

March 2016 Northside Meeting

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Business and Announcements

Nancy B. led the meeting and approximately 50 people attended. March is myeloma awareness month and the IMF is sponsoring many activities to promote awareness. Please visit <http://mam.myeloma.org> to learn more and please help by posting IMF-supplied brochures in public places where people gather.

The IMF has a prepared letter that can be distributed to primary care physicians and other doctors to help diagnose myeloma early. A digital version of this letter is available online to enable support of this effort. Also, The IMF sponsors educational workshops. On April 23rd there is a one-day Regional Community Workshop (RCW) at Duke (Raleigh/Durham, NC) and another workshop is being planned for the Atlanta area for mid-October 2016 (additional information to be provided at a later date). Please visit <https://myeloma.org> for more information on these educational conferences. The MMRF will sponsor a 5K Walk/Run in Atlanta on Sunday, May 15th. For more information and to register for the event visit <http://www.themmr.org/team-events/atlanta-2/>.

Member Updates

It was reported that **Mary J.** had radiation on her spine to eliminate pain and she is feeling better. **Monique F.** is on Velcade and doing well. **Frank** is planning a stem cell transplant this year. He mentioned that he harvested stem cells in 2009. **Ed** reported that **Lory M.** is taking Ninlaro (a first and only *oral* proteasome inhibitor) and experiencing tough side effects including nausea, dizziness, headaches, skin sensitivity (burning sensations) and GI upset. **Joseph** has been on Ninlaro for a month and experienced bad neuropathy and numbness in his feet. He is now taking Lyrica and after just a week the neuropathy has improved significantly. There was some discussion relative to specific treatments and secondary cancers. It is important to stay educated to understand the risks and benefits and the weights of each as treatment decisions are made. Consider the long term effects of treatments and stay educated so that you ask the right questions. Some questions and answers from group members that were discussed include:

Q: What is the importance of PET scans?

A: PET scans show hot spots and it is recommended that patients get a PET scan every 1-2 years at least. Infections that are hiding show up in PET scans. Remember that steroids mask the symptoms of infections.

Q: What are some tips for treating neuropathy?

A: Many members responded and the following was suggested: cocoa butter, alpha lipoic acid, B-complex, and L-carnitine supplementation (discuss with your doctor first) and check the Dana Farber website. **Sherry** mentioned that she had a compounded vitamin supplement customized just for her based upon her blood test results. She got a three month supply that helped. **Brenda** has had success with soaking her feet in either white or apple cider vinegar.

Q: What are some suggestions to improve appetite?

A: Legal marijuana prescription, THC in pill form can increase appetite.

Q: What are some suggestions to treat depression and anxiety?

A: Xanax was mentioned and also Cymbalta was mentioned as a drug that can help with both depression and neuropathy

Q: Any advice regarding Zometa and dental work?

A: Suggestions included getting off Zometa for at least 3 months or per doctor's recommendation, with the understanding that Zometa has a half-life of 10 years. **Jim** recommended being a liaison between the oncologist and dentist and do not perform any below the gum line dentistry without an agreement of plans from both doctors. Also suggested was to consider replacing Zometa with Aredia if necessary and possible.

The group then broke into separate patient and caregiver meetings.

Caregiver Meeting

There was a large turnout for the caregiver meeting and a wide range of situations, lengths of time in the caregiving role, and many varied needs. **Ed** led the meeting and the group discussed tips that can help improve the caregiving experience. For example, someone mentioned how helpful the Caringbridge website is for communication purposes. Someone else mentioned that they have learned to cook more nutritional foods and have improved their family's diet and eating habits. Also discussed was the importance of maintaining hobbies, social interactions, and other enjoyable distractions when possible. Do what you enjoy when you can: meditation, writing, exercise, Tai Chi, deep breathing, massage, visualization, and nature were all mentioned. Stay organized and have an updated list of things to do and resources in preparation of big events. Don't be afraid to ask others for help. Initiate contact and utilize your network. Very often people want to help but don't know how, so be specific when communicating with others to make your needs well known. Several members in the caregiver discussion expressed a desire for more frequent caregiver only discussions. When things are not going as well as expected remember to stay positive, don't take things personally, and remember to ask other caregivers how they are doing.

Patient Meeting

Nancy led the patient group and asked who had been on their MM journey more than eight years and who had less than three years since diagnosis. Hindsight being 20/20, the more experienced patients were requested to look back on their journey and offer advice to those just learning their way. One patient said “Take Charge”. Know what is right for you and actively participate in your treatment decisions. There are more options now, but that requires more information to make the next decision. The support group members are an excellent source of experiences, as well as other sources. At the end of your journey, you don’t want to have regrets that you didn’t speak up to go the best way for you. Another patient said “It’s tough”, especially after many years of ups and downs. Stay alert when something changes. Talk to others and God and know that you need help in many ways. Stay positive and focus on the next steps going forward. Use meditation and exercise to improve your outlook. Appreciate a good day. Instead of saying “Why me?”, know that this situation can serve another purpose, but you need to identify it. Adapting to your “new normal” means finding new ways to do what you really want to do. A patient wants to travel, but is concerned about side effects. Feedback came from a patient who travels regularly for business and noted that you have to be prepared and know where all the bathrooms are!!

