

Northside Meeting Notes - November 2014

Business & Announcements

Nancy B led the meeting and approximately 31 people attended. There were no new members at the meeting. The **December meeting** will be a combination of member updates and a holiday “potluck” celebration where everyone is invited to bring their favorite potluck dish to share. The group also donates toys to Children’s Healthcare of Atlanta to help brighten the holidays for children who are in the hospital during the December holiday season; and everyone is invited to bring a new, unwrapped toy to donate. **Please Note:** The January meeting will be held on the **second** Saturday of the month, January 10th, at Emory, rather than on the regular date and location. At this meeting, Emory doctors will report on highlights from attending the American Society of Hematology (ASH) conference that is held in early December. More information regarding the January meeting will be made available in a separate communication.

Guest Speaker

Thank you to **Joan Giblin**, Survivorship Program Director at Emory, who joined the group to explain the purpose of the **Survivorship Program at Emory** and how it came to exist. Joan is a registered nurse with 44 years of nursing experience and patient care. During her many years of experience Joan has seen all types of cancer and has seen some very positive recoveries. She also has witnessed cancer becoming a chronic disease versus a terminal disease for many types of cancer including myeloma. She explained that the Survivorship Program at Emory is very new and was developed from scratch and is still being developed as it is also in the process of being implemented as a resource for patients to facilitate continued good health and quality of life for cancer survivors. The program is not specific to myeloma patients and it is for cancer survivors at any time during their survival. Joan provided some history in order to understand why and how the Survivorship Program has become a reality. In 2005 the Institution of Medicine reported that the US does a poor job at taking care of cancer survivors. Currently in the US there are approximately 14 million cancer survivors and it is estimated that by 2020 there will be 20 million cancer survivors. More recently the Commission on Cancer (CoC) organization has mandated that all Cancer Centers in the US are required to provide the following by 2015: 1) a system for navigation, 2) a distress thermometer (relative to the social effects of cancer), and 3) a Survivorship Program with a treatment summary and a long term care plan for patients. Different Cancer Centers will implement these requirements differently however these requirements are now standard and must be met and will be monitored at all Cancer Centers. Joan has been developing Emory’s Survivorship Program from its inception. Emory is using the [LIVESTRONG Care Plan](#) which is concise, free, and can also be used by individuals to develop their own long term care plans. She personally meets with patients through all phases of the disease from diagnosis, where survival starts. For example she can help coordinate meetings with her, the patient, a social worker, and a dietician, and also can work with the patient’s primary care physician (PCP) to provide holistic reports for the patient. Joan graciously responded to many questions: **How can I get an appointment with Joan to help me develop a Survivor Care Plan?** Joan can be contacted at: Joan.Giblin@emoryhealthcare.org or survivorship@emoryhealthcare.org

I am an Emory patient and cancer survivor – should I have met with Joan already? Not necessarily since this is a very new program and is just in the adoption phase at Emory. To put this into perspective, an Emory goal is to have met with 10% of patient by 2015. **Do you have to be an**

Emory patient to meet with Joan? No; she also meets with patients who are not Emory patients.
What are some of the types of programs that are available to the patient through the Survivorship Program? Some program types that are available include diet/nutrition, exercise, yoga, and are often held at YMCAs. Also, the necessity of programs that are located close in proximity to the patient is considered.

Discussion & Member Updates

There was a short group meeting after the presentation. We discussed the importance of being your own best advocate by staying educated and keeping informed of new advances which is a continuous process. The International Myeloma Foundation (IMF) publishes the Myeloma Minute every Friday (via email – call the IMF InfoLine (800) 452-CURE (2873) to request a copy to be sent to your email address). The IMF also publishes Myeloma Today that is free and available quarterly upon request. Call the IMF Info Line to receive this valuable publication. **Nancy B** presented information from the IMF about the Black Swan Research Initiative ®. The presentation reviewed the flow cytometry test that can measure the minimal residual disease (MRD). Please note that you may need to request the flow cytometry (MRD) test in advance as a part of your regular bone marrow test; as it may not automatically be done at all facilities yet. The advantage of the flow cytometry test is that it can find a single myeloma cell in millions of bone marrow cells vs. one in a few thousand cells as was previously measured. This ability to detect minimal residual disease allows us to proactively measure and manage the disease rather than reactively manage the disease. From a clinical trial perspective an endpoint to the trial may be able to be much sooner using MRD test results. In other words, target criteria of a clinical trial could soon become available much sooner, expediting the trial. Consider that we may no longer have to wait for clinical trial patients to relapse before getting the results if we were to rely on MRD testing instead of current standards. Efforts are underway so that the flow cytometry (MRD) test will be performed as a blood test, rather than a bone marrow biopsy test at some point in the future. To see the video, click here -- <http://bsri.myeloma.org/imf-salamanca-flow-cytometry-workshop/> or go to www.bsri.myeloma.org to learn more.

Southside Meeting Notes, November, 2014

The November meeting was sponsored by **John Schwarz** of Takeda Oncology Pharmaceutical Company (formally Millennium) and was held at Paschal's Brothers Restaurant. **Doris** opened the meeting and led the group in moment of silence; she provided some background of the group including the fact that she started the support group in 2006 after her MM diagnosis. **Joe** blessed the food and **Harold** (our signing cowboy) sang a medley old time spirituals including: Just A Closer Walk with Thee, What a Friend We Have in Jesus, and Have a Little Talk with Jesus.

