

## October 2010 Meeting News

### **New Members**

The group welcomed new members at the meeting this month – **Bobbie** was diagnosed with myeloma in April 2009, and has had two stem cell transplants and is doing well. She is taking Revlimid for maintenance. **Sonny** was diagnosed with myeloma in January 2009. He and his wife, **Loretta**, live in Florida and are visiting their daughter, **Pat**, who attends meetings. **Madge** was diagnosed with myeloma in October 2008 after having smoldering myeloma. She was treated with Velcade, Revlimid, and Dex, and experienced a lot of neuropathy. She is currently on a break from treatments.

### **Business & Other Information**

**Nancy** led the meeting. Approximately 60 members attended. Thank you, **Jeannette**, who arranged for our guest speakers this month!

### **Guest Speakers**

Many thanks to Emory nurse **Melanie** and nurse practitioner **Charise** who explained multiple myeloma (MM) treatments for both new and relapsed patients. The presentation was followed by an informative question and answer session. Emory sees a lot of MM patients. Last year (2009) they saw over 900; the previous year (2008) they saw over 700. They are expanding their services and have seen many changes in treatments and improvements in the past ten years. Emory conducts many clinical trials and their doctors will accept referrals and consult with your doctors. When deciding on treatment for **newly diagnosed patients** it is necessary to determine if a stem cell transplant is being considered. If yes, Emory's current standard of care is to select an initial treatment that will not harm the bone marrow before stem cell collection is necessary, such as Revlimid, Dex, and/or Velcade. Then stem cells are collected and frozen for potential use at a later date (a transplant is not necessarily performed immediately post-collection). If the newly diagnosed patient is **not** considering stem cell transplantation as an option, then other treatment options are available, and clinical trials are also suggested. There is not currently a standard of care for **relapsed patients**, but Emory has seen good results using Carfilzomib (a second generation Velcade), without neuropathy side effects. Also, HDAC inhibitors such as Vorinostat and Panobinostat work well with Velcade for relapsed patients. Although the HDAC agents have some GI-related side effects, there is a new patch that is being used to reduce GI issues. Also mentioned as options for relapsed patients was the HuLEC study and oral Velcade (with reduced neuropathy side effects). Neuropathy can be caused by different things such as the MM disease itself, other diseases, and various treatments. Both the small nerve fibers (which affect pain and temperature), and the large nerve fibers (which affect balance) are affected by neuropathy. Emory has a tool to track the level of neuropathy using five stages: Stage 0 = no neuropathy, Stage 1 = mild pain, tingling, numbness, Stage 2 = moderate pain, Stage 3 = severe (affects quality of life), and Stage 4 = disabling neuropathy. This tool is used to determine the best way to treat the neuropathy. Most MM patients will need bisphosphonate therapy at some point. The latest ASCO guidelines support the use of bisphosphonates for two years, and then backing off, unless a bone density scan shows signs of osteopenia (then it is suggested to continue). Also mentioned was that when on a "**mid**" treatment (i.e. drugs such as **Revlimid**, **Pomalidomide**, **Thalidomide**, etc.), it is important to have your thyroid function checked on a recommended basis of every 3 months, as these drugs can affect thyroid function. Also noted were some things to expect in the future. It is likely that more maintenance drugs will be prescribed post stem cell transplantation. Emory is currently in the process of conducting a study to determine if it is better to perform a stem cell transplant immediately for those patients who are candidates, or to wait for another time. It is hopeful that newer generations of drugs won't cause such intense neuropathy. A goal is to find effective drugs that won't result in undesired side effects. Highlights from the Q&A discussion follow:

**Q:** What can cause leg and finger cramps?

**A:** This can be caused by neuropathy or drugs or both.

**Q:** With neuropathy, is it possible to be able to feel it sometimes and not feel it at other times?

**A:** Yes, this can occur.

**Q:** Is there a way to tell if you have neuropathy and how much? This is especially important for those who have neuropathy, but can't feel it and/or those individuals that can't determine if it has improved or worsened over time.

