

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Meeting

October 5, 2019

### News & Business

Thank you to **Jeannie** who stepped in for **Jim M.** to lead the meeting. Jim has been “grounded” by his doctor while his counts are low from a new treatment that he has just begun. We all wish Jim a quick recovery and hope to see him again soon!

### Upcoming meetings and events:

**November** – Everyone is encouraged to attend the free IMF event on **November 9<sup>th</sup>**, in lieu of a regular meeting on November 2<sup>nd</sup> (which will not be held): <https://www.myeloma.org/events/regional-community-workshop-atlanta-ga>. Registration is required to attend the event and additional details will be provided. Continental breakfast, lunch, and free parking are provided.

**December** – We will have our traditional holiday celebration at our normal meeting place and time. Everyone is encouraged to bring a favorite dish to share with the group during the meeting, and an unwrapped toy to donate to a local children’s hospital. The toy donations are especially appreciated as they really help to brighten the lives of children who are hospitalized during the holiday season.

### New Members and Updates

The group welcomed **Dennis** who had experienced low blood counts for 5-8 years and a fracture last September. Tumors were found on X-rays at diagnosis and he began Velcade and then Velcade and Revlimid. He had problems on the 11<sup>th</sup> cycle and had bilateral pneumonia and respiratory failure (terminal event) due to Revlimid. He is on Velcade only now, but it is not working, and he is considering starting *DARZALEX as a single agent*. **Carolyn** mentioned that she had success taking *DARZALEX as a single agent for four years*. We also welcomed **Tracy** who was diagnosed in March 2019. Tracy is currently on Pomalyst and waiting to hear if she is eligible for a stem cell transplant. She is doing OK and not experiencing any serious side effects. Also attending the meeting were **Angela** and **Allison** daughters of **Barbara H.** who passed away in February. One of Barbara’s daughters was diagnosed with MGUS and they plan to continue to join our

group when they are in town. **Sandy** mentioned that there is a study called "myeloma promise" that offers free screening for people who have a parent, child, or sibling with MM.

### **Guest Speaker**

Thank you to **Dr. Craig Hofmeister**, (he asked us to call him Craig), a multiple myeloma (MM) doctor from Emory's Department of Hematology and Oncology. Craig was a MM doctor for about 12 years in Ohio, before transferring to Emory about 18 months ago to join the other full time MM doctors of which there are now six. **Craig will be one of the speakers at the IMF Workshop on November 9<sup>th</sup>**. He joined our meeting to discuss research, expectations for the next drug approvals, and how patients can actively participate in their treatment decisions. There is a lot of ongoing research related to MM and a lot of clinical trials (CT) in process. There are different ways to learn about CT. Some of the CT websites, such as <https://clinicaltrials.gov> are hard to navigate, even for experienced medical professionals. A great website for finding out about CT is <https://sparkcures.com/>. You can also email Craig ([craig.hofmeister@emory.edu](mailto:craig.hofmeister@emory.edu)) and he will send you a link with information about available CT at Emory, which is updated in real time.

Some treatments that are expected to be approved soon include **CAR T-Cell therapies** that entail genetically re-programming your own cells to reinfuse back into your body. Anti-BCMA CAR T-Cell Therapy bb2121 from Celgene is a first generation CAR T-Cell therapy. Emory has three patients currently using CAR T-Cell therapy. **Venetoclax** is another drug that is expected to be approved soon. This is a drug that is specific for patients with 11/14 chromosome translocation and is very effective for this group of patients. Paired with Dex, it has resulted in great responses without a lot of side effects. It works for MM as well as acute and chronic leukemia patients. Also, soon to be approved is **Melflufen**, a peptide-conjugated alkylator for the treatment of relapsed and refractory multiple myeloma which considered a more tolerable form of Melphalan, yet is still tough on cells and is very effective. It has some challenging side effects such as nausea, fatigue, and diarrhea. Some patients that are taking Melflufen generally feel OK, but require lots of transfusions, and have a high risk for infections, which "dampens the enthusiasm".

Some ways that you can actively participate in your treatment is to look for clinical trials. Craig highly recommends having a doctor specializing in MM which will free you from being the primary MM educator of the medical staff. MM is all about numbers and understanding what those numbers mean. It's important for MM patients to know what types of protein (IgA, IgG, IgM, IgD, or IgE) your MM makes, and know your numbers – M spike and light chains (Kappa, Lambda) and to graph your numbers and watch for progression over time. These numbers will also tell you if your treatment is working. If you are not seeing a MM specialist, it is extremely important to be sure that you know your numbers and be prepared to continuously educate your doctors and be able to report progression to your doctors and entire medical team. Don't assume that your medical team will do this for you when you are not seeing a MM specialist. It is also important to stay updated on new treatments that might be good options for you.

Craig graciously answered many questions for us as follows:

**Q:** How often should I get MM labs? **A:** Generally, on average - for newly diagnosed patients, or for patients in treatment, monthly, or as required for any specific treatments. Otherwise, the standard is quarterly.

