

Northside Meeting Notes - February 2015

Business & Announcements

Joe B, led meeting. The March meeting will be held as a separate patient and caregiver session. The group expressed condolences to **Lee**, husband of Chris who recently passed. Lee explained that Chris had an aggressive case of MM but was able to fight for years. Last November tumors were found and Chris's fight became more difficult with radiology, some paralysis in her leg, and time spent in a rehab hospital. Lee said that he is grateful for the group's support.

New Members

The group welcomed two new members. **Katie** was diagnosed with MM at Northside in May 2011, and was referred to Dr. Lonial at Emory for a clinical trial. Katie has taken Revlimid, Velcade, Dex, and Vorinostat and achieved complete remission after a year. She has not had a stem cell transplant and has done very well, however her numbers have begun to increase. **Todd** was just diagnosed with MM in January 2015 and he joined the group to learn more and get to know others with MM. Todd has started treatment with Revlimid, Velcade, and Dex. He was diagnosed when test results revealed an elevated M-Spike. Todd mentioned that he had been feeling light headed with low-energy - he stays very physically fit and active and was having trouble "keeping up" prior to the diagnosis.

Guest Speaker

Madge who taught at the Emory School of Nursing for 25 years introduced the guest speaker, who had been one of her students. **Tammy Rabern**, MSN, APRN-BC is a Clinical Nurse Educator for Takeda Pharmaceuticals International. Tammy graduated from Emory's School of Nurses with a specialty in oncology. She has worked with all cancer types; and has worked in academic and community practice settings. Her initial experience with MM was working with a trial drug that became known as Velcade. She realized that MM was a disease that was not well understood, even by medical practitioners. This realization and her interest in MM drove her to move toward an educational position and she now teaches nurses about MM, including how to interpret blood test results. The immune system is the defense system in our bodies and it has two levels of defense (local and immunoglobulins) which a healthy body uses and stops using accordingly. With MM it is the immune system that is a big point of dysfunction. There are a few important terms/definitions to help better understand what follows:

- The following terms are used interchangeably and generally mean the same thing relative to MM:
 - (immunoglobulin = Ig = protein = M-spike = antibody = monoclonal protein)
- mono = one
- clonal = cell type
- gammopathy = "over-production" or "too much"

When our body senses that it needs to defend itself from the threat of an invader, white blood cells (the first level of defense) respond (often felt as fever and chills). Then, if necessary, the next level

of defense is called, and more specific protein antibodies respond to fight the body's invader. Protein antibodies are also known as immunoglobulins (Ig). This is a more specific reaction as the body begins to make antigens (IgG, IgA, IgM, IgE, and IgD immunoglobulins) to fight a more specific type of invader, i.e. bacteria, viruses, etc. These antibodies are made in the bone marrow by plasma cells (mature B-cells). In a healthy body the plasma cells make just enough antibodies to fight the invader and then stop. With MM, the plasma cells continue to make the antibodies and make too much of a single type of immunoglobulin; most frequently IgG or IgA., which is known as monoclonal gammopathy (over-production of a single type of type of cell). These antibodies are physically large types of proteins and cannot be filtered by the kidneys. The overproduction of a single type of plasma cell adversely affects other plasma cells. Too much of one type of an immunoglobulin does not equate to good immunity, but rather it results in not enough of other types of immunoglobulin cells and results in sickness' i.e. MM is a cancer formed by malignant plasma cells. A faulty immune system results in recurrent infections. Tammy mentioned that this is a reason why a patient should be tested for MM if they are experiencing recurrent types of infections such as UTIs, pneumonia, etc. Immunoglobulins are comprised of smaller components called heavy chains and light chains, which are produced by plasma cells. The heavy and light chains bind together to form whole immunoglobulins. When plasma cells produce too many light chains they enter the blood as "free" light chains (i.e. not bound) which is indicative of myeloma activity. If there is too much of one type of light chain (kappa or lambda) then there is a presence of a monoclonal protein. There are a variety of ways that MM is diagnosed, staged, and monitored. One way is by blood tests, and the elements from the CRAB criteria (Calcium, Renal, Anemia, and Bone issues) can be evaluated in blood tests. Tammy provided a pamphlet entitled, "Understanding Multiple Myeloma Laboratory Tests" (available in the group's Library or by contacting Takeda), which explains in detail the tests used to diagnose, assess, and monitor MM. The following information is available from the pamphlet.

