

Meeting Minutes
Northside December Virtual SG Meeting
Saturday, December 12, 2020

Business & New Members

Thank you to **Nancy B.** who hosted our annual holiday party gathering, with approximately 40 attendees. It was great to see so many of our members in festive attire surrounded by beautiful home decorations! Please note that our **next virtual meeting** will be held **on Saturday, January 9, 2021** with Emory Winship doctors – Dr. Lonial and Dr. Kaufman who will present information from December’s ***American Society of Hematology (ASH) Conference***. Additional details for attending this meeting will be provided separately. This will be an interesting meeting, as there are a lot of multiple myeloma (MM) drugs in the FDA approval phase, including CAR T-cell therapies and other immune therapy drugs. Then in our regularly scheduled **February 2021 meeting**, we will discuss what we learned in the January ASH review meeting, as much of the information presented from our doctors can sometimes seem complicated and feel overwhelming.

Molly reported that the **Leukemia and Lymphoma Society (LLS)** has funds available again for the co-pay assistance program, which helps a lot of people with insurance premiums and treatment-related medical expenses. It’s important to apply early, as funds become depleted each year. Information can be found [here](#).

We welcomed **Joyce J.** who joined the group for the first time. Joyce was diagnosed in October 2012. She had a third stem cell transplant (SCT) in January 2020 and is now in complete remission. Joyce explained that she got a mild case of Shingles a few weeks ago, even though she had received the vaccine, but is improving daily. She has been taking 3 mg Ninlaro for maintenance with a 21 day on & 7 day off schedule but does not like the side effects, which include nausea and constipation. She takes the medication with anti-nausea medication, which helps. **Sandy W.** mentioned that she also takes Ninlaro and takes anti-nausea medication at the same time as Ninlaro and it helps. Also, fiber and stool softener such as Miralax and Dulcolax every couple of days is helpful. Both Joyce and Sandy said that they really enjoy their week from the drug each month.

Discussion

Our holiday party has historically been a time to catch up with everyone, including members who we have not seen for a while. We were glad to see **Joseph C.** and wife, **Suzan** again. Joseph mentioned that he had had pneumonia but is better now and is doing well generally. We were also glad to see **Virgil P.** who has not attended meetings for about two years. Virgil was diagnosed in 2008 and had a SCT early in his treatment that did not work for him. He was on Revlimid for over 10 years, which kept his MM under control. He has been off Revlimid for about 2.5 years, due to the high cost, and is still doing well without it. Someone mentioned that hopefully a generic version of Revlimid will become available in a couple of years. **Carolyn** is 5 years into her MM journey and doing great. Carolyn harvested stem cells and had a SCT at Emory, where her extra stem cells are still stored. She then moved to TX soon after. She is followed by MD Anderson and stays updated with virtual education.

Members who have been away from meetings mentioned how much they appreciated the check-up calls from **Sandy B.**

Paul S. reported that his wife, **Cheryl** is busy preparing for a SCT next week, after harvesting 11.2 million stem cells. **Cappa W.** is doing well. She is currently on a treatment of Daratumumab (Dara), an immune therapy drug that is administered as an injection, and Pomalyst. **Jeff W. and Jim M.** are also getting Dara injections and are happy with the new way that the drug is administered. **Libba** had a second SCT last year using her previously harvested and frozen stem cells from 3 years ago. Libba is also taking Dara and has been in remission since February. She is not taking any other drugs and said that the Dara worked very well for her after only a month on it. **Frank M.** is also on Dara only and is doing well. Nancy mentioned that others in the group have taken Dara only (not in combination with other MM drugs) and have done well on Dara as a single agent. Libba also mentioned that after having MM for 14 years, a recent CAT scan showed osteoporosis in her spine for the first time. **Jeff W.** mentioned that he had osteoporosis for a few years before he was diagnosed with MM, which seems unusual to him since he is male and with no family history of osteoporosis. **Jeff B. and Jeff W.** have both enrolled in the MMRF CureCloud research study that provides genomic testing with a goal to help find smarter, more targeted treatments for the patient. **Jeff W.** is currently doing well on Venetoclax, a drug used specifically for high-risk patients with t (11;14) translocation. Nancy mentioned that in clinical trials (CT), high risk MM patients had better outcomes than low risk patients with Venetoclax. **Lory M.** is taking Dara and doing well. Her numbers have slowly progressed over the past 2.5 years, but they are considered to be stable. **Gail M.** is doing well on 3 mg Pomalyst maintenance with a 21 day on & 7 day off schedule and does not experience any side effects. She

was previously taking Pomalyst and Ninlaro together for maintenance. Happy Birthday to **Doris M**, who will turn 80 years young this month! Doris has had MM for 17 years and walks every day. She was able to achieve a 10-year remission by using Thalidomide and has not had a SCT. **Bob C.** has stopped taking Revlimid and is doing well and enjoying a “drug vacation”. **Alicia B.** has been on Revlimid for about 5 years since diagnosis. She reduced her dose from 10 mg to 5 mg about a year ago and is doing well on the lower dose. **Dirk B.** is on Dara and Pomalyst. He recently cut his Pomalyst dose in half, and then raised the dose again slightly and his numbers look good.