**Q:** What are the three main MM indicators to know? **A:** a) serum immunoglobulins - IgA, IgG, IgM, IgD, or IgE, b) monoclonal spike (M spike or paraprotein) on serum protein electrophoresis (SPEP) and c) serum free light chains – kappa, lambda, and ratio.

**Q:** I don't make M protein and I'm a kappa light chain patient. Why did my lambda increase and makes my ratio look OK? **A:** This particular patient should only follow kappa and ignore the lambda and ratio.

**Q:** Why are the 24-hour protein test results not one of the main indicators?

**A:** This test is not reliable, but there are some times when it is required: 1) for Amyloidosis patients when kidneys are affected, and b) when patient is on a clinical trial.

**Q:** How often should MGUS patients get MM labs?

**A:** MGUS and Smoldering patients have a "pre-cancer condition". There is no evidence that their condition will develop into MM. They should know their numbers and track them, but the frequency of testing should be determined by how high the risk is of them developing MM.

**Q:** How does a MGUS patient know their risk of developing MM? **A:** Low risk MGUS patients have 3 things in common a) type of protein – IgG, b) light chain ratio is normal, and c) M spike is less than 1500. Low risk MGUS patients have a 7% chance of their condition developing into MM. From historic data it is understood that with the highest risk MGUS patients, they usually progress to MM within the first six months after being diagnosed with MGUS.

**Q:** I'm on Pomalyst with a 21 day on/7 day off cycle, and have intermittent cramping in my hands and feet and can't sleep during my off week – why? **A:** IMiDs can cause cramping. Some off weeks can be bad in terms of side effects due to being off steroids (we can't predict the side effects of steroids). Suggest reducing the dose of the drug and staying well hydrated.

**Q:** I was diagnosed a year ago, was on Velcade off and on and got bilateral pneumonia resulting in a terminal event. I'm considering starting *DARZALEX*. *What can I expect?* **A:** On average, *DARZALEX* causes fewer side effects than IMiDs and protein inhibitors. But *DARZALEX* works better when paired with IMiDs and protein inhibitors and so it is unusual to use *DARZALEX* alone. A recommended pairing is *DARZALEX* with Pomalyst which should result in fewer side effects.

**Q:** When tests show progression, does having a bone marrow biopsy provide any more information than at original diagnosis? **A:** Yes, but a bone marrow biopsy test costs \$10,000. A bone marrow biopsy test is generally done only a few times post-diagnosis: a) when entering a CT, and b) before an autologous transplant (required by insurance), c) the doctor is confused about something and wants more information.

**Q:** I have been smoldering since 2008. I'm monitored 3-4 times a year and numbers are not great but consistent and I feel fine. I had a bone marrow biopsy test several years ago and plasma cells were a little high. **A:** You do not have cancer! Do not treat. Low risk MGUS patients have a 7% chance of their condition developing into MM.

**Q:** How is MM staged? **A:** There are 3 staging systems used with MM and it is important to know which system was used for your staging: a) Durie Salmon (1973), b) International Staging System (ISS) (2005), and c) ISS (2014). The ISS (2014) staging system is the most understood and the most accurate. Staging for non-MM cancers is related to "location", which does not apply to

MM because MM is a metastatic cancer at diagnosis. In MM, stage means “type”, which translates to risk – low, high, or unknown.

Submitted by Wendy

### **Southside Myeloma Support Group**

**October 26, 2019**

**November Program: What type of myeloma do you have? ...and what is new in myeloma drugs, Debra Thomas and Nancy Bruno will review the information from the recent IMF workshop.**

**Doris opened the meeting with a moment of silence in reflection and gratitude. We welcomed one new member. In 2008, while pregnant she was told that her red blood cell (RBC) count was low, but that she should not be concerned because ‘all African Americans have lower RBC counts.’ She was also told that her White blood cell count was low. She was diagnosed in 2009 with smoldering Multiple myeloma (MM). She was upset and in denial but continued her visits to Emory Winship every four months for monitoring. Her CRAB criteria were good – no back pain, or bone or kidney involvement. She had three bone marrow biopsies during this period. Her M-spike continued to climb. She was invited to participate in a clinical trial. She is seeing Dr. Nooka at Emory. Dr. Nooka is conducting a study to look at MM in African Americans. We will invite Dr. Nooka to share his research with the group. She was impressed that Dr. Nooka took his time to explain the disease. She recorded everything. She is doing well at this time but is seeking information to help her through this journey.**

**The focus of the meeting was to share what was learned from the many activities members have participated in during the month of October to learn more about multiple myeloma (MM) and to raise awareness about myeloma, especially among African Americans. The October agenda was printed on pink paper in recognition of breast cancer/health awareness.**

**Several members attended Light the Night with friends and family. It was a beautiful October night in Piedmont Park, with music, information on blood cancers, a health walk, and fireworks. Members said it was an inspirational, motivational event. Congratulations Southside for raising 132% of your goal of \$2,500 for the Leukemia and Lymphoma Society (LLS). The total raised was \$3,296. THANK YOU for all your hard work – and THANK YOU for all who contributed to the research, financial support, and information through print and**

webinars and conferences.

