

Northside Meeting Notes - June 2014

Business & Announcements

Nancy led the meeting; and over 30 people attended. Members who attended the IMF Patient & Family seminar in May reported that it was “amazing” and very educational. Slide decks from the seminar are available. The July meeting will be an open discussion forum. The September meeting will be held at a local restaurant, which is still to be decided.

Guest Speaker

Thank you to **Dr. Harvey**, Director Emory Clinical Trials.

Dr. Harvey trained as a pharmacist and now specializes in cancer, working closely with other Emory doctors. He joined the meeting to discuss clinical trials (CTs) and also addressed many other types of questions that the group had. There are currently 20-25 CTs open at Emory for multiple myeloma (MM). Patients who are eligible are encouraged to enroll in CTs, and some facts relative to CTs follow: 1) the medical team must see the patient and observe the activity more frequently than with standard care, so expect to be at the doctor’s office frequently, 2) no placebos are given in CTs - at least one effective agent is administered, 3) Phase 3 CTs are already known to work and are often administered in combination with standard care, 4) regarding participation in Phase 1 CTs, MM has shown an unprecedented improvement in the past five years which has resulted in some of the most promising agents when compared with other types of Phase 1 CTs. Additional highlights of the discussion follow in a Q&A format. **How can I find out about CTs?** Some options include asking your doctor, calling the Winship center, IMF publications, and visiting <http://clinicaltrials.gov>. **How is it determined if someone is eligible for a CT?** The process begins with the interested party contacting the Winship center. Then a records and background review can begin. Considerations include length of time since diagnosis, type of MM, age, kidney and liver function, prior treatment history including stem cell transplant, relapse history, other current preexisting conditions, overall health, genetics, blood counts, current drug status, etc. Then other things such as proximity to the trial location are considered. **Is there an age limit for participating in a CT?** No. Of more significance is the patient’s performance status for which there is a rating scale to determine eligibility. **If you want to participate in a CT but the center sponsoring the trial is not within the proximity boundaries, can arrangements be made for a local administration?** No, because of the strict accountability rules associated with CTs. An option would be to request the local center to open the trial. **How does insurance cover the cost of a CT?** For a MM CT, the insurance company pays for what would be the cost for a standard of care therapy. **How long does someone stay on a CT?** A few things determine your time on a CT: 1) your withdrawal for any reason, 2) a side effect that is intolerable to either you or your doctor, 3) the CT is not working for MM (either at all or any more). **What is the role of Dex?** Dex acts as an enabler for other drugs. Dex can make the MM cells available for the other drugs to kill the MM cell. Dr. Harvey mentioned that he thinks of Dex “like bacon, in that it makes a lot of things better, but too much for too long is not so good”. **How does the doctor determine whether or not to administer a drug (alone), or the drug with Dex?** Sometimes this is predetermined (i.e. if it is the standard of care), or it can depend on the patient’s tolerance or known issues. **If someone is extremely sensitive to Dex, can you assume that means that it is working well for them?** No, this assumption cannot be made with Dex, but this assumption can be made with some other drugs. Unfortunately there has been little association with drugs’ side effects and the effectiveness of MM drugs. **If you have strong side effects from Dex, are there other alternatives to taking Dex?** Another type of steroid is Prednisone. Both Dex and Prednisone contain cortisol, which triggers the “flight or fight” response. Each day your body naturally produces about 7.5 mg cortisol. 1 mg Dex = 7.5 mg cortisol. 1 mg

