

## June 2013 MM Support Group Meeting News – Both Groups Included

### Northside Atlanta Area Support Group June 2013

#### Business & Announcements

**Nancy** led the meeting. Over 60 people attended and there were no new members.

**Jim** who represents our group in the IMF advocacy action team spoke about the goals of obtaining support from state and federal representatives for the cancer parity bill. **Jim** is looking for volunteers to form a small team of approximately five people to join him and attend onsite meetings at government offices in August. You can contact **Jim** at **770-294-8491**. Find more information on the IMF advocacy team website where you can also get involved by completing a standard letter form and submitting to show your support of the bill.

#### Guest Speaker

Very special thanks to **Charise Gleason**, an Advanced Practice Nurse from Emory, who spoke to the group, sharing her knowledge of 15 total years of experience – 5 years as an oncology nurse prior to her past 10 years at Emory as part of the MM Team, where she sees approximately 1200 patients a year. Charise is also an IMF Nurse Leadership Board Member. Charise spoke of some of the major side effects of myeloma treatments including fatigue, chemo brain, gastro-intestinal issues, and cognitive changes that affect so many patients. She responded to many questions as follows:

**Q:** What are some common side effects of Revlimid?

**A:** Fatigue, diarrhea, chemo brain are some common side effects. Staying well hydrated and adding a probiotic to your diet can help with some of the intestinal side effects. Fatigue may be part of your “new normal”. Be sure to get extra rest for rebuilding your immune system.

**Q:** Do drug related cognitive issues diminish if the medication dose is decreased?

**A:** Yes, but this varies greatly by individuals. Researchers are learning more about cereblon altered by Thalidomide and Revlimid (the IMiDs) and the impact on mental health.

**Q:** Should green tea and Vitamin C be avoided when taking Revlimid, as it is recommended when on Velcade?

**A:** No, but let your doctor know of any supplements or OTC medications that you are taking. Charise also noted to have your vitamin D and thyroid levels checked.

**Q:** Are there recommended probiotics?

**A:** Evvea by Panacea Scientific can be ordered: <https://panaceascientific.com/> Note: if you are highly neutropenic, don't take probiotics and be sure to let your healthcare team know that you are taking them.

**Q:** I've heard that coconut/coconut water/coconut oil helps control diarrhea, is this OK to take?

**A:** Yes, it is worth a try to see if it works for you.

**Q:** What is the reason for being on a medication such as Revlimid one week, then off the next week?

**A:** The week off the treatment allows blood counts to recover.

**Q:** If a patient does not have a good response with a stem cell transplant, should they try another one?

**A:** No, studies show that subsequent stem cell transplants result in lesser responses.

**Q:** Is myeloma hereditary?

**A:** It used to be believed that it was not hereditary, but data is now showing that there are genetic components related to the disease. This research is just beginning, so family screening is not recommended at this time.

**Q:** Does everyone have MGUS prior to developing myeloma?

**A:** Yes, this is believed to be true.

**Q:** How accurate is genetic testing?

**A:** This continues to evolve and always gets better, but selected abnormal chromosomes have been found to identify high risk patients. Note that chromosomes can change with treatment and will need to be re-tested.

**Q:** What is the purpose of a stem cell transplant?

**A:** To be able to tolerate a tremendous dose of strong chemotherapy. The purpose of replacing the stem cells is for rescue.

**Q:** Is it recommended that all patients go on a maintenance regimen post stem cell transplant even if a complete remission is achieved?

**A:** Yes, clinical trial data shows a longer progression free survival (PFS) and new results are showing longer overall survival (OS). Also, now consolidation therapy of Revlimid, Dex, and Velcade done post-transplant and pre maintenance is gaining credibility.

**Q:** Is there another drug other than Revlimid that is used for maintenance?

**A:** Velcade is used sometimes, especially for patients with 4;14 translocation

**Q:** Is Pomalidomide more expensive than Revlimid?

**A:** Yes, but there are many financial assistance programs available.

**Q:** Can Melphalan be used for maintenance?

**A:** Yes

**Q:** Are there shortages of Melphalan?

**A:** Yes, there are shortages of a lot of drugs, but this usually gets resolved.

**Q:** Is there any data showing benefits of delaying a stem cell transplant vs. having a stem cell transplant soon after diagnosis?

