Northside Meeting Notes - April 2014

New Members

John was diagnosed with multiple myeloma (MM) in July 2012. He had a stem cell transplant (SCT) in December 2013 and is doing well. He sees Dr. Lonial at Emory and plans to begin Revlimid maintenance in the near future. He mentioned that his SCT experience was OK, but he contracted a central line infection during the process and has lost about 50 pounds to date.

Business & Announcements

Joe and **Tom** co-lead the meeting. In May (only) the regular meeting will be replaced by the IMF-sponsored Patient & Family seminar which will take place in Atlanta on Friday May 16th – Saturday May 17th. The seminar is free to group members if you call the IMF hotline and tell them that you are a member of the Atlanta Area Multiple Myeloma Support Group (AAMMSG). A regular meeting schedule will resume in June, and Dr. Harvey, Director Emory Clinical Trials, will join the group as a guest speaker. The July meeting will be an open discussion forum. Someone mentioned that they had attended the recent Winship Gala that raised $865,000. She asked what percentage of the $300 ticket price goes to research and learned that it is 2/3 which she explained is very good, as she is knowledgeable on that topic.

Updates

Sandy recently spoke with **Earnestine** Earnestine finished a clinical trial with good MM results, but soon after developed pneumonia in both lungs and then kidney failure. Earnestine is currently on dialysis and living with her daughter. **Sara**, wife of **Robert** who passed during the February ice storm rejoined the group for the first time since Robert's passing. Sara expressed her thanks for the communications that she received and for those who expressed their thoughts at www.legacy .com – and mentioned that it is not too late to express condolences at that site. A memorial service for Robert is planned for May 12th with the American Friends Meeting Center. More information will follow. **Sylvia** shared some information about her sister who lives in south GA. Her sister has had MM for about six years and has not been doing as well in the past year with drugs and side effects. She is currently taking Pomalyst and Dex; and has recently introduced Curcumin at Sylvia's suggestion and with the knowledge of the results that she has heard from other group members. Since beginning the Curcumin along with the Pomalyst and Dex her protein numbers have declined. Her doctor is very pleased and has lengthened the time that she is able to stay off of the drugs since the results from the Curcumin have been so good. Sylvia mentioned that she purchases the Curcumin at Rainbow Grocer in Decatur, who supplied pamphlets about Curcumin that Sylvia distributed in the meeting (she is not affiliated with the business). She also mentioned seeing a good price online at Amazon. **Marilyn** mentioned that she has had smoldering myeloma for five years and has been taking 1800 mg. of Curcumin daily that she gets at Vitamin Shoppe. Others in the group mentioned that they also take Curcumin and alter their doses (increase or decrease) depending on test results. Remember to inform your doctor of any supplements that you are taking or if dosages change.

Suzanne is currently six weeks out of a second SCT. Prior to the transplant she was in the hospital in December and January and received two treatments of VDCEP, then went immediately into the SCT. She is currently looking for future treatment options. **Mary** completed a Phase 1 clinical trial that lasted 6-8 months (per plan) and consisted of Velcade, Dex, and an undisclosed "study drug". She has now discontinued the Velcade and Dex and is only taking the "study drug" (one pill daily and still undisclosed). Mary explained that the drug must be taken on an empty stomach and side

effects include a queasy stomach and heartburn. There is only one other person besides Mary on the trial at Emory, and results of the "study drug" alone are pending.

Carolyn began a clinical trial six years ago as one of the initial nine people in the Phase 1 trial at Emory (all of whom are still on the trial). The trial began with participants taking Dex, Revlimid, and Elotuzumab. Carolyn explained that Elotuzumab has not been approved because at least 50% of the clinical trial patients must start to fail on the drug before it can be evaluated further to decide if it can continue to the next steps of the approval process, and the failure rate has not yet occurred. Recently, this therapy has stopped working as well as it had been and she noticed that she was becoming breathless. She visited her cardiologist and she was found to have an artery spasm, which is not noticeable to a patient, and is rare – occurring in only 1% of the population. Luckily this was noticed because it can lead to a heart attack, and now Carolyn is on a drug to relax arteries. The cause is unknown. **Sara** mentioned that her husband **Robert** had amyloidosis attached to his heart for over a year, and that breathlessness was a first symptom, so be sure to have any symptom of breathlessness checked right away. **Dana** and **Suzanne** have participated in a Phase 2 clinical trial at Emory with very different results. The trial is for Daratumumab and has two Arms with participants assigned to either Arm randomly by computer. **Dana** is still enrolled in the trial and doing well, but Suzanne is no longer participating because her Arm of the trial has ended. **Dana** was assigned to **Arm A and received 16 mg** of Daratumumab weekly for two months, then every other week for four months, then monthly. Bone marrow and blood tests show that he has achieved a complete response. He had a reaction to the first infusion and has lost weight. Currently he is experiencing complete fatigue on the first day, but then he is also taking a steroid, Methylprednisolone, that alleviates the fatigue. **Suzanne** was assigned to **Arm B and received 8 mg** of Daratumumab monthly. This Arm of the trial showed no good response and was discontinued. Now, participants of Arm B cannot go to Arm A because they had been on Arm B that failed, and they cannot get on the (unapproved) drug another way. The Arm B participants do not know if Daratumumab is a drug that could work for them since it did not work for anyone at the dose provided.

