

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

May 1, 2021

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Business News

Thank you to **Nancy B.** who hosted the meeting, with approximately 25 people attending. The meeting began with an informative discussion with Dr. Harvey, who joined the meeting to talk about clinical trials (CTs) and new multiple myeloma (MM) treatments. Afterwards we had a brief open forum discussion where members provided status updates and shared information.

Guest Speaker

Thank you to **Dr. Harvey, Pharmacist and Director of Phase 1 Clinical Trials at Emory Winship Center.** Dr. Harvey began the discussion by acknowledging how much he appreciates this group for its many years of engagement and in working with the team at Emory and across the Atlanta metro region for improving the lives of patients and their families affected by MM. Dr. Harvey was recently named the Medical Director of the Clinical Trials Office, and now oversees clinical trials across different cancer types in consultation and collaboration with his physician colleagues. He explained that about a third of their work is in MM, and Emory is one of the largest MM programs in the nation and throughout the world.

The recent past has been impressive in terms of MM drug approvals but there is still a lot of new treatments in development for patients across the whole spectrum of MM. I.e). newly diagnosed or those who have had transplants or other treatments and still need therapies beyond that. The new *CAR T cell* therapies are exciting and are continuing to expand their use in myeloma treatment. Another agent that Emory has been involved with for

a while is *belantamab mafodotin* also known as *BLENREP*. It's an interesting agent and it is the first time a drug of its type has been approved in treating MM. Emory has seen some interesting and deep responses with that drug. There are certainly side effects that need to be addressed but some really impressive data has been observed and patients tend to have a very long response to the drug. Other new agents on the horizon are the new "IMiDs" from Celgene. Next generation of these drugs are being developed now and there are two new ones that are coming through the pipeline. One is called *Iberdomide*, and another one that is not yet named. They are both very promising so far, including for those patients that have taken other IMiDs" including *Revlimid* and *Pomalyst*.

The Emory team continues to talk a lot about minimal residual disease (MRD) in MM and what that means by looking at MRD at a deeper level of how the drugs are working. We can think more about how to incorporate that into new measures of drug efficacy or how well the drug is working in Clinical Trials. It is exciting to be able to get the MRD down to a very low level of MM that is measurable in new ways.

Emory's physicians are doing a lot of work with MM and kidney problems to understand outcomes when aggressively treating newly diagnosed patients with kidney issues. We know that MM has causes kidney problems, and in the vast majority of instances we are using extremely aggressive therapy to improve and reverse kidney damage. One of our current CTs uses a four-drug regimen to try to reverse the kidney damage that MM has caused, and we believe that it's able to be done and we're excited to continue that trial and to get those questions answered. Lots of good things related to bone health are happening as well. We're getting a deeper understanding of how MM can cause bone problems. The bone problems that are caused by the disease itself become less with more effective MM drugs.

There are some general things that are important to know about Clinical Trials (CTs).

First, all the approved drugs that we use to treat MM today were at some point part of a CT that patients received. Those drugs were developed in the

process of CTS, and we take that responsibility very seriously. Secondly, we don't use placebos in cancer CTs because that's unethical. In a MM CT you're always going to get something that's going to be expected to treat your MM. Finally, when you participate in a CT, it is required that you be monitored very frequently, so even if you are receiving a standard care agent. Your condition will be measured and evaluated much more frequently than it would be in a non-CT environment, and you will receive the best of care. The people who contribute to the drug development process are of the highest form of patient advocacy because they help us understand how we go about asking questions and getting new drugs to patients in the community. We are trying to do this in the fastest and most effective way possible and get the right answers. CTs are our path forward. We really try and we, again, the big "we" are the FDA, pharmaceutical companies, and research institutions. We are trying to get treatment drugs to patients that are effective as quickly as possible. Because we know that we're far from where we need to be. CT patients are our heroes, as they are making the difference for future patients.

