

## **June 2009 Meeting News – New Members**

The group welcomed **Cindy** for her first visit. She was diagnosed in 2006 after having female problems that resulted in a transfusion. Her platelets did not recover after the transfusion and she was tested for MM. She had a transplant in 2006, but the disease came back this year. Cindy is on a clinical trial that includes Velcade.

## **Member Updates and Discussion**

Nancy led the session with Andy. Nancy passed around some forms to collect Patient History Summary. This is to track the experiences of the patients in the group and have it available for new members. The information includes: date diagnosed, Transplant (number or “No”), transplant location, remission duration, treatment prior to transplant, treatment after transplant. Nancy will reach out to members not in attendance to collect this information.

Sandy noted the passing of **Wanda**. She started with the group last year after moving here from South Carolina. She attended her first meeting in a wheelchair and was unable to walk. After treatment at Emory she was doing much better, but the MM got into her lungs.

**Ginny** reported that she is on a clinical trial that includes Revlimid, Velcade, Cytosin, Dex, and Zolinza. She is also taking morphine for pain from a fall that has caused disc problems.

**Suzie** is scheduled for her transplant at Emory on June 4. **Dana** is scheduled for a transplant on July 13. He was able to collect enough stem cells with the assistance of AMD3100, now on the market as Mozobil. **Karyn** is in CT for the MMRF Race for Research with Kathy Giusti, the founder of MMRF. **Carolyn** is on a clinical trial with Hulax 63, Revlimid, and Dex. She is experiencing side effects from the Dex, but minimal problems from the Hulax. Hulax is administered through an IV and her first treatment took eight hours. Now it only takes two hours. Dr. Lonial has been pleased with the results and may keep some patients on this regime for up to a year. There was general discussion about maintenance medication, even after a successful transplant. Even Arkansas is doing some maintenance programs. **Ray** said that he is on maintenance after his transplant at Arkansas two years ago. He is taking daily Revlimid at 10 mg. **David** is having his second transplant in 3 – 4 weeks, then will receive stem cells from his brother in a couple of months as a mini-allogeneic transplant. Sandy reported that she talked to Dee and her husband, **Carl**, is in the hospital. He had a transplant at Northside, but only had remission for five months. He was on a clinical trial, but no response and is now in the hospital with influenza and an infection. Sandy also reported that **Mary** had a biopsy and the MM cells were at 30%. She will start treatment with Velcade and Dex. Andy updated the group on **Susan**, a long-time friend of Andy and Cathy. Susan had kytoplasty five times and still had fractures before diagnosis. She had known Cathy’s journey with MM and talked to Andy before being tested for MM. Susan is moving to NY, where her husband is working. She appreciated the information and support of our group as she starts her own MM journey. Andy also wanted to extend greetings from **Susan** to let the group know that she is doing well. Susan’s husband, Ion, was an out-spoken member of the group who lost his battle with MM. **Drew** wanted veterans to know that VA benefits are available for MM disability as a result of exposure to Agent Orange. He noted that it takes time and work to get the benefits started. For women with cancer, Andy mentioned an organization that cleans houses: <http://www.cleaningforareason.org/> **Pat** mentioned that her father, who lives in FL, had the shingles and is taking Acyclovir, an anti-viral medication. **Milton** reported that he is

considering a transplant based on the feedback from this group. He is working on a schedule for later this year. **Gail** had a transplant in December 2008 and her counts continue to look good. She urges everyone to check the LLS web site for informative conference calls. These calls feature experts on MM subjects and they answer questions from patients. **J'mee** said that her numbers are holding. She is eating healthy and puts turmeric on her food. General discussion and questions came up on healthy eating, including foods to boost potassium and magnesium. Members were directed to the web sites of Dana Farber and Sloan-Kettering hospitals. Be sure to drink plenty of water, up to a gallon per day. **Carolyn** mentioned a cookbook for eating before and after chemo -- Eating Well Through Cancer, written by Holly Clegg and Gerald Miletell, MD. She got it free from Sanofi-Aventis. If anyone contacts them for copies, please ask for a couple extra for our library.

Submitted by Nancy