**February 2009 Meeting News –**
**New Members**
The group welcomed seven new members at the meeting this month. **Eric** was diagnosed with myeloma in August 2007. An emergency room visit after a car accident discovered no broken bones, however his bone marrow appeared "questionable"; and soon after a visit to an oncologist resulted in a myeloma diagnosis. Eric has had a stem cell transplant and is doing well. He is currently on a maintenance routine of 5MG Revlimid every other night and Aredia every three months. **Rebecca** was diagnosed with myeloma in October 2008, after experiencing a broken collar bone and rib pain. Rebecca is currently on a combination of Velcade, Thalidomide, and Dex, and is considering harvesting for a stem cell transplant. **Jerold** was also diagnosed with myeloma in October 2008, when a PET scan showed lesions. Jerold's type of myeloma displays no blood markers, so it is difficult to monitor. Jerold has periodic PET scans to monitor progress, and is currently on a combination of Revlimid, Velcade, and Dex. **Becky** was diagnosed with myeloma in April 1999, just after moving to Atlanta. Becky has had three stem cell transplants and a variety of chemotherapies. Becky has reached "near complete remission" (nCR), but has never reached a "complete remission" (CR). She was most recently on a combination of Velcade, Thalidomide, and Dex, and is considering her next therapy since the disease appears to be progressing. **Michael** was diagnosed with myeloma three months ago. Michael explained that he was originally treated for a plasmacytoma that became myeloma. He is currently on a combination of Thalidomide and Dex; and also receives Aredia. **Cheryl** and **Pat** also joined the group for the first time this month.

**Business & Other Information**
**Nancy** led the meeting. Approximately 55 people were in attendance.

**Guest Speaker**
Many thanks to **Dr. Sagar Lonial** from Emory Winship Cancer Institute who provided the group with an update from the most recent American Society of Hematology (ASH) Conference and the latest clinical trials at Emory. Also present at the meeting was **Melanie Watson**, a nurse who trained Dr. Lonial, and who is now a part of his staff. Dr. Lonial's staff specializes in multiple myeloma, with their entire collective focus devoted to the goal of "improving outcomes for patients". Melanie also commented on the importance of finding a doctor with a thorough understanding of myeloma. Dr. Lonial began the presentation noting that it is has now become very apparent that combinations (greater than one) of agents are better in treating myeloma than single agents alone.
Some reasons for this include: 1) good results can be obtained with lowered dosages, 2) side effects from a single agent can sometimes be reduced by varying the mix, and 3) the synergistic effects of the combined agents - when using a synergistic approach, the end result far exceeds what each drug can accomplish alone. In cases where a drug worked well in the past but no longer works alone, benefits from that drug can sometimes be improved when combined with other drugs. Trial participation has changed the standard approach to treatment, and now a standard upfront therapy is a combination of Revlimid, Velcade, and Dex. France is leading the way for trials involving these drugs in conjunction with stem cell transplants. Dr. Lonial also leads stem cell transplant research and expects that stem cell transplants for controlling myeloma will continue. For relapsed myeloma patients, there are trials in process for both brand new drugs and combinations of current drugs. One of the new drugs is Pomalidomide (a "third generation" Revlimid), in which those resistant to

Revlimid can use. Also new is Carfilzomib (a "second generation Velcade"), which results in different side effects than Velcade. (i.e. little neuropathy). There are also other protease inhibitors in development, some of which are oral (i.e. NPI-0002). Dr. Lonial commented that longevity results are very encouraging due to the ability to maintain control of MM. The following questions were addressed during the presentation:

**Q: Why are there so many different and varied symptoms between patients at diagnosis time?**

A: It might be because myeloma may be more than just a single disease.

**Q: How is an induction regimen chosen?**

A: The most commonly used upfront regimens are combinations of Revlimid (R), Velcade (V), and Dex (D) in combinations of all (RVD), RD, or (VD).