Dr. Harvey answered many questions for us as follows:

Q: Please comment on peripheral neuropathy and how it affects MM patients. **A:** Peripheral neuropathy is a big challenge. It can be caused by the disease itself, as well as the drugs used to treat it. It is advised that patients get a nerve exam before taking any MM drugs, to serve as a baseline before treatment. Also, we know that certain drugs such as *Thalidomide* cause neuropathy and we have stopped using that drug very often. *Velcade* also causes neuropathy, and although we still use that drug we have found that the sub-cutaneous version is better tolerated than the IV version. When you experience neuropathy, tell you medical team immediately. Neuropathy can sometimes be reversed, and the sooner it is identified and treated, the better the outcome. There are some supplements that have been shown to help with symptoms including Alpha Lipoic Acid and Vitamins C, B6, and D. It is not advised to take large doses of any supplements and staying hydrated is important.

Q: Do you recommend potassium for cramps, especially foot and hand cramps at night? I get charley horses in my calf muscles. What can you

recommend? **A:** Potassium is regulated by your body and eliminated by the kidneys. If your kidneys function well, then supplementing with potassium can help. Also, calcium and magnesium help with muscle function. Get supplements prescribed by your care team. Good foods to eat include bananas, lentils, and salmon. Tonic water can potentially help as well. Keeping your electrolytes stable and staying well hydrated is also important. Be aware that magnesium supplements can cause diarrhea.

Q: How many MM clinical trials (CTs) are currently in progress? **A:** There are at least 35 CTs including trials for MGUS at Emory. These trials consider such things as who progresses from MGUS, what happens if we treat MGUS aggressively and early, is there any changes in the outcome? There are also many trials for relapsed and refractory MM cases using both single and/or multiple agents for both low and high-risk patients. Additional CTs are using approved drugs that have been successfully used in other cancers to determine if they will also work for MM. There is a focus on bone and kidney health but not a lot of emphasis placed on anemia presently because we know that it improves as the MM improves. Dr. Harvey encourages blood and platelet donations.

Q: Why is the efficacy between *Velcade* and *Ninlaro* so different? I'm taking Ninlaro now and not getting quite as deep a response, and I'm also getting some side effects like nausea and maybe some reduced eyesight. Are those common side effects with *Ninlaro*? **A:** The eyesight issue could be caused by the Ninlaro, but it might be caused by something else, so it is recommended getting your eyes checked by an optometrist or ophthalmologist. Ninlaro is known to cause nausea as you described. Dexamethasone is a good nausea medicine so try taking your dexamethasone before you take your Ninlaro. Otherwise, I would encourage you to take something like Zofran before you take your Ninlaro.

Q: How much Vitamin D should you take daily? **A:** 2000 IUs is a good amount, and do not take more unless your doctor tells you differently.

Q: Would you comment on occasional and general pain management for MM patients with kidney function concerns. What kind of advice would you give us on that and on anti-inflammatory agents like curcumin? **A:** The use of NSAIDs in moderation, and sporadically will not generally cause kidney damage for those without kidney issues. However, if your kidneys do not

function well, then it becomes more challenging, and I would encourage you to know your creatinine clearance value, which is a measure of how well your kidneys work. If your creatinine clearance is below 50, then be more careful about how often you can or should take drugs like Advil or other NSAIDs. Steroids are anti-inflammatory and so there should be some pain management relief when using them because they also reduce inflammation. Thus, steroids are an option for treating both MM and pain. In addition, there are other topical agents that can be used safely and rubbed on areas where there is pain. Curcumin seems to be hit and miss, and it doesn't get absorbed very well from the gut, yet we see studies where people say curcumin really does help them. Therefore, I would say that if you are interested in curcumin, then try it, because it could help and it won't harm. Massage therapy is another option to consider for pain management that does not involve taking drugs.

