

December 2015 Northside Meeting Notes

December meeting was our annual Holiday Party. The great cooks in our group brought a wonderful variety of food for all of us to enjoy. Many thanks to the cooks, as well as those who helped set up and clean up.

The members brought toys for children who are in the hospital at Christmas. These went to Children's Healthcare of Atlanta (CHOA), next to Winship. Nancy took 21 unwrapped toys to the hospital. The group got a nice Thank You note from CHOA for our donation. Thanks to all who contributed.

Nancy discussed the big news about three new drugs being approved by the FDA in November. This is an unprecedented sequence of approvals for just one month. The drugs were: Daratumumab approved as Darzalex; Ixazomib approved as Ninlaro; and Elotuzumab approved as Empliciti. Darzalex and Empliciti are monoclonal antibodies that have shown great results with minimal side effects. These two drugs are not considered to be "chemo" and are called "biologic agents" that allow the patient's immune system to recognize the cancer and attack it. Ninlaro is the next generation of Velcade, but in a once per week pill. This is excellent news for quality of life issues so the patient does not need to go to the clinic weekly. All three drugs were approved for relapsed MM patients. They can be prescribed after a patient no longer responds to another treatment. Further trials will evaluate these treatments for newly diagnosed patients. This is exciting news to know that there are so many new options.

Updates – **Nancy Y.** is experiencing an increase in counts after five years of remission from a stem cell transplant. She is going on a clinical trial with Elotuzumab and Revlimid. She has some challenges with Medicare in regard to the Revlimid and would like to talk to someone who has worked through the Medicare issues for coverage of Revlimid. **Beth** said she will call Nancy. **Barbara** said that RevAssist helps with Revlimid co-pays and may also help with Kyprolis. Others recommended the Chronic Disease Fund or LLS for assistance. **Dana** is now on Pomalyst after a year and a half on Daratumumab. Another patient at the meeting is on Pomalyst with Kyprolis and has no side effects. **Ernestine** is on Pomalyst and Dex, but is not doing well. She is still on dialysis.

Prior to the meeting, the Board of Directors met to plan programs for 2016. Here are the plans for the first part of the year:

- January – ASH review at Winship, January 16. See details below.
- February – Open discussion and Meet Your Members
- March – Patient and Caregiver sessions along with Myeloma Awareness Month
- April – Dentist or Physical Therapist familiar with MM
- May – Dr. Lonial or Charise Gleason
- Other programs under consideration
 - Medicare representative
 - Eldercare attorney
 - Nutritionist

Upcoming Event – January 2016 meeting will be held at 9:30 AM on January 16 and there will be no meeting on the first Saturday. RSVP for the program will be needed since seating is limited and breakfast will be provided. We are also planning for lunch at Athens Pizza, just a couple of miles from the meeting. Attendance count will also be needed for lunch reservations.

Mark your calendars for the IMF conference call about the research and information discussed at ASH. Although we will be at Winship for their update, much of the news is complicated. The best way to understand options and get familiar with the new terminology is to hear it multiple times from different perspectives. The IMF call is Thursday, January 7, at 7:00 PM eastern. For more information and to register, go to <http://bestofash2015.myeloma.org>

Submitted by Nancy

Southside Multiple Myeloma Support Group

Meeting Minutes December 26, 2015

Doris opened the meeting and welcomed members who were present on this day after Christmas. There were 13 present. The January 23rd meeting will feature Nancy Bruno, IMF Support Group Director. She will discuss a patient checklist for long term treatment of MM and awareness of other health issues.

Myeloma Awareness Month

Myeloma Awareness month (MAM) is March. **Gail** outlined projects we agreed to pursue to recognize the month and promote awareness of myeloma. The Support Group viewed the video from the “Ask. Dr. Durie” series. In this video he discussed four IMF initiatives to raise awareness about Myeloma in the African American community. We will support those initiatives in our awareness campaign in Atlanta. Our efforts will include: **(1)** distributing myeloma information to churches to be placed in church announcements; **(2)** members should start giving out the Atlanta Area MM support group brochures in clinics and doctor offices; and **(3)** work with TV and radio media. Shaunya Chavis Rucker, Broadcast and Cable Director for Fulton County’s Public Government Television Station, FGTV and 11 Alive contract communication specialist, will assist to gain leverage with media to promote awareness of MM. Doris again suggested members should take opportunities to tell their myeloma story to persons they don’t know (e.g., senior citizen meetings, community social and civic meetings, medical waiting rooms)—this will help spread myeloma information. Tell your story. We will place **Patt’s** story on our website for March. Be sure to take brochures with you to remind you of your commitment to ‘spread the word’ about myeloma. **Alma** will continue to lead MM Action/Awareness efforts. We can also place messages in local newspapers who previously published information on MAM.