CBC - Complete Blood Count – measures the levels of a person's cells that are produced in bone marrow

- WBC – White Blood Cells – fight invasions of the body; a low WBC can lower a body's immune system and capability to fight disease
- WBC Neutrophils – a specific type of WBC that fight infections and inflammation
- RBC - Red Blood Cells – carry oxygen and remove carbon dioxide; low RBC = anemia
- Hgb – Hemoglobin – transport oxygen in blood to the rest of the body. Low Hgb levels may indicate that there are too many MM cells in the bone marrow and not enough normal bone marrow cells
- Platelets – necessary for blood clotting

Chemistry Panel – Panel of test for which each measure different substances of the blood to provide information about the function of different organs

- Glucose, serum – measures sugar
- BUN- Blood Urea Nitrogen – measures urea, which is a waste product produced when protein is broken down; high levels may indicate kidney dysfunction
- Creatinine, serum – a waste product from meat protein and muscle function; elevated levels indicate that the kidneys are not clearing waste products from the blood
- Protein, total serum – measures the total protein levels in blood and the amounts of two types: albumin and globulin; abnormal levels may indicate MM

- Calcium – measures the level of calcium in the body that is not stored in bones; high levels may indicate kidney and bone damage
- Beta2 Microglobulin – a protein found in cells and a marker of cell reproduction; high levels may indicate MM
- SPEP - Serum Electrophoresis – used to identify M-protein in blood / looks for monoclonal gammopathy (too much of one kind of protein) - is it there or not, Yes or No?
- M-Spike - myeloma gamma globulin – when large amounts of protein are in blood it will display as a large peak (spike) on the electrophoresis graph
- IGS - Serum Quantitative Immunoglobulins – detects levels of the major classes of immunoglobulins – IgG, IgA, IgM, IgE, IgD
- IFE – Serum Immunofixation – if an M-protein excess exists (identified via SPEP), IFE determines the subtype of M-protein
- Serum Free Light Chain Assay – measures the amount of free light chains and is linked to MM activity or plasma cell growth
- Serum free kappa light chains; Serum free lambda light chains - increased amounts may indicate myeloma
- Serum free kappa/lambda ratio – increased free light chain production and an abnormal ratio indicate MM progression

Many thanks to Tammy for an excellent presentation; her ability to translate some very technical, difficult to understand material into layperson's terms is very much appreciated.

Southside Meeting Notes, February, 2015

Gail opened the meeting. Nancy and Paulette lead group in a laughter release activity. Laughter is a tool used for relaxation. Many have said “**Laughter is the Best medicine**”- go ahead and give it a try. Turn the corners of your mouth up into a smile and then give a laugh, even if it feels a little forced. Once you've had your chuckle, take stock of how you're feeling. Are your muscles a little less tense? Do you feel more relaxed? That's the natural wonder of laughing at work. There were 14 present.

Next month, on March 28th, members will promote Multiple Myeloma month by participating in the Greenbriar Mall health fair.

Guest Speaker- Kim Nickels, Patient Access Manager for the Atlanta Leukemia and Lymphoma Society (LLS) was our speaker. Mrs. Nickels provided updates on the programs, services and resources offered by for patients and caregivers affected by blood cancers. She shared that the local office was in the process of developing a Blood Cancer conference to be held in Atlanta in June of this year. There will be some focus on multiple myeloma; she solicited and obtained input for the agenda from the group. She also shared LLS was in the process of obtaining funding that will pay up to \$500 per year for gas, hotel, and travel including airline fare, to medical appointments. She said while they no longer provide the \$150 yearly stipend for cancer patients, they still will provide up to \$10,000 per year for insurance premiums and co-pay expenses. (She noted, Cancer Care (www.CancerCare.org) will provide funds for patients that present receipts for travel and parking

and \$150 to females diagnosed with cancer). Mrs. Nickels described the volume of resources and services provided by LLS as described at www.lls.org. She encouraged us to watch “Biography of Cancer--The Emperor of All Maladies”. This is a Pulitzer Prize winning book, now a documentary from Ken Burns on PBS, The Emperor of All Maladies is a magnificent, profoundly humane “biography” of cancer—from its first documented appearances thousands of years ago through the epic battles in the twentieth century to cure, control, and conquer it to a radical new understanding of its essence. The documentary will air March 30, 31, and April 1, 2015 on GPTV/PBS (channel 8).