Dex = 6 mg Prednisone. So, it is not really about the type of drug you are taking, but more about the amount (dosage) of the drug you are taking that is causing the side effects. **I have been prescribed 20 mg Dex every two weeks. I have found Dex to help with arthritis. Can I break the prescribed dose down to take less more frequently?** This is not a good idea because you need to take a break from Dex so that your adrenal glands continue to produce cortisol normally. If Dex is provided to your body daily then your adrenal glands may not continue to function. You also need a certain dosage of Dex in each cycle in order to kill the MM cells. **Are MM chemotherapy drugs harmful to the heart?** Doxorubicin (Doxil) can damage the heart, and Carfilzomib is not good for patients with heart disease, but most MM drugs are not known to harm the heart. **What is the difference between Coumadin and Pradaxa as anticoagulants?** Regular International Normalized Ratio (INR) tests are not required with Pradaxa, but Pradaxa is released through the kidneys, so consider this if you notice that your creatinine level is rising. **Are there differences with drug dosage levels between the sexes?** In some drugs there is a known difference, for example with Ambien a 5 mg dose for men is the equivalent of a 2.5 mg dose for women. In general, there is not much known about the difference in dosage between sexes. **Would you comment on being on Thalidomide causing nerve damage and fatigue?** Thalidomide was originally developed in Europe as a sleeping pill for pregnant women, which explains the fatigue. A way to deal with the fatigue is to take Thalidomide at night or when you plan to sleep. Another common side effect with Thalidomide is constipation. Also, Thalidomide should be taken in conjunction with a blood thinner. **How is non-secretory MM measured?** This type of MM does not secrete antibodies to measure in blood and urine. Calcium levels, kidney function, RBC counts, and bone marrow tests can be used for measuring this type of MM. **Have you heard of an herbal remedy for neuropathy called Neuracel, which has claimed to cure neuropathy within two weeks?** No, but beware when considering and taking over the counter (OTC) remedies that are not FDA approved, and which bypass rigorous investigation and regulation. Many herbal formulas have been proven to not actually contain, or contain only trace amounts of the ingredients that are listed on the label and some ingredients can be harmful. Also note that nerve cells are formed early and cannot be replaced once they are permanently damaged. This is why it is important to tell your doctor about side effects before the damage progresses. Always keep your doctor informed of any OTC supplements that you are taking and be cautious. **What are your thoughts on medicinal mushrooms?** Some of the Chinese mushrooms are known to cause permanent liver damage. Some other mushrooms are not necessarily safe either, but we mostly hear about the bigger dangers. **What are your thoughts on medical marijuana?** There are currently no good drugs to help promote appetite (except Dex). There is some value with appropriate use of medical marijuana for increasing appetite and controlling nausea in some cases.

Updates

There was a short group update session after the discussion with Dr. Harvey. **Sandy** reported that **Earnestine** is in the hospital with kidney failure and is not doing well. **Chuck** reported that he has an aggressive form of MM and just exited the ABT-199 trial. He has tried the standard protocols, Carfilzomib, Panobinostat, and completed six rounds of VDCEP prior to entering the clinical trial. **Mike** reported that he had a third stem cell transplant two years ago that didn't work. Mike has been on Pomalyst for one year with good results – no cancer is detected. Mike mentioned that he works and is very active but fatigue was a very noticeable side effect of the drug for him at 4 mg, but when he reduced the dosage to 3 mg, he feels great. **Carolyn** commented that in a Phase 1 trial, the non-trial drug dosages can be adjusted, but not the dosages of the trial drugs. Someone asked about getting second opinions regarding treatments and many in the group have had second (or more) opinions and all recommended doing so. Some group members mentioned that their doctors encouraged other opinions as well. With MM being such a complicated disease to manage it is good

to get more than one opinion at times. Your relationship with your doctor is a key to your journey and survival and you need to respect and like your doctor. A doctor who is not supportive of additional opinions may be indicative of one that does not have your best care in mind. If you feel that your doctor is not on your team, then it is time to move on

--Respectfully submitted by Wendy R.

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Southside Multiple Myeloma Support Group Meeting -- **Meeting Minutes June 28, 2014**

Doris opened the meeting and Gail led us in a period of guided meditation for healing, stress reduction, and stress. There were present 17 members present.

