

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

April 6, 2019

Thank you to **Jim M.** who led the meeting. There is an IMF conference call scheduled for April 25th, Living Well with Myeloma: “MGUS, Smoldering Myeloma, and Newly Diagnosed”, with Dr. Durie. Register here: <https://www.myeloma.org>. There is other great information that Dr. Durie has addressed at this site on topics such as CRISPR technology, genetic mutations, MGUS and kidney issues, and stem cell transplant. See “Ask Dr. Durie” videos on the web site when you click on IMFTV at the top of the home page.

The MMRF is sponsoring a 5K race in Atlanta on May 11th. Register here: <https://themmrf.org>. Other resources for helping you stay updated with myeloma news include: <https://mmsg.org> (our group’s site has been updated with a new format), <https://www.smartpatients.com/partners/imf> and twitter (<https://twitter.com>). Below is a list of twitter accounts that Jim follows:

Dr. Harvey from Emory – DrDonaldHarvey; MyelomaTeacher;
Dr Vincent Rajkumar from Mayo – VincentRK;
Dr. Lonial –SagarLonialMD;
Dr. Kaufman – Kaufman MMdoc;
Dr. Nooka – AjayNookaMD;
Dr. Hofmeister – EagleMyeloma;
MyelomaCrowd; IMFmyeloma
The MMRF; NorthTxMSG – north Texas Support Group leader;
JackMAiello he is a very active support group leader.

There are many others to follow including support group leaders, patients, etc. but this list provides a solid start to building your own list. You can search by the person’s name and usually find them. Once you are following someone you can see who they follow and add them to your list, etc.

We have a busy year planned! Below is a brief overview of upcoming meeting agendas: May – Dr. Harvey from Emory will join the group; June –TBD; July – Open discussion; August – 7th Annual Luncheon; September – Open discussion; October - Dr. Hofmeister from Emory will visit the group; November – The group will split into separate meetings – one for patients and one for caregivers; December - Holiday celebration!

Updates

Loretta spoke with **Sandy**, who fell recently. She was hurt, but nothing was broken. She was not able to walk for a while, but she is walking now and feeling better. Sandy is also celebrating a birthday in April. The group wishes you a very **Happy Birthday, Sandy!** Best wishes to **Becky**, who is getting married in June and moving out of state. We will miss her and her great contributions! Several members attended **Barbara’s** celebration of life and found it to be a very beautiful and uplifting experience. **Dana** mentioned that her daughter expressed her deep

appreciation to the group.

New Members

The group welcomed Amerdean and her husband, Eric. Amerdean was diagnosed in April 2016 and she had a stem cell transplant in October 2016. She joined the group to get some helpful tips in dealing with pain and anxiety.

Guest Speaker

Thank you to **Charise Gleason**, a nurse practitioner from Emory who visited the group to discuss some big changes in testing and treatments for multiple myeloma (MM), gene sequencing, and to answer questions. Charise has been a nurse practitioner for over 15 years, and she's worked with Dr. Lonial since 2003. She began by talking about gene sequencing and profiling, which she gets a lot of questions about. She answered many of our questions throughout the discussion.

Gene profiling tests require a bone marrow biopsy which can tell us more about the biology of the disease. What the test selects are CD138 cells, which are plasma cell markers found on myeloma cells. Gene sequencing tests are done at Emory mostly for patients on a clinical trial (CT) to look at the whole genome. It provides information that we don't even know what to do with yet. This testing is also done for relapsed refractory patients when we're trying to tailor treatment to your specific disease. For example, we may see graph mutations, which is present in approximately 2-4 % of MM patients. This information can help us target your therapy for better outcomes. You will see more CTs targeting specific types of patients based upon these tests. For example, Melanoma (skin cancer) has a lot of mutations, and we're using Melanoma drugs now to treat MM based upon these test results. A new CT, "MyDRUG" is about to open at Emory for relapsed MM patients. From bone marrow biopsy tests, we obtain that genetic information about sequencing. There are multiple arms on this trial that patients will be divided into based upon their genetic profiling test results. Patients will be put in the arm specific to what their genetics tell us. There are about 10 arms, which is fascinating considering that this was not an option until recently. MM patients should continue to see a lot more CTs become available to them that are using targeted therapies.

