

October 2015 Northside Meeting Notes

New Members

The group welcomed **Judy** and **Paula**, wife and daughter respectively of **Walter H.** Judy explained that Walter was diagnosed with smoldering myeloma in 2010 for which he was monitored every 3 months at Emory. In 2014 he fell from a ladder and had multiple kyphoplasty and sacroplasty surgeries to repair 6 broken vertebrae. Walter is currently being treated with Carfilzomib, Dex, and Cytosan with good results and uses a Fentanyl patch for pain management.

Business & Announcements

Joe B. and Tom L. co-hosted the meeting. **Carolyn** mentioned that she was part of an interview that was conducted with Dr. Lonial for CNN. Joe asked 1) Has anyone taken Ixazomib (oral Velcade-related)? and 2) Has anyone taken Velcade long-term (more than 5 years)? If so, please contact **Nancy**. In the **November** meeting the group will divide into separate patient and caregiver sessions. The **December** meeting will be our traditional holiday potluck meeting where everyone is invited to bring their favorite holiday dish to share.

Meet Your Members

Susan and Joseph (Joe) shared their life experiences with the group. Susan explained that they were recently celebrating their 54th wedding anniversary when Nancy asked them to speak to the group. Susan is originally from Armenia and grew up in Lebanon. They are both multilingual; each speaks 3 languages (French, Arabic, and English). They met in Lebanon, where Joe had relocated with his company, and were married there. In 1964 with 2 children and another on the way Joe's company transferred him to Santa Monica, CA which they liked and Joe's family also relocated there. They built a house and Susan worked as a nurse in inhalation therapy. In 1966 Joe's company relocated him to Libya. Then Joe's company relocated them to Morocco, where their 4th child was born. Soon they were relocated again to Nigeria, and then Cypress. Joe explained that he had the opportunity to transfer with his company so often because he was multi-lingual. In 1974 Joe was asked to go to Kuwait which he accepted – their children attended American schools there. After five years Joe's company relocated him to the Bahamas where they stayed for nine years. Their next move was to Monte Carlo where Joe developed CIA connections. Joe was called to interview in Atlanta in 1993 where he was offered a consulting position. In 1993 just before moving back to the US Joe was told by a doctor in France that once he relocated he should get to a doctor for further testing, as his test results showed a high protein level. In 1993 Joe was diagnosed with smoldering myeloma which he had for 18 years, just monitoring but not treating. Four years ago Joe experienced anemia and fatigue and underwent 6 months of chemotherapy. He felt good and he experienced continuous improvement but his doctor suggested continuing with Revlimid therapy daily for a year. Two months ago his condition improved to remission and so he now takes Revlimid for 14 days, then a week off. Joe said that he is about to celebrate his 84th birthday! Susan mentioned that she is currently working as a part-time interpreter, an unexpected career move for her, and she also said that **Bill** introduced them to the group and she asked that we remember Bill in our prayers. She also recognized **Nancy** for her active leadership, connection and devotion to the group and its members.

Meeting Discussions

Kimberly joined the group 6 years ago, but has not attended a meeting for a while. She was initially diagnosed when lesions were found in the sacrum and was given a grim prognosis. She attended a meeting and learned more about her options from other patients, which renewed her hope. She had a stem cell transplant about 6 years ago and is in remission, and she attends the meetings periodically now. **Barbara** suffered back pain in 1992 but her doctor told her it was nothing serious and it was monitored every 6 months. In 2006 she had her gall bladder removed and found that her numbers increased and a myeloma diagnosis was given. Thalidomide was a suggested treatment but she decided to take a high dosage of Dex alone, which she did for 3 months and her numbers were dramatically reduced. In 2007 she had a stem cell transplant then moved to Atlanta and began seeing Dr. Lonial. She continued without maintenance, relapsed in 2010, and decided to monitor only. In 2011 she had a compound fracture in her back and began therapy with Velcade and Dex, which resulted in significant improvement at first but then stopped working. She tried Revlimid and Dex and took that for 2 years with good results. Her doctor recommended trials as next step options for her when she relapsed again and she explained that she looks at the disease with acceptance and makes her therapy choices with what is best for

her and she won't put herself through a lot of discomfort and decides when to begin therapy on her own terms. She went on a trip to Jamaica recently and then began taking Daratumumab, which is not yet approved as a single agent, not as a trial. The drug is administered as an infusion and takes about 10 hours. It starts at a low rate and increases until you cannot tolerate it. The infusion stops, the intolerance is treated, and the infusion is restarted again. This continues until the drug is fully administered. Reactions are expected and the medical staff is prepared to treat any reactions that the patient has immediately so that the patient can recover, and the infusion can be restarted and completed. Barbara explained that she experienced back ache during the first infusion and the side effect was treated and she continued with the therapy. The initial side effects are short-term as your body adjusts to the drug, as the first dose shocks the system. The second and third sessions were better and she is doing well. **Carolyn** commented that we must stay educated to make informed decisions and she likes that Doctor Lonial gives patients options then lets them decide on their treatments. Treatment is a personal decision – it is what is best for you based upon where you are in your life. Our doctors learn from this too. There was additional discussion reminding everyone to remember to tell your doctors and pharmacists all of the vitamins and supplements that you are taking. This is a good practice for everyone regardless of whether you are treating a disease or not. Someone suggested developing a good relationship with your nurse practitioners. They can sometimes offer better support and medical advice than your doctor, and are often who we see the most. **Bob** suggested bringing a comprehensive list of all drugs and supplements to the Emory pharmacist who can help you understand if there are any conflicting issues.

Submitted by Wendy

Southside Multiple Myeloma Support Group

Meeting Minutes October 2016

The group observed a moment of silence and guided meditation; **Doris** called the meeting to order.