New Members: There were two new members present--**Angie and Paul** who traveled from Vidalia (middle GA). Angie was diagnosed in 2007 with Lupus; she had an abnormal protein identified and in 2010 she was diagnosed with MGUS. Her MM is defined as IgA, Lambda, T 4:14 abnormalities which has progressed to smoldering. She had to fire her original oncologists because of poor communication from the staff. Angie is currently under the care of Dr. Sagar Lonial at Emory Winship Cancer Center, and attended the Patient and Family seminar in May. Angie and Paul moved to Georgia after spending a number of years in the military; she is a nurse practitioner by training.

Speaker: Our speaker was **Celia Lett, MSN, APRN:** Celia is an oncology nurse practitioner in the Emory Cancer Winship Infusion Center and Bone Marrow Transplant unit. She spoke on **Managing Peripheral Neuropathy –a major side effect from treatment for Multiple Myeloma.** Celia said exposure to toxins like VELCADE and THALIDIMIDE (used in MM treatment) are **risk factors for peripheral neuropathy (PN).** In addition, MM patients with co-morbid conditions are at higher risk for PN: diabetes (especially poorly controlled), Alcohol abuse, Vitamin deficiency (particularly Vitamin B1-B6), Lyme disease, shingles, hepatitis C and HIV, Rheumatoid arthritis and lupus, kidney, liver or thyroid disorders. She said **PN can cause** severe pain and can affect your ability to do things like walk, write, button your shirt, or pick up coins. If it gets very bad, PN can cause more serious problems like changes in your heart rate and blood pressure, dangerous falls, trouble breathing, paralysis, organ failure. **Treatment for PN** can include **medications** including Neurontin (gabapentin), pain relievers, anti-seizure medications, Lidocaine Patch, Lyrica, and antidepressants. One member reported getting acupuncture treatments for two weeks, which resolved her PN pain. She said her doctor made the referral and the treatment was paid by her insurance.) **Suggestions to help you manage PN** include taking care of your feet and exercise. Take care of your feet by checking them daily for signs of blisters, cuts, and calluses; tight shoes and socks can worsen pain and tingling and may lead to sores that will not heal. Wear soft, loose cotton socks and padded shoes. You can use a semicircular hoop, which is available in medical supply stores, to keep bedcovers off hot or sensitive feet. Regular exercise such as walking three times per week may reduce neuropathy pain, improve your muscle strength and help control blood sugar levels. Yoga and tai chi also have been shown to have many benefits, such as helping to control blood sugar levels in people with diabetes and reducing NP pain. **Other ways to help control PN symptoms** include: quit smoking, eat healthy meals including plenty of vegetables and fruits, emphasize low-fat meats and dairy products as well as whole grains; avoid alcohol, monitor your blood sugar levels, massage your hands and feet, or have someone else massage them for you,

avoid prolonged pressure—don't keep knees crossed or lean on your elbows for long periods of time, also try complementary medicine procedures, such as acupuncture and biofeedback. Celia said it is critical that you share your symptoms (and any other treatments) with the doctor as soon as you notice them. Chemotherapy dosage may need to be adjusted and stopped to avoid permanent PN. She provided a handout listing treatments for PN. Over the counter supplements for treatment include: Multi-B complex (B1, B6 and B12 at least 40 mcg/day), Folic Acid 1-2 mg per day, Vitamin B6 (in addition to that in a Multiple vitamin indicated above, an additional 50mg in am and 100 mg in pm); Magnesium -250 mg twice each day (may cause diarrhea in large dosages); L-Carnitine – 500 mg twice each day; Alpha Lipoic Acid -400-600 mg daily; potassium, tonic water. Specific prescription medications that might help include Gabapentin (Neurontin), Pregabalin (Lyrica), Duloxetine (Cymbalta); Lidoderm patches, OxyContin, Morphine, and Methadone. Also, cocoa butter applied topically may help with discomfort and keep hands and feet warm. Celia's other handouts included: signs and symptoms that should be reported to provider; symptoms and risk factors of PN; and Ways to cope with fatigue (also symptom of PN). We also discussed the importance of coordinating our regular visits to our primary care doctors while undergoing cancer care. On the nutrition side, we discussed frequent potassium deficiency in myeloma treatment. Unless there are kidney function problems, we need to include higher potassium foods in our regular healthy eating. For example, a baked white potato contains 500-600 mg of potassium – 2-3 times that of a medium size banana.

