

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Northside Virtual MM Support Group December 4, 2023

### Introduction

Thank you to **Nancy B.** who hosted the virtual annual holiday meeting with approximately 35 attendees. The meeting began with an open discussion to share patient updates and status on their multiple myeloma (MM) treatments. After the open discussion, the group broke into separate, smaller groups for more personal exchanges.

### Business & News

In the next meeting on January 6, 2024, MM-related findings from the annual American Society of Hematology (ASH) conference will be presented. The ASH conference, held every December, is where over 25,000 hematologist from around the world meet, and where MM is of big interest. There are over 1000 abstracts reporting research solely on MM this year. MM research is moving very fast, and some highlights include amazing treatments for new patients, as well as CAR-T improvements, and bispecific and immune therapies. Charise Gleason from Emory is arranging the meeting, and more details will be provided (including Zoom information) soon.

### Open Group Discussion

We welcomed a new member, **Bob F.**, who was diagnosed in August with non-secretory, light chain, low-risk MM. He is currently taking Revlimid,

Dex, and Darzalex. Bob explained that two years prior to his MM diagnosis, he was diagnosed with Amyloidosis and experienced heart failure which led to blood tests that showed light chains which lead to a MM diagnosis. He has been asymptomatic from the start and felt good without drugs. He currently has a rash from the MM drugs and is not considered a candidate for a SCT due to age. **Betsy R.** experienced a bad rash from Revlimid and stopped taking it for a month. She got a topical cream from her dermatologist to clear the rash. When she restarted Revlimid she did not get the rash again.

**Jim M.** completed CAR-T treatment in September, with his 100-day milestone date approaching and is doing well. Prior to the CAR-T treatment, Jim had two stem cell transplants (SCT) and relapsed four times on drugs. Jim has continued to work full time throughout his MM journey.

**Jeff** is doing well on a clinical trial (CT) that he has been on for years. He mentioned that his numbers go up when he is experiencing work-related stress. There was discussion about how negative stress affects our health and others in the group have reported their MM numbers fluctuating relative to stress.

**Betsy R.** reported that she was recently found to be MRD-negative. She has reduced her Revlimid dosage from 10 mg. to 5 mg. but has not gone off Revlimid completely due to concerns of relapsing. **Nancy** commented that if your M-spike is zero, then you can request a minimal residual disease (MRD) test, which measures the amount of MM cells that have survived after treatment and can detect 1 MM cell in 1 million healthy

cells. Otherwise, if your M-spike is not zero, then you already know you have MM, so there is not a reason to test MRD. **Jim. M.** mentioned that doctors are still researching to fully understand what MRD-negative means. Jim was also MRD-negative but relapsed while taking maintenance drugs.

Several members mentioned discontinuing MM drugs (for various reasons, including side effects) after being on them for many years with good results. **Bob C., Joyce,** and **Cynthia B.** have discontinued use of MM drugs and are doing well. Those who have opted to stop their treatments are continuing to monitor closely.

**Bianca M.** was diagnosed in September and has begun induction therapy of Revlimid, Dex, and Darzalex. She experienced a reaction to Darzalex initially, so has moved to non-infusion Darzalex FASPRO, which she prefers. She also had some liver toxicity issues early on and the non-steroid drug dosages were altered. The side effects with the biggest impact for her now are the highs/lows that she is experiencing with Dex. Overall, she feels that her treatment is going well and mentioned that she is changing doctors soon, which she is looking forward to. Bianca also mentioned that she is debating whether or not to have a SCT and is researching that topic. She is interested in hearing more about healthy patients that decided not to have a SCT. Many members provided information of why they opted to have or not have a SCT. Someone advised collecting stem cells early to store, before bone marrow is damaged from any further treatments, despite what you may decide to do later.

**Jeffrey R.** has non-secretory MM and has collected stem cells but is not eligible for a SCT due to heart issues. He mentioned that he had to get off steroids due to vision issues. He went through four different prescriptions and changes in glasses before understanding the cause of his vision problems being from Dex usage. He also has a nodule in his lung and will have further testing for that issue. He is currently looking for non-SCT MM treatments. **Vena** has been diagnosed with both MM and lung cancer. Her doctors will not treat both cancers at the same time, so while her MM is not active (due to prior successful treatment), they are focused on treating her lung cancer, which has spread to her brain.

Several members mentioned having neuropathy as a side effect from drugs. **Karen C.** has severe neuropathy in her feet from Velcade. She has stopped using Velcade but still feels the pain. She tried using Gabapentin, but it did not help with the neuropathy, and she is looking for long-term solutions for neuropathy and overall improved health in general. **Jim M.** recommended acupuncture to relieve neuropathy, which helped him tremendously. **Kimberly S.** mentioned a device that she saw on Amazon that uses acupressure to massage feet to help relieve neuropathy.

**Nancy B.** recommended two IMF videos: 'Living Well with Myeloma: Psychosocial Care' and 'Living Well with Myeloma: Can Nutrition Improve Quality of Life and Outcomes in Myeloma?' and provided navigation tips. From <https://www.myeloma.org/> click 'IMF Videos', then click 'Living Well with Myeloma' to select the different videos in that category. **Sandy W.** recommended checking the AAMMSG Southside newsletter from the November meeting for other health related tips. **Jim M.** mentioned that there are good Piedmont support groups that offer eating well seminars, cooking classes, and other health-related topics. **Nancy** noted that people

are living longer with MM, and it is important to live as well as you can for the long term.

Submitted by Wendy R.

