

## **Northside Meeting Notes - May 2015**

### **Business & Announcements**

**Nancy** led the meeting. She mentioned that the IMF is holding a Regional Community Workshop in Charlotte, North Carolina on June 6. Anyone who is interested in going can register at Myeloma.org and click on Meetings, the look for Community Workshops. Contact **Nancy** with any questions. The **June meeting** will be June 6, and will feature a brief session of chair yoga for gentle movement. Looking ahead, mark your calendars that the **July meeting** has been changed to Saturday, July 11, due to the Fourth of July holiday. The group voted for this one-time change.

The MMRF Race for Research was held on May 17. And it was a beautiful day in Piedmont Park for raising funds for Myeloma research. Thanks to all who participated.

### **Meeting Discussions**

Several new members asked about autologous stem cell transplants (ASCT): how to make the decision to get one, and how to plan and prepare for them.

- **Decision to transplant:** Based on current research, ASCT is recommended for appropriate patients as it increases the likelihood of having a long-term remission. An ongoing clinical trial is evaluating the role of ASCT with today's therapy—the trial is comparing RVD for 3 cycles followed by ASCT, or RVD for 8 cycles with no ASCT. This trial should help answer the question about the role of ASCT. Until these results are available, ASCT is considered to give a "deeper" remission than no ASCT.
- **Harvesting stem cells:** Nancy mentioned that it is important to go ahead and harvest stem cells when possible even if you are not planning to go straight to ASCT; cells can be frozen for ten years or more and used in the future.
- **Where to go:** In the Atlanta area, options include Emory, which is generally inpatient, and Northside, which uses more of an outpatient model. There are pros and cons to each approach. The inpatient model allows closer monitoring and is easier on the caregiver. The outpatient model allows patients to rest at home and sleep in their own bed, but requires the caregiver to take on more responsibility. Nancy pointed out that Northside admits patients when needed (fever, etc.). The time spent in the hospital varies based on each patient's situation.
- **Words of advice:** Words of advice from members who had been through one or more transplants included: take one day at a time and don't try to rush healing. Ask questions and be your own advocate. Community is important when going through the transplant process. Interact with people every day. One idea was to make a paper chain link of messages from friends and family, or through a church group. Each day, a new link can be read as a reminder of those who are supporting you through this journey.

**Genetic factors:** Another topic of discussion was the importance of genetic risk factors. Certain genetic characteristics are associated with higher-risk disease that is more likely to be aggressive. Having high-risk disease can affect treatment decisions. Emory does the testing necessary to track these genetic characteristics. Ask your doctor for genetic testing, also known as the FISH test.

**MRD test:** The MRD (minimal residual disease) test is a very sensitive test for detecting the presence of myeloma cells. It can detect small numbers of myeloma cells that still remain after treatment. It is a more sensitive test than the methods currently in use today. The MRD test is in the research phase and is being evaluated by Emory researchers **Dr. Lonial** and **Dr. Kaufman** who are part of the International Myeloma Working Group. The MRD test is a major project of the International Myeloma Foundation **Black Swan Research Initiative**. The thought is that attaining “MRD-zero” (no detectable myeloma cells) is a step towards a cure for myeloma.

**Maintenance therapy:** There was some discussion about maintenance therapy. Some members said that they had poor quality-of-life on Revlimid. Common side effects are diarrhea and low blood counts. Some patients are receiving Welchol for Revlimid-associated diarrhea. It also turns out that Revlimid has lactose, which can be a problem for some patients. On another note, **Bob** recommended patients have vitamin levels checked, as well as testosterone levels for men. Supplementation may be helpful. **Nancy** pointed out that you should always talk with your doctor before starting supplements. Some vitamins can interact with medications.

**Neuropathy:** Peripheral neuropathy is a common issue and it can develop with Velcade. Some members said that Dr. Lonial had recommended a supplement that is somewhat helpful for the neuropathy. There is a supplement list on the Dana Farber web site. Another option is capsaicin cream, a product that is derived from hot peppers. One member suggested that cold packs were helpful for her. Acupuncture works for some and for patients requiring medication, Lyrica and Cymbalta may be prescribed.

Submitted by Mindy

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## **Southside Meeting Notes, May 2015**

**Doris** opened the meeting with a moment of silence. There were 15 present, no new members.

**Next meeting:** Members are encouraged to attend the **LLS Blood Cancer Conference** June 27<sup>th</sup> from 8 am to 5 pm at the Cobb Galleria – see announcement below. **Gail** will conduct the regular Support Group meeting at Greenbriar for members who would like to attend a traditional support group meeting and for potential new members.

**Old Business:** **Gail** provided highlights of the MMRF-sponsored symposium called “**Clinical Insights in Multiple Myeloma**” held on May 16<sup>th</sup> at the Emory Conference Center. Members of the group attending the conference included Lorna, Paulette, Gail and Nancy. Several group members also attended the MMRF Walk/Run at Piedmont Park on the following Sunday, and said they had a great time. There were many attending the Symposium that were from the metro area, but not associated with any Support Group. **Gail** provided members present with copies of

handouts provided at the MMRF symposium and shared highlights from MM specialists across the country who presented.

**Myeloma 101, Disease Overview** (Jeffrey Zonder, MD – Detroit): A common disease, with more than 25,000 new cases diagnosed annually in the United States. Ten-twenty percent of Myeloma patients have no symptoms -- with MGUS or Smoldering MM, there are generally no symptoms. Active myeloma symptoms include calcium, kidneys, anemia, and bone. Myeloma is defined by increased protein (M-protein), antibodies IgG or IgA, kappa or lambda, and light or heavy chain.