Q: What do you hear concerning *CBD* oil? **A:** *CBD* is fascinating, and Dr. Harvey knows people who have been helped with sleep and pain issues. The challenge is that these products are not FDA approved or regulated and so we don't know what ingredients they contain. If you would like to try the products, discuss with your doctor, and try them if your medical team approves you doing so.

Q: You mentioned creatinine clearance earlier. Is that something that is measured in normal bloodwork tests? **A:** Creatinine clearance is a measure that can be derived from your laboratory values. Since drugs are cleared by the kidneys, we want to make sure you get the right treatment dose and creatinine clearance is the way that we assess those doses. *Revlimid* is a classic example. *Revlimid* is a drug that we dose based on how well your kidneys filter, as measured by creatinine clearance.

Q: I am having a problem with swelling of my ankles. I am currently taking *Pradaxa* 500 milligrams twice a day, and a water pill daily, and wear support hose because I have had blood clots. Even though I'm doing all these things, my ankles are still swelling. I also take 15 milligrams of *Revlimid* and four milligrams of *Dex* once a week. Any recommendations? **A:** The water pills should help to remove some of that swelling. If you notice more pain in your upper legs, that is when we worry about deep vein thrombosis and the clots that you may have had already probably formed in those veins and

those are ones that tend to be above the knee. Moving around as much as you can during the day and staying on your blood thinner is important. Keep wearing the support hose, as they're very effective and will help to mobilize that fluid. Weighing yourself regularly to know where your fluid status is can also be helpful. Things to be concerned about is a significant (four or five pound) weight change over a couple of days. Try to keep your feet elevated when you're seated.

Q: My husband has had a severe allergic reaction to *Revlimid* with a very bad rash on his second cycle. Is there any solution for that? **A:** We deal with it differently based on the situation. One way is to reduce the dose or hold off on taking the drug until reaction gets better. Using topical creams like hydrocortisone can also help, as can using Benadryl to treat some of the itchiness.

Q: How effective is the COVID vaccine for MM patients? **A:** This issue is being actively investigated in Clinical Trials – i.e. If you get the vaccine, how well do you respond? We know that the vaccine stimulates the immune system, but does it work well enough for MM and other blood cancer patients? We don't know, but from lab responses we believe it is effective, if not fully effective at least we think it is helpful. We recommend: 1) Get the vaccine (less response is better than none), and 2) Even when vaccinated, stay vigilant about protecting yourself.

Q: What if the antibody test shows negative a month after receiving the vaccine? **A:** Get antibody tested again, then ask your care team if you need another round of vaccines. Ask if you have a blunted immune system that doesn't process the vaccine?

Q: I have stopped taking *Pomalyst* due to shortness of breath and blood clots. Is there a replacement for *Pomalyst* in the works? **A:** There are two in development, but not on the market yet. One is called *Iberdomide* and works for patients who have used other IMiDs previously.

Q: Why do patients gain weight when taking *Dex*? **A:** Dex is a steroid, and steroids cause the body to produce cortisol, which stimulates the body to process sugar to produce energy. Dex does this and makes your body retain water and fat and stimulates appetite. This fight or flight response also causes a fat redistribution over time. Dex causes your body to hold onto sugar that stores as fat and makes muscles less strong.

Q: Can the use of a steroids cause AFib? **A:** No, not generally. AFib can be caused by physiological stress such as high blood pressure over a long period of time.

Q: Can a COVID vaccine reduce M spike numbers? My numbers went from the 600s to less than 2 after my vaccination. **A:** No, a COVID vaccine should not increase or decrease m spike numbers; I suggest repeating labs.

Open Discussion

We welcomed two new members, **Tom H.** and **Neil G.**

Tom H learned about the group from **Jeff W.** Tom was planning to start a CT in the upcoming week, but he did not pass all the required tests, so he will likely begin standard MM treatments instead. Tom explained that he is a very fit person who enjoys yoga and going to the gym. He started having back problems and learned that some of his vertebrae were fractured, which led to a very recent MM diagnosis. He has never been sick before and has anxiety and fears about potential side effects of beginning treatments.

