

March 2010 Meeting News –

New Members

There were no new members attending the meeting.

Business & Other Information

Nancy led the meeting; approximately 36 members attended. Nancy reminded the group to update the list with your doctor's names and contact information. This list is used for the monthly newsletter distribution. Nancy also alerted the group of plans for a teleconference with the IMF hotline during one of the regularly scheduled future meetings so that we may be able to get answers to some of our unanswered questions. Please keep this in mind so that you can prepare your questions in advance. **Carl** and **Dee** attended the meeting for the first time since Carl's tandem stem cell transplant. Carl has written a book entitled, "Still Here Kickin'", which was written for cancer patients and caregivers. Carl hopes to help others by telling about his experiences with myeloma. The book is available to purchase directly from Carl Dixon at 770-578-8604 or via email (Carldeed@comcast.net). Copies are also available in the group's library.

Carl's wife **Dee** recommended a "caregivers" support group that meets the second and fourth Wednesdays from 6:00 PM to 8:00 PM at The Wellness Community located at 5775 Peachtree Dunwoody Road, Building C - Suite 225, Atlanta, GA 30342 - 404 843-1880 www.thewellnesscommunity-atlanta.org,

Member Updates & Collaboration

Various members provided updates from those who were not at the meeting. **Carolyn** was recently hospitalized with pneumonia, but her condition appears to be improving quickly. **Virgil** also has pneumonia. **Karyn** (now residing in TX) is taking a break from chemotherapy.

Milton has postponed his stem cell transplant until the summer time. He is currently taking Revlimid and doing well, and has harvested stem cells in preparation of the transplant. **Sandy** is doing well since the removal of her port, which was the source of a recent infection. Sandy also mentioned that much of her pain has subsided and she is no longer using a cane! **Rosalynn** reported that she is doing well and currently on a break from Velcade since her recent test results were good but she has been experiencing very bad neuropathy. Rosalynn explained that she has collected stem cells and is preparing for a transplant. **Becky** who was diagnosed in 1999 has had a relapse since her third stem cell transplant. She is currently taking Revlimid and Dex with side effects of hand and leg cramps. Becky mentioned that she has harvested and stored stem cells to use if necessary. **Jerry** recently began to relapse following initial diagnosis in 2005, with a stem cell transplant in 2006. Jerry plans to begin an Elotuzumab (formerly known as HuLuc63) trial at Emory. **Jeanette** who recently began the Elotuzumab trial has results from one cycle and mentioned that to date it is working. **Vanessa** reported that it was approximately 60 days since her stem cell transplant and doing well generally. She experiences some fatigue and some pain usually late in the day. Vanessa also mentioned that her nails are splitting and someone suggested taking gelatin capsules and/or biotin may help. **Carl** recommended an over the counter product called "CUTEMOL", which is an emollient skin cream. Carl explained that he had badly cracked fingers and rough skin on his feet. After two days of treatment with the ointment, he had smooth skin with no cracks or bleeding. It can be purchased at any drug store but it may have to be ordered. **Nancy** provided a tip for those who have difficulties

associated with IV/needles and pain. Nancy has had good results using a warmed gel pad that can be placed in the microwave and made into a sleeve to warm the area just before a needle is to be inserted. The gel pads can be found in the pharmacy sections of drug and department stores. Nancy also 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.

Some questions were asked for which no one present knew answers; and these may be good questions for the IMF teleconference meeting: 1) Are there differences in prognosis depending on myeloma type (i.e. IgG, IgA, IgD, IgM, IgE, etc.)?, 2) Does gender play a role in complication and outcome of stem cell transplantation?

Various other topics were discussed, including: 1) Studies suggesting that Zometa (a bisphosphonate) may also have cancer fighting capabilities, 2) How to know when it is best to get a generic versus a brand drug. Theoretically they should be the same however some binding agents used in generic versions can cause unexpected results sometimes. The group was reminded that if you know that you want the brand (non-generic) to ask your doctor to ask for it to be dispensed that way. 3) Dental work when on bisphosphonates – generally if dental work is needed the suspension of the use of bisphosphonates for a certain time period prior to the work being performed is required. No one at the meeting reported ever having Osteonecrosis of the Jaw (ONJ). 4) There was some discussion regarding loss of height which is often the result of compression fractures, which is common in myeloma patients.

Submitted by Wendy