Our efforts to reach congregations will focus on member’s churches. Members submitted the names of six congregations where we will start. Additionally, we will try to get on the agenda of Concerned Black Clergy (CBC), an interdenominational group of pastors and community members that meets every Monday morning. **Vermell**, who was recently honored by CBC will help us with that agenda. We also asked for potential speakers from the group to address congregations and media requests for MAM. **Kimberly, Doris, Vermell,** and **Gail** have volunteered so far to be spokespersons. We need to shape our messaging for MAM to be in alignment with IMF and LLS, with emphasis on African Americans.

We discussed the need to know how to dispose safely of unused medications. One resource is the poison control center of County Health Departments. Another location is Hart’s Pharmacy in Riverdale.

We encourage members to keep members who are not in attendance in your thoughts and prayers.

Member Updates: **Harold** says he is still suffering from effects of neuropathy and Parkinson’s disease. **Valerie** says she is fantastic, she says her energy is better when she is moving, so she tries not to sit for too long, and to increase physical activity. She is still on maintenance 10mg of Rev daily after her Stem cell transplant. **Patt** says she is still in remission and feeling good except for neuropathy—says she is also better when moving. Patt is still on 5 mg Revlimid -- 21 days on; 7 days off. Says she had two mild cases of shingles before she was diagnosed with myeloma (at age 40 and age 45). **Selina** is doing alright—she says she is 5 years out from Stem Cell Transplant. She experiences excessive perspiration and shoulder pain. She is being referred to neurologist and PT. Tests showed a secondary malignancy that has since been determined to be “thrush.” **Kim** says she has been in remission since 2009 and on no medication. She said she had her transplant at Northside and appreciated being able to be in her own bed at night. She said she was ill for a short time and was hospitalized for 3days. Kim says she has some osteopenia (bone loss) but walks 3 miles per day. She does have pain in left leg. **Pat** is still in remission—since 2005. She is receiving care at Georgia Cancer Care in Fayetteville and loves her doctor. She had **tandem stem cell transplants** as an outpatient at Northside and said it went very well. She says she is appreciative for the care there. She has had family challenges over the past few months. Two very close relatives passed away one at 103 the other at 100. She is doing well physically. **Alma** says she is doing okay, she suggested MM patients on chemo should pay attention to **adrenal gland function** – that Dex (Steroids) might impact adrenal function. She has been seeing an endocrinologist for many years; her endocrinologist is now at Emory; she says she has spent a lot of time with her during recent appointments understanding and researching her MM treatment regimen. She says she was advised that steroid treatment regimen should be withdrawn slowly (not quit cold turkey) to avoid damage to the adrenal gland. Group suggested we have an endocrinologist speak during one of our support group meetings. She also advised patients to keep hard copies or electronic copies of medical records. Specialists may need to view history of lab results to provide best support. **Janet** says she was diagnosed in 2012 with MM and had a stem cell transplant that same year. She was diagnosed with a secondary cancer, Lymphoma, in 2013. She is no longer on REV – also developed rashes. She says she also developed toxicity to Velcade. Janet says she has been scheduled for a PET scan – there are too many “little things” going on, and she is hopeful the PET scan will help explain some of it. Her physician is not supportive of the PET scan so far – she wants to know the disadvantages of having the scan. She has also experienced extreme sweating that she thinks may be from Revlimid. Two others said they have experienced the

abnormal sweating. She is currently on Pomalyst and Dex. **Gail** reported a rise in her M-protein and she is considering her options. Gail says she will be studying some reports from ASH to make some decisions on next treatment regimen. So far **Doris's** 75th Birthday celebration has raised **\$2,945** (and counting) to benefit International Myeloma Foundation (IMF). Her birthday party was a beautiful event and very well attended. Congratulations Doris.

Announcements

1. **Cancer Care Workshops** Listen in by telephone or online as leading experts in oncology provides up-to-dated information about cancer-related issues in one-hour workshops. Go to www.CancerCare.org/connect to register.

Workshops are:

- **Update from the 2015 ASH Annual Meeting.** Thursday, January 14, 2016, 1:30 – 2:30 PM, ET
- **Nutrition and Healthy Eating During and After Cancer Treatments.** Monday, Feb 1, 2016 1:30 PM, ET.
- **Taking pills on schedule.** Wed, Feb 10, 2016, 1:30 ET.
- **Progress in the Treatment of Multiple Myeloma.** Thur, April 14, 2016, 1:30 PM, ET
- **Coping with the Stresses of Caregiving When Your Loved One Has Multiple Myeloma.** Thur, April 28, 2016, 1:30 PM, ET

2. **IMF-Patient and Family Seminar** Feb 26 - 27, Boca Raton, Florida Register at www.BocaRaton2016.myeloma.org or 1 800-452-2873 (\$60.00)

Alma closed the meeting by "Don't put a question mark where there should be a period. When something is over, move on to the next chapter." -- Joel Osteen Ministries

Respectfully submitted by Gail and Paulette