

March 2017

**Northside Multiple Myeloma Support Group Meeting  
March 4, 2017**

**Meeting Notes**

Many thanks to Beth and Sandy for providing refreshments. The good food is appreciated and enhances the conversations at the meeting.

**Business**

**March is Myeloma Action Month** and there is a wide variety of actions available for everyone to make a difference this month. The IMF has provided business cards for the group. Each member is encouraged to take a few cards and keep them in your purse or pocket. When you are at a doctor's office or out with friends, have them ready when someone mentions Myeloma to let them know about our group and the information that we share. Other actions are on the web page: [www.mam.myeloma.org](http://www.mam.myeloma.org). Scroll down on the home page for a list and links to actions including: letter to doctors about early diagnosis; template for a new article in a local paper; logo and banners for your Facebook page; stories of others taking action; easy ways to donate to research – Donate a Photo or Music for Myeloma. Be sure to submit a short paragraph when you take action.

Other Myeloma programs –

**Discussion**

After the business meeting, the group split into two sessions, patients and caregivers, for more targeted discussions.

**Patients** – Carolyn led the patient discussion. She went around the room to get status on each patient. There was a variety of stories about diagnosis and treatment issues. Several lost significant height before diagnosis. Several have high risks genetics. Two are preparing for transplant in the coming months. Two are on Ninlaro maintenance with minimal side effects. Several are on Rev maintenance with side effects ranging from peripheral neuropathy to heart issues. A discussion on peripheral neuropathy revealed problem with pain in the shower. One patient wears shower shoes and another puts a thick towel on the shower floor. Two patients were at the meeting after having a transplant in December. They both felt well enough to be at the meeting and share their journey. Two people told their stories of being in remission, but then a stressful event in their lives brought the Myeloma back. We all acknowledged that stress could be harmful, especially for MM patients. The group recognized that Myeloma is so different in each patient. Sharing stories helps to understand the differences and similarities.

**Caregivers** – The Caregiver session was attended by 15 individuals. We introduced ourselves with our first name and our relationship to our patient and all were spouses.

We had one participant who was a patient but we welcomed her as she was not only a patient but also a caregiver to others in her family. We also had two former caregivers who had lost their patients to MM but were with us to share their experiences and offer support and they contributed greatly to the discussion.

Questions were asked about whether/when/how to let go of trying to change or control the decisions being made by our patients. Some were distressed by their patient's obsession with

their blood work and others were distressed by their patient's decision to not even look at their blood work. In the end we all decided we must let the patient be their own version of themselves as patients and we should "let it go", support them in their decisions and have our OWN list of questions for the doctors during the visits. Most accompanied their patients for doctor visits.

There was an effort to focus the discussion more on care of the caregiver but the issues relative to their patients weighed heavily on them so there was much discussion about coping. Finally we did discuss taking plenty of time for ourselves, pursuing our friendships and taking time away from our patients when circumstances allowed and all agreed that we should do that. We all need time to be alone, patients *and* caregivers.

We had two very new participants who were still in the extreme crisis mode of caregiving. The dialogue with them was passionate and emotional. We offered them prodigious support and informed them of resources, both financial and otherwise, of which we had all availed ourselves. Emails were shared as well as phone numbers and offers of actual physical help if needed. We encouraged them to return to the support group whenever they could.

An excellent article by a Myeloma Beacon writer [patient] titled "The Art of Caregiving" was passed out to all participants. We ended our session with a 3 minute relaxation meditation ["I am here/I am calm"] lead by Molly, our facilitator.

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### **Southside Multiple Myeloma Support Group Meeting Saturday, March 25, 2017**

#### Meeting Notes

Doris led the group in a moment of silence. There were 15 present.

Speaker for our **April 22<sup>nd</sup>** meeting will be **Victoria Collier, Certified Elder Law Attorney**. She will address the following topics: Paying for Long Term Care, Don't Go Broke in a Nursing Home, Estate Planning & Elder Law and more. Bring your questions. Our meeting will be held at the usual location—the community room on the second floor of Macy's Department store at Greenbriar Mall 10am-12:00.

