

## July 2, 2016 Northside Meeting

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Happy summer to everyone! We had 28 attendees, including several new members.

### Support group business:

Macy's Shop For a Cause is coming up at the end of August. This is a great fundraiser for us and benefits shoppers as well! Here is how it works: the support group has available shopping passes that cost \$5 each. The savings passes can be used at the annual Shop For a Cause 3-day event to be held August 26-28, 2016. The passes are good for a 25% discount throughout the store on various regular, sale, and clearance merchandise and 10% in certain departments (electrics/electronics, watches, furniture, mattresses, and rugs/floor coverings). The passes are only good for those specific days and in-store only (not online). But for \$5, this is a great deal! Passes will be available for purchase at the August meeting.

### Educational opportunities:

When it comes to being an active partner in your or your loved one's myeloma care, education is power! This is especially important right now, with all of the new therapies coming out. There are a lot of great educational resources online. We encourage you to visit the "IMF TV" section of the International Myeloma Foundation, where you can view webcasts from medical meetings, patient and family seminars, and more. To see these videos, go to [www.myeloma.org](http://www.myeloma.org) and click the IMF TV tab on the top menu bar.

### Meeting recap:

This meeting, we enjoyed an open discussion where members could share updates, ask questions, and share information. Here are a few highlights:

- We have an Olympian among us! **Loretta** participated in the Senior Olympics and brought home several medals. She encouraged everyone to get out there and move. Loretta plans to continue participating in the Senior Olympics for years and encouraged others to join her.
- There is some confusion regarding what Medicare will cover in terms of newer regimens. Medicare *should cover* off-label regimens of FDA-approved drugs. As long as your doctor writes the prescription for it, Medicare should cover it.
- Minimal residual disease (MRD) testing is an important emerging concept in myeloma. This is a more sensitive method that can detect myeloma in people who already have a complete response. The idea is that attaining even deeper responses (called "MRD-negative") is associated with better outcomes. MRD testing is becoming standard in some blood cancers and is now being evaluated in myeloma. Some patients with myeloma may be eligible for MRD testing at bone marrow biopsies. Ask your doctor if it is appropriate for you.
- Several new members have joined us. **Amy** was diagnosed in March after a delayed diagnosis. By the time she was diagnosed, she had severe anemia and kidney failure. Amy is new to Atlanta and is about to start treatment. **Joe** was diagnosed in April. He is preparing for an autologous stem cell transplant in August. **Kyle** was diagnosed with smoldering myeloma in 2005 that has progressed to multiple myeloma. He recently started the standard induction therapy of lenalidomide (Revlimid®), bortezomib (Velcade®), and dexamethasone (RVD)
- Some of our long-time members gave some tips:
  - A good network is important. Reach out to others for support.
  - In some patients, an effective treatment can cause tumor site pain

If something seems "off" and you aren't happy with what your doctor is saying, seek a second opinion

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## Southside Multiple Myeloma Support Group July 23, 2016

**Doris** called the meeting to order at 10:05 a.m. and asked everyone to bow heads for a few moments of silent meditation. There were 15 persons in attendance.

We welcomed two new members - **Teonna (P)** and her husband **Ilksen**. They learned of the support group from a flyer they saw at Emory Clinic where she is being treated.

Our next meeting will be held on August 27<sup>th</sup> and will feature **R. Donald Harvey, PharmD, BCOP, FCCP, FHOA, Associate Professor, Hematology/Medical Oncology and Pharmacology, Emory University School of Medicine, Winship Cancer Institute**. His topic will be: **“Optimizing Drug Use in People Living with Myeloma”** Dr. Harvey will talk about drugs used in myeloma treatment, and will also discuss how drugs for comorbid conditions (e.g., diabetes and high blood pressure) might interact with cancer drugs. **Bring your questions and concerns for this well-informed pharmacist.**

**Guest Speaker: Ms. Shannon Reilly, MS, ACNP Clinical Nurse of Celgene Corporation.** Celgene is the company that makes of Thalidomide, Revlimid, and Pomalyst. These drugs are in a class called immunomodulatory or IMiDs. Also, Celgene is responsible for the development of a booklet called, **Standing in the Gaap: for African Americans living with Myeloma**. This publication was provided to us earlier this year by the Dr. Leon Bernal, MM specialist at Grady Memorial Hospital. If you missed getting your copy, be sure to get one from Doris.