Patient UP Dates: **Alma** says she finally was able to find a source of Vitamin D3 that was not a fish based oil – it comes from lambs and is called Replesta. Alma is allergic to fish and has been looking for some time for a supplement that she was able to take to address her Vitamin D deficiency. **Elizabeth** has had 3 MRIs in 3 months; they found a mass at L5; took her off of Rev/Cytosin. She has been vomiting. Her diagnosis was in March 2013, and is working towards higher quality communications with providers; **Angie** was diagnosed with Lupus in 2007 and is being treated for MM at Emory Winship for MGUS; **Mischa** had a SCT at Northside in March 2013 and is on Revlimid 5mg for maintenance. **Pat** has been in remission for 9 years-- she is not on maintenance or any medication. She is on regular Zometa treatment. **Pat** is scheduled for July 11 biopsy and has started her immunizations – post-one year transplant on June 24th; **Yvonne** is now having radiation treatment for breast cancer (Yvonne is a supporter and does not have MM.); **Harold** says “all is well”; **Gail** is in remission since 2009 following chemotherapy (Revlimid /Velcade/Dex) and a SCT conducted in December, 2008. She is battling PN and gets quarterly Aredia to strengthen bones; **Montine** and **Brenda** continue in their caregiver roles and support the group, and ask thought-provoking questions; **Doris** says it has been 10 years since diagnosis -- she was originally treated with Thalidomide. Currently is on no medication for MM. Doris reported that **Dorothy** doing okay and is travelling. Doris also reported that **Lonnie** was out of the hospital, but is now in treatment for lung cancer. **Andrew** is having trouble with eyes; not sure if it is related to MM. **Andrew** has been in and out of the hospital for the past year (both would love to get call/messages of encouragement from you).

Question for the month. Can you define your MM?: Ig_? Kappa, Lambda, Cytology, Chromosome status? Gail asked the Question of the Group. She explained this information is becoming more critical as treatment becomes more genetic-based personalized medicine. Two members were first to respond and received a door prize. **Pat** - IgA/Kappa and **Angie** - IgA Lambda T 4:14 abnormalities now smoldering MGUS. Gail challenged members to be able to define their disease.

Announcements/Upcoming Meetings – We are seeking a group member or members to take the lead for a Fitness fundraiser. The event should take place in MM Awareness Month (March 2015). This will represent the Group's fundraising efforts for the next year. The June 21st cancer event on

Peachtree is a model of what we hope to accomplish. It can include a “walk in the mall”; tai chi; cooking demonstrations, etc.

- IMF - archived videos/teleconferences including: "Making Sense of Treatment" series
- IMWG Highlights -New Myeloma Testing Methods - Milan, Italy – *you can view these videos by going to "Youtube" - IMWG Summit and select the topic of interest. Doctor's debate myeloma – **These are excellent presentations; most are less than 10 minutes.***
- Referral from Susan Novis - 7 steps to Move thru Sadness and what we can Learn from it - <http://tinybuddha.com/blog/7-steps-to-move-through-sadness-and-what-we-can-learn-from-it/>
- IMF – Special Veteran's Against Myeloma website - veterans.myeloma.org.
- Mike Katz - encouraging Support Groups to use -<http://smartpatients.com/myeloma> - new platform replacing ACOR from www.myeloma.org - Mike Katz

Respectfully submitted by Paulette and Gail