

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Meeting, February 2, 2019

The meeting was an open discussion and there was a lively exchange of issues and experiences. There were 32 people present. Nancy reminded the group how we make a big difference for new patients and even with experienced patients facing challenges. Patients get a lot of information from doctors and their healthcare team, but to hear real experiences from other patients makes such a difference in their journey.

The group talked about the ASH meeting at Emory and all the research. It was recommended to read the newsletter more than once to get more familiar with the terms. It was also pointed out that Dr. Durie has an overview of ASH with slides and discussion of many topics. That program is available at -- <https://www.myeloma.org/videos/best-ash-2018-teleconference>

Jim started the discussion with a situation with his dentist and ONJ (osteonecrosis of the jaw). He had an old filling that had cracked. The dentist took an x-ray and said that the cracked filling did not look good. After going to an endodontist, who said he had necrosis of the jaw, it turned out that the cracked filling had leaked bacteria into the roots of the tooth. They did a root canal and put him on strong antibiotics. Jim was on Zometa for eight years, every three months. He has been off Zometa for 18 months, but the half-life is seven years. Jim said that it is on his dental chart that he was on bisphosphonates and urged everyone to make sure that your dentist knows. When you have an x-ray, problems can be seen at the tip of the roots. He said that he did not have any pain but had broken off part of the tooth. Several other people talked about dental issues. Someone else had pain and when they went to the dentist, the bones were coming through. When a tooth is pulled and the jawbone is visible in your mouth, then you have ONJ. Many others indicated that they have had this experience. Lory had a tooth extracted early in her diagnosis and the bone came through. The dentist said he would not put a bridge over that gum because of ONJ. Cappa said her myeloma was first detected by the dentist when the x-ray showed a big blob in her jaw and it had spread. Nancy asked how many had ONJ issues and about five people raised their hands. A question was asked about an alternative drug. Nancy noted that Xgeva is a monoclonal antibody, but the warnings

include ONJ. This is an important discussion to have with your doctor about how long you will be on Zometa and the plan to reduce it. The bottom line is to be sure your dentist know that you have myeloma and you have been on bisphosphonates. Carolyn said that this is one of the components of be active in your treatment decisions and knowing the side effects. Know what the treatment plan is for the long term and make sure you monitor side effects. Vanessa said that she had been on Revlimid for ten years. She is only on 3 mg but is starting to notice some side effects and will discuss the risks with her doctor at the next appointment. Someone said that they on Revlimid and got lung cancer. The Doctor switched them to Pomalyst and Darzalex. Now having heart problems, Afib. Someone else had heart problems on Revlimid. Carolyn was on Pom for four months and had heart problems each month. She is seeing a cardiologist at Emory. She told her doctor that she flunked her stress test and they are exploring options. Someone else said that he has heart problems that he thinks came from Velcade, but it saved his life. So, he is living with reduced ejection fraction and his myeloma is under control. Someone else was on Revlimid for five years and has been off of it for two year but is still having the diarrhea side effect. Vanessa said that she has finally gotten her diarrhea under control in the last few months through diet. Coffee is out right away. She starts her morning with hot lemon water with a dash of red pepper flakes to give you a zing! She makes homemade broths and does not eat out very much. Lory said to be cautious about eating out and be careful about eating anything raw, like a salad and avoid salad bars. Make sure everything is well cooked and hot. Steamed vegetables are better than the sautéed ones covered in butter. Charise Gleason, with a dietician from Emory, did a teleconference about the impact of nutrition on side effects. You can watch that informative discussion here -- <https://www.myeloma.org/videos/impact-nutrition-side-effect-management> It was suggested that you watch it several times since you will pick up something new each time.

In this discussion of side effects, a new patient asked what is going on in the rest of the world. Nancy pointed out that RVd (Revlimid, Velcade, and dex) is given to most every new patient in the US because it works over 95% of the time. RVd is available outside of a clinical trial in the US, Japan, and a few countries in Europe (Norway, Sweden, Germany, Austria, and Switzerland). In other countries, they are usually getting melphalan, prednisone, dex, and thalidomide. It was restated that you need to be the

best advocate for yourself and do your research.

