

January 2010 Meeting News –

New Members

The group welcomed new members this month, **Patricia “Pat”** and her husband Patrick. Pat was diagnosed with myeloma in September 2009. After getting treatment for a prior back injury and rib pain, an MRI was performed, which led to the diagnosis. Pat has endured six Velcade treatments, the last leading to stomach pain which put her in the hospital for a week. She has just started using Revlimid since her recovery.

Business & Other Information

Nancy led the meeting. Nancy shared a few printed articles that were found on the “The Myeloma Beacon” website, <http://myelomabeacon.com>: 1) “Study Shows Benefits Of Vesselplasty In The Treatment Of Spinal Fractures”, 2) “New Recommendations Issued On Stem Cell Collection And Treatment With Revlimid, Thalidomide, And Velcade”, and 3) “Phase 3 Trial Indicates Denosumab Delays Skeletal Related Events In Cancer Patients”. Also mentioned was the American Society of Hematology (ASH) Conference that occurred in New Orleans in December. The International Myeloma Foundation (IMF) has posted videos from doctor’s presentations and other highlights of the conference at <http://ash.myeloma.org>. A social worker will attend the February meeting to discuss Insurance and financial support.

Member Updates & Collaboration

Various members provided updates from those who were not at the meeting. **Ginny** has begun a second round of oral Pomalidomide and also had Vertebroplasty surgery for back pain. **Sandy** has been on IV antibiotics for an infection for four weeks, and will be getting her port removed very soon. **Jeanette** plans to begin a new treatment soon. **Karyn** likes her new doctor and new facility in TX, and will begin a next cycle of treatment there. **Bill** is no longer planning for another stem cell transplant since he reacted well to the Neupogen injections.

David attended the meeting after some time away, and explained his history: he had a single autologous stem cell transplant in 2005 and was on Revlimid for two years after a myeloma relapse. Last April he was diagnosed with myelodysplasia, which can lead to a form of leukemia that is very difficult to treat. So, in 2009 David had tandem stem cell transplants, with an autologous transplant performed first with frozen stem cells collected 4 years ago; followed by a mini-allogeneic (donor) stem cell transplant 90 days later (early August) with stem cells donated by his brother. David experienced Graft VS Host disease and a lot of GI problems resulting in much weight loss. He was re-hospitalized in September, unable to eat, receiving IV nutrition while in the hospital to help gain weight. Tests performed in November showed no myeloma or myelodysplasia. He is still immune suppressed but is doing much better now. David noted that the mini-allogeneic transplant is not a guaranteed cure for the myeloma but may possibly be for the myelodysplasia.

Marion has completed a stem cell harvest, with a stem cell transplant planned for some time in the summer. Marion mentioned that he is losing his ability to walk and so he is seeing a new neurologist to try to determine why. **Frank** reported doing well. He has been taking Revlimid with Dex for about a year now and his counts are nearly normal. Frank has harvested stem cells but is holding off from a transplant at this time. He

mentioned that he tries to stay active to alleviate any fatigue caused by the drugs. **Latain** reported that she is beginning a third cycle of Velcade, Thalidomide, and Dex, and has had good results. Much of her pain has diminished and she did not have to have radiation treatments. **Hector** plans to begin chemotherapy at the end of the month in preparation for a stem cell harvest and transplant. **Vanessa** reported that she is scheduled for an in-patient stem cell transplant on January 11th and expects to be in the hospital for 2-3 weeks. Vanessa also mentioned testing that can be performed to determine cell characteristics to better understand the aggressiveness of the disease, which has lead her to start planning for post transplant maintenance plans.

Various other topics and reminders were discussed, including: 1) The importance of communicating with any mid-level practitioners that you see, since they communicate with the doctors, 2) **Nancy** reminded anyone preparing for Melphalan to keep ice chips in your mouth during the infusion, which can help prevent mouth sores. Someone also mentioned a drug that can help prevent mouth sores. 3) Suggestions for getting more protein incorporated into your diet included powdered protein mixed with ice cream, whole milk yogurt, etc., and frozen chocolate Ensure or Boost mixed with chocolate ice cream. A specific brand (Stonyfield) of whole milk yogurt made for babies was mentioned. 4) A reminder was made to be careful of, and report to your doctor any supplements – vitamins, herbs, etc. that you are taking, as they can sometimes interfere with treatments. 5) There was mention that a lot of drugs have a long half-life, and can continue to work (and have side effects) after they are no longer being taken. 6) The long term effects of taking Dex including making you more susceptible to infection, the wasting of muscle and deposits of fat, and bone brittleness was discussed. 7) Remember to harvest stem cells early before bone marrow is damaged by treatments.

Submitted by Wendy.