

September 2010 Meeting News

New Members

Lou was attending for the first time with his wife, Debra. Lou had several vertebrae collapse and after multiple tests was diagnosed with MM in March 2010. He is currently being treated with Velcade, Revlimid, and Dex (VRD) along with Zometa. He is preparing to start the transplant process in October at Northside BMT.

Business & Other Information

The group is looking forward to a visit from members of the Emory team at our October meeting. Dr. Jonathan Kaufman, Charisse, and Melanie are scheduled to join us for discussion of new treatments and open question session. Feel free to bring family members and guests to this important discussion. Please note that the yoga classes held in our meeting room will resume after a summer recess from 9:30 to 10:30. They have asked that we wait to enter the room at 10:40. We will need help in setting up the room for the guest speakers. Nancy reminded the group about the iMAGE Study for the causes of MM. They need about ten more patients and members are urged to contact Norma Heard at 404-756-8818 to participate.

Nancy brought news articles about clinical trials and side effects. The latest information on MM is available as a result of several key conferences: American Society of Hematology (ASH) in December, American Society of Clinical Oncology (ASCO) in June, and European Hematology Association (EHA) in June. The articles were discussed and copies were passed around at the meeting. Additional copies of these articles will be available at the October meeting. A brief synopsis of a few of the articles reviewed:

- **Carfilzomib-Revlimid-Dex** is well tolerated, showing less damage to peripheral nerves and fewer cases of low white blood cells. The overall response rate of 75% improved with long-term therapy; up to 18 cycles.
- **Nerve Damage in MM** was discussed at ASCO. Dr. Richardson explained that MM, itself, causes nerve damage that leads to pain. He urged close monitoring and regular assessment of peripheral neuropathy (PN) at each consult during treatment. Dose reduction may be necessary, but Dr. Richardson noted that PN dose modification did not appear to affect disease progression as the patients were able to continue therapy for a longer period of time.
- **Panobinostat** combinations show benefit when combined with Velcade or Revlimid and Dex. The study shows 60% response rate, even with patients who are refractory on other treatments.
- Combination of **Revlimid-Velcade-Dex** in a Mayo Clinic study with newly diagnosed MM patients yielded an **unprecedented 100% response** to the phase 2 dose level; 57% entered a complete remission within a few months of treatment. Although 40% of patients required dose modification due to neuropathy, further refinements of dosing and long term options are under review.
- **Heparin, Warfarin, and Aspirin** are equally effective in preventing blood clots in MM patients receiving Thalidomide.
- **Understanding Chemo Brain** – Symptoms identified and strategies to help with the effects.

Member Updates & Collaboration

Hector was attending with his family after a recent stem cell transplant. Hector's wife, Brenda, said that she used her nursing experience to put ice chips in Hector's mouth and cold water to the GI tract. Hector had no mouth sores and very little nausea since the cold suppresses blood flow that carries the high dose chemo into the mouth and gut. Hector was glad to be more mobile and was looking forward to continued improvement. **David** updated the group on his allogenic transplant from his brother. David's MM is gone, but he is dealing with Host vs. Graft (HVG). He is

experiencing a severely suppressed immune system and weight loss. **Chaz** went through the harvest process in July, but was not able to harvest enough stem cells, even with a drug for mobilization. He will not have a transplant and is back on Thalidomide at 50 mg. **Ernestine** was on a clinical trial that required her to be at Emory four days per week. She has ended that trial and is waiting on other options. **Jeanette** has been on the Hulac clinical trial since January. She is getting good results against the MM but is having GI issues and loss of appetite. **Carolyn** has been on the Hulac trial since March 2009 and has minimal side effects. Predisone has been added for a few cycles. Carolyn reported from some members that were not present. Everyone was glad to hear that **Karyn** is going on a cruise to get a much needed break. **Matty** is going to meet with the transplant team at Northside to begin that process. **Nancy** is still in remission from her transplant and is taking Tumeric (Circumin), which is a herb that is in clinical trial at MD Anderson to control MM. Nancy B. updated the group on **Mike's** status. He has been off chemo for over one year, but the numbers are creeping up. He is also dealing with amyloidosis, a rare disease that may develop in 15 – 20% of MM patients. Amyloidosis is a disease in which abnormal proteins accumulate in organs such as the heart, kidney, liver, or intestines. He is experiencing daily pain, which may be from MM, chemo side effects, amyloidosis, or all three. Nancy also reported that **Patty** had a transplant in February and is excited to announce that she is in remission and feeling great. She urges fellow MM friends to stay positive and keep the faith. **Monique** was re-assessed two months ago and is still in remission. She continues her Zometa treatments. **Ray** is still in complete remission, but peripheral neuropathy is causing sleep problems. He is doing yoga for flexibility and relaxation. **Mary** said that her MM is creeping back from her transplant in 2002. She is not able to harvest for another transplant due to damage from the old style chemo: VAD, DT-Pace, and Thalidomide. She will be exploring her options. **Becky** has had a long struggle with leg cramps. She is working with her doctor to adjust her medication. She has reduced her Revlimid from 25 mg to 15 mg and switched from Dex to Medrol every other day. This had led to reduced side effects and no reduction in muscle mass. She feels that her muscles are starting to rebuild. **Latain** had her 100 day evaluation from her transplant earlier this year and is in remission. She is on 10 mg Revlimid for maintenance. Jeanne reported that **Bill** had what was thought to be shingles, but turned out to be a fungus.

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