**Q: What are some of the main side effects from some of the more popular therapies?**

A: Thalidomide – constipation, neuropathy, fatigue

Revlimid – thrombosis, low red counts

Velcade – fatigue, nausea, neuropathy

Pomalidomide – suppression of counts

Carfilzomib – fatigue, possibly a change in kidney function

**Q: When is the best time to harvest stem cells?**

A: Experience suggests harvesting stem cells early, while the bone marrow is less likely to be damaged by chemotherapy.

**Q: Which of the chemotherapy agents are "gentler" on bone marrow?**

A: Chemotherapy attacks bone marrow. Revlimid and Velcade result in less of an attack on bone marrow.

**Q: Is there a downside to postponing a stem cell transplant?**

A: Yes, depending on how long you wait. Data suggests that the survival rate is about the same when a transplant occurs either immediately after the first remission or after the first relapse. However, if you wait to transplant for the first time after the third (or more) remissions have occurred, the results are not as good.

**Q: How do you determine the right time to begin treatment in relapsed cases?**

A: If the relapse pace is high, move more quickly. (**c**alcium elevation, **r**enal insufficiency, **a**nemia and **b**one abnormalities). With a slower, indolent relapse, consider CRAB criteria, and wait. This is the same way that new patients are treated.

**Q: What are the criteria for a complete remission (CR)?**

A: Criteria for a CR include less than 5% plasma cells in bone marrow, normal freelite test results, no detectable protein in urine, normal blood test results, normal immunofixation test results, and no bone lesions.

**Q: Are there any new strategies for prolonging remission?**

A: Data suggests that Thalidomide may be beneficial for those who are not in a complete remission (CR). There are also trials that are in progress testing both Velcade and Revlimid for maintenance purposes, but results are not yet available.

**Q: Who can benefit the most from maintenance therapies for those who have achieved a complete remission (CR)?**

A: Patients who are in a CR, but are considered to be "high risk" benefit the most. There does not appear to be much of a benefit for patients who are in a CR, but are considered to be "low risk" patients.

**Q: Is a second stem cell transplant recommended after a relapse if a long CR was achieved from the first transplant?**

A: This is a patient-specific decision but a general recommendation is that if the patient achieves a CR for less than two years from the first transplant, then a second transplant is not recommended.

**Q: In myeloma cases where there are bone lesions but no markers, how does monitoring occur?**

A: Non secretory cases occur in about 2% of cases and require monitoring the bone marrow and checking blood counts.

**Q: What drugs used to treat myeloma are also being used to treat other types of cancer?**

A: Revlimid can be used for other cancers. In general, if a drug can block the pathway to a cancer, it can be tried for another type of cancer with the same pathway.

**Member Updates & Collaboration**

**Nancy** provided an update on members who were not present. **Sandy** has broken the largest bone in her foot and was unable to attend the meeting. **Roslyn** is preparing for a stem cell transplant at Northside hospital, and is currently staying at the "House of Hope", which is a new facility near the hospital. **Nancy** recently received a stem cell transplant with no required hospital stay and was released after 30 days. **Karyn** reported that she is scheduled to begin a stem cell harvest in mid-February, with a stem cell transplant planned in March. **Wanda** reported that she has been unable to harvest enough stem cells using Neupogen alone as a stem cell mobilization agent, and so she is scheduled to begin trying a combination of Neupogen and Mozobil concurrently. **Vinnie**, who has had smoldering myeloma for approximately 5-1/2 years, discussed his use of Curcumin (Turmeric) for the past four years. Vinnie explained that he is following an MD Anderson trial protocol, although he is not actually a trial member. Curcumin has also been used as a maintenance therapy for myeloma patients who are in complete remission. There is more information about this in the group's library. There was some discussion about recent reports confirming that some components of green tea may counteract the beneficial effects of Velcade. It was also mentioned that "anti-oxidants" in general can potentially work against some chemotherapy agents, which are "oxidants"; and so it is wise to be prudent about taking supplements in conjunction with chemotherapies, and to always disclose any use of supplements to your doctor. **Elaine** commented on the importance of becoming and staying very educated on the subject of myeloma. Many in the group commented on how different and varied the treatments and their outcomes are depending on each individual; as well as the varied options and combinations that are now available.

**Submitted by Wendy**