After getting specific updates from our members there was a lot of interactive discussion and some questions and answers as follows:

Q: With our virtual meeting format, how can people get access for attending a meeting for the first time? **A:** They can send email to aammsg@gmail.com

Q: Is it OK to forward our newsletters to non-members? **A:** Yes; and our newsletters are also available on our website, www.mmsg.org

Q: Is anyone taking Acyclovir or other antiviral drugs? **A:** Many in the group responded that they are taking Acyclovir, and some were taking Valacyclovir.

Q: Is anyone getting Intravenous immunoglobulin (IVIg) gamma globulin treatment? **A:** Several in the group responded that they have gotten or are getting this treatment and it has been beneficial to them to help prevent infections and quickly build up their immune systems. **Cappa** mentioned that she has gotten monthly IVIg treatment, since taking Dara caused her gamma globulin levels to go to zero;

and **Dave O.** said that he has been on Dara and Revlimid for a couple of years and is also getting monthly IVIG treatment and has done much better since starting IVIG therapy. Someone mentioned that IVIG therapy may only work for IgG MM, since IgG molecules contain gamma-chains; and may not be an option for other types of MM.

Q: Will the COVID vaccine interfere with IVIG treatments. **A:** We do not know.

Q: Is anyone else taking potassium supplements? **Sandy W.** said that her potassium levels have been below normal since starting treatment and the supplements are expensive. **A:** Someone recommended getting more potassium from foods such as coconut water, sports drinks, bananas, and yams. A few recipes were described using yams: 1) Mashed yams, with apple sauce, butter, and cinnamon with pomegranate sprinkled over the top, and 2) Molly mixes mashed sweet potatoes with scrambled eggs and sour cream and puts back into the shell for serving.

Q: Is anyone else getting bisphosphonates as treatment? **A:** Most MM patients are treated with Zometa or Aredia, but the International Myeloma Working Group (IMWG) recommends not staying on these treatments for more than two years due to the long half-life of these drugs.

Q: Is anyone else also being treated for osteoporosis? **A:** Someone mentioned Prolia as an option for osteoporosis. This is the same drug as Xgeva, but a lower dose. Both treatments come with ONJ warnings but are not bisphosphonates. Someone also mentioned taking a standard level of Vitamin D (like in a multivitamin), and calcium. Taking the standard dose of calcium, but split up – i.e., once in the morning, and once in the evening can help keep balanced levels of calcium circulating in the blood.

Q: What is helpful for peripheral neuropathy? Is anyone else experiencing balance issues or feel uneasy walking? **A:** Since most MM patients experience peripheral neuropathy at least at some point in their journey there were many suggestions. Members have found help with the standard drugs such as Lyrica, Neurontin, and Cymbalta. Supplements such as those found on Dana Farber's website, and including B vitamins and alpha lipoic acid. It's especially important to continue moving the extremities and walking to help relieve the pain from peripheral neuropathy. Footwear can also make a difference, such as wearing sandals vs. shoes, wearing slippers with indoor/outdoor soles (Jim M. likes L.L. Bean), and stretchy material slip-on shoes (Libba likes Skechers). Also mentioned were topical pain relief creams, but the results are only temporary. **Carolyn H.** uses Aquaphor lotion on her feet with socks at night to keep the skin on her feet soft, as neuropathy can change skin texture. **Molly** does pole walking, which helps with balance. Physical therapy was recommended, and **Jim M.** said that acupuncture makes a big difference for him, but the results only last about a day. Someone mentioned that Emory has an acupuncture center.

Q: Does anyone else suffer from leg cramps? What helps? **A:** **Cappa W.** and **Bob M.** said that exercise helps keep their leg cramps under control. For those experiencing leg cramps at night, **Cappa** recommended a product called "CALM", a powder that contains magnesium that can be mixed with a drink and taken at night. **Jim M.** uses a stand-up desk when working. Others suggested compression socks and soft cotton socks from L.L. Bean.

