

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Meeting

August 3, 2019

The group enjoyed a wonderful lunch at the 57<sup>th</sup> Fighter Group Restaurant. We all look forward to this annual event at a great location and time to connect with others. Takeda sponsored the luncheon and we thank John Schwarz for putting this together. It was a delightful day.

Prior to the luncheon, the AAMMSG board met to talk about program plans for the coming year. For the January 4, 2020 meeting, we will again be at Emory for an update on the ASH research. The doctors want more time allocated since they have so much to review and want to address all questions. We will have pastry and coffee to start the meeting and hold us over for a later lunch. Dr. Lonial wants to provide a tour of the Winship Research Lab, so pizza will be brought in before the tour. This promises to be most interesting, so mark your calendar. The board is also working on meetings for the rest of next year.

At the luncheon, each table was asked to discuss and propose topics for meetings next year. There were some excellent suggestions that will be considered for later next year. Thanks to all for the input.

In October, Dr. Craig Hofmeister will visit the group to talk about new research and answer questions. If you have anything in particular that you would like him to address, feel free to reply to this email with topic suggestions. We will have patient and caregiver sessions in November and our Holiday party in December.

The next meeting on September 7 will feature Kim Burney. She has a great energy and extensive experiences as a myeloma nurse.

Submitted by Nancy

## Southside Myeloma Support Group

August 24, 2019

**Next Meeting:** September 28, 2019. Topic: **Living with Multiple Myeloma.** Speaker: Marilyn Pritchard, R.N., MSN, OCN, Clinical Nurse Consultant-South Region, Celgene Corporation.

Doris opened the meeting with a moment of silence. There were no new members. **Patient Updates:** Ted was originally scheduled for a Stem Cell Transplant (SCT), but he and his medical team have taken a different path out of precaution related to other medical issues

encountered. Instead, he is now going through his first cycle of Darzalex, once every week. He is also taking Revlimid and Dex. His white blood cell counts (WBC) and other numbers have improved. Larry has been on a similar regimen with Dara/Rev/Dex for almost two years and is doing well. Newly diagnosed patient Tracey has taken advantage of getting two “second opinions.” He felt he needed more information before making final decisions on a treatment plan. He discussed his concerns during the last Support Group meeting and was encouraged to get a second opinion at the July Support Group meeting, and he followed through. He did get a different recommendation from myeloma specialist than from his original oncologist. – recommending exploring a SCT early in his treatment. Part of consideration is that his original oncologist is more convenient to him for transportation. We encourage all patients to get a second opinion. It is your right – and responsibility to achieve your best possible health outcomes. Research discoveries and treatment advances are so rapid in the Myeloma world that it can be difficult for the usual hematology-oncologist to stay current. Tracey’s Mom, Betty, was there to help support him and help navigate through this process. **Second opinions** are now an expected part of treatment. The researcher-clinicians at Emory Winship have expressed their willingness to partner with community physicians – so you can keep your doctor if you like them, and the location is more convenient for you. You can get recommendations on treatment medications, dosages, regimens, and available clinical trials. You can get the best treatment for your myeloma with the collaboration of oncologists and remain close to home for your regular visits. Your insurance provider should support you with this. It is not an unusual request. Ask for help from your Support Group to help you find your voice, if needed. Rehearse what you will say out loud. As evidence of changes in therapy, the drug Selinexor, which has been in clinical trials for years, was granted an accelerated approval on July 3, 2019, by the Food and Drug Administration (FDA). Selinexor (Karyopharm Therapeutics) in combination with dexamethasone for adult patients with relapsed or refractory multiple myeloma (RRMM) who have received at least four prior therapies and whose disease is refractory to at least two proteasome inhibitors (i.e., Velcade, Kyprolis, Ninlaro), at least two immunomodulatory agents (Thalidomide, Revlimid, and Pomalyst), and an anti-CD38 monoclonal antibody. Selinexor represents an entirely new class of drugs, called **SINE** (**S**elective **I**nhibitor of **N**uclear **E**xport). (Source: <https://www.fda.gov/drugs/resources-information-approved-drugs/fda-grants-accelerated-approval-selinexor-multiple-myeloma>). In 2015, there were an unprecedented four new drugs approved for Myeloma – Daratumumab(Darzalex), Elotuzumab (Empliciti), Ninlaro (Ixomab), and Panobinostat (Farydak). For very capable and qualified oncologists who are not myeloma specialists, all this fast-moving progress on drugs, optimal combinations and dosages, and which patients will do better on these regimens is a difficult task. Patients should also take advantage of available free seminars and webinars to help them better understand the landscape of multiple myeloma. It will seem so confusing and even overwhelming at first. Attend as many Support Group meetings as possible and learn from and with others who have experienced your similar journey for many years. You will be able to ask different questions.

