

June 2008 Meeting News – New Members

The group welcomed **Wanda** who is 49 years old. After a car accident left **Wanda** with collapsed vertebrae and lower back pain that kept getting worse, she was misdiagnosed a few times. Finally, a small hospital diagnosed her with multiple myeloma in November 2007. **Wanda** has taken Velcade and has had radiation to shrink a tumor on her spine. She is currently taking Revlimid, and had been seeing a doctor in SC (where she is from), who recommended that she go to Emory for a stem cell transplant, since her disease is considered very aggressive. She is now seeing Dr. Lonial at Emory, but a stem cell transplant has not yet been scheduled because she is too weak due to an inability to eat. She had been on an intravenous nutrition therapy, called TPN, but has since gone off of that since Dr. Lonial has prescribed Megace, which has stimulated her appetite helping her eat again.

Business & Other Information

Nancy led the meeting. Some upcoming IMF Patient & Family Seminars include locations in Seattle, WA, Boston, MA, Short Hills, NJ, and San Diego, CA. To register online, go to the IMF website, or see Nancy for an application. Nancy reported that the Leukemia & Lymphoma Society will help pay for printing the group's new brochure. Also, the new website will soon become available. On June 21st Emory is hosting a "Celebration of Living" event at the JW Marriot in Buckhead from 8:00 AM – 1:00 PM. The group will have a table at the event, which **Joe** and **Andy** will operate. This is a FREE event, but registration is requested. Please call 404-778-7777 to register. Visit www.cancer.emory.edu for directions or additional information. We continually need help with meeting refreshments – please remember that there is a sign-up sheet available at the meetings if you would like to contribute for future meetings. Also, we mail the newsletter to over 60 group members and 100 doctors each month. If you receive a printed copy and can reduce this mail load by replacing it with an electronic version, please let Nancy know.

Member Updates & Collaboration

Sandy reported on some members who were not present. **Susie** is participating in a clinical trial, but there were no updates yet. **Tim** plans to attend a meeting soon, and may bring a new member. **Susan** celebrated her 60th birthday. **Carl** began a clinical trial in May. Carl experienced a six month remission after his second stem cell transplant, but then the myeloma returned aggressively. **Carl's** wife, **Dee** will be getting shoulder surgery soon. **Sharon** is currently taking 15 MG Revlimid and 20 MG Dex and her numbers are fluctuating; no trend has been discovered yet. **Mary** has left Minnesota and is currently in Texas. Mary is no longer working on an MD Anderson consultation, but instead is working with an Arkansas oncology group. **Sandy** also gave an update on herself. Sandy was diagnosed with myeloma nearly nineteen years ago. She has been in remission since 2004. She still experiences a lot of back pain since surgery when five screws were inserted into her back, and she continues to wear a back brace. It's been one year since her femur surgery and she no longer needs to use a cane. **Ray**, who was originally treated at Emory, then at Arkansas, reported that post stem cell transplant tests show him to be in a complete remission, yet he is experiencing a problem with plasmacytoma tumors. Ray has begun a protocol of eight weeks of Velcade with Dex daily. His doctor at Emory has refused to treat him, so now he is looking for a local doctor who is willing to follow the Arkansas protocol. **Bill**, who is participating in the immunomedics clinical trial, reported that originally the disease was progressing, but recently it appears to be more stable. Generally, minor results

are expected from this trial. Bill, who was diagnosed with myeloma on his 51st birthday, will turn 61 this month! He mentioned that he's been fortunate that the disease has not stopped him from continuing to do many of the things he likes to do – horseback riding, skiing, etc. even though at diagnosis the disease was considered to be at Stage 3 with invasive tumor activity. **Ginny** has just begun a Phase 1 clinical trial at Emory called SNS-032, which is a kinase inhibitor. Ginny is the first person to be placed on the 4th highest dose of 50 MG. Ginny got a waiver to participate in the trial as an out patient; usually the trial expects patients to be in the hospital due to the high risk. A long 12-hour day each week on site is required. Ginny mentioned side effects include much fatigue, some nausea, and a huge loss of appetite. **Nancy** reported that her husband, **Mike** was unable to harvest stem cells, and so is participating in a clinical trial at Northside hospital in order to stimulate his stem cells. It was also discovered that some of the high-dose chemotherapy has resulted in some damage to his heart, and he is being treated by a cardiologist. The high-dose chemotherapy has resulted in greatly reduced plasma cells in his bone marrow. In January he had 55% plasma cell levels, and now has only 10%. Mike is scheduled to begin Neupogen injections again, and then harvesting soon after. **Brian** reported that his post stem cell transplant test results showed him to be in complete remission. Brian's first stem cell transplant was in September 2007 and the second was in December 2007. **Dale** is doing well and continuing on 10 MG Revlimid on a 21/7 day sequence as he has for over a year. Dale has had Restless Leg Syndrome (RLS) for a while, and has been on Requip for about a year, but the RLS has become much more severe recently, and no longer is just his legs affected, but also his upper body. Dale met with a neurologist who questioned if he may be over-medicated and/or if the condition is medication related. Dale mentioned that he also had a lot of a "twitching" reaction with Velcade previously. **Earl** recently had kyphoplasty surgery to repair four vertebrae in his back. Earl found a doctor at Pinnacle Orthopaedics to perform the surgery through the IMF. Earl had some pain after the surgery, but feels better each day, and has already realized a great amount of pain relief after only a week. He also mentioned that it was recently discovered that he has a fractured sternum. **Helen** reported that her husband, **Jim** has been experiencing a lot of pain recently. Jim had a steroid injection, which seemed to alleviate the pain for a while. **George**, who had a stem cell transplant in October 2007 reported that his April test results showed a complete remission. George has back pain and may have some collapsed vertebrae. He also mentioned that he has experienced severe pain after receiving Zometa, and has switched to Aredia on a quarterly schedule. **Carter** is completing a clinical trial. Originally, he was taking Revlimid, Dex, and Velcade, but he discontinued taking Dex because it was pulling calcium from his bones, and he discontinued Velcade due to neuropathy. Carter continues taking Revlimid and recent test results showed a complete remission. **Carole** reported that her husband, **Raphael** began radiation treatment at Northside. Raphael had been on Velcade, and then was off treatment for three months and doing well until he experienced a lot of pain, and tumors were discovered. **Harland**, who was diagnosed in December 2007 is participating in a clinical trial at Emory and is on Velcade, Revlimid, and Dex. Harland is in his eighth cycle now, and in the seventh cycle got good results, so he is hoping to begin maintenance soon. **Vinnie** reported that his five year anniversary of being diagnosed with smoldering myeloma is approaching and he is continuing on Curcumin. Vinnie also mentioned that increased PSA levels were recently discovered and he is being tested for infection, and may get a biopsy depending on test results. **Dori** reported that her father, **Lou** is currently being treated with Velcade, Melphalan, and Prednisone, and is experiencing much exhaustion. **Jameca** reported that she recently had a pelvic lumbar fracture and just got off crutches. She had been receiving

radiation for 5 minutes a few times a week, which was successful, and is now only being monitored. Jameca is celebrating her four year anniversary since her stem cell transplant. **Lonnie** reported that he had been in the hospital for a couple of days with pneumonia, but is doing well now. **Doris** remains in remission since her stem cell transplant. She sees her doctor every two months, and takes 50 MG of Thalidomide every other day as maintenance. She mentioned that she experiences some neuropathy in her foot. **Doris** also provided an update for the Southside Group. Several members had been in the hospital recently with pneumonia, but all are doing well now.

Submitted by Wendy