

November 2016

**Northside Multiple Myeloma Support Group Meeting
November 5, 2016**

Business

Thank you to **Joe** who led the meeting. The following was discussed:

- The **December meeting** will be held on **December 3rd** and will be a combination of **member updates and a holiday “potluck” celebration**. Everyone is invited to bring their favorite potluck dish to share. The group also donates toys to Children’s Healthcare of Atlanta to help brighten the holidays for children who are in the hospital during the December holiday season. Everyone is invited to bring new, unwrapped toy(s) to donate. The Board of Directors will be working on 2017 programs and suggestions from the group are welcome.
- Everyone is invited to attend the **American Society of Hematology (ASH) review at Emory on Saturday, December 10th**. At this meeting Emory doctors will report on highlights obtained from attending the ASH conference that is held in early December. Breakfast and lunch will be provided. Look for more information via E-mail for RSVP counts. **Please note that you must RSVP in order to attend the event.**
- The **January meeting** will be a regular meeting held on **January 7th, 2017** at the **regular place and time**.
- **Joe and Sandy** recently celebrated Sandy’s 27-year survivorship! The group was very happy to see **Mary J.** at the meeting!

Guest Speaker

Thank you to **Tricia Hernandez**, Patient Access Manager, GA Chapter of the **Leukemia & Lymphoma Society (LLS)**, who educated the group on the purpose and goals of the LLS and its supportive programs for patients and caregivers. Tricia, a 14-year survivor of lymphoma, explained that the mission of the LLS is “to cure all blood cancers and myelodysplastic disorders”. To accomplish this mission, the LLS understands that cures are a result of research. They have funded more than a billion dollars for blood cancer-specific research and supportive treatments, with goals to get researched agents FDA-approved faster for patients. An example includes CAR-T targeted immunotherapies that harness the power of a patient’s immune system to combat their disease. These therapies are changing the force of cancer. Tricia specifically helps patients and caregivers find resources, support, and information. Examples of the types of free support available to you through the LLS include information on how to read and understand your lab results, financial co-pay assistance, travel assistance programs, and peer support programs. You can join the LLS Community at <https://communityview.lls.org>. Tricia can be contacted directly at tricia.hernandez@lls.org or call 404-720-7838.

Meeting Notes

At the November meeting the group broke into separate Patient and Caregiver sessions.

Patient Session

Thank you to **Jim M.** who led the group. Two new members were present. **Peter** was diagnosed in 2015 and had a bone marrow transplant in February 2016. He has been in remission since then. He takes Revlimid for maintenance and is being treated at Emory. **Carol** was diagnosed in April 2016. She is allergic to Revlimid and is not a candidate for a transplant because of a blood disorder (Osler-Weber). She is being treated at Kaiser and is not very happy with her experience there so far. **Sandy B.** mentioned that she has also been treated at Kaiser and provided the name of her doctor, and suggested Carol request that doctor. Carol also said she has had difficulty sleeping. Group members suggested that she consult with Emory doctors and that Emory has financial aid and will work with you. **Loretta** asked if anyone else has had a problem with bleeding veins. She had become very anemic and her doctors found that she had some bleeding veins in her abdomen when they did the pill cam. Another member who has had a 3 year remission asked the group if the blood

tests should change and what she should be paying attention to so that she could catch any flare ups early. The group responded that the blood tests are basically the same and that she should tell her doctor if she notices any changes. The group was glad to have **Mary** back at the meeting. Mary said that myeloma cells were present in her spinal cord and that she has spinal taps to check for myeloma cells and that chemo is injected in place of the spinal fluid for treatment.

Caregiver Session

Thank you to **Molly**, who led the group. Caregivers discussed how different personality traits between patients and caregivers can affect how caregivers achieve desired results. Also discussed was how both patients and caregivers are affected by careers; especially for those patients who continue to work after diagnosis. Time was spent discussing each of the caregiver's current situations in order to be able to support each other in the best ways. Also discussed was getting legal documents such as wills, living wills, and obituaries prepared during neutral times, rather than times of crisis.

Submitted by Wendy and Marilyn

Southside Multiple Myeloma Support Group Meeting Saturday, November 26, 2016

Gail opened the meeting with a moment of silence and breathing exercises. There were 11 present. We had three visitors, Evelyn, mother of Gail and Paulette, visiting from Fort Valley, GA and Alma's sister and niece were visiting from Vancouver, Washington.