**A:** Yes, a neurologist can test to determine loss of nerve damage, and report a percentage of damage.

**Q:** What non-drug treatments can help make neuropathy more tolerable?

**A:** Exercise is very important. Massage can also help, as can physical therapy. If neuropathy occurs in your feet, keep your feet warm. There is a home remedy that some patients say works – put Irish Spring soap under the sheets of your bed. Also, topical treatments such as cocoa butter, heavy emollient lotions with high emulsion ingredients, and other over the counter lotions found in the diabetic section of pharmacies work for some patients. Some vitamins and supplements can also help, including B vitamins (i.e. B6), amino acids (i.e. alpha lipoic acid, L-carnitine), and potassium. It is very important for you to keep your medical team informed and updated on the supplements you take - as some can interfere with treatments (i.e. green tea and vitamin C can interfere with the effects of Velcade). Note: lowering the dosage of some drugs may help alleviate the associated neuropathy and may help you stay on the drug as well – this is something to discuss with your medical team.

**Q:** What forms does neuropathy take / i.e. how can it present itself?

**A:** Neuropathy is usually associated with pain and tingling of extremities, but that is not always the case. Loss of sensation, numbness, burning, vibration, and ringing in the ears are other forms of neuropathy.

**Q:** Is neuropathy associated with Velcade reversible?

**A:** It can be with some patients, but it can take a long time to reverse. Many patients on Velcade experience neuropathy around the 4<sup>th</sup> and 5<sup>th</sup> cycle, and some new patients experience it sooner. There are many studies being conducted in France that suggest that using Velcade on a weekly basis, rather than the current standard cycle may help control the associated neuropathy.

**Q:** Is MM a form of bone cancer?

**A:** No, MM can affect bones, but does not always. MM is a cancer of plasma cells, and so it is categorized as a blood cancer.

**Q:** Can amyloidosis present itself as neuropathy?

**A:** Yes, it can, as can MM.

**Q:** Is there a relationship between Restless Leg Syndrome (RLS) and neuropathy?

**A:** Yes, and some medications can make RLS worse; those known to help with RLS include Ativan and Ambien.

**Q:** Can you get shingles more than once?

**A:** Yes

**Q:** Can shingles present itself in more than one area of the body?

**A:** Yes, and this is usually a worse than average case, so go to a hospital if this occurs.

**Q:** Is the shingles vaccine recommended for MM patients?

**A:** The shingles vaccine is a live virus and is not recommended for immune-compromised individuals.

**Q:** How can you become better protected if you are unable to get certain vaccines?

**A:** One way is to get family members vaccinated, which in turn could better protect you. If your caregiver is considering getting a shingles vaccine, discuss it with your doctor first, as there may be more to consider – this advice can vary on a case-by-case basis.

**Q:** Are MM patients in general more prone to getting shingles?

**A:** Shingles often surfaces when one's immune system is not operating at full capacity, so those taking immunosuppressive drugs are more susceptible. Also, stress can cause shingles. MM patients are more susceptible to getting shingles with specific therapies. Patients on Velcade and post stem cell transplant patients are examples of therapies that could make you more susceptible to shingles. It is recommended that these patients stay on an antibiotic as a precaution.

**Q:** Can neuropathy result from shingles?

**A:** Yes

**Q:** Can Revlimid and Velcade cause vision problems?

**A:** Yes, but more frequently vision problems are associated with the use of steroids, which can also cause cataracts.

**Q:** What is a good way to treat constipation?

**A:** Some things include Miralax, stool softeners, prunes and prune juice. It is important to stay well hydrated via caffeine-free liquids.

**Q:** After several kyphoplasty surgeries I still have back pain that is currently be treated with Oycodone. Is this a common occurrence?

**A:** Yes.

Submitted by Wendy