

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

News & Business

Thank you to **Jim M.** who led the meeting of approximately 20 members. Congratulations to **Marilyn M.** and **Tom L.** who won the drawing for beautiful prayer shawls that were graciously made and donated by caring members of the church. These special shawls are hand-made with heart and soul and donated to people throughout the world!

Thank you to our guest speaker, **Kim Burney**, who provided lunch! Please remember that if anyone in the group needs assistance getting to/from meetings or doctor appointments to let a group leader (Nancy or Jim) know. They are able to assist and find volunteers that can help you.

Upcoming meetings:

October – **Dr. Hofmeister**, a myeloma doctor from Emory will be joining us.

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

Guest Speaker

Thank you to **Kim Burney**, an oncology nurse for over 20 years. Kim has worked with cancer patients from the time that she graduated from college and she has spoken at national leadership conferences for the IMF, which is where she met **Jim M.**, three years ago in Dallas. She has a lot of experience working with a multiple myeloma patients, and she is currently contracted with Janssen as a nurse educator. She joined the group to discuss **DARZALEX** (daratumumab) and to answer questions for us. Janssen Oncology brochures for **DARZALEX** were provided and are available in the group's library. Kim's presentation is timely as we have group members, including **Jeff** who are already on this drug, **Jim** who will start in a few days, and others who are considering it as their next treatment.

DARZALEX is a monoclonal antibody in the targeted therapy group. It is targeted to find and attach to a protein called CD38, which is found on the surface of red blood cells and myeloma cells. Because it targets specific cells to kill there is less collateral damage for the patient, compared with conventional chemotherapy. The drug was approved in November 2015, and since then there have become multiple ways that it is administered, depending on the patient's history: a) in combination with many other drugs such as Revlimid, Prednisone, Dex, Velcade, Melphalan, and Pomalyst, and b) alone as a single agent. The drug was initially used as a salvage drug and then changed to a second line drug for relapsed patients. It is now also used as a frontline drug in combination with Revlimid and Dex for patients who are not stem cell candidates. The drug works by itself but works best - with better, deeper, and longer responses - when combined with other drugs and it is considered one of the best myeloma drugs available today.

DARZALEX is administered as an in-office infusion in a vein (no port necessary) each time. Before treatment begins, the patient will have a blood test to match their blood type and will also

be given medications to help reduce the risk of infusion reactions. You will likely be given Benadryl, steroids (i.e. Dex), and acetaminophen to start.

The first time that the drug is administered the process is long and drug infusion reactions are expected. When infusion reactions to the drug occur, the infusion is stopped, the patient is treated to recovery, and the infusion is restarted. The first infusion will last about 8 hours in a single (one day) setting, not counting the time to stop, treat, and restart. The FDA has now approved a two day infusion for the first dose and splits the dose between two days (4 hours each), not counting stop and restart times, which is better tolerated for some patients. It is the patient's choice of one or two days for the first dose. After the infusion the patient is given medications to lower the chance of delayed infusion reactions. Nurses are expecting, and prepared for, infusion reactions and are available to help patients overcome the reactions. Kim mentioned that most infusion reactions occur during the first infusion and within the first hour and a half of the administration. In her experience the most common infusion reactions have been fever-like symptoms, shortness of breath, throat tightness, tiredness, dry cough, sneezing, runny eyes, and nausea, which seem to occur early. Be sure to let the nurses know immediately if you begin feeling different than you did when you came in, so that they can take care of you right away. Nurses are ready to stop infusions and treat all of these symptoms until the patient is ready to restart the infusion. For patients who know that they are especially likely to experience a certain reaction, some additional and specific proactive preparation can be done in advance of starting the infusion. Subsequent infusions take less time with significantly less chance of infusion reactions. The second time takes about 5-6 hours, then expect about 3-4 hours each time after week 4. The times do not account for stopping/restarting the infusion, but infusion reactions are less likely to occur after the first time and with each subsequent infusion, as the patient has learned to tolerate the drug. The drug dosage does not change, rather the volume of the dose changes due to less liquids provided in the infusion as the patient adjusts to the drug over time.

