

December 2018

**Northside Multiple Myeloma Support Group Meeting
December 8, 2018**

The Northside group had their Holiday party on the second Saturday of December. It was well attended and lots of homemade food was enjoyed. We had a new member, Rod and his wife Kathy. Rod has been recently diagnosed and is scheduled for a transplant in early January. They had many questions and were able to enjoy the food while hearing about transplant experiences. Sharing the journey and addressing concerns is the heartbeat of the support groups and we welcomed the opportunity to make a difference. The attendees also brought new, unwrapped toys for the children who will be in the hospital at Christmas. After the meeting, 26 toys were delivered to Children's Healthcare of Atlanta.

There was a brief discussion about the upcoming meeting at Emory and the ASH videos available on the IMF web site -

<https://www.myeloma.org/> These videos include comments from myeloma experts about what they think are the most interesting topics at ASH. There are also videos of IMWG Conference with three experts discussing the latest news and trends in treatment of myeloma. Dr. Durie will be reviewing the Best of ASH on January 10. More information will be provided after the Holidays. Also, watch for news from the IMF Advocacy team about proposed changes to Medicare to reduce prescription costs by changing drug tiers and requirements for prior approval on prescriptions.

The Board of Directors gathered before the meeting to set some of the program schedule for next year. There will be several new programs along with returning favorites, so stay tuned.

We hope that everyone has a wonderful Holiday and all the best in the New Year.

Thanks for your continued support,
Nancy

Southside Multiple Myeloma Support Group Meeting
December 22, 2018

We used this last meeting of 2018 to address some of the possible gaps in our being the best patients, best caregivers, and best support we can be. We had a robust conversation about how we can improve in 2019.

Please include our members who are not feeling well over this holiday season in our thoughts and prayers. We thank Phillip D. for his holiday greeting wishing us a healthy holiday season, as we all remember his lovely wife, Ethel D.

Thank you once again to Pat C. and her congregation for their generous donation of \$3,000 to advance myeloma research and services. They have thought of us many years in their ministry of helping cancer patients. We thank Jameca for her thoughtfulness and hard work in creating a poster board with many of the resources we need over the course of myeloma treatment journey.

We discussed how we were doing in our efforts to support current, future, and potential members in their myeloma journey. Doris posed the question to member and her long-time friend, Louise. Louise has multiple sclerosis, not multiple myeloma. She attends the meetings because she always learns something new. The topics and information – whether biology, genetic, medical or social services – is usually something she can use. The other thing is that she finds the meetings and the people uplifting and positive, not sad. Her voice was important to our discussion because we want to be a positive experience for all concerned.

The basic questions of defining myeloma and clarifying treatment options were discussed. It is important to simplify terms and concepts to the extent we are able – and prepare our members to learn more about myeloma and to be the most informed participants they can be

in decision-making jointly with their providers. Gail brought in a flip chart with the thought of using more pictures to describe healthy cells and how they are impacted by myeloma – and how the medications work to control the myeloma. Many of those present thought this might still be too much detail for people who have not had biology since high school. There is also the question of how best to support our members who do not have a local support system– and to do this without invading their privacy. This was an issue brought forth by Carole. There are single women and mothers, as an example, who might be open to more communication from us. This is an area that needs our attention. In the meantime, we will all make more of an effort to call members and check in on a regular basis. We went on to discuss several other areas.

Discussion - 31,000 people will be diagnosed with myeloma this year. The CoMMPass Study (initiated by the Multiple Myeloma Research Foundation [MMRF]) results showed there are at least 12 different subtypes -- each defined by genetic mutations and other abnormalities that effect how the disease responds to specific treatments. There will be multiple relapses -- treatment is extremely challenging.

African-Americans are two to three times as likely as whites to be diagnosed with multiple myeloma. There are suggestions that the cause may be genetic. The good news is that when African-American patients have access to proper care, they often have a better treatment response and overall survival than European-Americans. Because treatment response in myeloma patients is associated with specific genetic subtypes of the cancer, participation in studies, including clinical trials, is crucial to development of more effective treatment strategies for African-Americans myeloma patients (Bionews, December 2018).

As a Support Group, we want to be able to be serve as a networking community to share new myeloma information, more learning opportunities with the myeloma specialists, more resources from pharmaceutical companies that make myeloma medications, financial information, and share personal experiences that could be of value to others. We all learn better through repetition and myeloma is no different. Information we share is included in a monthly newsletter that is joined with the Northside Myeloma Support Group and emailed by

Paulette or snail-mailed by Nancy. Hard copy newsletters are available at each monthly meeting.

