

December 2009 Meeting News –

Business & Other Information

Nancy led the holiday meeting. **Andy** introduced **Mary**, LLS in TN, who attended to observe the group's operations. Approximately 38 members were present; there were no new members. There was lots of good food and a festive feel in the air. Those who could not attend were missed and we look forward to seeing you in the New Year! We also discussed ideas and plans for upcoming meeting topics and speakers. Some ideas included speakers on nutrition, and legal documents such as power of attorney, living wills, etc. **Carolyn** recommended a book called "Multiple Myeloma: The plain English Handbook for Patients and Care Givers", written by Robert J. Heller. Someone else mentioned that they found a brochure in our library, on a service called "**CancerCare**" which proved to be very beneficial. They were impressed with the good quality and amount of support provided for both patients and caregivers.

Member Updates & Collaboration

Various members provided updates from members who were not at the meeting. **Tom** is participating in a clinical trial at MD Anderson. **Sharon** recently received a high dose of Cytoxan. Sharon provided the website of an organization that provides free housecleaning services to anyone receiving cancer treatment: <http://cleaningforareason.org/> **Sandy** recently had surgery to remove screws in her legs. Sandy's husband **Joe** was recently hospitalized due to a stomach virus. **David** had an allogeneic (donor) stem cell transplant approximately five months ago, with stem cells donated by his brother. It was reported that he is progressing slowly, but doing well. **Vanessa** reported that she is currently on a VDT-PACE regimen in preparation for a stem cell harvest in mid-December and a stem cell transplant planned for January. Vanessa mentioned that she is in need of caregiver assistance during the transplant time. Vanessa also mentioned that she was doing some physical work (vacuuming) soon after a bone marrow biopsy and experienced some fluid building in her hip, which resulted in some nerve damage. She is doing OK now, but wanted to educate the group of this occurrence. **Dana** reported that his 100 day post stem cell transplant results were great! **Mike** had been on a 7 days on/ 7 days off Revlimid (10mg) regimen, combined with Dex(40mg once a week). The mix worked well for him, and he has since halted the treatment after achieving near remission approximately 4-5 months ago. Mike fell down a short flight of stairs without breaking bones, but suffered skin damage. He does not recommend it as a test for bone strength! **Bill** explained that his body is no longer making enough blood due to a reduction in stem cells, although the quality is good. He is preparing for another stem cell transplant, but on a "slightly smaller scale". He will have a smaller dose of Melphalan; then have his stem cells injected to help boost production. He expects to be in the hospital for two weeks during this process. Bill also noted that he is now being monitored for leukemia due to the various chemotherapies he has endured for approximately ten years. **Latain** reported that she is no longer in remission after approximately 2-1/2 years and she has been experiencing pain in her hip. An MRI found lesions in her hip, shoulder and spine, and she has begun a combination treatment of Velcade, Thalidomide, and Dex, which worked for her before. She is preparing to begin the second cycle now. **Jeanine** has maintained remission obtained from a stem cell transplant in mid-2005, but wondered if anyone in the group experiences severe fatigue as regularly as she does. Jeanine did not feel that the fatigue was related to her age, and regular medical tests have not presented a reason for it either. Several in the group mentioned that the regular

daily use of Oxycodone may likely be contributing to the fatigue. Various members mentioned that experimenting with smaller dosages of pain medication might help. **Wendy** reminded the group to be cautious of withdrawal symptoms when halting or lowering dosages of pain medications. **Rick** mentioned that he uses small doses of Methadone to relieve pain, but mostly because he experienced gastrointestinal issues with Oxycodone. **Hector**, a practicing physician reminded the group that pain perception and pain control varies by person, and that the treatment is highly individualized. **Karyn** and her husband, **Greg** will be moving to TX in mid-December. Karyn said that she has completed two rounds of VRD therapy, a combination of Velcade, Revlimid, and Dex. The Revlimid has made her dizzy, and she is experiencing low blood pressure and anemia. Karyn explained that she plans to hold off on further treatment, and not begin the next round until after their move. Karyn also asked if anyone else in the group had tried Marinol, which no one else had. Karyn's attempt to use it to reduce restlessness and anxiety were not what she expected and she said it made her agitated and she also had leg cramps when taking it. She also said that it made her very awake, which was not the effect that she was hoping to achieve. **Carolyn** mentioned that the H1N1 vaccine might not be offered to those who are taking Dex.

Submitted by Wendy