**A:** High risk patients should have a transplant early. For low risk patients, the data to date shows no difference between doing transplant right after initial treatment vs. a transplant at first progression of the disease. It is important to collect and store stem cells early and try to get enough for multiple transplants.

**Q:** Does Carfilzomib have any secondary cancer risks associated with its use?

**A:** This is unknown – too soon to know.

**Q:** Is there a proven link to bisphosphonates and myeloma control?

**A:** There was a study in the UK showing better survival for myeloma patients receiving Zometa. Standard treatment is Zometa monthly for two years then quarterly thereafter.

**Q:** Can you become vaccinated after a stem cell transplant?

**A:** Yes, after a year, but avoid live vaccines.

**Q:** Is there a link to Velcade and shingles?

**A:** Yes and some patients are on anti-viral medication for life with Velcade treatment to avoid shingles. Check with your doctor before getting shingles vaccine.

**Q:** Is there a difference in myeloma treatments for patients who have lesions vs. those who do not have lesions?

**A:** No, the treatment options are the same.

**Q:** Is it thought that the use of stem cell transplants will be discontinued?

**A:** Not at this time. Transplant is still a primary component in the standard of care.

Submitted by Wendy

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### **Southside Atlanta Area MM Support Group Meeting – June 22, 2013**

We welcomed one new member, **Mischa** and her caregivers. Mischa was diagnosed two months ago in April during a regular medical visit with her primary care providers. She is being treated at Georgia Cancer Specialists in Midtown, and at Northside Hospital. She is in cycle 3 of 4 cycles of subcutaneous Velcade. She asked others who receive 'subQ' for advice on how to address the bruises caused by the injections. **Alma** has used vitamin E oil. Mischa introduced her two caretakers. She was referred to the group by member **Pat**, whose son told her that his Mom also has MM. We provided Mischa with a copy of 100 Questions and Answers about Myeloma.

#### **Guest Speaker**

Our speaker this month was our own Nancy Bruno. This is our first meeting with her in her official new job as regional support Group Leader for IMF. She has been involved in all aspects of myeloma research and patient access as caregiver to her late husband after his diagnosis in 1998. Nancy provides support for 25 Support Groups across six states in the Southeast.

IMF was co-founded in 1990 by Brian and Susan Novis, and Brian's physician, Brian Durie, when the late Brian D. Novis was diagnosed with this cancer he had never heard of. The mission statement of IMF includes a commitment to research and service through Support Groups -- *Improving the quality of life of myeloma patients while working toward prevention and a cure.* There are currently about 230,000 members in IMF. In the IMWG (International Myeloma Work Group), an international group of doctors who together seek and share progress in myeloma research and practice, there are 160 members, representing 31 countries.

IMF seeks to engage patients, caregivers, and providers in unique ways to advance treatment for myeloma. In addition to the 140 **Support Groups** across the country, each year there are several

**Patient and Family 2-day seminars**, designed to increase educational and networking opportunities. Communication among researchers, patients, and patient supporters is facilitated through these Seminars. The remaining Seminars will be in Chicago (Aug. 9-10) and Philadelphia (Aug. 23-24). **One-day regional workshops** also increase opportunities for learning and information exchange. Duke/UNC will host a regional seminar in October. Go to [myeloma.org](http://myeloma.org), “Meetings” for details. IMF also sponsors a **nurse leadership board**. Nurses are in a unique position to help to educate patients on medication side effects, and to educate both nurses and patients through handbooks, pamphlets, and tip cards; all patients should sign up to receive **Myeloma Minute newsletter** via mail. There are iPad and Smart **Phone Apps** from IMF; there are **blogs and webcast series** on Living with myeloma; the myeloma hotline 800-457-CURE(2873); the **Myeloma Manager** – “Personal Assistant” – is a tool to help patients understand and track their lab results. We encourage everyone to take full advantage of these resources.

The IMF- Advocacy team is now focused on “oral parity” – where oral drugs have the same low cost as those administered in doctor’s office via infusion or injection. Currently, the co-pay for oral drugs can be in the hundreds or thousands of dollars, and can be increased for the patient without notice. The idea is that “chemo” is “chemo” – however it is administered.