Submitted by Wendy R and Nancy B

Southside Multiple Myeloma Support Group March 2016

Doris called the meeting to order with a moment of silent prayer.

Our next meeting, April 23rd will be an opportunity for members to share.

There were 22 present with 2 visitors and 3 new members. We were delighted to see **Jeanetta** who was visiting from Wisconsin; she is the mother of **Falomi**, a beloved member who passed away a few years ago. **Pauline** was visiting as Doris’ guest. We welcomed **Carole**, a retired Atlanta police officer who was diagnosed 3 weeks ago and will begin treatment (Rev/Val/Dex) with Kaiser Permanente’ next week. **George** (P) and **Cassandra** (CG) were in attendance. Cassandra shared that after months of saying they were coming to the support group, she was happy they chose this morning to finally attend. George is receiving care at Grady. We also welcomed **Barbara** back after a year away; she underwent a SCT April 1, 2015 and is counting blessings.

Speaker: Dr. Leon Bernal is an Associate Professor of Hematology and Oncology at Emory University School of Medicine who treats MM patients at Grady Memorial Hospital. He has treated patients at Grady for the past 11 years. He was introduced by Katie Mull - Celgene Pharmaceuticals Representative who also distributed a booklet entitled “Standing in the Gaap for African Americans living with Multiple Myeloma.” Dr. Bernal helped to author this booklet and used it as a guide for his presentation. “Standing in the Gaap...” is an initiative to help bridge the gap in care for African Americans living with MM. The booklet is easy to read and informative for anyone living with MM. Myeloma occurs in African Americans at least twice the rate of other groups in the world. In the U.S., 40% of patients do not get adequate treatment. There are resources for more information and resources for financial support to treat MM. Honest communication with one’s providers is encouraged, and “asking for help” when needed is crucial to the best outcomes. Dr. Bernal says in his practice at Grady he treats a large number of AA MM patients. As we suspect, medical problems are made much more complex due to social issues, one of the main ones being that most of his patients are uninsured or underinsured. He boasted that generally his patients do better than other MM patients because AA MM patients tend to have a less aggressive MM and when treated with novel therapies have better prognosis. This is in line with Dr. Durie’s comments in his August 2015 video on MM and African Americans – and underscores the need to have equal access to care for all patients, Social workers in his practice are able to help patients apply and qualify for **Georgia Cancer State Aid** (CSA) Program Services through the Georgia Division of Public Health (<https://dph.georgia.gov/cancer-state-aid-2>).

Dr. Bernal provided us with a very clear description of how myeloma progresses. He was passionate in his delivery, using analogies of snipers and invaders, and bone being like a water-filled tank to help us visualize the various aspects of disease progression. MM is a rare cancer that affects blood and bones. It is a type of cancer that develops in the soft spongy tissue at the center of our bones, called bone marrow. About 5% of the U.S. population (4 million people) carry a MGUS diagnosis – or precursor to MM. Every MM patient first has MGUS, whether or not they are diagnosed. Not every MGUS diagnosis becomes MM. He talked about two different kinds of MGUS – high-risk MGUS (has 60% chance of becoming MM) and low-risk MGUS (1% chance of becoming MM). MM causes cancer cells to accumulate, so they crowd out healthy blood cells and can prevent the immune system from working properly. Healthy white blood cells help your body fight infection and disease. Multiple Myeloma affects a certain kind of white blood cell call plasma cells -- these plasma cells are made in the bone marrow. In people with MM, plasma cells develop abnormally. They grow and spread in the bone,

leaving no room for healthy cells to grow and work. When healthy plasma cells cannot grow, they cannot fight off diseases. **CRAB** is an acronym used to describe common symptoms of MM. It stands for Calcium, Renal, Anemia, and Bone. It may also be accompanied by infection caused by a weakened immune system. **Gail** suggested that CRAB should be CRABI (to include the Immune system) – this is something Gail has prompted for some time. Dr. Bernal said he would suggest the name change on the next Hematology conference.

Research has shown there are genetic markers for MM, and many of the newer therapies are targeted therapies. We need more African Americans to participate in clinical trials because we know there are differences in MM in blacks versus whites. Currently, only 9% of African Americans participate in clinical trials. Dr. Bernal was surprised to hear that the Tuskegee Study and suspicions of clinical trials is still expressed as reasons for the lack of participation. Most of the group was not surprised. Dr. Bernal stressed the importance of exercise and maintaining a healthy weight to have the best possible outcome.

Dr. Bernal left us with the following points.

