

February 2008 Meeting News

New Members

The group welcomed **Earl** and **Jean**. **Earl** was diagnosed with myeloma in late December 2007. He initially suffered from severe chest and back pain and after three emergency room visits was misdiagnosed with pleurisy. A recent scan with dye showed four tumors on the spine. He is currently taking 40 MG Dex / week and 50 MG thalidomide, with plans to increase thalidomide. The group also welcomed **Idalina**, who was diagnosed with smoldering myeloma in France in 2000. **Idalina** held off on treatment for six years, but in 2006 tests showed that treatment needed to start. Prior treatments have included Melphalan and Cortisone (a steroid), but she was unable to follow the schedule due to low white blood counts (WBC). Neulasta boosts WBCs, but it is not provided in France. She has also tried Thalidomide but was unable to tolerate it. In September she moved to Atlanta and has since begun a VAD protocol with 40 MG Dex / week.

Business & Other Information

Nancy led the meeting. The group discussed refreshments management and decided to go back to a volunteer basis. A big thank-you to **Carole**, who has been coordinating and providing refreshments for the group for quite some time; her efforts are much appreciated! There is a doctor's list that is used for newsletter distribution; please verify that your doctor's name and address is on this list. **Nancy** mentioned that **Mike's** doctor both reads and discusses items from the newsletter at their appointments. In the March meeting, the group's **T-shirts** will be available for purchase in time to wear to the next **IMF Patient and Family Seminar**, which will be held in Buckhead in March. T-shirts will also be available for sale at the seminar. The IMF-sponsored seminars are local to Atlanta about every two years. This year's seminar follows the recent worldwide American Society of Hematology (ASH) seminar that was hosted in Atlanta in December 2007. It is expected that results from the ASH seminar relative to myeloma will be discussed and interpreted in the IMF seminar. The IMF website also contains a synopsis of the ASH seminar in layperson's terms. Also on the IMF website is more detailed information about the seminar including an agenda: http://myeloma.org/main.jsp?type=event&id=300&tab_id=7&menu_id=0&event_type=U If you plan to attend the seminar, comfortable dress is encouraged. Also, be prepared for the open Question & Answer sessions after each presentation. Have your questions prepared in advance. These seminars often move quickly and it can be easy to forget your questions as the seminar accelerates.

Member Updates & Collaboration

Sandy provided an update on some group members that have been absent from recent meetings. **AJ** is currently taking Velcade and Doxil and is doing well. **Tim** is continuing with Velcade and is doing well. **Susan** wanted the group to be aware of a GEM (gene expression mutation) test that can be performed to check the p53 gene prior to deciding on Velcade as a treatment. If the test outcome is "positive", then Velcade will not be a suitable treatment. *Note:* The p53 gene is a tumor suppressor gene, i.e., its activity stops the formation of tumors. Velcade stimulates p53 activation. **Nancy** received email from **Mary**, asking if anyone in the group is taking Revlimid alone with good results. **Mary's** mother is currently taking a combination of Revlimid (15 MG every other day) and Dex (40 MG / week) which is producing good results, but is negatively affecting her quality of life. **Carter** mentioned that he is currently taking 15 MG / day of Revlimid for two weeks, then takes a week off, and then restarts the cycle again as maintenance. **Carter** mentioned that it was discovered

that the Dex was pulling calcium from his bones so he stopped taking it. **Dori** reported that her father who lives in Florida was “near death” on Christmas day. His condition has improved and he was released from the hospital in mid-January, and is beginning treatment with Velcade. **Nancy** reported that her husband, **Mike** is in the process of diagnostic testing in preparation for a stem cell harvest and transplant at Northside. This will be **Mike’s** second stem cell transplant after a six year remission from the first that occurred in 2001, also at Northside. **Vinnie** reported that a recent blood test showed RBC, WBC and platelet counts were lower than previous results. Also, the M-spike was detectable, but low. On a re-test some of the counts were normal and some others were better than in the first test. **Andy** mentioned that some of the low counts could be due to an infection. The best thing to do is to continue to monitor. **Dana** reported that he has not been taking any myeloma drugs since Thanksgiving time and has maintained stability. Dana experienced severe pain for about two weeks and it is unclear whether it was muscle or bone pain. Someone that he knows recommended using Zyrtec, which is known as an allergy medication, for pain. There was some discussion surrounding muscle pain versus bone pain, and how to tell the difference. This is hard to determine. Although soft tissue damage is rare with myeloma, it does sometimes occur. It was mentioned that potassium can help as a muscle pain reliever. **Ginny** mentioned that muscle relaxants can also help relieve muscle pain. **Nancy** reminded the group that physical therapy can also help relieve muscle pain, and recommended Karen Davis Warren, from “**One-on-One Therapy**”, <http://onetherapy.com/>, who presented to the group last July. Karen has in-depth knowledge of myeloma and can recommend other therapists with similar knowledge. **Joe** stressed the importance of finding a therapist with experience with myeloma patients from his experience of one who did not have this knowledge. **Earnestine** has been off of Thalidomide for six months. She experiences pain in her feet and nerves in her face which is progressing and wonders if it is neuropathy. Someone mentioned that chemically caused neuropathy is usually symmetrical, so would likely be felt in both feet. **Andy** didn’t think that the progression of the pain would still be from the effect of the drug, even considering half-life and withdrawal issues. **Sandy** mentioned that she has been taking Thalidomide since 1999, and is currently taking 50 MG every other night, which also helps her sleep. On the off night she has trouble sleeping. Her point was that even when you are not taking a drug, it can still affect your body. Someone else mentioned the importance of staying well hydrated which helps with half-life and withdrawal effects. **Idalina** had questions pertaining to assistance with transportation, specifically to and from doctor appointments. **Andy** suggested checking with the American Cancer Society as they offer volunteer transportation assistance. **Earl** asked if it was possible to achieve a long-term remission using drugs only, or if a SCT was necessary. While there are a lot of group members who have had SCTs, many have also achieved good results with drugs alone. **Nancy** mentioned that a lot of new progress is being made with gene therapy and customized plans. **Andy** noted that when you come out of remission the myeloma could have mutated into a different type. What worked to control it before may not work again, so another controller will need to be found. Once again, at this meeting it became very apparent at how differently everyone is affected by, and responds to, drugs and treatments; and how important it is to find the customized plan that works best for you. This can be an ongoing, continuous quest since what works today may not in the future and vice-versa.

Submitted by Wendy