

September 2011 Meeting News

New Members

The group welcomed two new members this month. **Sara**, a figure skater, was diagnosed in January 2011. Sara initially had back pain and was prescribed prescription medication, but didn't get better. This eventually led to an emergency trip to the hospital. Lesions were found and a biopsy led to a myeloma diagnosis. She had a stem cell transplant in May, and has achieved a complete remission. Sara is back to skating and leading a very active life and is feeling good again. **Lory** was diagnosed in May 2011. She had no symptoms but her physician noticed high protein levels. Lory has not begun treatment yet, but mentioned that she is considered to be at a high risk level and plans to begin treatment soon, as she has also just become symptomatic.

Business and Other information

Nancy led the meeting; approximately 47 members were present. Nancy is in the process of building an information repository to allow group members to share information with each other in an easier way. Please note that a member from the group's Outreach committee may be in contact with you soon to collect information for this purpose.

Guest Speaker

Thank you to **Kena Miller**, a nurse practitioner specializing in multiple myeloma, who graciously provided a very informative presentation via a conference call on her birthday! Kena is from the Roswell Park Cancer Institute and a member of the IMF Nurse Leadership Board. Topics discussed included:

Side Effects Related to Multiple Myeloma

Anemia; High Protein Level; Bone Damage; High Blood Calcium; Reduced Normal Amounts of System Functions (leading to infections)

Clinical Manifestations & Common Symptoms of Multiple Myeloma

Low Blood Immunoglobulin; Monoclonal protein in blood Amyloidosis; Hypercalcemia; Neuropathy; Renal Failure; Hyperviscosity

Managing Side Effects of Novel Agents

Possible Side Effect: Gastrointestinal (GI) / Possible treatments include liberal fluid intake, but restrict fluids with meals, eat less more often, cool vs. hot foods, fresh air, avoid strong odors and acidic food, eat small amounts with medication if allowed, try peppermint or ginger, hypnosis, cool compress, and avoid caffeine.

Possible Side Effect: Myelosuppression (low blood counts) / Possible treatments include monitor blood counts regularly, red blood cell supplements and/or transfusion, platelet transfusion, rest, reduced medication dosage, avoid crowds and use mask as instructed, avoid aspirin to reduce risk of bleeding, and talk to medical team about preventative antibiotics.

Possible Side Effect: Peripheral Neuropathy / Possible treatments include: massage, B-complex vitamins, folic acid and amino acid supplements, reduced treatment dosages, pain medication, and physical activity.

A question/answer session followed the presentation.

Q: Is it OK for myeloma patients to get a flu and/or pneumonia vaccine?

A: It is generally OK if the patient is not receiving active therapy. Please check with your doctor.

Q: What identifies a light chain?

A: A serum free light chain test is used for this purpose.

Andy advised that anyone on steroids that has a temperature of 100 or more to go to their doctor immediately. Steroids can mask symptoms and a temperature of 100 for someone on steroid treatment can be equivalent to a temperature of 105-106 for others not on steroid treatment.

Updates

Libba is feeling great and preparing for a stem cell transplant. **Virgil** is doing well and has been in remission for 3-1/2 years using Revlimid. Virgil has recently had a skin cancer spot removed on his arm, which he explained began as a tiny red spot. **Lory** mentioned that her dermatologist told her that when undergoing treatment you may be more prone to skin cancer, as some drugs such as Revlimid cause high sensitivity to the sun. **Roslyn** reported that she is doing well and has been in a complete remission for nearly two years. **Vanessa** is currently taking Revlimid, Velcade, and Dex and is doing well. She recently reduced her Dex dosage and noted that her side effects change frequently but she has mostly experienced fatigue as a side effect. **Janice** is in the process of preparing for a stem cell transplant. It was reported that **Bill** is much better and feeling good again, with lesions reduced and a significant drop in protein levels in the past three weeks. **Harland** has been in a complete remission for nearly four years using Velcade and Revlimid as part of a clinical trial at Emory. He is currently deciding whether to continue with the trial or not. He has been able to reduce some of the dosages of the Velcade while on the trial. **Frank's** brother in law has achieved a complete remission using Velcade and was currently taken off of the Velcade. **Bob** is considering having a second stem cell transplant. He had a stem cell transplant seven years ago and has stem cells frozen from that event. Since relapsing he has begun treatment with Revlimid and Velcade. There was some discussion about colonoscopies and how frequently they should be performed. **Dr. Hector** informed the group that the standard is generally one colonoscopy every five years after age 50; and every three years after age 60 unless polyp(s) are found and/or if there is additional risk due to family history. In that case, colonoscopies should be performed more often. If polyp(s) are found, another colonoscopy should be performed within 1-2 years until a normal result is obtained. Once a normal result is obtained, go back to the appropriate five or three year cycle unless polyp(s) are discovered again; or if you are considered to be in a high risk category due to family history. Please always check with your doctor for instructions that are most appropriate to your situation.

Submitted by Wendy