

January 2011 Meeting News

New Members

There were no new members at the meeting.

Business & Other Information

Joe led the meeting in **Nancy's** absence. Nancy's husband, Mike began in-home hospice care just a couple of days prior to the meeting. We have learned that Mike passed away at home on Thursday, January 13, after a brief visit with family. ***Please keep this family in your thoughts and prayers.*** Joe reminded us of Nancy's dedication to the group, specifically noting how much time she spends on a daily basis. Many in the group commented on the quality of the leadership that Nancy has provided and how important it is to retain that quality leadership for the group's continued success. Joe is looking for five volunteers to help continue to support the group, specifically caregiver members who can serve on the board, help coordinate the programs, and coordinate refreshments. Helping with the programs is especially needed. **Jeanette** has worked for years coordinating programs for the group and needs assistance. Please contact **Joe** if you can help. Also noted: the group received a thank you note from the children's hospital where toys were donated at holiday time.

Guests

A **Millennium** (producers of Velcade) representative attended the meeting and provided literature and refreshments. He explained that he works with doctors and local support groups. While regulations do not allow him to answer direct questions, he can assist with helping you formulate questions for your doctor, or help you find additional resources. Examples of the kinds of things he can assist with include financial resources, transportation, drug reimbursement, ways to get drugs if you don't have insurance, etc. He can help you work through your doctor's office or social worker to get what you need, not with Millennium directly. Please consider this valuable resource when you need assistance. Contact information is available in the group library.

Also, **Norma Heard** attended the meeting to recruit members for a study sponsored by the **Morehouse School of Medicine**. This project has been extended to October 2011. The goal of the study is to determine what causes myeloma. A one-time visit to complete a questionnaire, along with a blood test is required to participate in the study. The participant will receive a \$25 Visa gift card for contributing to the research. The entire process takes approximately two hours, and you have the option of getting the results from the study. **Norma** has attended many of our meetings, and has established a rapport with the group. Some of the members who have already participated in the study mentioned how easy it was to get to the facility from the highway, and the courteous staff that they worked with - the written questionnaire was even filled in for them by the staff - participants did not have to do a lot of writing. Participants will need to be able to recall some things in their past, such as medical history, medications, etc. To participate, please contact **Norma** at 404-756-8818, or nheard@msm.edu.

Member Updates & Collaboration

Sandy reported on some members who were not present at the meeting. **Milton** had a stem cell transplant in September and is doing well. **Tim** was on Velcade for many years and it is no longer

working well, so he is looking for other options. **Carl** is doing well and is continuing maintenance with Cytosan, Velcade, and Thalidomide. We then got updates from those at the meeting. **Bob** (from Savannah) is doing well, but has relapsed since a stem cell transplant six years ago. He has met with doctors at Emory and is considering an “IMiDs” Phase 3 clinical trial drug. Bob also stressed the importance of having a doctor who understands and has experience with myeloma. **Carolyn** is doing well and has participated in the HuLuc63 (also known as elotuzumab) clinical trial for two years. The trial is in Phase 3 currently, and Carolyn has plans to continue with the drug since it is working and she is having no adverse side effects. **Latain** is doing well and continues with Revlimid for maintenance purposes. **Nancy** reported that her husband, **David** is in remission after having an allogeneic (donor) transplant in August 2009. David’s brother was the donor for the transplant. David suffered from myeloma and also myelodysplasia prior to the transplant; and experienced graft-versus-host disease after the transplant, but is doing well and feeling good now. **Terrell** reported that he is taking a break from Velcade for a couple of months while monitoring closely. In the mean time he is reconsidering trying to collect stem cells, although he had such a hard time previously and experienced much pain, it’s been hard for him consider retrying, although his doctor is encouraging it. **Chuck** also reported that he has been hesitant to attempt another stem cell collection. He was able to harvest enough for one transplant last summer, but his doctor is encouraging him to try to collect additional stem cells. **Dana** mentioned that he was able to collect stem cells after having had a stem cell transplant, but that is not the usual protocol. **Monique** is doing well and in remission after a second transplant in March 2009. She mentioned that she suspected that she had relapsed (prior to her last transplant) after experiencing pain again. **Dale** had been on a clinical trial that was not working for him and is now being treated with Velcade and Dex. He said that the Velcade is working well on the myeloma, but he is experiencing neuropathy. **Hector** reported that he is in remission since his stem cell transplant and has gotten his taste back, so much in fact that he had to start exercising again! He is speed walking on his treadmill and is not on maintenance drugs. **Bill** reported doing better after a tough year. Bill explained that he was diagnosed 12-1/2 years ago. In the past year he has had shingles and much exhaustion. He did 4 or 5 rounds of Velcade with a good response for the myeloma, but resulting in very bad neuropathy. He’s been off of the Velcade for about 3 months and the myeloma is progressing, but slowly and he does not need to treat it currently. He’s also been having a difficult time sleeping due mostly to the pain from the neuropathy. He’s been using morphine for the pain but plans to discontinue the morphine soon. Neuropathy is a problem for nearly all myeloma patients at some point and various members offered some things that have helped them. **Carolyn** said that she has used the information on the Dana Farber website which consists of a combination of about eight different supplements that she takes at night and it has helped her. **Dale** mentioned that he has also tried the same regimen for six months in the past and it did not help him. Recently his doctor suggested trying two of the supplements (one was alpha lipoic acid) specifically so he may retry those two. **Earnestine** reported that using alpha lipoic acid has helped her, not just with neuropathy but also with trigeminal neuralgia. **Chuck** reported that he began taking 500 mg. of vitamin B12 after getting neuropathy from Thalidomide which helped tremendously. He is now actually taking a combination of B12 and vitamin C. **Virgil** said that he has used Lyrica to help with neuropathy with good results, and has also used aloe vera juice to help with pain. **Joe** reminded the group to refrain from green tea consumption while on Velcade.

Submitted by Wendy