# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

## Northside MM Support Group

**December 6, 2025**

## Introduction & News

Thank you to **Nancy B**. for hosting the virtual, open discussion meeting, where we shared treatment information and helpful tips for improved quality of life. During our December meeting, the annual American Society of Hematology (ASH) conference was occurring in Orlando, Florida, where 30,000 hematologists from around the world meet to discuss blood disorders. Last year, there were over 1,000 abstracts related to myeloma, and we expect big news on new research breakthroughs and treatment options to be presented this year. We look forward to hearing about what was discussed at the ASH meeting in our January meeting, where Emory doctors will report on ASH findings. In order to prepare for learning and understanding the ASH information that will be shared in the January meeting, it is highly recommended to review webinars and information posted on the IMF website, as changes in the myeloma world happen quickly and the information can be complicated and technical in nature. Many of us review the information several times, stopping and restarting the videos to take notes and formulate questions, etc. in preparation for a better understanding of the material and how the information can best help your individual needs. Remember, patients who are well informed have the best outcomes!

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## Discussion & Updates

The group welcomed **Steve D.** who was diagnosed in 2021 and is new to the group. He is currently on his first line of treatment and is beginning to display signs of relapse. **Steve** had some kidney issues and was initially treated with the quad standard of care, a stem cell transplant (SCT), and participated in a Phase 2 clinical trial (CT) at Emory, which was a good experience for him. He is currently watching and waiting, per his doctor's recommendation, while considering next treatment options if needed, including participation in another CT. Since he has t(11;14) translocation he is considering Venetoclax and Sonrotoclax as possible next treatment options. **Jeff W.** also has t(11;14) translocation and was previously on Venetoclax, progression-free for 63 months, with no side effects. He also used Dara (once a month) with the Venetoclax, along with Dex and reported the treatment as being a good experience for him. After that, Jeff had a CAR-T in January 2025 and is doing well.

**Chuck M.** reported doing well and being treatment-free for 27 months. He recently had a bone marrow biopsy and PET scan with no progression identified after 5 years, since he was diagnosed. He mentioned that some other numbers are increasing so he is considering next treatment options and will meet with doctors soon to discuss CAR-T and learn if he is a candidate for CAR-T.

There was discussion about CAR-T being used as an earlier treatment option now and that there are different types of CAR-T, with different targets. Initially CAR-T targeted only the BCMA antigen, but newer CAR-T therapies target other antigens, which allows for more than one type of CAR-T being able to be used on a patient in the event that a patient would benefit from a different type of target. And, if CAR-T or another bispecific drug stops working for a patient, then perhaps they can benefit from a different CAR-T or bispecific drug that has a different target than the one that no longer works for them. **Nancy** commented that this is a good question to ask at the January meeting with Emory.

**Jeff B.** was diagnosed in 2016 and had a SCT in 2017 which worked for about 1.5 years. He was then on the Darzalex and Pomalyst for about five years that worked well for him. He had CAR-T in April 2025 and is doing very well with a good quality of life. His experience with CAR-T was good, he had a fever for a couple of days, and he never felt too bad. He mentioned that it was much easier than a SCT. **Nancy** commented that the fever is due to the cytokine storm, which is an expected CAR-T reaction, and doctors get that under control quickly now. He has been re-immunized and that went well. **Jeff W.** asked if the re-immunization after CAR-T was necessary since CAR-T doesn't destroy the bone marrow like a SCT does. **Nancy** commented that this is a good question to ask at the January meeting with Emory.

**Rhea P.** recently moved to an assisted living facility and is facing new challenges with being around contagious people who are not being careful not to infect others. She is learning how to navigate these situations to protect herself and is looking for suggestions. How do others protect themselves at social gatherings and when around others who may be contagious, and at times when you can't always wear a mask (i.e. dining) and sometimes can't leave the area quickly enough to not be exposed, other than having to isolate yourself? It was acknowledged that this is a huge challenge for all of us. It was recommended that Rhea discuss IVIG therapy with her doctor. **Marilyn M.** commented that she has been on IVIG since October 2024 and it has helped her immune system tremendously. **Jeff W.** said that it helps him avoid upper respiratory infections. Others have considered IVIG and report having challenges being able to get it approved, with mention that oncologists are hesitant to approve IVIG therapy and it is expensive without insurance. **Marilyn** commented that her oncologist would not approve of IVIG for her, but she obtained approval from an infectious disease doctor. She mentioned that she gets an infusion every 28 days. It takes approximately 4 hours total (including labs and visiting a doctor), and she feels tired afterward on the day she gets the infusion, but it has helped her tremendously overall. **Molly** asked why doctors are hesitant to approve IVIG for patients. **Jeff W.** commented that your numbers have to be extremely low to obtain approval for insurance to pay for it. **Steve D. mentioned that he uses Zarxio (generic Filgrastim) for immune boosting in the form of** self-administered injections, twice a week. He thinks that **Zarxio might be easier on kidneys with fewer side effects than IVIG. Lory M. commented that she has chronic kidney issues from treatment yet has been on IVIG for nearly two years (post** CAR-T**) without any issues. You have to get the right version of IVIG for your individual circumstances and her kidney doctor has approved her use of IVIG. Lory said IVIG is working well for her.**