Our speaker was Rebecca Wallace from the **Leukemia and Lymphoma Society** (LLS). Rebecca reviewed some of the programs available to Multiple Myeloma patients through **Patient Access** - 800.944.4572. There is the **First Connection Program** for those persons recently diagnosed. You can talk with someone who has lived with a myeloma diagnosis at least two years. **Financial Support** is available through many programs within the Patient access realm. For Myeloma patients, there is a one-time grant of \$100 for any patient who calls the number and provides their information. There are no other qualifications needed. The funds are

to help defray any cancer-related expenses. There are programs for **Co-pay Assistance**, **Travel Assistance**, and an **Urgent Need Program**, in addition to the one-time \$100 grant. She also shared a new LLS publication, "Advance Care Planning: Making Decisions about your Future." This publication can be of benefit to all of us, regardless of our disease status. We will have more discussion on this topic at a later meeting.

This year's **Light the Night** event is **Saturday, October 5 in Piedmont Park**. The event begins at 5:30 PM. Because more than 12,000 people are expected, please take MARTA, if possible. The better parking might be in the Grady High School parking lot for a \$10 fee. LLS continues to work on free parking for attendees. They are also looking at the possibility of having a Lyft Code related to the event. Rebecca will keep us informed. On that day, everyone will get a lantern – *Gold* to remember those who have passed away, *Red* for Caregivers, and *White* for Survivors. The walk is about 1 mile –at dusk so you see the lanterns "Light the night." There will be great fireworks at the end of the event. Bring your friends, family, and children for a great evening of music, food trucks, and entertainment. Bring your chairs and personal snacks, and maybe a shawl for the cool night air. Retail partners for the event include Northside Hospital, Starbucks, Burlington's, and Walgreens.

Rebecca shared that the "Secret Shopper" program will begin in September and go through December. Please call her if you wish to participate.

Southside Support Group has a fundraising page. Share the event on social media – on your Facebook page and on Twitter to help raise funds for Blood cancers, including myeloma. Direct them to our page for their donations. Our goal this year is @2,500. Everyone gets T-shirts, a lantern, and a meal. Our team raised \$2,000 last year. LLS raised \$1.8 million. We should send a list of those who plan to attend – and identify those who are patients. Please make a donation, if possible. Ask your friends, co-workers, and family to make a donation to control blood cancers. The amount is not important. Many of us benefit from the LLS programs each year. If you need assistance to make a donation, let us know. You can contribute online, or if you need assistance, call - 800.944.4572 **OR** go to

<https://pages.lls.org/ltn/ga/atlanta19/southsidemultimyelomasupportgroup>

Doris shared some of her experiences at the IMF Support Group Leaders' meeting in Dallas in July. She got to walk the red carpet with others – and received a Certificate honoring the 15 years for the Southside Atlanta Support Group's existence – 20 years for the Atlanta Area Support Group. She was encouraged by the focus on inclusivity and focus on increasing awareness, treatment quality, and treatment outcomes for African Americans. Doris also encouraged members in the group to volunteer for activities and leadership in the Support Group. Currently, Southside has three co-leaders with different foci– Doris (point person), Paulette (focus on communication), and Gail (focus on meeting minutes). Each of the Support Groups received a new IPAD to facilitate sharing myeloma information during Group meetings.

**Respectfully submitted, Gail**