

## August 2010 Meeting News

### **New Members**

The group welcomed two new members and their spouses at the meeting this month - **Alan** and **Susan**; and **Matty** and **Rita**. **Alan** was originally diagnosed with smoldering myeloma in March 2009, and then with stage 3 myeloma in February 2010, when he was hospitalized for 15 days with stroke-like symptoms and found to be anemic, with a low sodium level and bone pain. He is being treated with Velcade, Dex, and Revlimid, and has experienced few side effects, mainly peripheral neuropathy. He has also had two separate kyphoplasty surgeries to repair fractures in his back, and has discussed stem cell transplantation with his doctor. He is currently off drugs as he prepares to harvest stem cells – he wants to collect enough for three stem cell transplants. **Matty** was diagnosed with myeloma in February 2010 during a routine checkup. Two days after the checkup he was ordered to go to the hospital immediately, as he was very anemic. He is currently being treated with Velcade, Dex, and Revlimid; and is consulting with Northside on stem cell transplantation. In March he experienced leg pain and remained hospitalized for over two weeks, highly medicated. He has experienced much pain and has had kyphoplasty surgery to repair fractures in his back. **Matty** mentioned that he has family members with prostate cancer and myeloma (a great grandmother). He also mentioned that he was in NYC during the 9/11 attacks.

### **Business & Other Information**

**Nancy** led the meeting. Approximately 27 members attended. Various members commented that the recent Pain Management seminar hosted by the IMF was very good and worth attending. An archived recording is available at the IMF website. It was also noted that the IMF provides a patient handbook which covers a good amount of detailed information – it is free and available to download from their website. **Monique** has provided greeting cards for the group to purchase, with all proceeds going to the group. **Correction**: In the last newsletter it was incorrectly reported that **Jeannine's** hip replacement surgery was not related to myeloma, however Jeannine reported that “My hip replacement surgery was made necessary by the Multiple Myeloma lesions.”

### **Guest Speaker**

Many thanks to our guest, **Missy Klepetar**, from the International Myeloma Foundation (IMF) hotline, Missy joined the meeting remotely to respond to questions that the group had gathered in advance. Throughout the discussion various IMF resources were mentioned such as the Myeloma Manager and the hotline, where those affected by myeloma are highly encouraged to utilize this beneficial resource. The phone number is 1-800-452-CURE. There is also a lot of free information available from the IMF website to either download or receive in the mail (your preference); as well as availability of experts that can offer second opinions. Highlights from the Q&A discussion follow:

**Q:** What is the cause of pain associated with peripheral neuropathy, and how is the pain best managed?

**A:** Pain can be caused by various things – the disease itself, medications, protein deposits on nerves, etc. Prescription medications as well as supplements such as fish oil, vitamin E, amino acids, alpha lipoic acid, L-carnitine, Super B Complex, evening primrose, and flaxseed oil can help. Patients with vitamin deficiencies, including vitamin D deficiencies can experience worse neuropathy pain.

**Q:** What is an IGG infusion? How is this beneficial?

**A:** Immunoglobulin therapy is not common for myeloma patients. The intravenous blood product extracted from the plasma of blood donors can be used to prevent infection and is usually given as a series of treatments over weeks or months.

**Q:** What is, and how is multiple myeloma staging defined; and how is it used? Does staging determine outcome?

**A:** There is no single factor to determine myeloma staging. Staging is determined via many indicators and is most definitely detected by using the “CRAB” criteria: **C**alcium, **R**enal (creatinine), **A**nemia (hemoglobin), and **B**one lesions. Not a lot of emphasis and discussion with patients surrounding staging occurs with myeloma patients because (unlike some other kinds of cancer), the stage can be overcome with treatment.

**Q:** What is M-spike, and what role does it play in determining progress, or lack of progress?

**A:** M-spike is an indicator of the monoclonal protein pattern. When myeloma is not present there is no M-spike; it is not considered normal to have any M-spike.

**Q:** What are the various types of multiple myeloma?

**A:** The most common types of myeloma are IGA and IGG; type IGM is rare; and types IGD and IGE are very rare. The means to monitor the disease can vary by type. For example, a nonsecretory type may only be monitored via bone marrow aspiration, since the disease does not present elsewhere. Heavy chain types

**Q:** What factors determine remission?

**A:** Remission is determined by the CRAB criteria, along with the absence of monoclonal protein. There are different levels of remission determined by the levels of the various criteria (i.e. complete remission, very good partial remission, etc.).

**Q:** What are some of the causes of dizziness and what blood components might affect dizziness?

**A:** Causes of dizziness include anemia (common), hypercalcemia, hyperviscosity (thickening of the blood), medications (including Revlimid, Velcade, Dex), and radiation (can cause residual dizziness).

**Q:** What supplements in general are recommended and not recommended for myeloma patients? In general, should myeloma patients plan to boost their immune system or not?

**A:** Since myeloma is a cancer of the immune system, it is unknown whether boosting the immune system with supplements will also boost the disease, so it is suggested to proceed with caution when taking supplements – i.e. don’t take mega doses, discuss with your doctor, and avoid antioxidants on days just before, during and after treatment.

Due to time constraints, Missy responded to some additional questions after the meeting as follows:

**Q:** What recommendations can be made for patients who are treating other chronic conditions such as heart problems, arthritis, and diabetes along with myeloma?

**A:** Conferring with their various doctors who are treating the various conditions is very important. Asking your hem/onc to consult with your cardiologist, to make sure everyone is on the same page re: treatment can be helpful too. This may be a challenge at times, but it can be done. As always, consult with your various doctors before starting certain treatments – for example steroids, which are often used to treat myeloma, can cause serious issues for people with diabetes.

**Q:** What genetic testing does the IMF recommend?

**A:** FISH (Fluorescent In Situ Hybridization) and cytogenetics should be done to determine if there are chromosomal deletions or translocations that can be associated with shorter durations of remission.

**Q:** Can myeloma patients harvest post stem cell transplant? Is it recommended?

**A:** They can, usually at least a year after the first transplant. Receiving high-dose melphalan damages stem cells and it takes quite some time for them to recover. It is recommended to harvest enough for two transplants the first time a patient collects stem cells.

## **Member Updates & Collaboration**

With sadness the group acknowledged the passing of two of our members, **Fred** and **Kim**. We extend our thoughts to their loved ones as they are remembered. **Carolyn** has joined a Peer Partners Program, in which volunteers are matched with newly diagnosed myeloma patients for coaching and talking in a 1:1 setting. **Frank's** wife reported on her brother who is 82 years old. Her brother's latest bone marrow biopsy was clean and he has achieved a full remission using Velcade with no noted side effects. It is planned that he will receive Velcade for maintenance twice a month. **Bob** reported doing well and that his current doctor has now begun consulting with an Emory doctor, as he considers next steps. **Frank** reduced his Dex dosage a few months ago down to none, continuing to take his regular dose of Revlimid. He developed swelling in his hands and so has begun taking a slight amount of Dex again, which has corrected the problem. There was some discussion surrounding the use of stored stem cells and what happens if you have stem cells stored, but don't expect to use them. **Vinnie** reminded the group that even if you don't intend to have a future stem cell transplant, sometimes the stem cells may be injected and used in ways to "boost" other treatments, without actually having a full stem cell transplant.

Submitted by Wendy

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