The meeting for the month of **November** will feature an archived video from IMF. Also, remember that Doris' birthday party celebration will be held the same day. Hope to see you there.

Old Business: Committee members provided updates on new member packets, outreach to MIA members, and the proposed Caregiver Appreciation event. **Paulette** reported the inventory of MM supplies and brochures at **Doris'** home is complete. She suggested that packaging for new member packets a re-purposing of The Takeda Oncology Company's zippered purple notebooks that currently are designed to hold information on Velcade primarily. It can be used for new members with inserts of treatment and financial resource information and other materials essential to myeloma patients; **Kim** reported she phoned several members to see how they are doing and agreed to call more; **Vermell, a nurse consultant to the Group,** reported she contacted 3 new MM patients and responded to medical questions. **Gail** reported she has been in contact with Atlanta Metropolitan College and Atlanta Technical School to discuss their location for the Caregiver's Appreciation luncheon and workshop. Doris and Gail are seeking funding for the event. Doris will order more purple resource books from Takeda. We need to continue to work on "We Miss You" cards for members that are not attending meetings, sympathy cards and get well soon cards. We are making these cards personalized from the Support Group. We also asked members to contribute stories on their cancer journey, pictures, and other info they might wish to contribute to the website.

New Members: The group welcomed two new members—Virginia and Gary. **Virginia** was referred to the support group by Debra; she was diagnosed with smoldering MM in 2007, her status has not progressed therefore, she is not in treatment. Virginia she is being monitored at Northside Cancer Care. **Gary** was diagnosed with MM in April 2013, and began treatment with Rev/Vel/Dex; he had a stem cell transplant in December, 2013. In August 2014 he finished second round of Karyprolis and Pomalyst. **Gary** is receiving treatment at Piedmont hospital. He is married and has a 17 and 12 year old. Gary has challenges with neuropathy and has not been able to work.

At this month's meeting, we watched a 6 minute "Ask Dr. Durie Video" entitled: **Do African Americans have an Increased Risk of Myeloma?** Dr. Durie says **YES**; but, he also says African Americans have a better response to treatment. In this video, Dr. Durie explains it is important to understand the details and made the following points: (1) African Americans are at higher risk for developing Monoclonal Gammopathy of Undetermined Significance (MGUS) more frequently and at an earlier age – especially in men. MGUS raises the probability of developing Myeloma (MM). All MM patients have had MGUS, whether diagnosed or not, but not all people with MGUS go on to develop MM; (2) Only 1% per year of those with MGUS actually develop Myeloma; 3) while the transition from MGUS to myeloma is the same in all populations, African Americans (AA) are less likely to have some of the high risk genetic features of myeloma. He defined high risk myeloma as those with chromosome translocation 4 and 14 or t (4; 14) and 17 p deletion (loss of all or part of chromosome 17). Additionally, AA may have extra chromosomes or trisomy: and, (4) AAs do not have full access to the diagnosis and/or treatment spectrum for MM. He says AAs, when treated with novel therapies and transplant, respond better than Caucasians. Therefore, **early diagnosis is key**. Several projects through IMF and IMWG are in development or being conducted to increase awareness among the public, and within health professionals about MM and the black/white differences. A representative attended the National Medical Association meeting (primarily AA physician membership) in August 2015 to provide MM updates and information on these genetic differences.

*Brian G.M. Durie, MD is the IMF Chairman and Co-Founder and welcomes questions about the latest myeloma treatments, research, controversies and quality of life issues. If you have a question you think might be of interest to the myeloma community, it can be asked at Dr.Durie@myeloma.org. For questions of a specific personal nature, please call the **IMF InfoLine** coordinators at 800.452.2873 or email them at infoline@myeloma.org. Archived videos with useful information directed at - and asked by - patients, caregivers, and other interested parties are available for you to view. Go to Myeloma.org; then IMF TV; then Ask Dr. Durie. Then page down to view a topic of interest.*

Announcements/Resources/Upcoming Meetings

Emory Winship will host the annual ASH review on January 16th at Winship Cancer Institute. Breakfast will be served. Registration begins at 9:30.

Fundraiser for IMF

• **Doris Morgan - 75th Birthday Celebration-** You can send your gift to: 2866 Darrah Dr., Atlanta, GA 30331 or to donate on line <http://myeloma.donordrive.com/event/DorisMorganBirthday>

Publications, Webinars, etc.

- **IMF - New publication.** Understanding the Immune System in Myeloma <http://myeloma.org/pdfs/U-ImmuneSystem.pdf>
- The IMF Advocacy team held a webinar on Wednesday, November 11, "Understanding Clinical Pathways". Go to replay.myeloma.org and select Teleconferences.
- IMF Webinar - **Multiple Myeloma and Veterans Administration Benefits.** Thursday, November 12, 2015. Replay at replay.myeloma.org and click on Teleconferences.
- IMF - Webinar -Living Well with Myeloma: **Myeloma 101 - Updates on Treatment & Pain Management.** Go to Myeloma.org, click on IMF TV and select Living Well with Myeloma.
- **Best Options for Treatment - Point-Counterpoint. From ASH meeting** (American Society of Hematologists). December 4. 12:30-3PM. To register: <https://online.myeloma.org/netcommunity/ash2015>
- MMRF - Patient Immunotherapy Webcast Series. <http://www.themmrp.org/living-with-multiple-myeloma/education-programs/immunotherapy>
- IMF - Smart Patients is an online peer-to-peer program - community where patients and caregivers learn from each other about treatments, challenges, and how it all fits into the context of their experience. <http://www.smartpatients.com/imf>

Respectfully submitted by Paulette and Gail