Q: Will the MyDRUG CT be in Phase 1 when it opens at Emory? **A:** Probably. **Q:** How many patients will be allowed to participate in the MyDRUG CT at Emory? **A:** Probably many, especially due to the number of arms in the CT.

We are seeing a lot of cross over for **approved drugs for treating other cancers being used in CTs to treat MM**. Venetoclax, an approved drug used to treat refractory acute leukemia patients that cannot have a stem cell transplant and CLL is in a CT for use with MM because there are a lot of genetic components to these diseases that are very similar.

We get a lot of questions about **minimum residual disease (MRD) testing**. Our standard testing blood, urine, bone marrow biopsies etc. can provide us with results which are about 10 to the minus five, or what's above the surface. Minimal residual disease (MRD) testing can provide us with 10 to the minus six, which is one cell in a million and helps us see what is below the surface. If you're MRD negative, we use this tool for prognostics, not to change treatment. There's no consensus on how to use this data yet within the MM community. What it tells us from a clinician standpoint, is you're the best place you can be when you're MRD negative, and it's going to take a while for that disease to come back, if it does. At Emory, we start MRD

testing one year after stem cell transplant and then annually after that as part of bone marrow biopsy testing. If you do not have a stem cell transplant, then MRD testing is introduced once you achieve remission.

Q: Have you seen people that are MRD negative that progress? **A:** Yes. **Q:** Have you seen MRD negative people who remain MRD negative? **A:** Yes. **Q:** Do you see people who are not MRD negative, but stay stable for 10 or more years? **A:** Yes.

For **induction therapy**, the RVd (Revlimid, Velcade, Dex) regimen has been used successfully for years. New data from the Griffin CT shows that adding a fourth drug, Daratumumab, for induction therapy is even better. The good news is that Daratumumab is generally well tolerated. Now, RVd-D is used at Emory for induction therapy for patients with standard risk MM. There are sometimes financial implications when adding Daratumumab to the regimen. In those cases, we can add Carfilzomib instead of Daratumumab as the fourth drug.

Everybody always wants to know about **CAR T-cell therapy**, which uses a patient's own immune system **to** fight their disease, which is very exciting. It's another really good treatment option but it's not for everyone; there are many qualifications to be eligible for this treatment. The procedure begins by collecting T cells, then they are sent to the manufacturer for four weeks to be genetically modified and more are grown. There is some chemotherapy involved to reduce your T cells. Finally, the altered T cells are injected back into the patient. One change to come for this type of therapy will be to start CAR T-cell therapy at the beginning of being diagnosed, rather than using as a salvage therapy after many other drugs have already been used. What's different about a CAR T-cell therapy is there is no additional treatment or maintenance afterwards. Some of the long-term side effects are blood count related issues.

One of the **antibody CTs** that is going on now is called the "GSK DREAMM" trial, where you take a monoclonal antibody, and you attach chemotherapy to it. There are no more openings on that CT. There are a lot of toxicities related to this trial and patients who are participating are having eye issues, which is not permanent but they are experiencing vision changes.

Charise took time to answer many more questions for us:

Q: Please explain serum free light chain and testing. **A:** There are heavy chains and light chains. In myeloma, the cancerous plasma cells make different antibodies called immunoglobulins (Ig). Each immunoglobulin (Ig) is made up of two whole protein chains (heavy chains) and two partial protein chains (light chains). Immunoglobulins (Ig) can be one of five types depending on their heavy chains. These are A, G, M, D and E. The heavy chains are the whole chain, such as IgA, IgG, IgM, IgD, and IgE. There are two types of light chains that all MM patients have - kappa and lambda. A serum free light chain test can detect free light chains in the blood. Doctors measure the ratio of the two different types of light chains (kappa and lambda). If myeloma cells make either kappa or lambda light chains, then the level of that light chain increases, making the ratio abnormal. Since MM has so many variables and they fluctuate a lot, this is just another tool that can help us understand what is occurring with the disease. It is the ratio that tells us a lot.

Q: Are there any known benefits for using marijuana specifically for MM patients? **A:** MM patients can get a prescription for medical marijuana. We send people to our support oncology group for assistance. As a group, there's physicians and advanced practice providers to help patients. They handle a lot of pain type issues and other problems. I've met patients who say

that it helps with neuropathy, anxiety, generalized pain, appetite, and that it helps them get off of some other medicines.