LLS provides four categories of programs **1. One-on-One support with Information Specialist; 2. Disease, Treatment and Support Resources; 3. Financial Assistance and Related Resources; and 4. Chapter Support.** Information Specialists can answer general questions about diagnosis and treatment options, offer guidance, resources and support and assist with clinical-trial searches—communication in other languages is available. To connect with this resource: Phone **800-955-4572** (M-F 9am-9pm); Email-infocenter@lls.org; For information on Disease Treatment and Support Resources – LLS provides free support and resources to help you understand your disease and treatment. Information for these resources can be acquired as follows: www.lls.org/diseaseinformation; Clinical trials search tool www.lls.org/clinicaltrials; Online chats and discussion boards: www.lls.org/getinfo; Online videos: www.lls.org/educationvideos . For **Financial Assistance and Related Resources** LLS offers information and programs help patients understand and pay for the cost of treatment. To do this they have a Co-pay Assistance program www.lls.org/copay and other financial assistance: www.lls.org/finances. **Chapter Support** includes services and support offered in our community: LLS offers support and services in United States and Canada through a network of chapters. They include Resource and Support in our Community, www.lls.org/chapterfind; Support Groups: www.lls.org/supportgroups; Peer to peer support first Connection Program www.lls.org/firstconnection. **Pat, a member of our group**, is an active participant in this program and connects with other individuals across the country with myeloma. Training for this program is provided via teleconference every 6 months. The Education programs in your community: www.lls.org/chapterprograms.

MM Awareness Month: Alma provided an update of MM month. Next month, on March 28th between 10am and 1pm, members will promote Multiple Myeloma month by participating in the Greenbriar Mall health fair. Members signed up for times to man the Multiple Myeloma table—sharing information with the public about the disease. Gail agreed represent the group by making an announcement describing MM to the Greenbriar shoppers during the Health Fair. Also, during this month varies newspapers will run article about the disease. The South Fulton Neighbor, Atlanta Daily World, 85 South and possibly the Patch are some that have agreed to run articles. Remember **“EACH ONE TEACH ONE”**-tell someone about MM and wear your “Ask me about myeloma” button.

Announcements/Upcoming Meetings

- Watch for re-runs of this HBO Documentary initially aired on February 27th title "Killing Cancer" - use of measles virotherapy to treat myeloma; narrated by Dr. Stephen Russell of Mayo Clinic.

•IMF presents -Living Well with Myeloma Series: Understanding the Immune System " - Dr. Brian Durie, Thursday, March 19 at 7:00PM EST. www.myeloma.org . You can connect to listen again at www.replay.myeloma.org

LLS - "Clinical Trials or Standard Treatment". Wednesday, March 18, 1:00 PM EST. www.lls.org

•MMRF - Atlanta 5k. Sunday, May 17 @9 am. at Piedmont Park. www.themmr.org/Atlanta. **Also**, MMRF will offer a conference at Emory on May 16th at the Emory Center Hotel; **this education session is free**. Clinical Insights. When: Saturday, May 16, 2015 8:30 AM - 9:30 AM Registration and Networking; 9:30 AM - 2:30 PM Program (Breakfast and Lunch included), Where: Emory Conference Center Hotel, 1615 Clifton Rd NE, Atlanta, GA 30329.

- New from IMF: Updates on Myeloma Glossary. Download the PDF version. Acronyms, new drugs. www.myeloma.org Publication "Understanding MGUS and Smoldering Myeloma" Questions about Myeloma? Time sensitive - 800.452.2873 from 9AM -4PM PST
- Email-info@myeloma.org; AskDrDurie@myeloma.org;
- Understanding Myeloma Risk Factors? Few are known, but age, gender, race, and environmental agents (chemicals) (e.g., work place, agriculture, 9/11).Source: American Cancer Society (ACS)

New Drug Approval from FDA - Panobinostat from Novartis. In a reversal of the November 2014 decision, Panobinostat, also named Farydak has been approved for use in patients with at least two prior therapies. It is to be used in combination with Velcade and Dex. This is an HDAC (histone deacetylase) inhibitor. Ixazomib (MLN9708) from Takeda- oral proteasome inhibitor (Velcade in a pill) is in Phase III clinical trials.

Another level of approval from FDA for Revlimid in frontline therapy -- based on results of FIRST trial. Added more detailed guidance after first 4 cycles of therapy...also considering the potential risk of second primary malignancies. Continuous research - is REVLIMID recommended as maintenance for many patients, but not everyone? Revlimid approval by both European Commission and FDA.

Precision Medical Initiative - President Obama's proposal - compiles and analyzes 1 million genomes for advancement of cancer treatment... announcement from MMRF.

Alma closed the meeting with a quote: "Some of the best days of our lives have not happened, relax and keep going". Simplereminders.com

Harold led the group in closing prayer.

Submitted by Paulette and Gail.