

August 2009 Meeting News – New Members

There were no new members at the August meeting.

Business & Other Information

Nancy led the meeting. Approximately 28 members were present. Nancy shared some highlights from some of the discussions at the IMF Support Group Leaders Retreat that she attended in Dallas, TX in July. She mentioned how well received the group's newsletter was by the other attendees. Currently, 150 patients and 90 doctors receive the newsletter each month. Also discussed were some improvement ideas, including a collection of patient history summary information, which began at the August meeting. Nancy met two members from Proteolix, who were research inventors of the drug, Carfilzomib, at the Support Group Leaders Retreat meeting and there was discussion of potentially having them as guest speakers in a future meeting. The group also discussed ideas for future guest speakers and topics. All agreed that meetings devoted to such topics such as exercise, nutrition and nutritional supplements specifically tailored to myeloma patients would be beneficial.

Member Updates & Collaboration

Nancy provided updates on members who were not present at the meeting. **Dana** had a stem cell transplant on July 31st. **Pam** has maintained remission for 27 months after an initial 4-5 rounds of Velcade and Dex. Pam has harvested stem cells but has not had a transplant. **Earnestine** reported that she is doing well and that her m-spike (also known as paraprotein) level has been reduced and is now being maintained. She is continuing without maintenance drugs, which she has done for about nine months. **Monique** is in remission and doing well after a stem cell transplant in March. **Karyn** is in remission and eating well. She is still having problems with her kidneys and continues with the current type of dialysis, which she is told she can continue for 4-5 years. Karyn plans to see a new nephrology doctor at Emory for further direction. **Suzie** is doing well about two months post stem cell transplant. Suzie said that she is back to walking and golfing regularly and feels great. She mentioned that she no longer has bone pain and feels "back to pre-myeloma normal". **Latain** reported that she is doing well and maintaining remission two years post stem cell transplant, without the use of maintenance drugs. **Mike** is doing well. Mike received two (tandem) transplants four years ago at the Arkansas facility and has been in remission since then. Mike does not use maintenance drugs. He maintains a healthy and very active lifestyle. Mike mentioned that he pushes himself to his physical limits daily. **George** mentioned that he has been experiencing bone pain and he is unable to find a cause for the pain. He has had a series of various tests including X-rays, CAT scans, and bone density tests; and the results are normal. George had a stem cell transplant in October 2006 and has been in a complete remission since then, without the use of maintenance drugs. He is aware that bisphosphonates can cause bone pain, and so he is planning to stop taking Aredia to find out if this helps. **Suzanne** had a stem cell transplant in March and has achieved a very good partial response. Suzanne is not taking any medication at this time.

We have several members who are participating in clinical trials. The group applauded their "pioneer" spirit and the benefit that they are bringing to all patients. **Janice** had been participating in a Pomalidomide trial in Jacksonville, FL, which ended after a couple of

months. Janice is now participating in a very new Phase 1 trial at Emory called ARRY-520 (Array BioPharma). Janice is the 2nd patient at Emory to participate in this trial, and she is one of four patients in the trial at Emory currently. The trial is being offered at only two other locations at this time. Janice said she is feeling OK, but her white count has been affected. The disease has slowed some, but not drastically to date. **Carolyn** began a clinical trial in March for HuLuc63 (Celgene). The trial combines Revlimid, Dex, and HuLuc63 agents. She has not experienced any adverse side effects except for a rash that presented about six weeks ago. She plans to reduce the Revlimid dose and stay on the trial. Carolyn explained that since beginning this trial her counts have dropped dramatically and she is in near remission. **Sandy** has recovered from an infection in her port called Pseudomonas. In hindsight Sandy realized that prior to the Pseudomonas diagnosis, for the last couple of times when her port (which she has had for approximately 10 years) was utilized, she had chills and a fever right afterward. She took Tylenol, and she was OK the next day. She actually had an infection that was being masked with the use of the Tylenol. As a remedy to the infection, Sandy endured an infusion every 12 hours for 14 days and was actually able to keep the port. Sandy mentioned that if you ever have a fever over 100 degrees, to be sure to tell your doctor. **Harland** has been taking Revlimid and Velcade for 1-1/2 years. Harland achieved remission six months ago and is doing well. He plans to continue staying on maintenance drugs.

There was some discussion surrounding the anxiety that many (if not all) group members feel right after diagnosis and in preparation for upcoming treatments, including stem cell transplants. The discussion focused on maintaining a positive attitude and communicating openly with doctors and caregivers. It is important to communicate feelings of fear and anxiety to your health care providers. They are trained to listen for signs of stress and to help you once they are made aware. **Sharon** is a medical psychologist and mentioned that she has some helpful relaxation procedures on tape that can be made available for group members - please contact her if you are interested. Also, it was noted that the available statistics related to myeloma may drive our fears. It is important to remember that statistical data found online is generally outdated – i.e. it is “what was”, not “what is”, or “what can be”. The group recognizes that we are at an important time when research is moving very fast and many new drugs are coming available through clinical trials.

Submitted by Wendy