Q: Are there any known benefits for using CBD oil specifically for MM patients? **A:** There is no data to support using CBD oil to help MM patients. If it's something you're interested in, ask your medical team as you do when you are considering other supplements. And be sure to tell your medical team of all supplements that you are taking, as they can sometimes interfere with treatments.

Q: I haven't taken any medication for about 15 years and I feel good. My doctor has told me that the disease is slowly creeping back, but I need not worry because of how long it took for the disease to come back. Should I start treatment? **A:** This is called biochemical relapse. It is important to know how fast you are progressing. Also, consider "are you having symptoms"? You're essentially going back into that MGUS phase after you've just been smoldering. For people that are progressing very slowly with no symptoms it makes sense to monitor only. Since every treatment that you're on will only work for you for so long, you do not want to treat too early or change treatments too quickly. Another recommendation is to get a PET scan. If the scan results are normal, do not start treatment. If the scan results are positive, then consider changing or starting treatment.

Q: Is there any downside for a MM patient getting a PET scan? **A:** Some insurance does not cover PET scans, but otherwise, no. An alternative is to get a full body MRI, which takes approximately 2-1/2 hours. **Q:** Can an open MRI be used for MM patients who are claustrophobic? **A:** Yes, but the views are not as good as when using a closed MRI. **Q:** Can stress cause a MM patient to relapse? **A:** Yes, very extreme stress can result in relapse. **Q:** How high should you allow M protein to get before treating?

A: This is different for everyone. Consider the CRAB criteria when assessing. Some people can have a high M protein with no symptoms and others can have a very low M protein level with problems.

Q: The drug, Welchol that is used to control diarrhea has fallen out of formulary for some insurance. Is the replacement just as good? **A:** Cholestipol, when prescribed for diarrhea caused by Revlimid works just as good. (Note: Jim mentioned that the Welchol website has a coupon that can be used for a 30-day supply of Welchol for a cost at about \$10 at Walmart).

Submitted by Wendy R.

Southside Myeloma Support Group

April 27, 2019

Next Meeting: Patient and Caregiver sharing – updates and resources

The meeting opened with a moment of silence. There were four new members present. They are Myra C., Andula C., Kechia M. and Minnie C. also attended the meeting. While Minnie has leukemia, not myeloma, she accepted Doris' invitation to learn all she could about how she could be a better patient with blood cancer. Myra C. was diagnosed in 2018, is currently on a therapy that includes Revlimid, Dex and Zometa. She is being treated at the VA Hospital, and is scheduled for a Stem Cell Transplant (SCT) in June 2019. Andula is taking only Revlimid and has not had a SCT. Kechia was diagnosed with smoldering myeloma after having lab tests

including urine analysis and a PT scan. She is not taking any medications for her myeloma and goes to Northside for her treatment.

Our scheduled speaker, Elizabeth Carter, RN from Takeda, was unable to attend the meeting to speak about Cancer Survivorship and will be rescheduled for another date. We thank her for providing a wonderful lunch for us even in her absence.

To provide practical educational information for our new guests on living with myeloma, each of those present introduced themselves and provided information on their dates of diagnosis, current treatment status, and some pearl about the reality of living with multiple myeloma. Glenda and Doris are in remission and Doris is on maintenance therapy with Revlimid. Doris was diagnosed in 2007.

There are three groups that have multiple myeloma as a major focus of their health promotion and research. They are the International Myeloma Foundation (IMF www.myeloma.org), the Leukemia and Lymphoma Society (LLS, www.lls.org), and the Multiple Myeloma Research Foundation (MMRF, www.themmr.org). Each of these organizations has resources specific to the myeloma patient, including print materials, webinars on important topics, and someone who can help to answer your questions about your own myeloma. Each group has a telephone number, so you can reach them by phone if that is your preference. See contact information for these organizations at the end of this newsletter. Additional reliable organizations and websites for myeloma include the American Cancer Society (www.cancer.org) and the National Cancer Institute (www.cancer.gov).