Thank you to Pat who has been involved in the Cancer Awareness Group in her church; they raised major funds to donate to 4 cancer groups. Multiple Myeloma is one cancer that benefited from their efforts. During the campaign, they also identified two people in their congregation who had multiple myeloma. Thank you! **New Life Presbyterian** at 6600 Old National Highway - donation to IMF (MM), Sisters by Choice (Breast Cancer), and two other Cancer organizations. **Nancy, Doris, Portia** and **Pat** were present to accept the contribution for the International Myeloma Foundation (IMF).

Gail shared information from the **Pre-ASH-What Myeloma Patients and Care Givers need to know**-webinar presented by the International Myeloma Foundation. IMF's Chairman of the Board, Dr. Brian G.M. Durie, provided a summary of what to expect from the American Society of Hematology's (ASH's) Annual 2016 Meeting for multiple myeloma patients and their caregivers. Of note, Dr. Durie distills the most high-level topics into knowledge for patients to apply to their day-to-day care. Dr. Durie outlines his summary in the "Bottom Line Takeaways" and "The Clinical Pearls" from the latest medical research. There were 687 presentations focused on myeloma at ASH – there were two of these that had a focus on African Americans specifically. The group discussed this webinar with help from Nancy.

Bottom Line Takeaways from ASH 2016 as outline by Dr. Durie

- New Genetics confirm old ideas
- MRD: Strong Support for "Black Swan" concepts
- Nelfinavir: AIDS drug works in Myeloma
- Venetoclax: drug for dislocation genes (11;14) Myeloma
- Selinexor: data for "unmet need"
- CASTOR/ POLLUX: Daratumumab/Darzalex - combo updates
- CAR-T: status of immune therapy
- Amyloid: Carfilzomib (Kyprolis) active – Sometimes MM patients develop amyloidosis which occurs when protein accumulates and damages organs – such as heart, kidneys, liver, or intestines
- Diet and MGUS (iSTOPMM research Study from Iceland) – those who consumed diet high in meat and low in fish increased the progression to MM
- Clinical Pearls: knowledge for Day-to-Day care

Dr. Durie's Clinical Pearls from ASH 2016

- Daratumumab (Darzalex) combinations very Active: CASTOR/POLLUX
- Daratumumab (Darzalex) Effective for Cardiac Amyloids
- Daratumumab (Darzalex) can be given by subcutaneous injection (versus IV)
- Pembrolizumab (check point inhibitor) combos also active
- Elotuzumab/Empliciti and Revlimid: active for Hi Risk Smoldering MM (HRSMM)
- Freelite and Hevylite useful for monitoring
- High uptake on PET is poor risk
- Carfilzomib (Kyprolis) combinations (Thalidomide; Revlimid; Pomalidomide) all very active
- Racial Disparities an HLA type/plus presentation management and outcomes
- High cut-off (HCO) dialysis improves renal failure

To view the entire presentation, go to: <https://www.myeloma.org/videos/pre-ash-what-myeloma-patients-caregivers-need-know>.

Another very well done presentation Post-ASH is a discussion with Drs. Brian G.M. Durie, Joseph Mikhael, and Sagar Lonial as they present the latest news and trends in the treatment of Multiple Myeloma at the 58th Annual ASH Meeting in San Diego, California. **ASH 2016: IMWG Conference Series: Making Sense of Treatment.** Go to www.Myeloma.org TV to view. Also, register for the upcoming Teleconference: **Best of ASH 2016 Teleconference**, Date: Thursday, **January 12, 2017 Time: 7:00 EST**; Go to www.myeloma.org to register.

Also, see what the 14 Support Group Leaders who attended ASH had to say about their impressions during ASH – 2016.

Announcements/Resources/Upcoming Meetings

- Easy way to give to IMF. Shopping at AMAZON can be a way to donate to IMF. Bookmark amazon.myeloma.org. No added cost to you. Donations are sometimes as much as 7% of purchase.
- **iSTOPMM**. Early diagnosis project funded by the Black Swan Initiative: All 140,000 Icelanders over age 40 will be screened for MM.
- Game changer? - Darzalex (Daratumumab) - data are strong -- and so may be preferred choice by many...based on high response rates and prolonged remissions.
- **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, contact us at 1-800-813-HOPE (4673). To join an online support group, please register through our website at 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>.