Raise awareness about Multiple Myeloma: We commit to participating in 1-2 health-fair type events each year to spread the word about myeloma. We want to particularly meet African Americans who are the group at highest risk for myeloma. We have a limited number of members who can volunteer for these events, so we do not wish to over-commit. In one faith-based event this year, of more than 200 people we spoke to face-to-face, fewer than 10 people had heard of MM. Some thought it was melanoma (skin cancer). Of those 10, three were health care providers (HCP), and at least three of them had relatives who had been diagnosed with MM. We worked with LLS through several faith-based organization to raise awareness and share information about myeloma to hundreds of African Americans in the metro Atlanta area.

What kind of MM do you have? Is it IgG? IgA? IgM? Kappa or Lambda? Is it MGUS – or smoldering? Have you had cytogenetics done with your Bone Marrow Biopsy? What is your protein level? – your Light Chain levels? What should those values be? What therapy are you on and why? This is a conversation to have with your provider. We will do more to help members define their MM in the coming year.

What are the main MM therapies and what are the categories? The number of medications being researched and being approved by FDA continue to grow at an impressive rate. All the medications have at least 2 names by which they are called – I have no idea why. The basics of MM therapy is below. You will learn more about the therapies as you move through your MM journey (Source: <https://themmrf.org/multiple-myeloma/treatment-options/standard-treatments/>).

- Proteasome Inhibitors - Proteasomes are a staple of myeloma treatment. They are protein complexes that help cells—including cancer cells—dispose of old proteins so they can be replaced by newer versions. Proteasome inhibitors are drugs that prevent cancer cells from doing this. As the old proteins pile up, the cancer cells die. Proteasome inhibitors can be used throughout the course of MM

treatment. Velcade/Bortezomib, Kyprolis/Carfilzomib, and Ninlaro/Ixazomib) and

- Immunomodulating – also called *IMiDs*. This class of immunotherapy drugs is the mainstay of standard regimens used to treat multiple myeloma. IMiDs work by regulating certain aspects of the immune system. They can activate certain immune cells, prevent certain types of growth signals for cancer cells, and directly kill myeloma cells. This class can also be used throughout MM therapy. (Thalidomide, Lenalidomide/Revlimid, and Pomalidomide/Pomalyst).
 - Antibodies/Immunotherapy – Monoclonal antibodies enhance the cancer-fighting abilities of a patient’s own immune system by introducing antibodies into the body that target specific proteins found on multiple myeloma cells. (Daratumab/Darzalex, Elotuzumab/Empliciti), and Xgeva/Denosumab.
 - Chemotherapy drugs - Chemotherapy uses drugs to treat cancer by killing cells that are in the process of dividing. Because cancer cells grow and divide more frequently than most normal, healthy cells, they are affected more than normal cells. However, some healthy cells will be affected by chemotherapy as well. This is what causes side effects. Most [side effects can be prevented or lessened in severity](#). (e.g., Melphalan, Vincristine (Oncovin), Cyclophosphamide (Cytosan), Etoposide (VP-16), Doxorubicin (Adriamycin), and Liposomal doxorubicin (Doxil)
 - Steroids - Steroids are a staple of multiple myeloma treatment and are used at all stages of the disease. In high doses, steroids can kill multiple myeloma cells. They can also decrease inflammation by stopping white blood cells from flowing to the disease-affected areas, helping relieve pain and pressure (e.g. Dexamethasone)
- Other therapies are being studied in clinical trials, for which you may be asked to participate. CAR-T cell therapy is showing great promise. Venetoclax is in another category called BCL-2 inhibitor. Take your time to find out what all these terms mean to *your* myeloma.
- Right team and communication. We have witnessed much frustration and fear when there is poor communication with the HCP and their team. Oftentimes, this delayed effective treatment for the patient and heightened anxiety in

the patient and their family. At the same time, we note relative smooth treatment when the HCP team is prepared and well-trained for patient engagement. Your MM journey is likely to be a long one – try to establish an open relationship with them or seek help in finding another provider. It takes a team for optimal care coordination and experience – doctors, nurses, social workers, pharmacists, palliative care specialists, etc. You should feel confident in discussing anything, including finances and transportation, that might impact your therapy. Caregivers. We must continue to hold up the Caregivers in every way possible. They unselfishly volunteer to go on this journey with patients. We could not have the successful outcomes we do without the strong voices of caregivers.

Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com web site: ssatlanta.support.myeloma.org
Southside Meetings: 1/26/2019; 2/23/2019

Northside Meetings: 2/2/2019; 3/2/2019
Meets 11:00 AM on the 1st Saturday of each month
Shallowford Presbyterian Church
2375 Shallowford Rd.
Atlanta, GA 30345
mmsg.org, email: aammsg-2@comcast.net
For additional information, contact:
Nancy Bruno 404-374-9020;
Sandy Brown 470-514-5330

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.