We had one new member, **Deirdra** who was diagnosed in March 2016 at the age of 48. She says she has always been very conscious of her health and worked out regularly. Deirdra had lower back pain and went to other emergency rooms twice before the Atlanta Medical Center emergency room ran a series of tests resulting in the diagnosis of Multiple Myeloma. Deirdra is in treatment at Winship and had a stem cell transplant in August, 2016 and she is currently on a Pomalyst regimen. She is a medical records professional requiring her to sit—something she can no longer do for long periods; but she has difficulty *staying still*. She is currently on disability – against her desire. Her mother and 18-year-old daughter are her caregivers.

We had a successful Myeloma Awareness Month (MAM). Several area churches carried the message of MM. Pat's church made a significant contribution to IMF earlier this year. Portia shared the message with her congregation at Edgefield Baptist Church. LLS and their new faith-

based program had physicians address the congregation at Cascade Road Lutheran Church and Cascade United Methodist Church's 8AM and 11AM. More than 1000 people heard the MM message. Others wore their MAM pins and spread the word one-to-one.

**Gail** reviewed the IMF-sponsored webinar "**Living Well with Myeloma: Novel Agents and Clinical Trials 2017: What Patients and Caregivers Need to Know**" featuring **Craig Emmitt Cole, MD**, Department of Internal Medicine, Division of Hematology/Oncology, University of Michigan Comprehensive Cancer Center, Multiple Myeloma and Plasma Cell Dyscrasias Clinic. The webinar was first offered on Thursday, April 23<sup>rd</sup>. Dr. Cole reviewed the International Myeloma Working Group definitions for the various responses to treatment: **Complete Response (CR)**, **Very Good Partial Response (VGPR)**, **Partial Response (PR)** and **Stable Disease (SD)**. He also discussed mechanism of action of two new Novel agents: **BCL-2 and Check Point Inhibitors** (BCL-2 has been proven particularly effective in the treatment of Myeloma disease with Chromosome 11 and 14 involvement). There is also much discussion regarding clinical trials and the importance of participation. To view the entire webinar go to <https://www.myeloma.org/event/living-well-myeloma-novel-agents-clinical-trials-2017>. The webinar is about 60 minutes with questions and answers; and we can engage as much as desired.

### **Member Updates**

**Joyce** was diagnosed in 2012 and had a tandem stem cell transplants in 2013 at Northside Hospital. She had a re-staging last month consisting of bone biopsy, blood work and urine analysis. Her para protein level is .07, so she is being monitored, not on medication. She says her doctor suggests if her para protein gets to 1.00 they will begin treatment.

**Larry** was diagnosed with MM in October 2012 after a car accident; he had a stem cell transplant in June 2016 and is now on Daratumumab, Revlimid, and Zometa. He was going to clinic every other week for 6 hours for infusion. He is now retired at age 62. Larry shared that last month he was hospitalized for a week with pneumonia and sepsis. He said he had fever and his wife asked him to go to the emergency room. When he finally did he had developed pneumonia. **Larry** says pay attention to your body and symptoms and go to the doctor when you feel changes – *and "guys, pay attention to your wife." The pollen creates real problems for him and others in the group.*

**Sheryl** is the caregiver of our Ozzie who passed away from a stroke last year. He was diagnosed with MM in August of 2007 and went into remission in 2010. When his numbers began to rise he started treatment again. After novel treatments did not control his MM he became a part of the Empliciti (Bristol Myers Squibb) clinical trial. **Donald** was diagnosed with MM in March, 2015, he says he got sick with back pain and was hospitalized. In April 2015 he had a stem cell transplant and says his doctor says things look good. He says he still has some back pain.

**Frances and Marie** were present as supporters of Doris.

**Gail** was diagnosed in July 2008, she went through standard treatment of Revlimid, Velcade and Dexamethasone; then had a stem cell transplant in December 2008. In spring of 2009 she was determined to be in "near complete remission." During remission she had quarterly infusions of Aredia, a bisphosphonate. In 2016 her numbers began to slowly rise and she began treatment in May with an oral regimen consisting of Ninlaro (4mg) Pomalyst (4mg)

Dexamethasone (40 mg/week). After noticing swelling in hands and feet, and increased neuropathy **Gail's** Ninlaro was reduced to 3mg and the Dexamethasone was first reduced to 12 mg then 4 mg. Gail goes to the clinic twice a month; once to give labs and then to visit with her oncologist to obtain results of the lab work.

