

April 2010 Meeting News –

New Members

There were no new members attending the meeting.

Business & Other Information

Nancy led the meeting. The International Myeloma Foundation (IMF) has provided a polycom conferencing phone to the group. In the **May** meeting we will prepare questions for the **June** meeting conference call with the IMF nurses board. There are also plans for a conference call during the **August** meeting with the IMF hotline. Please keep these dates in mind so that you can prepare your questions in advance. Also mentioned was the [IMF's Patient and Family Seminars](#) scheduled for this year in the U.S. - Portland, Cincinnati, Philadelphia, and Los Angeles. None are scheduled in Atlanta this year but if you have an opportunity to attend elsewhere it is good to know that they are highly recommended by group members who have attended prior seminars.

Nancy shared some articles that were found on the "[The Myeloma Beacon](#)" website; "[Thought Leader Perspective: Dr. Robert Kyle On Treating Multiple Myeloma](#)". Also, from the "[Medical News Today](#)" website; "[First Patient Treated In BioInvent's Phase I Study Of The Drug Candidate BI-505 To Treat Multiple Myeloma](#)".

Member Updates & Collaboration

Sandy is doing well and provided updates from those who were not at the meeting. Sandy spoke with **Dee** who mentioned that her husband, **Carl** had a port removed, resulting in a high fever, so was unable to attend the meeting. Carl wanted to thank everyone for the "Still Here Kickin" book purchases. Also, Nancy reported that **Vanessa** (who had a stem cell transplant in January) is in remission and is beginning maintenance therapy using Velcade and Revlimid. **Doris**, who leads the Southside support group was present and reported that there are now approximately 25 members. Doris reported that her group is supporting a health fair by attending to raise myeloma awareness. She also noted that an oncologist nurse will be attending the Southside group's May meeting and can help interpret lab/blood test results. **Carolyn** has recovered from pneumonia and is doing well. We discussed that Carolyn began a clinical trial for Elotuzumab (formerly known as HuLuc63) trial at Emory when it was in Phase 1 just over a year ago and it has already been approved to move into Phase 3. **Virgil** is still recovering from pneumonia that he contracted while traveling on vacation but is doing better. Virgil mentioned that his recent biopsy results were good. He had been taking both Velcade and Revlimid, but is now continuing with Revlimid only. He also had some interesting information, mentioning a nutritional drink that he has been taking for about 25 years, which he has used to curb nerve pain associated with TMJ. He purees canned asparagus with tomato juice and aloe vera juice and drinks this each morning. This generated a lot of discussion about nutrition in general. **Becky** reported that she is currently off Revlimid because of a bladder infection, fever, and a highly elevated liver function. She is OK now, but continues to monitor her liver function results. Becky explained that her liver function readings were three times above the normal range and it took about two weeks to be lowered. She suspects that the abnormal readings were due to her use of prescription quinine that she takes to alleviate leg cramps. Becky also mentioned that the use of quinine is not recommended by the FDA. **Dale** is doing well but explained that after 2-1/2 years of good results using Revlimid (with no adverse side effects) it is no longer working well for him. His IGA counts have been rising significantly for the past 4-5 months. He plans to

begin a Phase 1 clinical trial at Emory for an oral agent called MLN9708. This trial is sponsored by Millennium Pharmaceuticals, who also developed Velcade. The side effects are expected to be much less than those of Velcade. Dale mentioned that he was diagnosed with myeloma about 7-1/2 years ago. He participated in a Phase 1 Velcade trial, and has had a stem cell transplant. He's been on Revlimid for the past 2-1/2 years. **Ginny** is participating in a clinical trial with Pomalidomide, Velcade, and Dex. Ginny is in her third round and results are pending. She reports much fatigue and low counts with this therapy. **Rebecca**, who was diagnosed with myeloma in October 2008 had a successful stem cell transplant and was taking 25 mg Revlimid for maintenance. She has had no problems with the Revlimid except for low platelet counts, and has now stopped the Revlimid and continues to do well. **Earnestine** reported that she is seeing two new neurologists for neuropathy, and she is considering the use of botox for relief. **Hector** is in his third round of Velcade, Revlimid, and Dex and is experiencing neuropathy. Hector tried Neurontin to alleviate the neuropathy, but it made him very fatigued. He has also tried Lyrica and he said it made him feel "goofy". Others in the group also mentioned feeling "high" when on Lyrica. It was also noted that it can sometimes take up to six weeks to get the full benefit of pain alleviation associated with Lyrica and Neurontin. Someone also mentioned that it may be possible to take these drugs every other day and get the same effect once they begin to work. There was some discussion on neuropathy associated with Velcade. It seems that there are many group members who have experienced neuropathy from Velcade that does not appear to be temporary. **Wendy** reported that midway into his third round of Velcade her husband **Rick** had very bad neuropathy. He completed a total of four rounds of Velcade, and took Lyrica to relieve the neuropathy, which helped. Finally after a few months the neuropathy fully subsided and he was able to get off the Lyrica. Some group members have reported taking a break from bisphosphonates such as Zometa and Aredia. **Sandy** has reported bone brittleness from long term bisphosphonate use. **Hector** reported jaw pain with a metallic taste in his mouth after seven months of bisphosphonate use. Hector has halted the use of bisphosphonates for about two months and the pain has diminished and X-rays appear fine. Various other topics were discussed, including: (in no specific order): 1) Clinical trials – there are many in process; (including locally at Emory), and this group has been very supportive of clinical trials collectively. Unfortunately overall it is reported that less than 5% of myeloma patients in the U.S. participate in clinical trials. Group members gave thanks to, and are very appreciative of those who have participated in trials. 2) Genetic research is moving fast – there were some members present who have had genetic testing. Now some treatments may be able to be prescribed (or not) based upon chromosomal test results. 3) There appears to be much general confusion about oxidants and antioxidants; and the best way to proceed with the use of supplements before, during, and after treatment. There seems to be a plethora of information available and some of it seems conflicting such as when to reintroduce supplements once treatment is completed. It was agreed that this would be good topic for upcoming teleconferencing meetings with the IMF. 4) There was some discussion about whether it is better to start a new treatment at higher or lower dosages. Generally it seems that doctors prefer to begin treatments at higher dosages (aggressively) to gain control faster, and then lower dosages once the disease is better controlled, but patients often prefer to start a new treatment at a lower dosage, then raise dosages only if necessary.

Submitted by Wendy