** mentioned plans for upcoming guest speakers in 2010 including a nutritionist, someone from the social security office, and an associate from Emory after the American Society of Hematology (ASH) conference, which occurs in December. The annual MMRF Race for Research will be in Atlanta on November 1, 2009, starting at Manuel's Tavern. There is a website to join and make donations; and everyone is encouraged to attend the event for support, even if you can not actively participate. Our goal is to raise at least \$10,000. **Joe** mentioned that **Andy** from the International Myeloma Foundation (IMF) recommends that anyone taking Velcade to avoid green tea during treatment, as green tea can interfere with the drug's capabilities. Various members reminded everyone to discuss getting the H1N1 vaccine with your doctor. **Jeanette** recommended a new book called “Your Brain after Chemo” written by a doctor. **Vinnie** highly recommends the book, “100 Questions and Answers about Myeloma” by Dr. Asad Bashey, especially for newly diagnosed patients and caregivers. The book is available in the group's library.

### Member Updates & Collaboration

**Sandy** provided a status from some members who were not present. Sandy mentioned that she no longer has accurate contact information for **Mary**, who moved to TX. **Carl** was recently hospitalized for three weeks and he plans to begin a trial at Emory. **Earnestine** is doing well. **Sandy** also provided a status on her own progress. Sandy is nearing the 20 year anniversary of her myeloma diagnosis. For the first five years the myeloma was considered smoldering, and so there was no treatment. Since then, Sandy has endured traditional chemotherapy, which was highly toxic always leaving her sick. There were far fewer options for her early on than there are today. Sandy finally obtained remission in 2004 (after ten

years of treatment) and continues in remission today. Long-term steroid and drug use (since 1994) has made her bones brittle, leading to a good amount of fractures and surgeries. **Virgil** mentioned that he has experienced neuropathy since being on Velcade. In order to relieve the neuropathy he has reduced the dosage of, and also the frequency of the Velcade to one day a week, which is helping with the neuropathy, however the myeloma may be increasing slightly. Virgil mentioned that the pain has diminished, but he still has burning sensations. Virgil has tried two over-the-counter neuropathy relief products – 1) FreezIt, and 2) Biofreeze, which have worked well for him. It was noted that it seemed like of the two, FreezIt had more active ingredient, was less expensive, and actually worked a little better, but both offered relief. Both are available in gel, cream, and roll-on form. Virgil also stated that he was originally incorrectly diagnosed with Shingles prior to his myeloma diagnosis. He had painful skin because the damaged vertebrae were pressing on his spine. His wife, Dottie, demanded an X-ray, which resulted in a myeloma diagnosis. **Latain** is doing well and remains in remission two years post stem cell transplant. Latain explained that her physical therapist diagnosed her myeloma when she complained of shoulder pain. **Rick** is doing well and remains in remission 3-1/2 years post stem cell transplant. Rick mentioned that he has some back pain but it is not related to any new myeloma activity. **George** was diagnosed with myeloma in 2003. Prior to his diagnoses he experienced anemia and back pain which was continuous for ten years. His primary care physician sent him to an internist, then to another doctor who suggested a hip replacement. Another doctor sent him to a hematologist and a bone marrow biopsy resulted in a smoldering myeloma diagnosis. By 2006 the myeloma had advanced and George began chemotherapy, and then had a stem cell transplant in October 2007, resulting in a complete remission, which is his current status. George mentioned that he still experiences a lot of pain, however. **J'mee** recently changed doctors and now sees Dr. Hefner at Emory. J'mee explained that she is currently waiting for test results from a recent MRI and that she feels good. **Helen** reported that her husband, **Jim** recently tried reducing the amount of Revlimid that he was taking from 25 MG to 12.5 MG but the results were not good, so he returned 25 MG of Revlimid. Jim has also doubled the amount of curcumin that he takes. Also, a doctor discovered that Jim was close to getting glaucoma due to the increased pressure in his eyes from taking Dex. Jim will continue changing the various agents trying to find the right mix. **Karyn** reported that she will be moving to the Dallas, TX area soon due to her husband's job transfer. Karyn explained that she is just reaching a year since she was diagnosed with myeloma, and she still continues with the home dialysis four times a day. She recently changed nephrologists and is seeking aggressive treatment since a kidney transplant is not likely due to the myeloma. Since her stem cell transplant in March and then with news of a complete remission status in June, there appeared to be some new myeloma activity noted recently, but then, no longer appeared active. Karyn is holding off on additional treatment and she mentioned that she actually feels great. Karyn also mentioned that she has stopped the Epogen shots, which increase red cell growth. **Ginny** is beginning a new trial called ARRY-520, which entails an infusion on Days 1 and 2 every other week. A cycle lasts for 14 days. **Bill** was diagnosed with myeloma eleven years ago. Bill mentioned that about two years ago he developed vertigo, which was caused by the various chemotherapy agents administered over the years. Bill noted that one of the advantages of being a part of this group is listening to the different stories, reactions, suggestions, and remedies from a variety of people with similar issues. **Shemeka** provided an update on her father, who is not doing as well as he had been. After a blood transfusion, he experienced jaundice and he also has some pain. He was previously on Revlimid, but is currently on Velcade. **Marc** stated that

his father, **Fred**, had a successful stem cell transplant in November 2008, and is doing very well. Marc mentioned that their family had initially been very hesitant and concerned that they would not be able to have the stem cell transplant at Emory, but instead had to have it performed at Northside. Marc mentioned that they had a chance to talk to others in the group who were very supportive of the facilities and care at Northside and now, after their own experience, they agree. Marc specifically mentioned his appreciation for Dr. Solomon at Northside. Updates on members not at the meeting: **Franklin** is doing well and in complete remission as of his last evaluation in August. He is taking 5mg Revlimid every other day. **Dana** has a transplant and is waiting for his 100 day tests on November 1. **Michael** collected 12 million stem cells in one day and is ready for his transplant.

Throughout the meeting, various members offered helpful advice (especially) for those who are newly diagnosed. Highlights include (in no specific order): 1) the free “Myeloma Manager” tool from the IMF website is an invaluable tracking tool (the group also has a manual tracking tool/printed spreadsheet in the library if that is a preferred method), 2) always get copies of your test results, 3) ask a lot of questions, 4) if you don’t have a good rapport with your doctor, it is probably best to find another one, 5) second opinions are a good idea, 6) keep notes on how you feel each day and what medications and dosages you’ve taken – it will be easier to find patterns, especially if you experience negative side effects, 7) in spite of all the specialists that you now see frequently, don’t forget to continue to see your primary care physician on a normal, regularly scheduled basis – don’t neglect the rest of your body because you’ve become so focused on the myeloma.

**Submitted by Wendy**