Common side effects of *DARZALEX* treatment (post infusion) include tiredness, nausea, diarrhea, shortness of breath, trouble sleeping, fever, cough, muscle spasms, back pain, joint pain, vomiting, cold-like symptoms, dizziness, chills, constipation, swollen hands, ankles, or feet, nerve damage. Kim mentioned that some of the side effects that occur may actually be side effects of the other drugs taken with the *DARZALEX*. All side effects from all of the combination regimens must be documented in the brochure. For example, vomiting, back pain, swelling of the hands, feet and ankles are likely caused by steroids. *DARZALEX* alone does not cause diarrhea, but Revlimid can cause diarrhea. *DARZALEX* alone does not cause neuropathy, but Velcade can cause neuropathy, etc.

Kim provided a lot of information and answered many questions for us:

Q: Why is this drug so successful? **A:** It is one drug with one target, but this one drug can kill that target more than one way, depending on what other drug it is paired with. **Q:** Is the drug given weekly? **A:** It is administered weekly in the beginning but then the frequency tapers off and changes depending on the combination regimen that the patient is on. For example, it is administered weekly for a while, then every 2-3 weeks, then every 4 weeks indefinitely. **Q:** When does the patient stop taking the drug? **A:** It is designed for the patient to continue on the drug for as long as it works and can be tolerated. **Q:** Why is a blood test to match their blood type performed before the drug is administered? **A:** An initial blood test to determine type is

performed as a baseline. When on *DARZALEX*, it can appear as if you have antibodies, which could actually be the drug itself attached to the red blood cells (not an actual antibody). The drug doesn't change your blood type or cause problems with your blood, but the blood banks need to be aware of this in the event that that you need a blood transfusion. If the blood banks know you're on this drug, then they know what to do to remove the antibody to get a match. **Q:** Will the drug be given by an injection versus an infusion in the future? **A:** Yes, and even for the first dose. We are expecting more information about this in January 2020. **Q:** Are there some patients who take the drug as only a single agent? **A:** Yes, but clinical trials show that the drug works better with results lasting longer when combined with other drugs. Progression-free survival rate significantly increases when combined with other drugs. **Q:** The drug that I have been on for years and that I am comfortable with has stopped working for me. It is a drug that is normally paired with *DARZALEX*. *If I introduced DARZALEX into my current therapy, could the combination likely work for me?* **A:** *Yes, the combination could work, and it is worth investigating with your medical team. One of the things that are most interesting about DARZALEX is that it is being paired with other drugs that are known to work well already. It is being added to existing regimens, not replacing other drugs, as they work better and longer together.* **Q:** *How is the DARZALEX dose determined for a patient?* **A:** *The dose is based on a patient's height and weight.* **Q:** *Would a patient with a history of asthma, COPD, and breathing issues be able to use/tolerate DARZALEX?* **A:** *If you already have breathing issues of any kind or if you smoke, you need to make sure the doctor knows, and an inhaler would be prescribed for you to bring to your treatments.* **Q:** *Would a patient who has had shingles be able to use/tolerate DARZALEX?* **A:** *DARZALEX can reactivate shingles and so an increased dose of Acyclovir would be prescribed. Note that patients should be on an antiviral medication anyway when on this drug, even if they have had the shingles vaccine.* **Q:** Are there any age limits for using *DARZALEX*? **A:** *Patient ages in clinical trials have ranged from 40-90. There are special precautions necessary for anyone pregnant or expecting to become pregnant.* **Q:** When reactions occur and the infusion is stopped, do symptoms clear up quickly? **A:** Yes, because the symptoms are treated until the patient recovers. Depending on the symptoms, the patient might be given oxygen, Benadryl, anti-nausea medication, etc. When the infusion restarts, it has to start slowly and ramp up again; it cannot start at the dosage where it left off. **Q:** Do you recommend having someone go to the clinic with you for at least the first time the drug is administered? **A:** I urge patients to bring somebody, if possible, for a number of reasons: a) most of the time the patient is overwhelmed and you may need help remembering important instruction, and b) it's comforting to have somebody there that you know. That's another person watching you and making sure that you're doing well. **Q:** What is 11/14 translocation? **A:** It is a condition when chromosome 11 is where chromosome 14 should be, and chromosome 14 is where chromosome 11 should be (the two chromosome locations are switched). 15% of myeloma patients have this abnormality. **Q:** Is the drug expensive? **A:** Yes, it's an expensive drug. Janssen CarePath can help you find payment assistance. More information can be found in the back of your brochure, beginning on Page 32.