Submitted by Wendy R

Meeting Minutes
Southside Virtual MM Support Group
December 26, 2020

This meeting was held during unprecedented times -- the day after Christmas and just before a brand-new year -- after a fiercely competitive presidential election in November and looking forward to a January 5 Senate runoff election, where the nation is looking to Georgia for a balance in the US Senate. This was all amid a still growing global pandemic that has killed more than 350,000 people in the US. In Georgia, the death toll is approaching 10,000. Parents cannot spend the holidays with children/grandchildren. Sisters, brothers, nieces, nephews and good friends keep each other safe by staying at home. There is hope for vaccines. We have two that are approved for Emergency use – one from Pfizer BioNTech and the other from Moderna. How we access those vaccines and information in response to our concerns is TBD.

During these facts and challenges, we must continue to move forward. We asked members to share thoughts on: **What Reflections Do You Have on 2020? Do you have any new approaches to health for the New Year? How Can We Help Other Myeloma Patients Know about our Support Groups? What Effects has COVID-19 had on you and your family?**

Selina had a difficult time after her second transplant which was July 6. She was tired much of the time. She is now taking Pomalyst —21 days on -- 7 days off (21/7) (about three years ago, Selina had negative reactions to Revlimid – in the same class as pomalyst, including increased heart rate and rashes). She had to have six COVID tests during this time as she went back and forth to Northside during follow-up visits for her transplant. She and her sister stayed close by at the Atlanta Hope Lodge/Clifton Road, where they could cook their own food, though she had no appetite. She lost her balance. Her blood pressure increased to dangerously high levels. She was admitted twice during a six-week

period. She was unable to drive due to some of the medications she was taking.

Doris is on Revlimid – 2 weeks on, two weeks off.

Carole W. is doing well. She enjoys her daily workouts and her two dogs and five cats. She has been in remission now for four years in August, taking 5 mg of Rev – 21/7 for maintenance.

Alma is on a Phase 2 clinical trial (CT) with the drug, CC220 –in the same Imid class as Relimid and Pomalidomide (Pomalyst). She explained that CC220 is a stronger version of Pomalyst. The medication is taken with Dex. After the first cycle the medication dosages are reduced. There are a host of side effects associated with the drug, including chronic constipation, chronic fatigue, blood clots, and respiratory congestion. She is on a schedule of 21 days on, 7 days off (21/7). She is feeling better today. Her family is a close one –accustomed to spending time, especially the holidays at each other’s homes. They did drive-bys this holiday – talked to friends in a parking lot. Her favorite nephew, Legend, turned 13 years old!

Marcia was diagnosed with plasma cell leukemia – a light chain myeloma. She is being safe and maintaining social distancing, wearing masks, and doing all she can to be safe. For three months, she has had good numbers, and has been declared in stringent complete remission (sCR). She takes Pomalyst 21/7, and recently had them reduce her dex to 4 mg. This is her maintenance regimen.

Teonna was diagnosed at age 40, five years ago. *This is on the younger side of usual diagnosis. African Americans are diagnosed at earlier ages than Whites. We need more support for people who are diagnosed at earlier ages.* She has been in remission for two years now and is taking 1 mg Pomalyst 21/7 for maintenance. Since the pandemic, she and Dr. Kaufman at Emory have turned to telemedicine for regular visits.

Bernard B is also in remission – taking 10 mg Rev -21/7.

has Dr. Nooka/Emory as his myeloma specialist and is working with a community oncologist as well. *We are fortunate to have a respected myeloma research center in Atlanta at Emory Winship. The specialists*

there have expressed they are more than willing to work with community cancer doctors to offer support and advice. Myeloma treatment options change rapidly, and it is difficult for oncologists who are not myeloma specialists to keep up with the changes. This includes both regular treatment and Clinical Trials. Bernard also recently stopped taking Zometa, the bone strengthener that many of us have to take. Other drugs in this family of bisphosphonates include Aredia and the newer drug, Xgeva (Denosumab). Be sure to have a conversation about how long you should remain on this medication. The long-term side effects must be considered.

Ted (and Mattie) had a great Christmas and are looking forward to a great new year. He is doing well – taking 15 mg Rev-21/7. He continues to see Dr. Kaufman and sees his cardiologist. Ted was always an active man – walking intense hills 3-4 times a week with no difficulty. He wants to get that capacity back safely. His blood counts are good – he follows this with Kaufman and his Physician’s Assistant (PA). He is Thankful.

Deborah shared that she has gotten the first dose of her COVID-19 vaccine. She is a nurse at the VA Hospital. They had the Moderna vaccine. She did urge those who have allergies and respiratory problems to be extra cautious. These conditions increase one’s risk of a negative reaction. After receiving the vaccine, each person must sit for 15-30 minutes for observation and any post-inoculation reactions. A co-worker experienced problems and had to be taken to the ER. We must continue to be safe – stay physically distanced and continue to wear masks and wash our hands frequently. Since Halloween, the number of cases, hospitalizations, and deaths have been on the increase as people let down their guard and went back to old habits. We must also be sure we go back for the second dose of the vaccine from either company.