Other patient updates were given. Libba had a mass on her back that was six inches wide. It could be seen through her clothes. She took Pomalyst for 14 doses and her platelet count plummeted and she had to stop. Four days later, the whole tumor was gone. The Pom wiped it out! Libba has a pacemaker due to heart issues but doing well. She said that if anyone has been told that they need a pacemaker, contact Libba for details on her positive experience. Tony is supposed to start Ninlaro, but his co-pay will be \$2300 per month. Frank is on it, but his insurance pays it since he is still working and not on Medicare. Tony contacted the manufacturer and will get it without a co-pay. Note that all the drug companies have patient assistance programs to help with financial burdens. Frank said that Ninlaro is a tiny pill, so be careful opening and do not open over the sink. Joe has been on Ninlaro, Rev, dex for about a year and a half. Ninlaro has slowed protein increases, not decreased yet, but doing much better. He had some skin cancer removed from his back. Did not realize there as a correlation to the treatment but will be talking to the doctors. Cappa said it is 11 years since diagnosis and she is doing well, despite a round of lung cancer. She said that there are some great clinical trials going on at Emory.

Someone mentioned that she was on pain pills and the doctor never said to get off them and kept renewing the prescription. Finally, she mentioned her concern and the doctor said the try taking less. She is now off them but felt like the doctor wasn't going to address them. She was not good about discussing things with your doctor, but getting a lot better about asking questions. There was a discussion about Acyclovir for shingles prevention. There have been no studies about using the newest shingles shot instead of staying on Acyclovir, so doctors are just keeping patients on the daily dose of anti-viral. Becky said that she has been on another type of anti-viral for 20 years. Lory is on Dara and Rev, but the myeloma is slowly progressing. She changed from monthly to every other week to see if they can keep it under control. Roslyn said that she was diagnosed in 2008 and has been in remission for ten years, the last five years without medication. Her stem cells were harvested, but no transplant. Still has problems with neuropathy. Some others said that their neuropathy went away after stopping medication.

There was a discussion about hemp CBD oil, which is found in health food

stores. Someone taking it for a while said they feel better and it helps them sleep better. It is available in drops or capsules, which cost about \$100 for 30-day supply. One brand is at Luna.com and another is Mary's. One caregiver said he has had three hip surgeries and it works for pain. He has a brother who has been in military conflicts and said that the soldiers are taking it for PTSD, and it works. This may be something to discuss with your doctor. Dana gave an update. He was diagnosed in 2000 and took Mike Bruno's advice to lay low, and just enjoy life and try not to talk too much about cancer. Last summer, Dana has the CAR T procedure. They harvested the T-cells in May, which is similar to stem cell harvest. They send them to a company to re-engineer the cells and grow more. That takes 30 days. On July 9, they put the super-charged T-cells back in his body. He was in the hospital two weeks and experienced high fever and chills. Dana has had two stem cell transplants. He said that the CAR T process was not as hard as the stem cell transplant, but there are different challenges. He had a bone marrow biopsy 30 days after the fevers and there was no myeloma! Dr. Kaufman said that the fevers are from the great war going on as these supercharged T-cells are attacking the myeloma. The remaining effect is that his bone marrow is not creating platelets and enough red blood cells, so he has to get platelets about once a week and red blood cells about every three weeks. They say that the bone marrow will start producing platelets. In December, he started have chills about every ten days and ended up in the hospital. Turns out, he had pneumonia and has finished a round of antibiotics. Someone mentioned that they had a transplant seven years ago and in remission on 10 mg Rev. In recent check-ups, the platelet count is dropping. They checked her vitamin B-12 level and it was very low. Pills did not help, so she was getting shots once a month. She feels so much better and feels like she got a big boost. She recommends that patients ask their doctors about checking B-12. Vicky asked how people deal with stress with all the medical issues. Stress reduction is critical to better health. Becky said that her job went away two and a half years ago just as the doctor decided to take her off Rev. She has been off treatment and her counts are stable. She has never been in remission for 17 years, but everything is stable, and she gives some credit to the CBD oil helping her system to run better. Many people had recommendation for stress reduction: get a massage, exercise, travel (which is also good for the caregiver!), volunteer, yoga, play a musical instrument, or take up a new hobby. Carolyn said she had to become more aware of people causing stress and remove them from her life. She

volunteers as a MM mentor at LLS and Fourth Angel. She said that there is so much reward in mentoring a new patient and let them know that they won't die. Share your journey and hope because you are a survivor. Jim noted to be aware of the things that you can change and there are other things you can't change. If you are worrying minute to minute with stress, it will get you, whether you have myeloma or not. Learn to let it go. Look at issues objectively and identify what you can't fix, then let it go.