**Pat** was diagnosed in 2004; went through treatment with Thalidomide which placed her in remission. She then had a tandem stem cell transplant and has been in remission since. She is on quarterly infusions of Zometa, has some neuropathy but is not treated with prescription medication.

**Darcel** was diagnosed in September 2012 after breaking her collarbone. She had a stem cell transplant in January 2013. She takes acyclovir to prevent shingles but is now in remission. She monitors her lab reports during annual visits to Dr. Kaufman at Winship.

**Ethel** was diagnosed in February 2015 and had a stem cell transplant on July 20<sup>th</sup> 2015. She gets Zometa quarterly, has blood labs monthly and urine every 2months. She, and her caregiver, Phillip, were encouraged to find out why 24- hour urine collections are so frequent. She was recently in a car accident and has back pain. She is in treatment at Winship and sees Dr. Lonial for treatment.

**Doris** was diagnosed in 2004 during her routine physical examination because there was too much protein in her urine. She found Dr. Heffner at Emory. She had bone biopsies and other tests. Doris was initially treated with Thalidomide, harvested her cells but has not had a stem cell transplant. She currently is 15 mg Revlimid and 2.5 mg Dexamethasone.

**Portia** is a caregiver for the group and has been a part of the group since its inception.

**Selina** was diagnosed in 2010 when they found bone lesions in her legs, ribs, and Selina had the Kyphoplasty\* procedure to place cement in her bones to treat vertebral compression fractures. She is not on any medication at this time.

**Note:** \***Vertebroplasty & Kyphoplasty** are minimally invasive procedures used to treat vertebral compression fractures (VCF) of the spine. In Myeloma, when the vertebra collapses, the nerves are pinched, which causes pain. A balloon is inserted into the collapsed vertebra and inflated. This will raise the bone and relieve the pressure on the nerves. Then cement is injected into the bone to hold it up. This is a quick procedure (20 minutes) that can provide relief for MM patients.

Thoughts and Prayers are with Mr. Harold Pullen at Pruitt Heath Center 7560 Butner Road, Fairburn, GA 30213. 770-306-7878 - Please call before visits; Geraldine is off all medications; Janice has had knee surgery; Vena is having challenges – send prayers; Andrew hopes to attend a meeting soon.

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

- **IMF Advocacy:** The Cancer Drug Parity Act has been reintroduced in the U.S. House of Representatives by Congressmen Brian Higgins (D-NY) and Leonard Lance (R-NJ). The bill, H.R. 1409, would require that any health plan that provides coverage for anti-cancer treatments must provide access to oral forms of treatment at a cost that is no less favorable than what the patient would pay to receive IV treatment.

- **Join SMART Patients** – This site allows you to have conversations with other MM patients regarding various issues and concerns. <https://www.smartpatients>

**Today's Question:** Name three of the four classes of myeloma drugs.

### **Clinical Trials Definitions of phases**

- ☐ Phase 1 - see if experimental medicine is safe - Very few patients (n=10-30)
- ☐ Phase 2 - see if treatment is effective (More patients - generally less than 200)
- ☐ Phase 3 - see if treatment is safe and effective AND works better than currently available drugs (Large numbers of patients - several hundred to thousands)

### **To Locate Clinical Trials for Multiple Myeloma**

New! IMF - Myeloma Matrix 2.0 - provides information on myeloma clinical trials.

<https://www.myeloma.org/matrix> sponsored by SMART patients

MMRF. <https://www.themmr.org/pipeline-clinical-trials>

[www.clinicaltrials.gov](http://www.clinicaltrials.gov)

### **Answer: Multiple Myeloma Classes of Drugs/Therapies:**

1. **Proteasome Inhibitors** - Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib
2. **Immunomodulating** - Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst
3. **Monoclonal Antibodies** - Daratumumab/Darzalex; Elotuzumab/Empliciti
4. **Histone Deacetylase** - Panobinostat/Farydak.

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.