Should Myeloma patients get the COVID vaccine? From Dr. Durie’s posts, it is advised that most myeloma patients should get the vaccine. The benefits outweigh the risks. However, each patient is different. Please check with your doctor. *(Post meeting: The Emory Myeloma team recommends that MM patients get the vaccine. Still, check with your*

doctor. For Emory Winship patients, Emory will provide the vaccine. They will ask if you consent to a study designed to determine how long antibodies last in myeloma patients. You will be notified when the vaccine is available for you.)

Doris expressed her thanks to all who continue to participate in the Support Group – over the past 15 years. Those who have been there since the beginning include Bridgette, Montine, and Portia.

Vena appreciated how uplifting the meetings are. They are lively, and she always learns something. She wishes there were a similar group for lung cancer, which is also her challenge. We thank Vena for always offering us truths clothed in just the right amount of humor. Vena is doing okay but does have shortness of breath. Her lung cancer and her myeloma are both stable right now.

Glenda states that she is grateful. Rev was not the medication for her – her myeloma numbers increased exponentially. She is no longer in remission and is on Daratumumab-Pomalyst-Dex, and her numbers are normal. She has a pacemaker and a low heart rate. She has been working with her heart specialist since 2018. She had an MRI and radiation -- challenges with her upper arm, low back, and upper thigh. Deborah suggested she ask how much radiation she will get and to have the discussion with her oncologists and have some peace with her decision. She is to have chemo for the first part of February.

Glenda expressed thanks and appreciation for the dedication for organizing our meetings each month. Her advice to others is: 1) Keep a positive spirit, 2) Don't hesitate to ask questions, and 3) Take copious notes, write questions in advance, keep a notebook in an accessible place. Questions/symptoms come up at inconvenient times. Some unintended benefits of COVID-19 include increased use of technology for patients and:

- It is much easier to have a second opinion consultation. You can do this with local specialists as well as at other Myeloma research centers whether in Texas, Minnesota, Boston, etc.

- Encourage us to use the portals more when available. Telephones are busy with those who have no other options.
- Virtual meetings/Telemedicine is accelerated and accepted by insurance companies. Use it when appropriate. It can save time, gas, parking fees, etc. This is important for us all but consider if you lived in Albany and Emory Winship was the location of your myeloma specialist.

Post Meeting:

In this space we talked about peripheral neuropathy and Gabapentin. Alma read that there are warnings against taking Gabapentin with opioids and might have some negative cognitive effects. **Gail** has been taking this combination for years and will review. Other potential help with neuropathy include alpha lipoic acid, Vitamin B-12 and B-complex (nervous system vitamin), and Turmeric. We also chatted about nutrition and the importance of **magnesium and potassium**. Magnesium is a micronutrient that is involved in nervous system regulation and muscle movement. It is an anti-inflammatory and has a role in reducing blood pressure and insulin resistance (diabetes). It has a role in reducing depression and migraines. In myeloma, we often become potassium depleted, whether from medication or not paying attention to our diets. Potassium helps regulate fluid balance, muscle contractions, including the heart muscle and nerve signals. A high-potassium diet may help reduce blood pressure and water retention, protect against stroke, prevent osteoporosis and kidney stones. This is sometimes a contributor to the muscle spasms (Charlie horse) many myeloma patients suffer. Be careful of potassium intake if you have kidney problems. Gail will send lists of magnesium-rich and potassium-rich foods.

Announcements/Resources/Updates. January 9 at 10:00 on Zoom.

- The Power of **Vitamin D**. for Myeloma – for COVID-19. Get your Vitamin D levels checked. Bones, joints, heart health, immune system

- Patient Empowerment Network (PEN). **5 min Educational sessions.** Why Myeloma Patients Should Speak Up; How a Second Opinion Saved a Patient's Life; Myeloma targeted therapy; Myeloma Treatment Decisions
- **Patient Power.** What's Next after a myeloma diagnosis? 3:04; Myeloma and COVID-19 – What the Experts Have Learned.
- AMAZON Shopping? [Smile.amazon.com](https://smile.amazon.com) – You can choose IMF, Atlanta Area MM SG, or a charity of your choice.
- Searching for **Myeloma Clinical Trials**? Myeloma Matrix 2.0 and SparkCures - <https://sparkcures.com/clinical-trials/multiple-myeloma>
Respectfully submitted, Gail