

November 2010 Meeting News

New Members

The group welcomed some new members this month. **Tarriel** and **Peri, Madge** and **Don**, and **Alvinia**. **Tarriel** was diagnosed with myeloma in June 2010, after experiencing declining health for about six months prior. In December 2009 he had a stent implanted due to a heart condition, which was successful; and he felt fine for a while afterward. But, by the end of 2009 he felt sick and didn't know why. The unexplained sick feeling continued, and in May 2010 his kidneys failed completely. His nephrologist did a complete blood panel test and sent him to a hematologist, where he was diagnosed with MM. **Tarriel** has completed six cycles of Velcade, Dex, and Thalidomide; and is scheduled to harvest stem cells but is unsure if he will actually have a transplant. He was at the meeting to talk with other patients who had experienced a transplant. **Madge** was diagnosed with smoldering myeloma in October 2008. In May 2010 she began treatment with Velcade, Dex, and Revlimid with good results. She ended that treatment and has recently begun a different treatment regimen of Revlimid (only) and is doing well. **Alvinia** attended the meeting for her brother, **Bob**, who lives in Florida. She joined our discussion to learn more about this disease and the treatment options.

Business & Other Information

Nancy led the meeting. Approximately 35 members attended. The MMRF Race for Research was on 11/20 at Piedmont Park. "Team Together" combines resources from both local MM support groups to participate in this event by walking and/or making donations. The MMRF focuses on research which accelerates clinical trials. The team web site will be available until the end of the year for donations: <http://support.themmr.org/goto/teamtogether>

Nancy is looking for a few members to assist her with contacting local legislators to promote issues of interest to the MM community. The IMF supports this activity and provides information at: www.advocacy.myeloma.org An **IMF Patient & Family Seminar will be held in Boca Raton, FL** beginning on 2/25/11. Find out more by going to the web site (www.myeloma.org); click "meetings and events" tab for the most up to date information and the seminar agenda. These events provide the most intense MM information and a chance to interact with experts. Also, a local one-day seminar is being planned for the first quarter of 2011. **Andy** is in the process of organizing this event; more information will follow. As family members upgrade their cell phones, a box for cell phone recycling will be available at meetings to generate revenue for the group. The group will **celebrate the holiday season in the December 4 meeting**. Please feel free to bring a dish or beverage of your choice to share meeting and feel free to invite friends and family members to attend with you!

Important Note: The January meeting falls on a holiday (New Year's Day), and so the **meeting date will be moved to the following Saturday, January 8, 2011**. This is a one-time change, and the location and time will remain the same.

Member Updates & Collaboration

Nancy provided news articles for discussion. Topics included: "Highlights from ASCO", "Battling Cancer – Fringe Therapies Go Mainstream", "Once-Weekly Velcade Is Equally Effective But Better Tolerated In Elderly Multiple Myeloma Patients", "Maintenance Therapy Gains Ground In Blood Cancers", "Combination Of Thalidomide And Cyclophosphamide May Negatively Impact Stem Cell Collection", and "MGUS And Smoldering Multiple Myeloma: Experts Identify Risk Factors For Disease Progression And Establish Monitoring Guidelines". Some members have had success with some over-the counter neuropathy treatments. **Mike** has achieved some relief with "Stop Pain" (a spray), and also "Neuragen" (gel). **Carolyn** recommended "Udderly Smooth", which is a cream to be massaged on hands and feet at bedtime. Also discussed was the use of acupuncture for pain relief. **Ray** reminded the group not to use acupuncture when the myeloma is active – it could spread

the disease. As is often the case, some in the group have tried acupuncture with good results and others have not had good results. **Earnestine** mentioned that it has helped her feel much better, but **Sandy** mentioned that it did not help her. If you are considering acupuncture, it is recommended that you find a highly qualified, licensed practitioner with referrals and be sure to check with your doctor first. For the remainder of the meeting the group split into separate groups – one for patients (led by **Sandy**) and one for caregivers (led by **Joe**). The caregiver meeting focused on “burnout” and the discussion included ways to both prevent burnout and also relieve the effects of feeling burned out. The patient session talked about family relationships and identity outside of this disease.

Submitted by Wendy