Sara and others in the group suggest taking steroids right before going to bed and be sure to fall asleep within 30 minutes before the drug begins working. Then, the next morning you will be able to take advantage of the extra energy without it affecting sleep. **Jim** asked how others have coped with neuropathy. Various members spoke of their successes and/or issues with drugs Neurontin, Cymbalta, and Lyrica. Also mentioned was the list of supplements that can help at the Dana Farber website. **Suzanne** mentioned that she had been on Lyrica and when she stopped taking it she had trouble sleeping. Someone else mentioned that sometimes it is best to gradually withdraw from drugs, rather then abruptly stop them, especially when adverse side effects occur. It is best to notify your doctor so that they can assist you with the process. Someone asked why sometimes attempts are made to get a patient on a "next generation" of a drug when a prior generation of the same drug had not worked for them. **Tom** explained that from a chemistry standpoint one of the reasons is that the active part of the drug may be the same but the inactive agents may be different. So, it is possible to get different results with a next generation drug. This is why the OTC Prilosec version of Nexium works for some people and not others. Prilosec contains the same active ingredients as Nexium, but the rest is different and can make a significant difference in results in some cases. Someone reminded the group that the patient is responsible for contacting the FDA to report side effects not the doctor! This is noted on prescription information, but not always recognized.

Submitted by Wendy

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Southside Multiple Myeloma Support Group Meeting -- April 26, 2014

In Doris' absence, Gail led the group and began with a moment of silence and guided relaxation breathing exercises. There were 9 members present.

Myeloma Awareness Month (MAM)-Final Report : Alma shared final comments about her efforts as chairperson of MM Month and thoughts for 2015. She shared there were 8 cities in metro Atlanta that recognized and proclaimed March, MM month. She said during course of the campaign, there were about 20-30 individuals in each gathering – very few acknowledged they were aware of the disease. Several people commented that MM must be the disease their loved one passed away from some time ago. She said going forward she hoped we could expand and have the State legislature acknowledge MM month.

Understanding Lab Tests for Multiple Myeloma: Our featured speaker was **Vermell Sanford, RN, MSN, ONP:** Vermell is an Oncology nurse who retired from the Atlanta Veteran Administration Hospital last January. Since her retirement she has been the nurse consultant for our support group and has provided very valuable clinical information during meetings. Vermell provided examples of lab values from three visits for an unidentified MM patient. All members had been encouraged to study their own lab tests from past visits – and bring the tests and questions to this session. She walked us through the significance of lab tests and their relationship to MM and how the information is critical to patient care. She said it is important to **KNOW YOUR MULTIPLE MYELOMA.** Ask your doctor what values are being followed for ***your*** disease; ask to define what he/she is looking for to manage your disease, so that we may monitor our own progress. The diagnosis of Myeloma is complex as no single test is used to determine the presence of disease -- a trend or pattern is better than any single test. The presentation was extremely informative and helpful. Though the terms can be very confusing, myeloma will be a part of all our lives for a lifetime. *There are many abbreviations that are used to describe tests, and a huge part of the battle is to become familiar with those abbreviations.*

Tests for myeloma fall into several groups: lab tests; imaging studies (X-rays, CT scans, MRIs, etc.); pathology and genetic studies (done in biopsies, e.g., bone marrow biopsy). **This session will focus on lab tests.**

Blood and Urine Tests

A Complete Blood Count (CBC) identifies anemia, low white blood cells and platelets. It measures the number of red blood cells, white blood cells, and platelets in the blood, as well as the number or relative proportion of the different types of white blood cells present. *You should always request a copy of your complete lab results with the normal ranges of each value printed on the copy.* A **Chemistry profile** checks levels of various blood components such as albumin, blood urea nitrogen (BUN), calcium, creatinine, and lactate dehydrogenase (LDH). Increased BUN and creatinine indicate decreased kidney function, while LDH levels help assess tumor cell burden.

Serum levels of **beta-2 microglobulin (*ß*2-M)** reflect the tumor mass and are now considered a standard measure of tumor burden. Test shows abnormal protein –can be a marker for poor outcome.

C-reactive protein is made by the liver and is a surrogate marker (meaning it follows the same pattern of increased or decreased levels) for IL-6, a growth factor for myeloma cells.

Protein in urine is bad – and can indicate kidney damage. A routine **UA** (urine analysis) will show the presence of protein in urine, indicate kidney damage, or infection.