Submitted by Wendy

Southside Myeloma Support Group

September 28, 2019

Doris opened the meeting with a moment of silence.

New member, **Marcia W.** shared part of her journey with Myeloma. She was diagnosed in April 2019 and has had a transplant. Her primary care doctor diagnosed her as slightly anemic. She had a soreness in her chest and back – maybe inflammation in her muscles. She had a few tests. They suspected Lupus or some other autoimmune disease. She saw the results of her tests through an app on her cell phone. The results showed up all in red. She should see a GI (gastrointestinal) specialist. She should see a phlebotomist. She went to see the GI specialist because she could not get an appointment with the hematologist for a month. The GI recommended a colonoscopy which she had – just to cover her bases. She has decent insurance. In two weeks, she received a phone call with the diagnosis of myeloma.

The GI doctor took the time to draw a picture of her bone marrow and her cells. He used the terms MGUS and smoldering. She got a confirmed diagnosis with Dr. Kaufman at Emory Winship. She is 30 days out from her Stem Cell Transplant (Aug 29, SCT), which went very well. **Steve W.**, her husband and caregiver shared that things were challenging. He took several weeks off work to care for her and has just recently gone back to work. Things are going well.

This month's speaker was **Marilyn Pritchard**, R.N., MSN, OCN, Clinical Nurse Consultant-South Region, Celgene Corporation. Her topic was survivorship and **Living with Multiple Myeloma**. Thank you so much for lunch, Marilyn.

Some history: Marilyn reflected on her early days as a young nurse, about 32 years ago in 1987. She had her first patient with multiple myeloma. He had compression fractures in his back and was in full renal failure. Lots of myeloma patients had long body braces for the many fractures. Melphalan and prednisone were the only drugs available to treat myeloma. Then there was the “pump” in 1998 – with VAD (Vincristine, doxorubicin [Adriamycin] and dexamethasone). Then came Thalidomide, which worked for some, but had a side effect of peripheral neuropathy. The proteasome inhibitor, Velcade, came next, and now there are many more drugs and classes of drugs to treat myeloma (four approved in 2016). Patients are living longer. It is a

heterogenic disease (different genes)... everyone is different. Research is ongoing. Each person has a different journey. She advised that we all get to follow our medical records through the electronic portal. Multiple myeloma patients are some of the most informed patients. Cancer is a very expensive disease. Fortunately, since the Affordable Care Act, insurance companies cannot cancel policies due to “pre-existing conditions.”

In your survivorship plan, in addition to financial planning, you should consider your emotional needs and physical needs. For many with peripheral neuropathy, there is no real fix. The therapies appear to be more of a band-aid -- Gabapentin, Vitamin B-complex, etc. *Gabapentin is to become a controlled substance later in 2019.* Check with your doctor, insurance carrier, and your pharmacist for any changes in access to the medication. Gail currently gets her Gaba with a three-month prescription from insurer through the mail. This could change with a controlled substance status.

Treating myeloma continues to be more advanced. Where there was once a “watchful waiting” approach to Smoldering Myeloma, now there is treatment to keep suspected cells from transitioning into cancer cells. Some are still diagnosed “by accident.” Marcia had bone loss, anemia, and was feeling rundown and tired.

There is an emotional impact from the diagnosis – and all the changes in your life and decisions that must be made while adjusting to your new normal. Marilyn had several tips for us to live well with myeloma. Your being a survivor begins at the moment you are diagnosed and goes on forever.

Speak up. Communicate with your providers if you feel that issues are not addressed sufficiently. **Admit you need help.** Anxiety and depression are realities of a lifetime serious diagnosis. Take medication for depression if needed. **Take a proactive role in your care.** Get a notebook. Prepare for your doctor’s visits. Write down everything, including questions for your doctor’s visits on side effects, and other issues with your therapy. Make your limited time with the doctor count. Do not allow the apparent ‘hurriedness’ of the doctor intimidate you.