Members were asked at June Meeting to bring their lab reports from 3 to 4 oncologists' visits so **Shannon** could help with interpreting and understanding values. After reviewing lab reports Shannon made recommendations: One practical recommendation was to get two pill boxes-- one a **bright color** for your **cancer medications** and a **clear box** for **calcium, vitamins, etc**. Mark your bottles to be sure you are not duplicating your medication. **Shannon** distributed notebooks for all members and provided the additional considerations: (1) When you go to the doctor, be sure to get a copy of your lab reports and put them in your notebook (2) Continue to see your primary provider and have all recommended health checks; be sure to watch for kidney function. (One member (**Gloria**) reported she was on dialysis for four months but is doing better). (3) After Stem Cell Transplant make sure to get **all immunizations** again to enhance the immune system which is destroyed with the high dose of chemotherapy used in SCT.

#### **Member Updates**

**Geraldine's** MM numbers are decreasing with Pomalyst. **Larry** is in stringent complete remission. **Doris** is taking Revlimid; her para protein numbers are declining also; IMF reports **Doris** raised **\$4,600** for her November, 2015 birthday celebration (**WONDERFUL, DORIS!!**). Doris thanks all who donated IMF and supported her in this effort. **Harold** is in remission; but, has neuropathy and Parkinson. He is taking Gabapentin to ease the discomfort. **Darcell** was diagnosed in 2012 and in 2013 she had stem cell transplant and is now in remission. **Teonna** is taking Alendronate. This is in the group of medicines like Aredia and Zometa called bisphosphonates. It alters the cycle of bone formation and breakdown in the body. Alendronate slows bone loss while increasing bone-mass, which may prevent bone fractures. **Teonna** reported her doctor is using Alendronate instead of Zometa due to kidney problem. **Patt** moved to California on July 28th, we will miss her and wish her the best. Patt was a faithful member of the support group for several years. On a sad note, **Ozzie** passed away on July 13<sup>th</sup>; **Ozzie** and **Sheryl** were featured in a marketing publication developed by Bristol-Myers Squibb (makers of Empliciti (Elotuzumab)). Our prayers and thoughts are with Sheryl and their family. On the day of this meeting, **Vermell** and **Deborah** are attending the Leukemia/Lymphoma Blood Cancer Conference at the Cobb Galleria Center. **Gail** and **Paulette** are attending the International Myeloma Foundation Support Group Leader's Summit in Dallas, Texas.

#### **Announcements/Upcoming Meetings**

**“Shop for a Cause”:** **Paulette** has tickets for Shop for a Cause, please support this effort this is the only fundraiser we have. Passes can be used Friday through Saturday **August 26th - 28th** you might be the lucky one to win the \$500.00 gift card. Remember all the money collected goes to the support group. It has been our largest fund raiser over the years. Contact Paulette for Macy's passes (470-428-2988).

**LLS – Light the Night** – RSVP – 404.720.7826 Join us for the 2016 Georgia Light the Night Walks. Light The Night is a nationwide evening fundraising walk to celebrate and commemorate lives touched by blood cancer. Saturday October 8, 2016 04:30 PM EST Centennial Olympic Park at 265 Park Avenue West NW, Atlanta, GA 30313

**LLS. Oral Therapies in Myeloma.** Medication Adherence... <http://www.lls.org/patient-education-videos/oral-therapies-in-myeloma-medication-adherence>

**Telephone Support Groups.** CancerCare's telephone and online support groups are free and professionally facilitated for people living with cancer and their loved ones. To join a telephone support group, call 1-800-813-HOPE (4673). To join an online support group, register at [www.cancercare.org](http://www.cancercare.org)

**IMF - Smart Patients** is an online peer-to-peer program – get daily emails from patients and caregivers regarding their MM treatment journey. They share experiences from preparation for SCT to hints on increasing energy to discussions on new medications, side effects, and more. <http://www.smartpatients.com/imf>

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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.