We greeted the new member in attendance. Dayo was diagnosed in July 2017 and was attending with his son as caregiver. He had a transplant in September 2017 and is on Dara/Pom/dex. The Pom was causing confusion. He is CEO of a small company and needs to make decisions, so he called the doctor to find something else. We introduced Dayo to Sandy, a 29-year MM survivor. Loretta is 14-year survivor and participates in the Senior Olympics. She also volunteers weekly with meals on wheels. Frank walks a lot and does yoga. Hector enjoys his grandchildren. His wife, Brenda, had a tumor in her kidney and it was removed from the kidney. She had two kinds of cancer in her kidney.

The meeting was great discussion and connection among those in attendance.

Nancy talked about March as Myeloma Action Month and more information will be available at the next meeting. See more at <http://mam.myeloma.org/> There is an IMF Patient and Family Seminar in Boca Raton, FL, on March 15-16.

Nancy

**Southside Myeloma Support Group**  
**February 23, 2019**

**Gail** opened the meeting with a few moments of guided imagery, meditation and chair stretching. We had two new members – patient **Ted** and his wife and caregiver, **Mattie**. They were referred to the Support Group by the Social Worker at Northside, Kimberly Walker. Many thanks to Kimberly for connecting myeloma

patients with Support Groups. Today's meeting was an opportunity to hear from group members about their experiences, concerns, and successes. We shared our myeloma status and lessons learned through responses to our new members questions and concerns.

**Ted** was diagnosed January 2019 and is currently being treated at Georgia Cancer Specialists/Midtown. He was diagnosed during his annual physical exam with his primary care doctor and had no symptoms. Both Ted and his wife have made it a habit of getting their lab results and reading through them every time. Usually, he tracks his PSA and she checks her A1C because she is diabetic– but they monitor all lab reports. At home, as he reviewed these lab results, he noticed that his neutrophils/white blood count was abnormally low. He called his doctor to ask what this meant. After repeating the labs, he was referred to a hematologist.

He had a bone marrow biopsy and bone density test. They will get a second opinion at Emory Winship with Dr. Kaufman early in March. His current therapy is Revlimid and Dexamethasone. Ted says it was not pleasant to read about Myeloma on the Internet. He became very concerned, and had many sleepless nights, reading that expected survival was about 3-5 years. Asked from what websites he got his information, he reported WebMD and Emory University's website. He was grateful to see so many survivors of more than five years, 10 years and more.

**Carole** shared that she also had no symptoms. She is a patient at Kaiser and had her Stem Cell Transplant (SCT) at Northside. She is now in total remission and does not have another appointment until August 2019. She applauds them for going to get a second opinion at a myeloma research center. Support is so important – she was diagnosed in 2015 and had a SCT in 2016. Prayer is important to healing.

**Vermell** advised that patients write down all questions and concerns. Write down how you are feeling – physically, but also mentally and emotionally.

**What is the experience of a Stem Cell Transplant like?** Myeloma is a cancer of the bone marrow plasma cells. The cancerous plasma cells are called myeloma cells. In the beginning, your treatment will work to kill the existing cancer cells. Then, if you are eligible, your doctor will offer a stem cell transplant as the next step towards treatment and control of myeloma. Then for an autologous stem cell transplant (ASCT) which most people have, you harvest your own cells. Harvesting your cells is a lot like a session of dialysis. After harvest, you will receive a very high dose of chemotherapy to kill all the remaining cancer cells – and your immune system. Your cells will be to be re-introduced into your system much like a blood transfusion rather than an organ

transplant. Having a positive attitude is almost as important part of the regimen as many of the medications you get along the way. Everyone has a unique experience, but the research supports SCT as an effective way to achieve remission in myeloma.