- Always talk to your doctors and nurses if you're feeling any pain or discomfort.
- Bring someone with you for office visits, such as a friend or family member.
- AAs are twice as likely to be diagnosed with MM as whites - the reason is not understood.
- Some studies suggest that the type of MM that affects AA tends to be less aggressive with better prognosis. However, it's still important to seek the proper care.
- AAs are diagnosed at a younger age (66) compared to whites who are diagnosed at age 71.

Dr. Bernal said he was impressed with the level of knowledge of the group and agreed to share our brochures' with MM patients in his clinic. He is a principal investigator with a clinical trial -**TOURMALINE MM1** – A phase 3, randomized study comparing Oral Ixazomib plus Rev/Dex vs. Rev/Dex in relapsed MM Patients. He encouraged AA MM patients to participate in clinical trials where the new drugs are showing great results.

Clinical Trials - Updates (clinicaltrials.gov)

Multiple Myeloma Bone Study – Randomized Double Blind. Denosumab versus Zoledronic Acid (Zometa) in newly diagnosed

Smoldering Multiple Myeloma (SMM)

- A Study to Evaluate 3 Dose Schedules of Daratumumab in Participants with SMM
- Lenalidomide or Observation in Treating Patients with Asymptomatic High-Risk SMM
- Daratumumab in Participants with SMM
- Phase II for relapsed or refractory MM. Kyprolis and dex. Compare Kyprolis once a week versus twice weekly dosing.
- Selinexor (STORM) - For those heavily treated for MM, Receive Selinexor (KPT-330) and Dex three times a week.
- **TOURMALINE MM1** – A phase 3, randomized study comparing Oral Ixazomib plus Lenalidomide and dex vs. Lenalidomide and dex in Adult Patients **With Relapsed and/or Refractory Multiple Myeloma**

Classes of MM Medications:

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

*New agents - Farydak, Darzalex, Ninlaro, and Empliciti

Janice attended the **IMF Patient & Family Seminar** in Boca Raton, FL last month and says it was a wonderful experience and learning opportunity. The Seminar offers a program to get up-to date, vital information and access to the experts with time to ask questions about treatment options. **Nancy** shared that IMF will host a Regional Community Workshop in Atlanta in October of this year. The Workshop is a half-day meeting and is designed to provide much of the same information as that of a Patient & Family Seminar but in a condensed form. The faculty consists of myeloma specialists and a nurse. Stay tuned for more information.

March was Myeloma Action Month! Our Message was: Since African Americans are at higher risk for myeloma yet respond better to treatment, early diagnosis is the key. We were able to increase awareness of MM through efforts of group members during the month of March. Our activities included: (1) a presentation to the Concerned Black Clergy of Atlanta with 15 members signing up to receive more information; (2) a 30-minute Health Matters show with Morehouse School of Medicine - MM interview on WYZE/1480 AM Radio-the interview afforded us an opportunity to discuss MM with large Gospel Music listening audience. (3) We developed a relationship with the Atlanta Leukemia Lymphoma Society

to increase MM awareness among AA congregations. LLS will sponsor a Round Table to Discuss Myeloma Outreach. (4) On **2/26/2016** representatives from our group taped a segment on the Fulton County, Georgia TV station—**Health Line** and dedicated it to Lonnie Ward a devoted support group member. You can view the episode on **Youtube** by clicking on the site below. <https://www.youtube.com/playlist?list=PL0-TMSgrfmJxOOSHRPyqgrX89eUR7MOV>

Announcements/Resources/Upcoming Meetings

- CMS (Center for Medicare and Medicaid Services) will now cover allogenic stem cell transplants (SCT) for patients with Stage II or Stage III myeloma
- IMF - Archived Patient and Caregiver webinar “Understanding Next in Class Novel Therapies in Multiple Myeloma” March 23rd at 1:00PM EST. <http://www.cancereducation.com/cancersyspagesnb/a/mmr/m1602/register.html>
- IMF - Smart Patients is an online peer-to-peer program - community where patients and caregivers affected by MM learn from each other about treatments, challenges, and how it all fits into the context of their experience. Collectively, our experience is a vast and often untapped resource. <http://www.smartpatients.com/imf>

Education opportunities offered by Cancer Care Connect – Go to connect@cancercare.org to register

- Progress in the Treatment of Multiple Myeloma
Thursday, April 14, 2016, 1:30 – 2:30 PM, ET
- Coping with the Stresses of Caregiving When Your Loved One Has Multiple Myeloma
Thursday, April 28, 2016, 1:30 – 2:30 PM, ET
- Managing the Side Effects of Immuno-Therapy
Tuesday, May 10, 2016, 1:30 – 2:30 PM, ET
- Managing Symptoms and Treatment Side Effects of Multiple Myeloma
Thursday, May 26, 2016, 1:30 – 2:30 PM, ET

Submitted by Gail and Paulette