**Meeting Minutes**  
**Southside MM Support Group**  
**December 22, 2023**

**Next Meeting:** January 27, 2024 - Virtual. **All about Darzalex/Daratumumab in myeloma therapy.** Speaker: Kim Y. Burney, BSN, RN, MSNed, OCN, Oncology Nurse Educator. Janssen Pharmaceutical Co.

**Next meeting “For Men Only”:** – Tuesday, February 26, 2024, at 6:00 PM  
The December meeting included some holiday cheer, education discussion, and patient/caregiver-partner voices. The IMF has created a *Men’s Only Group*, and you are invited. Stay tuned.

Group Discussion

The meeting started with a 7-minute video from **Patient Power**, called [“Multiple Myeloma Treatments: What’s New at ASH 2023?”](#) presented by Dr. Brandon Blue, Hematologist, Moffitt Cancer Center, Tampa. Check out the link if you missed it to get a quick overview of myeloma topics discussed at ASH 2023 including CAR-T, immunotherapy, and why there are such differences in the recommended therapy for myeloma patients. Two handouts were emailed after the December meeting. The first handout was a [List of Financial Resources](#) provided for us by Kendelle, Emory Winship Social

Worker, who presented at the November Southside meeting. The second was PEN [Myeloma Resource Guide](#) with possible treatment options. This can be especially useful as patients and caregiver partners make important informed decisions with their healthcare provider about their next treatment options.

Some time was taken to remember and reminisce about those members we lost too soon in 2023. Questions posed to those in attendance. “*What makes you happy? What gives you joy?*” The holidays can be a very sad and difficult time for family members and friends who have lost loved ones recently, and over the years. There are helpful resources in one’s time of need.

- *Contact 988 (crisis hotline) for 24/7 year-round assistance from trained counselors who will listen and address your concerns. Be sure to use and share the hotline with others.*
- *Connect with community, family members, and friends.*
- *Confide in a trusted friend or family member about your feelings or any concerns.*
- *Plan personal time for cultural, spiritual, or religious activities.*
- *Volunteer with organizations that hold personal interest for you.*
- *Giving back to others can provide self fulfilment.*
- *Explore outdoors. Enjoy nature with others.*

The group also discussed ways to reduce the perils of daily stress.

- 1- **Be active.** *Take a dance break!* Lift weights. Do push-ups or sit-ups or kick around a ball.
- 2- **Reset.** *Close your eyes, take deep breaths, stretch, or meditate to refocus your mind.*
- 3- **Write down three things you are grateful** to revisit regularly.
- 4- **Check in with yourself.** Take time for *self-reflection* and to assess how you are feeling.
- 5- **Laugh!** Think about *what makes you laugh* or when you have *laughed so hard you cried.*

6- **Gather** *inspiring songs or quotes* (print/screenshot) so you have them handy nearby.

### Patient/Caregiver Updates

**Geraldine** has had a difficult time in the last month. Her daughter suddenly passed away after a brief illness. She also had surgery for a brain tumor and shingles. **Vena** is doing better after being hospitalized. She is being monitored for her myeloma while being treated for lung cancer at Emory and Kaiser/St. Joseph's. **Teonna** is healing after undergoing "nailing procedure" rod inserted surgery for a cracked femur. She is currently taking *Venetoclax and Dara with Zometa* after a relapse. **Wanda P.** has had a difficult time harvesting her cells. She also has a history of kidney disease. After dealing with several rounds of [Cytosan](#) and its side effects, Dr. Morris admitted that her case is a special one with no definitive solution. Wanda appreciated his honesty. There was poor communication about generic options for [Zarxio](#) injections to help stimulate her cells for harvesting. She paid about \$4,000 co-pay for Zarxio instead of a generic alternative with a negligible co-pay. Be sure to ask about the cost of any new medication and seek the help of the medical staff and social workers in seeking lower costs. **Flora** has had no success in getting LLS funds, even after calling every day. Review the list of possible funding sources supplied by the social worker that was recently sent out. Flora is also concerned about her weight gain from steroids. She has had SMM smoldering for about 11 years. Some suggested focusing on a whole plant-based diet. LLS has a resource for one-to-one nutritional counseling for patients and caregivers. It is an underutilized resource. There is an optimal health, whole plant-based eating series that will begin again in January. These sessions are led by Jennifer Rooke, MD at Morehouse School of Medicine. **Jeff** has been on *Venetoclax and Dex* for about five years now and is doing well. His primary side effect includes feeling breathless at times. He receives [IVIG](#) (*Intravenous Immunoglobulin*) therapy to increase antibodies that fight

infections. **Dirk** shared some “good news.” He had a SCT (Stem Cell Transplant) about five years ago. About a year and a half ago, his light chains started to increase. He started on *Dara-Pomalyst-dex* via six hours of infusion. Dara is now administered subcutaneously (sub-Q), so the time commitment is much less. **Sandy B.** gave us a positive update on finally getting a set of dentures that fit well after several tries with different dentists over the past year. Unfortunately, she has a new challenge – a hairline fracture in her femur after a fall in the bathroom. Sandy has fractured her femur twice before. **Ted** had an accident on December 15 when his riding mower tipped over. He fractured a disc in his neck that had to be removed on December 19 at Emory Midtown. We wish improved health and continued healing to each of our members.

Ted also shared that the Men’s Only Group is continuing to share and bond. They have important exchanges that he is sure they would not have in general. He and Anderson attended a national Men’s Only meeting sponsored by HealthTree. This was their second meeting, which was initiated after hearing about the Georgia Men’s group. That group will meet quarterly.

Respectfully submitted, Gail.