**Support groups are important for learning and networking with others.**

**Carole** shared that some important information she learned in November from something Nancy said -- the reason people are on medications 21 days on /7days off is to allow your body to rebuild and heal. She had been on Rev nonstop as maintenance but continued to have low white blood cell count. She was then treated for the low blood count Neupogen SOSY which has its own set of side effects, including bones and muscles, GI issues, headaches, fatigue and skin rash. After talking with her provider, they changed the schedule to 21 days on/7 days rest – and her labs have been very responsive. It is so important for all of us to read and listen. The patient and caregiver must be active partners in their treatment. It is also important to attend educational seminars in person when possible and listening to webinars when they are offered.

**Bernard** shared that he had extreme fatigue that sent him to the doctor, He is generally a very active person – to the extent that he will work two jobs to stay busy. They found he had a low kidney function and on seeing the nephrologist, found that he had stage 4 kidney disease. He is currently being followed at the Fayetteville Cancer Group and by Dr. Kaufman at Emory Winship. Bernard had his SCT at Emory – and got up and started walking right away, though his feet hurt. The doctors told him he was a Poster Child of everything going well with his SCT. He could eat a few things, like oatmeal. He was in the hospital for 11-12 days – and still feels good except for neuropathy. He wears thick socks, rubs his feet.

**Peripheral Neuropathy (PN)** in myeloma is a side effect of some of the medications (including, but not limited to Revlimid, Thalidomide, Velcade, Pomalidomide, and Ninlaro), radiation, or surgery. It is nerve damage primarily noticed in the hands and feet. Doctors try to minimize the occurrence by adjusting dosages, but each patient is different, and the symptoms in each patient may be different so the patient must report how they are feeling. The aim is to avoid getting neuropathy at all, but once you have it, there are a few things you can do to help. Some tips to get some relief from the pain of neuropathy include a combination of medications, vitamins, lotions, and exercise. Some examples are: Pain relievers (over the counter or prescribed), Gabapentin (Neurontin) is one popular medication. Supplements include the B- complex vitamins (nervous system vitamin), alpha lipoic acid (ALA), topical creams -- like

cocoa butter, menthol-based cream, or capsaicin cream, physical therapy, exercise, and healthy eating. Magnesium, potassium, and tonic water can help with the cramping. Carole shared that she uses Emu oil to massage her feet and hands. She gets it at Walmart for about \$15. She feels that eating 8-15 cherries and eating a diet rich in fruits and vegetables helps with pain and medication side effects. Read more about neuropathy, safety, and alternative medicine at the Dana Farber and Mayo Clinic websites. <https://www.dana-farber.org/health-library/articles/tips-for-managing-neuropathy/>; <https://www.mayoclinic.org/diseases-conditions/peripheral-neuropathy/diagnosis-treatment/drc-20352067>.

We do have to be very careful about the information we get from the Internet. Reliable websites for myeloma specific information include the IMF (International Myeloma Foundation) – [www.myeloma.org](http://www.myeloma.org) and the Leukemia and Lymphoma Society – [lls.org](http://lls.org). The American Cancer Society and the National Cancer Institute are additional sites to explore ([www.cancer.org](http://www.cancer.org) and [www.cancer.gov](http://www.cancer.gov)). We talked about the importance of each patient knowing **what kind of myeloma** they have. Myeloma is several different types, and for each person, the best treatment might depend on your specific type. We encouraged Ted and Mattie to ask for their cytogenetics, and to define the myeloma as IgG or IgA and kappa or lambda. You do not have to understand it all right now. But knowing is the first step to know what to listen out for.

**Communicate with your healthcare team.** Be sure they listen to you. Alma shared that she is a 13-year survivor of myeloma. She learned of her myeloma after going into kidney failure. Her kidney function did come back over time. She follows her Free lambda light chain numbers on her lab reports. Ask your providers what you should follow. Alma has had several other experiences over time that we can use as lessons to ensure we remain engaged in our treatment. All medications have side effects. However, she reported to her team several times severe and unusual shortness of breath in taking Kyprolis. She went into heart failure after, and is getting better now, but has to follow-up with a cardiologist, though she never had heart issues before. She feels the medication should have been stopped earlier. Other meds seem to cause blurred vision. Steroids can cause elevated glucose, and now her insurer has labeled her as a diabetic and was ready to prescribe her metformin and provide counseling for diabetics. Thankfully, the insurer is staying on the case, but she is rightfully advocating for what she knows to be true about her condition. She refuses to be labeled as such, since this was a temporary situation. She saw an endocrinologist and had an A1C of 5.3.