Learn all you can about myeloma. On the Internet, go to reputable websites like myeloma.org (International Myeloma Foundation), cancer.gov (National Cancer Institute -NCI), cancer.gov (American Cancer Society – ACS). and LLS.org (Leukemia and Lymphoma Society). In addition to Support Groups,

take advantage of the in-person seminars and online webinars that are free most of the time.

Stay Healthy. Keep active. Move your legs and arms especially to reduce chance of blood clots. A side effect of many of the myeloma medications is a risk of blood clots. Any exercise you get above and beyond what you get now is important. **Eat right.** Focus on a colorful plate – lots of green and red and orange vegetables and fruit. If you are neutropenic (low white blood cell count), do not eat raw vegetables. **Stay positive.** Life is 10% of what happens to you, 90% of how you respond to it. **Feeling lonely?** Reach out to Support Group members. **Communicate** with Health Care Providers (HCP), but also with your family. **Set goals** – weekly, monthly, yearly. What is your treatment plan? Call the care team in between appointments if you have problems. Do not wait until late in the evening – or until Friday evening to reach out to your medical team with problems. Keep up with all your other medical appointments – physical, mammography, and colonoscopy. Talk with your HCP about immunizations – flu. You can find a booklet for your Cancer Plan at the American Cancer Society or at http://mncanceralliance.org/wp-content/uploads/2013/07/SurvivorCarePlan3202012_Final.pdf

Other Discussion Why do we have so much problems in getting men to diagnosis and treatment, especially African American men. Could be an attitude of wanting to be strong and not appearing weak. Some call it the John Wayne complex. A similar reference in African Americans is folk hero, John Henry who felt he could compete against his environment if he just worked hard enough. This strong personality trait is a theory to cope with psychological, social, and environmental stressors and is a consideration in unexplained hypertension and cardiovascular disease.

More Member Updates. **Alma** is considering a randomized clinical trial CC228, a Celgene drug that is a stronger version of Pomalyst. There are four arms to the CT with differing arms including Daratumumab, Velcade, and Kyprolis. Neither Dara nor Kyprolis were successful with Alma. **Janet** has had shortness of breath and A Fib. She is on a break from Myeloma regimen of Dara and Pomalyst. Her lungs were filled with fluid. **Geraldine** is recovering from her second SCT in four months. She was able to remain in the hospital for the procedure at Northside Hospital (versus going and coming each day for weeks). Her sister came to stay with her. She is to stay clear of meetings, but she is feeling good. **Vena** wondered if anyone in the group had heard of

the **soursop herb**. This herb (aka Graviola) has been used as tea to fight cancer. Other uses have been for herpes, infections, and for pain. Other information includes its side effects – nerve damage that may lead to Parkinson’s-like symptoms like tremors or stiff muscles. (Medicalnewstoday.com and Memoria Sloan Kettering- <https://www.mskcc.org/cancer-care/integrative-medicine/herbs/graviola>). This is a reminder to all of us that all medications, foods, and herbs have side effects. Should you decide to take soursop or any other herb, please share with your HCP. If you are taking hypertension or diabetes medications, do not take with this herb, as its effects may be additive. **Vermell** has been traveling and spending time with family over the summer months but us back, and happy to review lab results with anyone who desires it. **Carol’s** daughter has been ill and is fine now. She had her annual biopsy recently and is awaiting results. It’s an emotional period of the unknown waiting for test results.

There are many opportunities for fundraising, raising awareness for Myeloma, and learning more about current treatment of myeloma in the next four weeks. See the schedule below for upcoming events and participate in the ways that are most comfortable for you.

We distributed brochures for the Promise Study. This is an opportunity to help determine if there are particular genetics that place African Americans at the higher risk of three times that of whites. Any patients and family members aged 40-75 are invited to participate. We will continue to spread the word among African Americans over the next few weeks at churches (Pat C., Portia, and Doris) and Morehouse School of Medicine (Gail).

(<https://promisestudy.org>).Gail will order more brochures for the next meeting.

We celebrated the birthdays of members in September and October.

Inspirational quote to end the meeting:

Nothing can dim the light which shines from within. – Maya Angelou

Respectfully submitted, Gail