One question that came up was how long should one take Zometa? Zometa (zoledronic acid) and Aredia (pamidronate) are two of the more common bisphosphonates used in myeloma to help reduce negative impact of the disease on the bones. Bisphosphonates are used to treat bone pain and to strengthen bones weakened by the myeloma. A new bone strengthener called XGEVA (denosumab). In terms of time to administer, Aredia takes longer through infusion (about 2 hours), Zometa takes about 30 minutes, and Xgeva is an injection under the skin. The Xgeva is reported to have a more anti-myeloma effect. According to the updated (May 2018) guidelines of ASCO (American Society of Clinical Oncology), bisphosphonates should be given for 2 years and then at the physician's discretion. Renal issues: Zoledronic acid can cause renal toxicity depending upon dose and duration of infusion. Denosumab has no negative side effects to the kidneys and is superior for patients with Kidney (renal) failure. The other concern of long-term use of bisphosphonates is osteonecrosis of the jaw (death of bone tissue).

<https://www.myelomacrowd.org/new-bone-strengthener/>

We expressed our gratitude for all those four members who assisted with the Health Fair at West End Mall on March 23. Our table was at the main entrance to the Mall, so we were able to get most people as they walked in. We asked each person if they had ever heard of Myeloma – more than 95% said they had not. We then provided them with the IMF educational pieces on Signs and symptoms of myeloma and African Americans and myeloma, told them it was a blood cancer that effects blacks at least twice the rate as whites, and encouraged them to share the information with at least one more person. We had additional educational pieces from LLS, the Southside banner, and more. The event was sponsored by the Master of Public Health Program, Morehouse School of Medicine. They were very attentive to the vendors and provided lunch. Though we count, we estimate our audience was over 98% African American and we touched at least 100 adults – men and women, on a Saturday morning and afternoon.

Thanks to Doris and Jameca, we were able to deposit an additional \$140 into our Support Group treasury from sales of Belk Store Charity sale event. Doris sold at least \$100 worth of

tickets.

There are new myeloma educational pieces of material. Thank you to Celgene for the church fans to go with the African American initiative, Standing in the GAAP. The other piece is a coloring book from LLS that shows the graphics of a stem cell transplant. It may be designed for children with leukemia, but it can most certainly help adults to understand the process.

We have been corrected on the telephone number we provided for free rides to appointments through a partnership with the American Cancer Society and Lyft: Patients seeking the free rides can coordinate with the American Cancer Society by calling 800-227-2345 or visiting www.cancer.org. ACS will then use the Lyft Concierge service to arrange a ride.

Announcements/Resources/Upcoming Meetings

IMF - Teleconference - Living Well with Myeloma, Dr. Brian Durie April 25 at 7 PM. MGUS, Smoldering, Newly Diagnosed. Replay at: <https://www.myeloma.org/imf-tv?category=24>

MMRF- Spring Webinar Series: MRD/Blood Biopsy, May 15; ASCO Highlights - June 27, 2019.

REGISTER at www.myeloma.org

MMRF. MyDRUG (Myeloma – Developing Regimens Using Genomics), the MMRF is leading the charge in this new research approach. The MyDRUG trial was developed based on key findings from the MMRF CoMMpass Study and the Multiple Myeloma Research Consortium (MMRC) Molecular Profiling Initiative. Myeloma is not one uniform disease but rather a variety of different disease subtypes defined by different genetic mutations. This is Precision Medicine – individualized treatment based on specific genetic mutations.

FDA has placed a hold on Venetoclax, including clinical trials. FDA reviewed data from the BELLINI clinical trial (NCT02755597, Study M14-031) evaluating the use of Venetoclax combined with Bortezomib (Velcade), a proteasome inhibitor, and dexamethasone in patients with multiple myeloma. Patients who are receiving clinical benefit can continue treatment in these trials after they re consent.

Ask Dr. Durie this month: What new information is there about myeloma drugs in clinical trials?

IMF – Amazon donates 0.5% of all purchases you make to the IMF when: You shop at smile.amazon.com, AND You designate the International Myeloma Foundation as your preferred charity. All donations are made at no added cost to you! It's that simple.

Respectfully submitted, *Vermell and Gail*

Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com
web site: ssatlanta.support.myeloma.org

Southside Meetings: 5/25/2019; 6/22/2019

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Northside Meetings: 6/1/2019; 7/6/2019

Meets 11:00 AM on the 1st Saturday of each month

Shallowford Presbyterian Church

2375 Shallowford Rd.

Atlanta, GA 30345

mmsg.org, email: aammsg-2@comcast.net

For additional information, contact:

Nancy Bruno 404-374-9020;

Sandy Brown 470-514-5330

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.