Nancy commented how important it is to keep stress under control and to let your doctor know immediately of any anxiety and side effects that affect your quality of life, no matter how minor they might seem. The medical teams are prepared to help you with these issues and want a good experience and quality of life for their patients, as they know that patients that have these issues under control have better outcomes.

Neil G. learned about the group from **Jim M.** Neil was diagnosed in October 2018 and had a stem cell transplant in June 2019. He is currently taking Dara and Cytosan. Neil explained that he has end stage renal failure and has a very low platelet count, so he must be very careful.

Jim M. thought he broke his foot, but it turns out that he had blood clot in his calf muscles which made the bottom of his foot hurt so bad that he could not walk on it. He has gained weight from being on Dex, which is causing multiple issues with his body. He was in ER recently with breathing and coughing issues and went through a multitude of tests. He is working on ridding all sugar from his diet and changed his diet to only eat fish and vegetables; and is trying to stay active as much as possible. His doctors

have stopped the *Pomalyst* for now, which controls his MM well. Jim mentioned that he is starting to look for options for future MM treatments. Jim mentioned that while these ongoing issues can be discouraging, he knows that “there is a pony in the manure field” and he won’t let these problems ruin his life. **Nancy** commented that this is what we call resilience.

Jeff W. recommended that patients learn what type of MM they have, as it is especially important when doing research and looking for options. **Nancy** recommended viewing the IMF website (myeloma.org) for Patient & Family webinars and Dr. Durie postings for staying updated with COVID information. The IMF is watching patients and how they react to COVID and vaccinations. There are new studies on antibody levels that addresses things like getting your antibodies tested and how often.

Submitted by Wendy R

Meeting Minutes

Southside Multiple Myeloma Support Group

May 22, 2021

Business News

Next Meeting: June 26, 2021. **Karen B Stevenson, M.D., M.Div. -- psychiatrist, author, and ordained minister. Former Chaplain at the VA Hospital.** Topic discussion is “*Thoughts on the Gift of Grieving.*” Please join us.

Doris opened the meeting with a moment of silence and greeting those in attendance, including new members. We acknowledged May as the month to highlight other disease areas like *High Blood Pressure, Older Americans Month, Physical activity, National Mental Health Awareness Month, Lupus Awareness Month*, among others.

Guest Speaker

Our speakers were **Jennifer Rooke, MD, Preventive Medicine Specialist** and **Carlton Morse**, one of her many successful patients. Dr. Rooke's research interests include the toxicology of food, which has led to her sharing her passion for regaining health through plant-based diets. Dr. Rooke is the **Director of the Optimal Health Lifestyle Medical Clinic, Morehouse School of Medicine.**

Dr. Rooke emphasized the work of her medical specialty is one of prevention versus curative care. She mentioned the COVID-19 vaccine as an important step for us all to take. We are suffering from the first pandemic in over 100 years. Considering all the diseases we have suffered over the decades and the many vaccines that have been developed (e.g., polio, smallpox, mumps, measles, and whooping cough), only one disease has been determined to be cured, smallpox. It took almost 200 years to rid the world of smallpox (official eradication was in 1979). We must each do our part to ensure we do not lose more lives unnecessarily from COVID-19.

Dr. Rooke presented a brief overview of myeloma, its epidemiology, and how cancer affects the body, focusing on the immune system risks of myeloma. Features of myeloma include the *CRAB criteria* (**C**alcium, **R**enal, **A**nemia, and **B**one loss), and the **I**mmune system (CRAB-I). Natural defenses for the immune system include [phytonutrients](#). Most fruits and vegetables contain phytonutrients which can kill cancer cells. We can suppress our own immune system by consuming alcohol and from psychological stress. When we are stressed, cortisol is released. When animals are stressed just prior to death, the cortisol remains in the tissues. Eating meat and taking steroids can also weaken the immune system and lead to a proliferation of cancer cells. -- 1 cm cancer mass contains about 1 billion cells. All of us set up the conditions within our bodies to grow or suppress cancer cells. Studies show that those who eat more animal foods have the highest rates of cancers. Changing the percentage of animal protein in our diets to less than 10% can reduce cancer incidence for several different cancers.