The fellas had a side question that was important to them. The ladies did not quite get it. “Do you still cut your grass? I love being in my yard and cutting the grass”, asked Ted. Bernard said they told him to stay away from the grass, because of the immune system. Vermell offered insight from Winship that the spores in the ground might negatively impact those who are immune compromised. Bernard also cannot practice his craft of plumbing due to the immune system issues.

**Financials and Myeloma.** The group encouraged our new members to seek financial support for co-pays, transportation, medications and other related costs. They should work not to go bankrupt while working towards a cure. Carolyn gave her “green forms” of all the financial resources to Mattie and Ted. This financial form came from the Myeloma Social Worker at Emory Winship. Insurance premiums can be reimbursed. Assistance can be in a form from \$500 to \$10,000. The myeloma treatment journey is long and cancer care is extremely expensive. You will also learn there are some differences in how private/employment-based insurance differs from Medicare/Medicaid. For all financial support, you must complete financial forms each year, but it is well worth it. Keep your grants active, as LLS and others can run out of money. **Myeloma means Life Interrupted – not halted.** Mattie and Ted shared that they feel so much better after sharing at the meeting. Listening to others’ stories was comforting. They are an active pair. Ted challenges himself with the regular walk at Benjamin Mays High School – *up* the steep hill. He also has volunteered for the past 15 years one day each week for Meals on Wheels. They have a passion for travel and love cruises. Alma recommends that they are careful with the food on cruises – no raw food as they travel. They have been married for 43 years. Bernard and his wife are celebrating 38 years of marriage. **Jameca** shared that she was diagnosed at age 26 and is currently on no maintenance. She shared that it’s important to listen to your body – and when you feel tired, give yourself permission to slow down – and take a nap. Myeloma and its treatment will have an effect on your physical health, but also your mental and emotional well-being. Stay active, but rest when you want to. Alma is a 20-year volunteer with the Adult Literacy Program at her church. It is important to keep your purpose in life.

**-Learn all you can about myeloma, so you can share the messages.** Since Myeloma occurs at more than twice the rate in African Americans than whites, early detection is the key. Go to [www.myeloma.org](http://www.myeloma.org) to learn more.  
=Send/Give the letter from Dr. Durie to your primary care doctor to remind them

of the Signs, Symptoms, and Cost-effective tests for Myeloma. Download the letter from [www.mam.myeloma.org](http://www.mam.myeloma.org) and personalize it.

-Get Tip Cards from IMF

Early Warning Signs of Multiple Myeloma *and*

Important Questions to Ask after a Myeloma Diagnosis

**Things you should Know – from the IMF Early Warning Signs Tip Card**

-Primary care physicians are the first to diagnose half of all myeloma patients.

-When diagnosed by primary care physicians, more than 50% of myeloma patients experience a delay in diagnosis of more than 6 months.

-Delayed diagnosis is associated with a greater incidence of secondary complications.

-Earlier diagnosis can result in earlier treatment and fewer secondary complications.

-Myeloma is now being diagnosed in people younger than 50 years of age. It is not only a disease of the elderly.

-African Americans are diagnosed with myeloma at more than twice the rate of whites

**Do you have one or more UNEXPLAINED symptoms?**

**BBF:** Back pain (persistent or recurrent); **B**one pain (persistent or recurrent); **F**atigue (unexplained progressive tiredness)

**CRAB:** **C**alcium elevations; **R**enal impairment (elevated creatinine); **A**nemia; **B**one lesions

Any ONE of the BBF early warning signs could indicate myeloma. Any ONE of the CRAB diagnostic criteria could indicate myeloma.

Respectfully submitted, 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](http://ssatlanta.support.myeloma.org)

**Southside Meetings: 3/23/2019, 4/27/2019**

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**Northside Meetings: 4/6/2019, 5/4/2019**

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