Several members attended the Myeloma Crowd seminar at the Emory Conference Center on October 12 and shared highlights from the conference. They heard topics from newly diagnosed to bacterial infections, shingles, and the immune system to new therapies in CAR-T, T-cells, B-cells and other immunotherapies. Some of the sponsors of this conference, in addition to the more common pharmaceutical companies of Takeda, and Celgene included: AMGEN (studies in AMG 420 is a bispecific T-cell engager or “BiTE”, targeting cells through surface antigens, like BCMA); Adaptive biotechnologies (partnering with Sanofi to study Minimal Residual Disease and Isatuximab); Karyopharm (recently approved Xpovio™ or Selinexor), and GSK (GlaskoSmithKline) (drugs that target the B-cell maturation antigen, or BCMA – also being studied by Johnson & Johnson and Celgene). These pharma companies and their research represent the ever-changing and advancing landscape for the treatment of myeloma. Selinexor, for example is a first-in-class, oral selective inhibitor nuclear transport (SINE). Speakers, which included Drs. Kaufman and Hofmeister from Emory Winship, reported on updates for the use of vaccines in MM treatment. Vaccines are now being used as a preventive approach in smoldering MM and as an approach to extend the effectiveness of myeloma treatments—now in clinical trials post-transplant. The speakers were excellent, according to those who attended. The Myeloma Tree was introduced as a way to track their myeloma journey and to navigate treatment options ([www.healthtree.org](http://www.healthtree.org)). Bernard shared that they talked about the importance of using bone strengtheners with MM. Patients are most commonly taking Zometa or Aredia. The most recent one is Xgeva. Please check with your provider on the risks and benefits of bone strengtheners and how long you should take them.

Members also promoted myeloma awareness stations at three churches – Pat C.’s annual cancer awareness day, Portia’s annual cancer awareness day, and a Health Fair at Doris’ Church of God and Christ. Gail represented the group at a Community Engagement Day sponsored by Morehouse School at YWCA on Campbellton Road attended by over 400 people. We continue to ask attendees if they have ever heard of MM. Out of more than 100 individuals, only 4 had heard of it. They were either nurses or had family members who had been diagnosed. We had 2-3 cards that we distributed with MM signs and symptoms – and what to say to your doctor (both pieces are from IMF).

Several members have been struggling with their health and myeloma. Please keep them in your thoughts and prayers – Geraldine (2<sup>nd</sup> transplant of a tandem transplant), Janice, Darcel, and Sharon. Alma has started a new clinical trial, CC-220-MM-001. She will keep us posted. Pat C. continues to grow stronger after her third transplant.

During October, we reached an estimated 500 people with the MM message, encouraging people to share the information with at least one more person, at Sunday dinners, family reunions, etc. We also distributed brochures on the Promise Study. The Promise Study is a MM study funded by the Stand Up 2 Cancer. Participating institutions include Dana Farber, Harvard, Johns Hopkins, and the Mayo Clinic. The request is to collect samples from first degree relatives of MM patients (mother, father, sister, brother), and from African Americans from 40 – 75 years of age. The stated purpose is to find out why MM occurs at three times the rate in blacks versus whites. Gail has had problems signing up online. ([www.promisestudy.org](http://www.promisestudy.org)). Stay tuned.

Questions: With the compromised immune system of MM patients, the question came up as to whether they should get the flu shot and other vaccines. They wanted to know about the Shingles shot. Should people who continue to take acyclovir as a preventive for shingles also get the Shingles shot.

Post-Meeting Response from LT Heffner, MD – Hema Oncologist – Emory Winship: From Dr. Heffner...

- 1. Yes, please get the flu shot.*
- 2. We have not made a strong recommendation that all myeloma patients get the shingles shot. However, if getting the shingles vaccination, myeloma patients should get the 2-shot Shingrex and NOT get the old shot since the old one is a live virus.*
- 3. I will need to check with Infectious Disease about the acyclovir question, but at the moment I would continue the acyclovir, even with the Shingrex unless it is clear that the patient has proven immunity after the vaccination.*

Do you know what kind of myeloma you have? Do you follow your lab results closely? What is your IgG, IgA – trend over past four months? Is your MM kappa, lambda – is it a healthy ratio? Many of the new treatment discoveries will target the specific type of myeloma you have, making the treatment more precise, more personalized. It is important that you can define your MM.

Living well...

Advice from Vena on living well with myeloma –“stay positive. Surround yourself with positive people...”;...from Ted – “stay Spiritual. It is a big part of my daily life. I pray for the group – those who are present, and those who were not here...” from Deborah – “take some time to relax,...stop doing, just be.”

Respectfully submitted, Gail