Dr. Rooke explained the contrasts between a focus on veganism or vegetarianism and a whole food plant-based diet. The main difference is largely based on the processing of foods. Many cookies, chips, crackers, etc. are deemed as vegan based, but are so overly processed as to make their

nutritional value unhealthy. Eating whole fruits, vegetables, grains, nuts, and seeds is the essence of a nutritious plant-based diet.

So, if we don't eat meat, where do we get the protein, we need? Dr. Rooke stressed that it is always important to first and foremost follow the advice of your oncologist or other specialist and then to add the whole-food plant-based diet to your daily routine. The longest living populations have the lowest cancer rates and have the lowest consumption of animal protein. Take note that elephants eat a plant-based diet and are not malnourished. Of all race/ethnic groups, blacks eat the most meat—it's mostly chicken. Turkey bacon is just as bad as regular bacon. It is the "processing" of foods that makes it unhealthy. Blacks do not consume as much beef and have lowered their consumption of table salt based on the health education messages. Studies show that blacks are more sensitive to salt and should consume 1,500 mg of salt each day vs 2,300 mg (1 tsp) for those with less risk. **Chicken is linked with higher rates of blood cancers such as multiple myeloma.** African Americans have at least twice the rate of myeloma as non-Hispanic Whites. Eating 50 gm of chicken a day (1/3 chicken breast) may increase the risk of developing myeloma. Eating chicken may also increase the risk of developing Type 2 diabetes.

The [EPIC](#) (European Prospective Investigation into Cancer and Nutrition) study showed that chicken increased the risk of Multiple Myeloma and Lymphoma. For every 50 mg of chicken, the cancer risk increased. NIH and AARP compared eating meat and smoking cigarettes. The conclusion was that eating meat has the same risk as smoking 10 cigarettes. Other health problems related to meat consumption include high blood pressure, kidney disease, clogged arteries, and heart disease.

References: Meat consumption and cancer risk: a multisite case control study in Uruguay (2009) https://www.tier-im-fokus.ch/wp-content/uploads/2009/11/aune_2009.pdf; Lifestyle Interventions for Optimal Health Handbook: Whole Food Plant-based Meal Plans and Recipes.

Dr. Rooke then answered questions from the group.

Q What if I need the calories? I am active, and a big plate of broccoli does not sound so appetizing. A: A plate of broccoli would include rice, mushrooms, and other vegetables. A very colorful bowl of phytonutrients can provide an appealing, attractive, and nutrient meal. Animal products cause

chronic inflammation in the gut. The only supplement Dr. Rooke recommends is **Vitamin B-12**. Other deficiencies are rare on a plant-based diet. The bacteria that make B-12 lives in the soil, which is ruined by pesticides. We need an estimated 500 mcg. For Vitamin D, most doctors/labs are using the wrong test to determine deficiency. The usual test ordered is 25 hydroxy Vitamin D. This is the stored form of Vitamin D In addition, ask for a test of level for 1,25 Dihydroxy Vitamin D. This is the active, biodegradable form, which is the most important. People from southern Spain, China, Africa, and African Americans – whose ancestors had lots of sunshine -- should be tested for the active form of Vitamin D. People with diabetes and who consume a high meat diet will have low levels of the stored form of Vitamin D.

Q: Should we not have high levels of both the stored and active forms of Vitamin D? **A:** Note: Medicare and Medicaid will not pay for supplements. Some of the Vitamin D is toxic. Foods that block **angiogenesis** – the growth of new blood vessels that feed cancer cells (oxygen and other nutrients).

