

November 2015 Northside Meeting Notes

Business & Announcements

Tom Lozano led the meeting and approximately 40 people attended. We welcomed one new member, **George**, who had been diagnosed just 3 days prior. George was diagnosed after he noticed a suspicious lump that prompted further testing. He found out about the support group from someone he met at Winship. This is a great reminder about how we can reach out to others to tell them about the support group and how valuable it is.

Speaking of reaching out to others, the Outreach Committee is looking for new members. These are volunteers who make phone calls to support group members who have not attended a meeting for a while, to check in with them and see how they are doing. This is such an important job, and it doesn't take much time. If you are interested in helping, please contact Sandy Brown at 470-514-5330

In other notes, the Winship 5K **Lorymac Team**, led by **Ed** and **Lory**, raised over \$40,000 for the Winship Cancer Center. Congratulations on this amazing accomplishment!!

The December meeting will be our Holiday Party on Saturday, December 5, at 11:00 AM. Please bring a dish to share and an unwrapped toy for the children in the hospital at Christmas. These will be taken to Children's Hospital of Atlanta, next to Winship Cancer Institute.

Discussion & Member Updates

A topic of great interest and discussion at this month's meeting was the issue of healthcare cost, especially the differences in copays and insurance premiums among different insurance companies and plans. Certainly, this is an issue that touches all of us. There is a wide range of copays that people pay, especially for specialty drugs like Revlimid. For those on Medicare, or soon to be on Medicare, attendees suggested carefully shopping for your Part D plan to find what might best fit your situation.

Several attendees provided updates: **Frank**, who has had myeloma for 7 years, is now scheduling his first transplant. **Jackie** was in attendance after just recently having completed an autologous transplant.

Group Discussions

This month, caregivers and patients split into separate discussions.

Thank you to **Dana D.** who led the patient discussion. The group discussed how they dealt with fear and worry, remission, recurrence, changes in therapy, and pain. Also discussed was how having the disease has prompted changes in positive ways and what we can offer to others because of what we have learned from these challenges.

Thank you to **Ed** who led the caregiver discussion. Attendees discussed ways to best support your loved one while taking care of yourself. Like the patient group, caregivers also noted the potential for positive changes as a result of the diagnosis, including an opportunity for other family members to step up and contribute. It was also noted that caregivers should not be hesitant to call the clinic in case of a question or concern about your loved one; it is best to go ahead and call and get those questions answered.

Submitted by Mindy T.

Southside Multiple Myeloma Support Group Meeting Minutes November 28, 2015

Doris opened the meeting with a moment of silence. We asked for special prayers for **Lonnie** who was moved to hospice this past week* and for **Elizabeth**, who is scheduled to undergo a stem cell transplant (SCT) on December 18.

We welcomed one new member, **Gloria**. She was invited by Alma. Gloria was diagnosed with MM in 2009. Initially, Gloria was misdiagnosed, and after almost a year of complaints of unusual fatigue, she was in kidney failure, before

successful diagnosis. After a SCT in 2009, she is in remission, taking Revlimid for maintenance, and is doing well. **Kimberly** has continued to contact SG members, and has gotten mostly supportive feedback.

The agenda for the day was to focus on issues of concern for patients, family members, caregivers, and friends. One issue of note was that in 2015, there were four new drugs approved by FDA for Multiple Myeloma (MM) – three of those drugs in November. All drugs are for patients who have had at least one prior therapy – not for new patients. The first is **Farydak** - aka Panobinostat by Novartis. It is combined with Velcade and Dex; for patients with at least 2 prior therapies. **Darzalex**, aka Daratumumab by Janssen. This drug received accelerated approval as a single agent drug for patients who have had at least 3 prior therapies. It is the first monoclonal antibody and is delivered by infusion. Darzalex produced excellent remissions for relapsed and refractory myeloma in clinical trials. **Nilaro**, aka Ixazomib by Takeda. This is an oral once per week therapy -- for patients with at least one prior therapy. This is the first oral proteasome inhibitor (in class with Velcade) -, and is used in combination with Revlimid and Dex. According to Dr. Durie, Nilaro will be used in Black Swan Research Initiative® (BSRI) clinical trial. Finally, **Empliciti**, aka Elotuzumab by Bristol-Myers Squibb, is a different monoclonal antibody. Along with Darzalex, this is a new class of drugs that are not considered chemo, but are biologic agents that allow the patient's immune system to recognize the cancer and attack it. They also have very low side effects. This has been an exciting year for MM patients with so many new options to control this disease for the longer term. It is important for everyone to become familiar with these drugs. Take time to participate in conference calls where doctors explain the treatments.

For those who might want to join the IMF Advocacy team – and monthly meetings by phone, the focus is on the cost of cancer care and the 'financial toxicity' of cancer. We remind everyone to participate when asked to contact our legislators when laws are pending to help to address this issue.

Doris is celebrating her 75th birthday. In lieu of gifts, she has asked those who desire to donate to the IMF. She has set a very ambitious goal of \$5,000. You can submit your tax-deductible donation directly to Doris (please make checks payable to the IMF – Doris' name in purpose line)– or submit online at this link: <https://myeloma.donordrive.com/index.cfm?fuseaction=donate.event&eventID=550>.

Upcoming MM Educational opportunities.

- The annual ASH meeting (American Society for Hematology) is in December. Please register to hear MM researchers from across the globe engage in debates on the best treatment for MM, e.g., to treat smoldering MM or just watch it closely; what are advantages/disadvantages of ASCT; etc. Most IMF webinars can be found in the archives (www.myeloma.org) to view at your leisure. **Best Options for Treatment - Point-Counterpoint - December 4. 12:30-3PM. To register:** <https://online.myeloma.org/netcommunity/ash2015>.
- Association of Community Cancer Centers Webinar Series - <http://www.accc-cancer.org/resources/MultipleMyeloma-Webinars.asp>. **Psychosocial Support and Financing Cancer Care - November 18 and Patient Education and Engagement - December 1 - 12:15 - 1PM.**
- January 16, 2016. **Updates from ASH Meeting.** Emory Winship Cancer Center. Clifton Road. 9:00 AM.
- December 26, 2015. The agenda for our meeting will be a focus on member concerns.
- January 7, 7:00 PM, IMF conference call with Dr. Durie on the Best of ASH. Sign up at <http://bestofash2015.myeloma.org> .

*Lonnie passed away on Tuesday, December 1 from complications of lung cancer. His request was that as many Support Group members as possible attend his services in Cordele, GA. Six members were able to attend.

Respectfully submitted by Gail