

May 2010 Meeting News –

New Members

The group welcomed new members this month. **Frank** attended the meeting, representing his brother in law, **Armand** who is 82 years old and diagnosed with myeloma in December 2009. Armand was initially hospitalized for a month, and then relocated from CT to live with Frank and his wife. He has been on Velcade and Dex for approximately two months, with no apparent negative side effects from the Velcade. Frank mentioned that he has first-hand experience with the benefits of support groups and he was there to gather information and get help with understanding what to do to help. **Chuck** attended the meeting with his wife, **Sue**. Chuck is 54 years old, and was diagnosed with myeloma in March 2009. Symptoms included back pain for which epidural shots were not working. A pet scan/MRI detected a tumor, and then months later a diagnosis of myeloma resulted. Chuck's current treatment is 50 mg. Thalidomide daily. He is in remission and monitored monthly. He also gets Zometa monthly, and uses Percocet and Oxycontin for pain. He experiences leg cramps, but not neuropathy. Chuck mentioned that he is a professional landscaper and is very active. He has been told that he is not a candidate for kyphoplasty surgery due to the extent of his spine damage. Also, he was told by his doctor that he is not eligible for a stem cell transplant due to his age, for which the group urged him to get a second opinion, and also with a recommendation to harvest stem cells early before bone marrow damage from treatment occurs. **Karen** also attended for the first time. Karen is a former caregiver for her husband, who passed away in July 2008 after having myeloma for five years. Karen noticed signs for the meeting in the church bulletin, and attended for the purpose of bringing her knowledge to help the group.

Business & Other Information

Nancy led the meeting. There were approximately 37 members present. Some meeting time was used to collect questions in preparation of the June meeting conference call with the International Myeloma Foundation (IMF) Nurse Board. The group is looking for access to a toll free or local (Atlanta) phone number with conferencing capability to enable members to attend meetings remotely. Please contact **Nancy** if you can assist with this request. Prepaid envelopes are available for collecting cell phones that are no longer in use. Some proceeds for this effort go to the AAMMSG. New AAMMSG brochures have been printed and are available. Members are encouraged to bring some to their doctor's office and asked to ensure that administrators are made aware of the importance of getting the brochures to all myeloma patients, and especially to newly diagnosed myeloma patients and their caregivers.

Member Updates & Collaboration

With sadness the group acknowledged the passing of **Raphael**, a long time group member. Sincere condolences are expressed to his wife, **Carole**, an active and respected group member. Notification was also received as to the recent passing of two other members. **Janice** had extensive treatment but enjoyed her daughter's wedding last year and family gatherings. **Juanita** was a member in South Carolina who appreciated all the discussion information in our newsletters.

Nancy spoke with **Tim** recently. Tim has been on Velcade for seven years with minimal side effects. He stopped eight weeks ago and his counts began to rise, so he may be going back on this treatment after the next round of tests. Tim mentioned that Alpha Lipoic Acid should not be used in conjunction with Velcade. **Latain** is doing well and attended the

meeting after having a second stem cell transplant on April 8th. **Roslyn** has been off Velcade for two months and is currently taking Revlimid and Dex and is doing well. **Jim** is currently on Revlimid and Dex and reported having fatigue and night sweats. There was some discussion and recommendations about taking Dex early in the day so that one can make use of the energy during the daytime and still be able to sleep at night. There was also discussion about some of the benefits of Dex, side effects, and dosages. **David** mentioned that he is currently taking Prednisone (another steroid) for the purpose of suppressing graft vs. host disease, which he has found to have side effects far worse than those of Dex. David specifically noted much worse muscle atrophy (a common side effect of steroids in general), for which lots of exercise helps to manage. **Harland** was diagnosed approximately 2-1/2 years ago and has been in remission for about 1-1/2 years. He is currently taking Revlimid and Dex as part of a clinical trial. Harland reports having some manageable leg cramps and foot neuropathy. **Frank** is also on Revlimid and low dose Dex and reported experiencing leg cramps. **Becky** is having problems keeping her potassium and magnesium levels correct. She reported having severe leg cramps for which she uses quinine to alleviate. It was also noted that inadequate potassium levels can cause leg cramps. [Note: Many members reported experiencing leg cramps; some manageable and some very painful and extreme. This topic generated much conversation and at some point the group surmised that taking Dex with the Revlimid might reduce (or mask) leg cramps, but then seemed to disprove the theory with later conversation on the same topic. Since we know everyone is different, this might be something to research further with your doctor if you suffer from leg cramps.] **Carolyn** mentioned that she has experienced treatment related drops in blood pressure resulting in dizziness. Her doctor ordered an echocardiogram and she learned from this experience that myeloma patients may be prone to have fluid buildup around their hearts. **Mike** reported that his recent echocardiogram revealed some heart damage that was not considered serious, but could make him feel less energetic. Mike has also had Amyloidosis, which is a bone marrow disease (not cancer), resulting in a protein buildup (called amyloid) around organs. Amyloidosis may be treated with chemotherapy (similar to MM treatment) and stem cell transplant. **Milton** has previously harvested stem cells at Northside, with plans for a stem cell transplant as an in-patient at Emory later this year. **Bill** mentioned that he had oral surgery recently and his doctor requested that he take Dex prior to the surgery because of the effect that Dex has in raising blood pressure. Also, although Bill has been off Aredia for quite a while he learned that because of the half life of the drug, it still has an effect. It appears that it is not as much whether you are currently on the drug (bisphosphonate), but rather if you have ever been on the drug (bisphosphonate). Bill advised the group to remember to let all medical personnel know what you are taking - including over the counter medications because you never know what effects they may have in seemingly unrelated places that you would not expect. Basically, we don't yet know the long term affects of many treatments being used today. **Hector** mentioned that he has completed recent dental work, yet his jaw pain persists. He also mentioned that during a recent pre-transplant evaluation process he was required to get dental permission/clearance to proceed. **Vanessa** commented that with such a conglomeration of agents, frequent changes in dosages, etc. it is often very hard to determine potential causes of side effects. Several group members commented on the benefits of keeping a journal of what you've taken and their dosages to try to find root causes. Someone specifically mentioned a Treatment Planner by the Celgene Corporation that they found when attending a conference sponsored by the Leukemia & Lymphoma Society that they found useful for this purpose.

Submitted by Wendy