**Frontline Therapies** (Ajay Nooka, MD-Emory) We should be mindful there are several **different types of remission** – that may require a different treatment strategy. Minimal Residual Disease (MRD) is what we seek – very small amounts of myeloma cells. New technology/more sensitive tests help determine any MRD. MRD –negative patients may have better outcomes.

**Relapsed and refractory Myeloma** (Ravi Vij, MD – St. Louis): Relapsed refers to myeloma that returned after a response to therapy. **Refractory** is Myeloma that continues to progress, despite ongoing treatment--the patient's myeloma is resistant to current treatment. Relapsed/refractory myeloma is treatable. There were no new therapies for MM for more than 30 years; but, there have been least 7 new therapies since 2003. Specifically, **there have been 3 new drugs in the past 3 years** (Kyprolis, Pomylast, and Farydak). Categories of drugs include: Proteasome inhibitors (Velcade, Kyprolis); ImiDs (Revlimid, Pomylast; and Histone Deacetylase Inhibitor (Farydak [Panobinostat]). We must remember that the immune system is an essential part of the disease and the treatment. New drugs within the same type (Proteasome inhibitors, Imids, etc) have similar structures, but function differently, usually with lower side effects. Advances in genomic testing are also becoming available.

**Gail** reminded the group that many advances in treatment of MM have occurred over the last 10 years and in our group there are MM patients who have had the disease for 10-25 years. **Gail** shared that going forward much focus will be on **targeted therapy for MM**; therefore, the more we know about our disease the better. **Ask your doctor to define your MM.** Specifically, ask: (1) Which immunoglobulin is elevated? (IgG, IgA, etc.); (2) What is the serum Light Chain involvement; (3) Do you have Kappa or lambda associated?; (3) Am I missing a chromosome or is one misplaced –if so which? What are the results of cytogenetic testing? (4) Know the names of the drugs with which you are treated. Like any other medication, know the name of the drug and the dosage. **If you cannot pronounce the names of these medications now – it's okay.** You will learn as you go through your MM journey. Write this information down; and know it as part of the definition of **Your MM.**

There was much discussion about **Acyclovir (treatment to prevent shingles)**. **Elizabeth** shared her dosage of Acyclovir was reduced from 800 mg 2 times per day to 400 mg 2 times per day after reminding her doctor she had one kidney removed a few years ago. **Doris** said she has recently been prescribed acyclovir. (*Neither Elizabeth or Doris have had a SCT, they said, oncologist observed declines in WBC counts.*) **Alma** said her dosage of Acyclovir was reduced also to 400 mg –twice daily. **Danielle** said she was on Acyclovir; frustrated with taking so many medications, she stopped taking it and developed a rash that her nurse later told was shingles. **Gail** said she also developed shingles after an interruption in Acyclovir treatment. She shared some providers on the Myeloma team at Emory Winship (including Dr. Lonial) continue to recommend Acyclovir for post-SCT -- forever. Other members of the team may not necessarily agree with indefinitely taking Acyclovir. We also

heard other Myeloma specialists during the MMRF Symposium placed limits on acyclovir – some said 6-12 months post-transplant.

**Gail** reminded us that MM is a Cancer that affects several systems in the body including the **Calcium** levels in the blood, the **Renal function**, **Anemia**, **Bone** and the **Immune System**. She said we must always remember the immune system is compromised with MM whether we have had a SCT or not.

**Speaker -Danielle Spann-** Ms. Spann is a part of the *Multiple Myeloma Journey Partners* sponsored by Sanofi which provides educational information about myeloma and Autologous Stem Cell Transplants (ASCT). She shared her journey with multiple myeloma. The presentation is non-branded and Danielle was not allowed to discuss specific information about names of drugs used in her MM treatment.

Danielle's journey started with pain in her hip that she ignored. It later became an unmanageable pain in her leg during a vacation trip to Jamaica with her husband. After seeing her primary doctor, she was referred to an orthopedic oncologist, where the leg pain was finally diagnosed as a tumor in her fibula (calf bone) with an initial recommendation of removing the fibula. She would later (December 3, 2011) learn she had multiple tumors throughout her body caused by a cancer -- unknown to her called Multiple Myeloma. It required immediate treatment. She went to the Internet, but the information was overwhelming. She was age 46 working every day with a husband and two boys. She was very active, working out in the gym 5 days per week -- 3 classes on Saturdays. In January 2012, Danielle went through 7 rounds of radiology with no measurable effect on her M Protein numbers and in February of 2012 she sneezed and fractured her vertebrae... she had kyphoplasty. Fortunately, her job was downsized about this time and she was very happy to receive a severance package.

Many present had been through a SCT and related with much of her journey; but this was the first time members were hearing a journey of a MM patient that was hospitalized twice with high doses of chemotherapy followed by a tandem SCT (2 stem cell transplants within 6months) at Emory Winship. That was 3 years ago. Danielle's MM was extremely aggressive requiring immediate treatment. She suffered loss of hair, bouts of depression and enormous pain; but was comforted by the love and presence of 18 family members who came to support her during and after treatment. Her disease is now stable as she receives infusion two days every other week. Danielle travels across the country to present her journey to other MM patients. She shared a resource list with the group. Danielle is treated by Dr. Nooka, Oncologist/researcher at Emory Winship who verified her MM diagnosis December 3, 2011.

Respectfully submitted by Paulette and Gail