New Members: Valeria and Ted

Presenters: Tammy Rayburn, Nurse Practitioner, The Takeda Oncology Company -- and Dr. Petronella Mbu and Dr. Jordan Howard, Department of Psychiatry, Morehouse School of Medicine.

Understanding Your Lab Values and The Immune System: A General Overview was presented by Tammy Rayburn, Nurse Practitioner/Educator for Southeast area US for The Takeda

Oncology Company. She began working with MM early 2000 with the clinical trials for Velcade at that time known as PS340. She said her experience has shown the more you understand *your* disease, the better equipped you are to help manage and understand the treatment regimen.

Ms. Rayburn said it is natural for our body to defend itself against invasion. She described the immune system as the defense system in our bodies – and provided an analogy between it and a community's defense against invaders. When a community is attacked the municipality has the police as the first level of defense, maybe the fire department, maybe the SWAT team, if necessary they will call in the National Guard or specific defense staff to address the specific type of threat. Likewise, when our body is attacked by threat of disease our body has the ability to defend itself. The white blood cells are the first to respond, then more specific protein antibodies (or **immunoglobulins = Ig** = a class of proteins in the blood that functions as antibodies). The body then begins to make antigens (IgG, IgA, IgM, IgD, IgE immunoglobulins). We usually make normal cells; but when the body is invaded our body will make antibodies with the virus. In MM, plasma cells get confused and instead of making just enough antibodies to fight off the invasion, it makes too much of one immunoglobulin, usually IgG or IgA. This is called **monoclonal gammopathy**. The breakdown of this term -- The **over production** or too much is **–gammopathy**, **mono** is **one**, and **genetic cell type = clonal**. Tammy reminded us that there are usually several terms in medicine that mean the same thing -- and are used interchangeably. For example M (spike) = protein = monoclonal protein level = antibody = immunoglobulin (Ig).

She referenced The Takeda Oncology Company's **Understanding Multiple Myeloma – Laboratory Tests** booklet and reviewed the various tests doctors use to help diagnose Multiple Myeloma, determine the severity of the disease, monitor the effectiveness of treatment, and evaluate progress. MM is diagnosed by blood tests (serum electrophoresis, serum free kappa/lambda light chain assay, bone marrow biopsy, urine electrophoresis, and X-rays of commonly involved bones. Plasma cells (a type of white blood cell) produce both heavy and light chains -- the building blocks of antibodies. The typical structural unit of antibodies is two large (immunoglobulin (Ig) heavy chains and two small light chains. There are **two types of light chains** -- **kappa** chain on chromosome 2) and **lambda** chain located on chromosome 22. In healthy people, the total ratio of kappa to lambda is 3:1 (read 3 to 1). Page 8 of the publication describes the Serum Protein Electrophoresis (**SPEP**) test -- used to examine specific proteins in the blood, called **globulins**. There is also a Urine Protein Electrophoresis (**UPEP**). Light chains can pass through the kidneys (and so can be analyzed in urine), but heavy chains cannot pass through. Some MM patients have what is called "light chain disease" and follow mostly their light chain values. In light chain disease, the plasma cells typically produce more light chain than required, which then enter the blood as **free light chains**. The **Serum Free Light Chain Assay** (assay = test) is a new, very sensitive blood test, not available 5 years ago, It identifies the amount of free light chains in the blood and is linked to activity of Myeloma or plasma cell growth (This brochure and others are available from Takeda or Doris M.). This is yet another reminder of how each person's myeloma is unique. It is important to understand the type of myeloma *you have* and which tests are used to monitor *your disease*, and what "normal" values *you* are looking to achieve.

Treatment plans are based on the aggressiveness of the disease and genetic factors. The number of chromosomes may be affected by MM. Also translocation of chromosomes may be a factor. About half of MM cases are linked to the deletion of Chromosome 13. The exam to look for chromosome abnormalities is called **cytogenetic analysis**. This is conducted during bone marrow biopsy. The

plasma cells are examined for abnormal numbers, deletions, and translocations. This is the direction of current research in and treatment of MM.

Beating the Holiday Blues: To help control holiday depression, two Morehouse School of Medicine Department of Psychiatry Residents (Dr. Petronella Mbu and Dr. Jordan Howard) provided valuable tips on **Beating the Holiday Blues**. These are tips for everyone, but especially if the holiday Season reminds you of your illness, or family and friends who are no longer with us. They suggested we: **1.)** Take *should* out of your vocabulary—sometimes we feel obligated to do things we don't desire, such as attending special events or continuing a specific tradition-- **Do only what you want to do.** **2.) Prioritize your daily activities** with the most important tasks. If you don't get to the bottom of the list, don't feel disappointed. –You are the most important—take care of *you* first. **3.) Create new traditions.** During the holidays we place pressure on ourselves to uphold timeless family traditions such as cooking special meals, hosting dinner parties, or decorating. These are not things you must do. **4.) Brighten someone else's holiday.** Share your time and resources with people less fortunate. Some examples include volunteering at a homeless shelter, soup kitchen, nursing home, or donating clothes and toys to the underprivileged. **5.)** Don't forget yourself. Create time to do hobbies and tend to your physical, spiritual and mental health. – **Take at least 10-15 minutes for yourself each day or when feeling stressed.** **6.) Acknowledge your feelings**—you don't have to keep your feelings bottled up if you feel sad because of the empty chair at the table, memories of loved ones who have passed, illness or regret. It is okay to grieve. **7.)** Finally, **count your blessings.** We all have things for which we should "**Give Thanks.**"

Have a great Holiday Season!!