

## Northside Meeting Notes - July 2014

### Business & Announcements

**Nancy** led the meeting, and approximately 30 people attended. News of upcoming meetings was discussed. In **August**, Hazel Jackson from the VA Hospital will attend the meeting as a guest speaker to discuss living wills and end-of-life care. The **September** meeting will be held at a local restaurant, [The 57<sup>th</sup> Fighter Group](#). More details will be provided and friends and family are welcome! The **October** meeting will be held as a separate patient and caregiver session. In **November** another guest speaker is being planned, and the **December** meeting will be a holiday party format. The kindness of **Greg & Suzanne's** request that donations be made in honor of Suzanne to the AAMMSG has resulted in \$475 for the group.

### Updates

**Sandy** provided an update on some members who have not been at a meeting recently. **Earnestine** is home from the hospital and living with her daughter. She is currently on dialysis three times a week and has been having rehabilitation at Emory for a blood clot. She is not on any myeloma drugs and her numbers are fluctuating. **Madge** is doing well on a clinical trial, getting good results and feeling well. **Inga** had been on Thalidomide since 2008 but is now off and is experiencing sleep difficulty. She has lesions and is currently getting radiation. **Nancy** is doing well on Revlimid but is experiencing diarrhea and asked how others in the group are managing this side effect. Some in the group have used Imodium and coconut water to help. **Jim** mentioned that "Welchol" is a binder that was discovered in Europe and now available in the US. Emory has been prescribing Welchol for patients on Revlimid with diarrhea as a side effect. Jim mentioned that it works better if taken with a meal. Revlimid may also cause lactose intolerance. **Jim** takes 5 mg of Revlimid for 21 days with 7 days off and is in a stringent complete remission. He gets Zometa every 4 months. He just had a MRD (Minimal Residual Disease) test and is waiting for results. Jim and Nancy explained that the MRD tests can be performed in conjunction with bone marrow testing. The patient can make the request for a MRD test which is now available locally. This test is for patients who are in remission and tests much deeper than prior tests. Although the test results are not fully understood at this time, a baseline can be established for future use and it makes sense for patients in remission to request this test now when they are getting their routine bone marrow test. Learn more at <http://blackswan.myeloma.org> **Bob** takes 15 mg of Revlimid and is in a stringent complete remission. He has not had a stem cell transplant but has collected stem cells. Bob has been on maintenance Revlimid since diagnosis over three years ago. **Sandy** is doing well and has been in remission since 2004. **Marilyn** was diagnosed with smoldering myeloma in 2008. She has had no treatment, is monitored every four months and her numbers are remaining steady. She walks every day before work, eats healthy, and takes supplements, including turmeric. She was found to be low in potassium and has added potassium supplements to her diet and feels much better since taking them. **Loretta** recently began getting Zometa monthly and is doing well with stable kidney function. She was taking 325 mg iron three times a day, but has now reduced it to once a day. **Nancy** mentioned that Zometa is known to have anti-cancer properties and that a standard for myeloma patients is to get it monthly for two years and then to have it reduced to quarterly after two years. **Brenda** was diagnosed in 2009 and plans to have a stem cell transplant later this year. She is currently taking 15 mg maintenance Revlimid and Dex and this is working well. She was recently prescribed an antiviral drug, Acyclovir because her doctors noticed a virus in a urine test and she said that she feels great and has more energy now that she is taking the Acyclovir. Someone mentioned that many patients are prescribed Acyclovir for life due to a compromised immune system and the risk of getting shingles, since myeloma patients should not get a shingles vaccine because it is a live vaccine. **Mary** completed a Phase 1 clinical trial that consisted of Velcade, Dex,

