

January 2017

Northside Multiple Myeloma Support Group Meeting

Business

No meeting due to weather.

Southside Multiple Myeloma Support Group Meeting Saturday, January 28, 2017

Meeting Notes

Doris opened the meeting with a moment of silence. There were 19 present and four were new members.

The new members included Ethel, Donald, his wife Pamela and Joyce. **Ethel** was diagnosed in March of 2015 and had a SCT in July 2015. She is currently on 10 mg of Rev 21 days on 7 days off. **Donald** was also diagnosed in March of 2015, has not had a SCT. He is on 25 mg Rev 28-day cycle -- 14 days on/14 days off. His wife, **Pamela**, a three-time Lymphoma cancer survivor (2006, 2008 and 2010) was also present. **Joyce** was diagnosed with MM in 2012; she had tandem SCTs at Northside. Her labs show signs her M-spike is going up and she will be meeting with her oncologist to determine next steps.

We were happy to welcome back **Teonna** and her husband **Ilksen**. **Teonna** had a SCT on December 8th at Emory Winship and is looking and doing well. We were also happy to see **Sheryl** who lost her father in December and her husband, our beloved **Ozzie**, who passed away in July. **Selina** also returned after her husband's passing in August (not from myeloma); then she lost a nephew due to a car accident in November.

Mark Your Calendars!! We have confirmed **Saturday May 20th, 2017** for the **Caregivers Summit**. The summit will be held at the **Atlanta Metropolitan College from 8:30 to 1:00 PM**. This summit is for patients and caregivers – a salute to our valuable caregivers with many resources - - so be sure to make your caregiver aware and encourage them to attend.

Our speaker: Lawrence E. Morris, Jr. MD, Hematologist and Cancer Specialist, with the Blood and Marrow Transplant Group of Georgia at **Northside Hospital Cancer Institute**. He was introduced by Kathleen McNatt, Northside Hospital Blood and Marrow Nurse Consultant. Dr. Morris explained that years ago there were not treatments specific to the treatment of Myeloma. Since then, he has seen patients live longer and newer drugs have been developed specifically for the treatment of Multiple Myeloma (MM). He confirmed that the cause of MM is still unknown – environment, genetic, chemical exposure? No one knows for sure. He shared, in his opinion; the best treatment resulting in a cure is the allogeneic Stem Cell Transplant-where a patient is given the cells of a matched donor (Most SCT in MM are autologous-[ASCT] cells are provided by the MM patient). This treatment risks graft versus host disease which can be extremely risky.

Dr. Morris began his talk with a review of myeloma including its symptoms, exams, tests and treatment. Go to our support group website, www.SSatlanta.support.myeloma.org, or www.myeloma.org to learn more about Multiple Myeloma basics. He also shared details of a new clinical trial now offered at Northside Hospital – joining Johns Hopkins Cancer Center and others in a multicenter clinical trial research project. This **Novel MM Immunotherapy** BMT Clinical Research Trail is available to high risk MM patients who have not had a Stem Cell Transplant. The new trial is called **MILs – Marrow Infiltrating Lymphocytes**. Lymphocytes are immune cells that live in the bone marrow.

The definition of high risk myeloma is based on tests that include FISH* – Chromosome abnormalities that include 1P deletion, 4;14, 14;16, and 17P. Your type of myeloma – including cytogenetics you should get from and discuss with your health care provider.

As a reminder, symptoms of MM are sometimes referred to as the CRAB criteria – Calcium, Renal (Kidney), Anemia, and Bone. An additional criterion is the **I** for the **I**mmune system. There is a category of new drug therapies that work with the immune system to control MM. This new treatment will use a new T-cell **immuno**therapy called MILS. T-cells are taken from the bone marrow of the patient -- enhanced and expanded in the laboratory, and returned to the patient in an autologous SCT to target the specific myeloma cancer cells.

This is a phase II multicenter study. Patients will be randomized 2:1 to MILs or to no-MILs groups – seeking to recruit a total of 90 patients. All patients will undergo an ASCT, will receive Tadalafil (Cialis) and Lenalidomide post-transplant for maintenance therapy at approximately day 60 until disease progression. Patients randomized to the non-MILs arm of the trial will be able to receive MILs upon relapse.

For more information please call **404-255-1930** or visit northside.com/leukemia or BMTGA.com or <https://clinicaltrials.gov>. The Leukemia Program at Northside Hospital in partnership with the NSH-BMT Program also provides comprehensive, patient-centered care for adult patients battling acute leukemia, and other hematological disorders.

*FISH - fluorescence in situ hybridization – test for different types of MM to arrive at best possible treatment option.

Announcements/Resources/Upcoming Meetings

MMRF - Congratulations! - Atlanta Area MM Support Groups - Spirit of Hope Award - 2017. To be received by **Sandy Brown and Doris Morgan** during annual walk. The award will be presented on Sunday, April 9th. It is given to one ... "who inspires hope with their work and demonstrates extraordinary commitment to the MMRF." We hope members will attend to provide support and help honor our very special members.

Free Education Program - NINLARO (Ixazomib) an oral treatment for patients who have received at least one prior treatment for Multiple Myeloma. When: March 14th 11:30 at the Doubletree by Hilton Atlanta-Buckhead (3342 Peachtree Road, NE, Atlanta, GA 30326) Featuring Elizabeth Carter, RN,BSN,OCN and A NINLARO Patient Ambassador. **To register dial 1-844-**

247-1641 or go to www.MyelomaEvent.com Friends and Family are welcome. Complimentary refreshments will be provided.

Multiple Myeloma Classes of Drugs/Therapies:

1. Proteasome Inhibitors - Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib
2. Immunomodulating - Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst
3. Monoclonal Antibodies - Daratumumab/Darzalex; Elotuzumab/Empliciti
4. Histone Deacetylase - Panobinostat/Farydak

*Newer agents - Farydak, Darzalex, Ninlaro, and Empliciti

Respectfully submitted by Paulette and Gail

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.