Q: I have acid reflux. What to do? **A:** Also known as *GERD* – Gastroesophageal Reflux Disease can be a serious problem that could call for major medical interventions. Conditions that increase one's chance of developing GERD include obesity, pregnancy, hiatal hernia, and connective tissue disease. *Lifestyle behaviors* that increase your risk of heartburn or GERD: smoking, eating large meals, lying down, or going to sleep shortly after eating, certain types of foods, such as deep fried or spicy foods, drinking certain types of beverages, such as soda, coffee, or alcohol, and using nonsteroidal anti-inflammatory drugs (NSAIDS), such as aspirin or ibuprofen.

Honor your sweet tooth. Grapes for resveratrol, dried fruits, Carrots, sweet potatoes, cruciferous vegetables (broccoli, cauliflower, collards, turnips, cabbages, brussels sprouts), mushrooms (big cancer fighters), nuts and seeds (few Brazil nuts – high in selenium), herbs and spices (including

turmeric), cloves, cinnamon, oatmeal, rice. Use nuts and seeds sparingly, not as a snack, due to the high fat content.

About cholesterol. Your liver makes cholesterol which has important functions in our bodies. The three main functions are: 1- the production of sex hormones; 2- a building block for human tissues; and 3- it assists in bile production in the liver. The problem is **oxidized cholesterol**. There are specialized lab tests that measure oxidized cholesterol or OX-LDL. This is a better indicator of CVD (cardiovascular disease).

Additional factors that improve your immune system, mental, physical, and emotional health. Exercise/physical activity, sunshine, sleep, stress reduction, social engagement/Relationships, and happiness -- avoid social isolation. Make physical activity a social event – find a committed exercise buddy.

Carlton Morse spoke next on his success with a plant-based diet.

Carlton's Story

"I am you" ... born and raised in Sparta/rural Georgia. Soul food was what we ate. My favorite breakfast was my grandmother's grits, eggs, ham, and white biscuits. My grandparents were farmers and worked hard. Being overweight was not one of the risk factors of my parents, aunts, and uncles – who all have a love of food. Pot roasts and grilling were a part of my regular routine. My parents were both from large families and were among the first to go to college. From my parents' home, I moved to fast foods – I knew the menus of Burger King, Wendy's, etc. by memory. My father had three bouts of cancer, including colorectal cancer and Type 2 diabetes. Mother had cancer. At age 40, I had a rising PSA and my cholesterol drugs were not working. Polyps were found at my colonoscopy screening, and I was diagnosed with a benign neoplasia (tumor growth). I Promised myself I had to "do something". Grandparents died from lifestyle-related diseases, including alcoholism, cigarette smoking, and second-hand smoke. I met Dr. Jennifer at a 'Forks over Knives' movie at a midtown cinema. After some time with Dr. Jennifer, my numbers started to improve. I am now 68 -- My cholesterol dropped from 200 to 124 and triglycerides from 194 to 107. My LDL is an acceptable range. Your body adjusts to a nutritious way of eating – wanting salads and greens. 'The Game Changers' is a documentary you should check out. Check for it on YouTube. Give yourself permission to

change. From Voltaire – “Perfect is the enemy of the good” – do your best and enjoy your journey.

Patient Updates

Marcia shared her experiences with **Sparkcures**. Since 2019, she has received personal assistance and advocacy from them. They call to check on me – to see how I am doing. They have helped in understanding labs, clinical trials, and will help to connect you with clinical trials. In the past couple of weeks, she has completed a survey with them about blacks and clinical trials. They asked her to share her personal story with them and they provided a nominal fee. Others may wish to connect with Sparkcures as a resource and/or to respond to their survey. Her personal assistant was “Gail”. Sparkcures is sponsored by the “myelomacrowd.”

Respectively submitted, Gail.