and an undisclosed oral drug. She is now continuing to take only the trial drug once a day, and has been on this drug for a year. Mary explained that the drug must be taken on an empty stomach – fast for one hour, then take the drug, and then fast for two hours; and it is recommended that the drug be taken from 7-10 AM. Side effects include a lot of fatigue. She is doing well and plans to continue with the drug for as long as it works for her. Since she is participating in a trial she is monitored closely and has an EKG and 24 hour urine test every three weeks. **Dana** is continuing in a Phase 2 clinical trial at Emory with good results. The trial is for an antibody, Daratumumab which is administered via IV. It started with weekly infusions for a few months, then went to biweekly infusions for four months, and now has graduated to a once a month infusion. He gets the IV and then takes Prednisone for 3 days after the infusion. Side effects include feeling “woozy” for 2-3 days after the infusion, but other than that he is feeling good. **Monique** was initially diagnosed 10 years ago. She has had two stem cell transplants four years apart. After the first stem cell transplant she was not on maintenance drugs. After the second stem cell transplant in 2009 she has been on maintenance Velcade every two weeks. She is in remission and doing great. There was some discussion related to managing pain. **Wendy** mentioned that her husband **Rick** is doing very well from a myeloma perspective, but he has chronic back pain from initial broken vertebrae that is treated with Methadone which causes fatigue and many other side effects including gastrointestinal issues. Someone mentioned that 12 hour Lidocaine patches can help a lot with pain, but you need to be careful as they can raise blood pressure. **Jim** mentioned that he had success with ridding severe neuropathy pain using an acupuncturist. After just the first session the pain was much better and after the second session the pain went away. Someone mentioned that Emory has an acupuncture department and to be sure to get a licensed and certified professional. There was some discussion about how eating spicy foods can temporarily relieve some pain as it causes endorphins to kick in. **Barbara** has experienced a lot of pain as myeloma has left a bone marrow mass on her spine which is treated with radiation. She is not on pain medication now and walks on a treadmill to help manage the pain. **Nancy** mentioned that walking is good weight bearing exercise for bone health, and is better than biking, which is not a weight bearing exercise. **Bob** does water aerobics, which removes the impact from the knees and ankles. **Molly** (Bob’s caregiver) helps Bob do Nordic Pole Walking for total body strength and she’s an instructor in this type of exercise.

--Respectfully submitted by Wendy

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## Southside Multiple Myeloma Support Group Meeting – **Meeting Minutes July 26, 2014**

The meeting was called to order by Doris who also led the group in a moment of silence. There were twelve present.

**Old Business:** The group decided not to participate in the Leukemia Lymphoma Society “Light the Night” event as a group this year.

**Member Updates:** **Lonnie** says he is currently being treated for lung cancer, which is a new diagnosis, not related to multiple myeloma (MM). He is tolerating the treatment better now. **Loretta** is receiving a new treatment for MM – B2062, which is an antibody drug, as well as Revlimid and Dexamethasone. **Darcel** discussed banking fetal cord blood for possible treatment later. **William**

discussed being on medications; he shared that his immune system is stronger. **Miriam** discussed taking acyclovir to prevent viral infection and shingles. **Alma** will possibly begin treatment with Pomalidomide; she will discuss with her Hematologist/Oncologist. Alma's sister was here visiting from Vancouver, Canada. **Harold** discussed feeling tired mostly, but he is getting by with God's help.

### **New Business:**

**Speaker:** Deborah Austin Thompson, RN, Atlanta Veterans Administration Medical Center Nurse. Ms. Thompson's presentation included an overview of the International Myeloma Foundation's Patient and Family Seminar held on May 16-17 in Atlanta. She led a discussion of information contained in the Seminar's Booklet. The presentation was interactive with lots of questions from the group.

Ms. Thompson led the group in a Game: "Multiple Myeloma White Elephant" to define statistics group members. Among those in attendance 8 patients have had stem cell transplants; 6 patients are actively receiving treatment; 3 patients receiving IV chemo treatment; 3 patients in remission; 7 patients with MM for 5 years; 3 patients with MM for 10 years ; 1 patient with MM for 12 years (Loretta); 0 patients with MM for 15 years; 5 patients who had radiation treatment for MM and 4 patients with ports. The interactive way of learning was fun and effective.

There was additional discussion about last month's presentation on peripheral neuropathy (PN) and the IMF Black Swan Research Initiative® which is focused on identifying a cure for MM and tests to help define a cure for MM.

Harold P. helped close the meeting with a rendition of "Ain't Got Time".

### **Announcements/Upcoming Meetings**

- **IMF** - archived videos – **Go to -- [www.myeloma.org](http://www.myeloma.org)** and click on "videos" on the red bar at top, then click on "#Ask Dr. Durie" for this week's topic – "Is it OK to take vitamin B12 on the same day as Velcade?" Check out other Dr. Durie videos and feel free to submit a question.
- **Advocacy Updates -- Newsletter** - Your Vote is your Voice!  
New members needed!! Find your federal and state elected officials by zip code at -- <http://www.commoncause.org/siteapps/advocacy/search.aspx?c=dkLNK1MQIwG&b=4860375>  
**Next Meeting: August 23, 2014** will be a discussion about Gail and Paulette's trip to Dallas and what they learned for meeting programs and sustaining the group.

Minutes respectfully submitted by Vermell, Paulette, and Gail.