There are many different types of plasma in all our bodies. Each plasma cell has a specific Y-shaped immunoglobulin or antibodies. All normal tests have immunoglobulins (abbreviated Ig), **e.g., IgG, IgA, IgD, IgE, & IgM**. In myeloma, one particular plasma cell is duplicated many times, causing

an excessive production of one type of immunoglobulin protein, called a monoclonal protein, or M-**protein** – also called myeloma protein or **paraprotein,** or **M-spike**. In Myeloma, IgG paraproteins are the most prevalent, followed by IgA and IgM. IgD and IgE are very rare. *Which of your Igs have spiked?*

Electrophoresis (EP) measures the levels of various **proteins** in the blood or urine. When performed on blood, it is called serum protein electrophoresis (**SPEP**). When performed on urine, it is called urine protein electrophoresis (**UPEP)** and shows the absence or the presence and the amount of monoclonal protein (or M-spike) in urine. An additional test, called an immunoelectrophoresis (**IEP**) or immunofixation (**IFE**) can identify the subtype of M-protein that is being produced by the plasma cell, such as heavy chain (G, A, D, E, or M) and or light chain (kappa/lambda), i.e., IgG kappa or IgA lambda. Assessing changes and proportions of various proteins, particularly M (monoclonal) protein (also called **paraprotein**), helps track the progression of myeloma disease and response to treatment. Myeloma is characterized by a large increase (or spike) in M protein. Paraprotein level should be "0."

Light Chain/Heavy Chain Normal immunoglobulins (or antibodies) are composed of heavy and light chains (the building blocks of antibodies). There are 5 types of heavy chains – each one is assigned a letter. The five types are abbreviated as **IgG, IgA, IgD, IgE, & IgM. There are two types of light chains -- called** Kappa or lambda. Each type of plasma cell has only one type of heavy chain and one type of light chain, such as IgG Kappa or IgG lambda. Light chains may be bound to the heavy chain or are not attached to the heavy chains. They are called *free light chains*. For some unknown reason, the plasma cells produce more light chains than are needed by the antibody, and the excess light chains enter the bloodstream as *free light chains* (that is, they are not attached to the heavy chains. The amount of free light chain production is associated with the activity of myeloma or plasma cell growth. For diagnosis and monitoring purposes, a test (or assay) of free light chains is used (especially when paraprotein levels are low). This test may also be useful in monitoring MGUS. Only the monoclonal light chains show up in the urine. Heavy chains cannot pass through the kidneys and are found only in the blood. The SPEP, UPEP, and IFE are all not sensitive enough to determine the amount of free light chain is present.

A new serum free light chain assay, called **FREELITE™,** which detects and quantifies free light chains (those not associated with intact immunoglobulin), is now available. Evidence suggests that this test may help predict the risk of progression from monoclonal gammopathy of undetermined significance (MGUS) to multiple myeloma. Free light chain is better detected in the blood than the urine – because part of the kidney's function is to prevent protein loss from the body. Thus, excess protein will show up first in the serum. Some people with myeloma produce only light chains (called Bence Jones myeloma), but excess light chains might be present in all types of myeloma. The ratio of kappa/lambda light chains is as important as the levels of light chains (IMF, Understanding Free Light Chain Assays).

Those with **MGUS** have less than 10% plasma cells. Only 1% of MGUS patients go on to develop MM. Those with ***smoldering*** myeloma have more than 10% plasma cells and have an M-spike. There is no anemia, bone lesions – only monitoring is required for these patients. About 30% of those with smoldering myeloma go on to develop MM. Much research is being conducted to prevent smoldering MM from progressing further.

Pathology studies include **bone marrow biopsy** (and other tissue biopsies) – to assess the percent of myeloma cells in the bone marrow. Myeloma cells are typically CD56, CD38, CD138 positive or C19 and C45 negative. There is special testing to assess prognosis based on chromosomal abnormalities. **Cytogenetics** is conducted with bone marrow biopsy specimen. Cells must be actively dividing – and are photographed to show chromosome arrangement. It will show which chromosomes are missing or translocated and this can identify higher than average risk for myeloma.

Fluorescence in situ Hybridization **(FISH)** – test is conducted to identify high risk myeloma patients with certain chromosomal genetic mutations and deletions. Much of current research and treatment is towards **personalized medicine**, where each patient is treated based on his/her genetic disease problem.

Vermell remained at the end of the meeting to review lab tests with individual members. She reminded the group that lab tests might look different – as different laboratories use different units. Always double check the units when comparing lab results. **See more at**: International Myeloma Foundation - www.myeloma.org; National Cancer Institute – www.cancer.gov; and Leukemia and Lymphoma Society – www.lls.org.

Announcements/Upcoming Meetings

- IMF Living Well with Myeloma Teleconference Series. **"Stopping to Breathe While Moving Forward: Benefits of rest, relaxation, exercise, and nutrition."** May 8th go online www.myeloma.org- check for archived presentation.
- **Myeloma Support Group at Emory Winship** meets each second Tuesday 1-2:30 pm with Alice Mullins, MS, LSW as the leader – bring your lunch.
- IMF-www.veterans.myeloma.org **Veteran's Against Myeloma**:

VISIT OUR UPDATED WEBSITE, WE NEED YOUR FEEDBACK . WWW.SSATLANTA.MYELOMA.ORG

For the ***Next meeting*** *members should consider* ***if we will participate in the LLS-Light the Night 2014.***

Respectfully submitted by Paulette and Gail