MM Vocabulary for today: What is meant by Precision and Personalized Medicine?

Clinical Trials - Updates (www.clinicaltrials.gov)

- **Smoldering Multiple Myeloma**
 - Trial of Combination of Elotuzumab and Lenalidomide +/- Dexamethasone in High-Risk Smoldering Multiple Myeloma
 - Study to evaluate 3 Dose Schedules of Daratumumab (Darzalex) in Participants with Smoldering Multiple Myeloma
 - Lenalidomide or Observation- Treating Patients with Asymptomatic High-Risk (smoldering) Multiple Myeloma
- Amgen (Carfilzomib/Kyprolis) and Janssen (Darzalex/Daratumumab) will collaborate to co-fund study combining their two drugs for MM therapy.
- FDA approval of Lenomide/Dex or Bortezomib/Dex for first relapse patients. Treatment is based on clinical trials POLLUX (Rd) and CASTOR (Vd) as a new standard of care. Other first relapse therapies include Carfilzomib (Kyprolis), Ixazomib (Ninlaro), and Elotuzumab (Empliciti) -- all recently approved,

but without direct comparison data to each other. This means patients and doctors must study and decide what is best for them in each case. Darzalex (Daratumumab) may be a game changer here based on high response rates and prolonged remissions.

Precision Medicine/Personalized Treatment: In 2015, President Obama launched the Precision Medicine Initiative (PMI). Advances in Precision Medicine have already led to powerful new discoveries and several new treatments that are tailored to specific characteristics, such as a person's genetic makeup, or the genetic profile of an individual's tumor. This is helping transform the way we can treat diseases such as cancer: Patients with breast, lung, and colorectal cancers, as well as melanomas and leukemias, for instance, routinely undergo molecular testing as part of patient care, enabling physicians to select treatments that improve chances of survival and reduce exposure to adverse effects. It's health care tailored to you. Until now, most medical treatments have been designed for the "average patient." As a result of this "one-size-fits-all" approach, treatments can be very successful for some patients but not for others. Precision Medicine, on the other hand, is an innovative approach that takes into account individual differences in people's genes, environments, and lifestyles. It gives medical professionals the resources they need to target the specific treatments of the illnesses we encounter, further develops our scientific and medical research, and keeps our families healthier. (Source: <https://www.whitehouse.gov/precision-medicine>)

MMRF Founder Kathy Giusti – in recognition of the MMRF's longstanding leadership in precision medicine – was appointed to the White House Precision Medicine Working Group, which is made up of key leaders in research, science, technology, epidemiology, investment, policy, and patient advocacy. MMRF recognized that precision approaches in oncology require the generation, centralization, and analysis of clinical and molecular data. They have built a Data Bank that makes it possible for global research to work together as one. The Multiple Myeloma Genomics Initiative (MMGI) allowed the MMRF and its partners to be the first to sequence the myeloma genome. The CoMMpass (Relating Clinical Outcomes in MM to Personal Assessment of Genetic Profile) Study, the most expansive and comprehensive longitudinal genomic research ever conducted in myeloma and a landmark initiative in the field of cancer research. In 2011, before Precision Medicine was a familiar term, the MMRF started the CoMMpass Study. MM is so different in each patient, the CoMMpass set out to recruit 1,000 patients who would provide tissue samples when first diagnosed, and each time the treatment changed. Mapping the genomic profile to clinical outcomes of these patients provides a more complete understanding of patient responses to treatment (Source: <https://www.themmr.org/research-partners/mmr-data-bank/commpass-study/>).

“One of the unique pieces about how important CoMMpass is for us as a myeloma community is that it gives us a very large genomic database for the patient at the time of diagnosis. And because of the multiple countries involved, it gives us a good spread amongst different ethnicities, ages and treatment approaches. This will allow us to really look at those different categories and understand what they mean with the genomic information at the same time.” – Sagar Lonial, MD Professor and Chair of Hematology and Medical Oncology Emory University School of Medicine.

The CoMMpass study is now closed for new participants. Each participant will be followed for eight years, with assessments every six months. Most enrollees are non-Hispanic males, with 18 percent of the participants being self-reported African Americans, significant because of higher incidence of MM in this population.

Multiple Myeloma Classes of Drugs/Therapies – Which is better for you and Why:

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

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

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.