

March 2008 Meeting News – New Members

The group welcomed **Marilyn**. When **Marilyn** was having her cholesterol checked in December 2007, an M-Spike was discovered. A bone marrow biopsy resulted in 19% plasma cells on one side, and 8% on the other. In February 2008 she was diagnosed with IgG Kappa smoldering myeloma. Bone scans show no tumors; she is not in pain and is not anemic; and is currently not undergoing any treatment for myeloma, but does take statin drugs for cholesterol. She mentioned that her doctor, who is associated with Northside Hospital, and who recommended she join our group, suspects that she may have had MGUS previously. **Andy** mentioned that taking statin drugs to control cholesterol can also have a positive affect on the myeloma.

Guest

Debi, who began a myeloma support group in Pensacola, FL last July, attended the February meeting. **Debi** reported that the endeavor is going well but slow. There are currently seven regular members, many of whom have an hour-long drive or longer, so she is planning to change the meeting time to later in the day to better accommodate the members. **Debi** is planning to have one of the doctors from the IMF visit as a guest speaker at a future meeting.

Business & Other Information

Nancy led the meeting. There is a sign up sheet for **refreshments**. Please sign up to help with refreshments when you can. The group's **T-shirts** are available for purchase - \$20 for long sleeved, and \$10 for short sleeved. **Ginny** received a "thank you" note from the Ronald McDonald house thanking the group for our "snack" contributions. **Sandy** alerted the group of an Emory-sponsored "Celebration of Living" event on Saturday, June 21st, 2008 from 8AM – 1:30 PM at the JW Marriot in Buckhead. Admission is free, registration is requested. **Andy** reported that there is a new IMF-sponsored interactive spreadsheet available on the IMF website that can be used to track your personal test results. The program can be downloaded, the data is stored locally (i.e. where only you can access it); and the program will calculate, measure, and compare your data for you. A means to provide feedback also exists.

Member Updates & Collaboration

Sandy provided an update on some group members that were not present at the meeting. **Idalina** who joined the group in February has returned to live in France. **Nancy** commented that there is a lot going on in both France and Germany from a myeloma perspective. **Carl** is 100+ days beyond his second of two stem cell transplants with 5%.plasma cell results. When **Sandy** spoke with **Carl** he answered his phone from Disney World! **Susie** had been taking part in a clinical trial that was not successful for her and is working on next steps. **Ginny** mentioned that Susie is considering a monoclonal antibody trial, which Ginny is also considering. **Yvonne** is moving to Griffin, GA but will continue with treatment at Emory and is beginning radiation treatment. **Nancy** reported that she heard from **Janice** who is currently experiencing lots of fatigue while taking Velcade and Doxil as she plans for a stem cell transplant. **Shemeka** reported that her father, **George**, who lives in Hawaii, is doing well. **Dori** reported that her father who lives in Florida is doing much better, although he did return to the hospital for one overnight stay due to a Velcade-induced fever spike. **Dana** who had not been taking any myeloma drugs since Thanksgiving

reported that recent tests showed a jump in his protein level, and so he began Revlimid 15 MG (21 day regimen) and Dex (once a week) and is seeing good results, although he is experiencing dizziness, which he also experienced when taking Thalidomide. **Dana** mentioned that he is dizzy about half of the time during the 21 days he is on the Revlimid. **Carole** reported that her husband, **Raphael** is back on Velcade and is doing well. **Bill** plans to begin a new “monoclonal antibody” protocol in March. His expectations are that it “won’t do a whole lot”, but he understands that there should be no side effects. Bill will try this while he decides what else he might try at a later time. This is the same trial that **Ginny** is considering, as mentioned earlier. Ginny is currently on her seventh type of chemotherapy. **Nancy** reported that her husband, **Mike** is preparing to harvest stem cells for a transplant at Northside (he didn’t harvest for a second transplant during the first transplant seven years ago). Mike’s schedule was slowed due to a problem - when the catheter dressing was changed it removed some skin and so a 10-day IV antibiotic was prescribed. If all goes as scheduled from this point on, Mike should be ready for the actual transplant by late March. Nancy noted that when Mike’s myeloma returned he lost a lot of weight fast due to amyloid deposits in his stomach found during an endoscopy. His doctor mentioned that about 20% of MM patient get this condition. Myeloma patients can get amyloidosis all over the body (organs and tissues), and a stem cell transplant works very well to treat amyloidosis. **Jerry** commented that doctors are very reluctant to discuss the average remission time expectancy post stem cell transplant. **Andy** responded that *stem cell* transplants have only been used for myeloma patients since the late 1990’s; before that time *bone marrow* transplants were used; and thus, doctors won’t commit to a response since there is not enough data. Currently doctors are not in agreement regarding single versus tandem transplants and the amounts of chemotherapy related to the transplant process that is best. Some additional discussion on stem cell transplants transpired. **Jim** mentioned that there is a case study being conducted at Emory regarding stem cell mobilization without chemotherapy. **Andy** mentioned that Neupogen stimulates stem cells as well as myeloma cells. There are certain drugs, such as Melphalan, which damages bone marrow that cannot be taken in excess if you intend to have a stem cell transplant at some point. **Wendy** mentioned that there are some documented cases where the length of remission is actually longer after a second (non-tandem) transplant, than in the first, although it is rare. **Andy** responded that these could be cases where, when the myeloma returned, it was of a different type than the first time. When myeloma returns it is generally more aggressive and can be a different type. Don’t expect the same type to return; skew tests to check for a different type. **Joe** broke rib and shoulder bones recently, and the breaks were all on the right side of his body, which is his dominant side. **Joe** wondered if there is a more (or less) likely chance of breaking bones on one side or the other based upon a more (or less) dominant side. **Earl** asked if anyone in the group has had kyphoplasty surgery. **Wendy** reported that her husband, **Rick** had kyphoplasty surgery in September 2005 with good results. The surgery was conducted at Northside Hospital in Forsyth by Dr. James of Resurgens Orthopaedics, who has experience with myeloma patients. Someone in the group asked if myeloma patients should receive a shingles vaccine. **Vinnie** replied, “No, if it is a live virus”, to which many in the group agreed. There was some discussion about how and when to take Dex. Some members took their daily dose all at one time, while others spread it out throughout the day. No consensus as to what was best was identified within the group, but it was mentioned that whatever you decide to do, make sure that your doctor is aware of how you are administering the drug. **Ginny** suggested taking an antacid the day of, and the day after,

taking the Dex, to combat digestive upsets, but be sure that the antacid does not interfere with any other drugs.

Submitted by Wendy