### **Myeloma Updates**

Results from a Phase I clinical trial (CT) of **MLN9708** (or Ixazomib, an oral version of Velcade) suggest it may be effective in treating patients with relapsed or refractory MM; a new analysis of results from Phase III international study of **POMALYST®**(pomalidomide) showed that patients who received low-dose dexamethasone (Dex) had longer periods of progression-free survival and overall survival than those receiving high-dose Dex. A separate analysis found that Pomalyst may be effective in treating those with kidney disease. The “Gold standard” for effective diagnosis of MM remains a combination of bone marrow biopsy, protein electrophoresis, and conventional X-rays. Other techniques may contribute to a better assessment of patients with myeloma include molecular cytogenetics\*\*, immunophenotyping, MRIs, and PET-CT scans. An article in Cancer Genetics explores more how chromosome status and Ig arrangements can help to stratify patients into treatment groups based on conventional cytogenetics and FISH (fluorescence in situ hybridization). You can view the *abstract only* for no cost at the link listed in the references. Another article of interest is called Multiethnic Myeloma, by Brendan Weiss. The authors state that “*Myeloma has one of the most striking ethnic disparities in incidence and outcomes in cancer (Langran and Weiss, 2009). Both MM and MGUS are 2-3 times more common in blacks. Is it the IgH?*” Full article is FREE at link below.

### **Announcements/Upcoming Meetings**

**Fundraisers:** Two of our annual fundraisers are coming up: in “**Light the Night**”, we join LLS in raising funds with a culminating family and fun event in Centennial Park – on October 12. Fundraising starts now – please educate friends & family about Myeloma, and ask for whatever financial support they are comfortable with. **Macy’s “Shop for a Cause”** event is on August 24. Get the shoppers in your circle to purchase tickets for \$5.00 to get up to 25% discounts. Support Groups receive all the funds from the sales.

**Teleconferences:** Available at [www.replay.myeloma.org](http://www.replay.myeloma.org).-- **Living Well with Myeloma - Speaker: Angela Hummel MS, RD, CSO, LDN.;** Myeloma Updates 2013 Post ASCO/EHA/IMWG.

**Advocacy:** We will be making a major push on the Oral Parity bill on both the federal and state levels. Postcards are available for everyone to get the support of friends, family, neighbors for the

campaign at the federal level. There are now 25 states that have passed state legislation to make prescription drugs the same low cost, whether administered orally or intravenously or by injection. Jameca will keep us informed in this effort, and of the next meetings. Others on the team include Selina, Alma, Mischa, and Gail. *Go team!*

### **Patient Updates**

**Arthur** is improving; **Andrew** has lots of pain in his leg; **Gregory** had a transplant; **Patricia** had a transplant two weeks ago, after being diagnosed last October. Please keep our members in your thoughts and prayers.

We encourage everyone to review the Q&A with Charise in the May newsletter. Lots of frequently asked and unique questions are discussed. **Montine** had a question about anemia and MM - some meds cause anemia. Receiving Velcade subcutaneously: Alma, Loretta, & Mischa. Help with the resulting bruises? Try Vitamin E oil. Member **Gerald** transitioned from complications of multiple myeloma on July 2013. Please keep his wife Brenda and the family in your thoughts and prayers.

**\*\*Cytogenetic analysis is a myeloma word to get to know. It is the term for a lab test used to examine the chromosomes in the marrow, blood, and lymph node cells. It can confirm that the cells are cancer cells (malignant) and in some cases the results may guide the intensity of the therapy, treatment approaches, and in following the response to treatment. It is the process of analyzing the number and size of the chromosomes of cells.**

### References

**\*\*The prognostic significance of cytogenetics and molecular profiling in multiple myeloma,** Jeffrey R. Sawyer Department of Pathology and Myeloma Institute for Research and Therapy, University of Arkansas for Medical Sciences, Little Rock, AR, USA. Abstract only: <http://www.sciencedirect.com/science/article/pii/S0165460810005649> .

**\*\*Multiethnic myeloma, Blood, Journal of the American Society of Hematology. Brendan M. Weiss, April 18, 2013 vol. 121 no. 16 3062-3064. Full article FREE.**

<http://bloodjournal.hematologylibrary.org/content/121/16/3062.full.pdf+html>.

**\*\*Patterns of monoclonal gammopathy of undetermined significance and multiple myeloma in various ethnic/racial groups: support for genetic factors in pathogenesis. Leukemia 2009;23(10):1-7 Landgren O, Weiss BM.**

Respectfully submitted by Gail and Paulette