**Jim M.** reported that he has been sick for weeks and is no longer on the CT that he was participating in, as it was not working for him. Jim mentioned that he has recently lost a lot of weight and he has a lot of back pain and had to go back on the Fentanyl patch. **Jim** explained that although he supports CTs and has participated in CTs before with success, this one did not work for him after a couple of cycles, and he did not receive the support he expected and needed once it began to fail. While he was on the CT he was not getting the personal level of support that he needed from the CT doctor that he usually would from his regular doctor who knew him and his history well. Since then Jim and his family has met with his regular (non-CT) doctor again, who is very concerned for him, and Jim is planning to start a new treatment, Talquetamab, a bispecific with a different target than BCMA, and beginning with a lowered dose, under his regular doctor's care soon. **Jim and Nancy** both reiterated how important it is to take good notes, have someone go to your appointments with you, and notify your care team when you have any issues or are not getting the appropriate level of care; always be your best advocate.

**Sandy B.** was diagnosed 36 years ago. Currently, her main problem is with mobility. She had a fall in 2023 and since then she has not gotten the strength back in her legs, so she uses a walker in her house and a wheelchair (to prevent falls) when she goes out. She's had physical therapy and continues to exercise to help keep her strength and tries to maintain consistency despite some fatigue and peripheral neuropathy (from treatment with Thalidomide in 1999), which causes balance problems. She's been on Revlimid since 2016 which works for her, but has caused some mouth issues and caused her teeth to loosen. She has had her teeth extracted and wears dentures that need to be refitted frequently, after any mouth surgeries. This has resulted in an inability to eat solid foods and some weight loss. **Sandy** enjoys sharing her myeloma experience with others and enjoys talking with and helping anyone she can. She mentioned that she sometimes gets requests from other support groups who want to talk with her because of her long journey! She credits her longevity to following her doctors' advice, and good support from her family, church, and our support group. **Sandy** also thanked **Nancy** for her being here for us to keep the support group running.

**Doris M.** was diagnosed 21 years ago and is doing well. She is taking Pomalyst, which is working well for her.

**David H.** has been on Revlimid as maintenance for two years post SCT and is doing well. David explained that he has not yet tested as MRD negative, although the numbers have continued to fall with each subsequent MRD test, so is hoping for that in his upcoming test.

**Bianca M.** is currently on Pomalidomide, Daratumumab, and Velcade as maintenance post SCT, and is not yet MRD negative. She's been experiencing fatigue and just started a medication used for ADHD to help with that. She is trying to be more active but has been getting out of breath and has communicated that side effect to her healthcare team.

There was discussion about exercise and especially easing back into exercise slowly after a treatment-induced hiatus. Several members talked of walking and/or running slowly in the Peachtree Road Race. **Steve D.** provided an encouraging comment, stating that there are huge numbers of people who just walk the Peachtree Road Race or jog a little, so it's still fun and good way to see the city. **Joyce** commented that she's walked the Peachtree Road Race every year since 2014. Someone else suggested looking into the Silver Sneakers program to see if your health insurance covers it. Others are using e-bikes and a suggestion to get a stand for a bike to turn it into a stationary bike was mentioned. **Steve D.** provided a link to some additional information: https://becanceractive.org.

## Meeting Minutes

## Southside Virtual MM Support Group

## December 27, 2025

**Next Meetings:**

Southside group meets **Saturday, January 24, 2026, at 10:30 AM. Virtual Only**. *Blood Cancer United/LLS. Kim Nickels, Senior Manager, Patient & Community Outreach.*

**For Men with (with Myeloma) Only.** Tuesday, January 27, 2026 @ 6:00 PM. Virtual Only.

## Group Discussion

Southside opened the last Support Group meeting of the year with a series of deep breathing exercises. Encourage everyone to practice using their breathing for relaxation, focusing, improving the mind/body connection, and improved optimal use of lungs and oxygen/energy exchange.

December is the month of the ASH (American Society of Hematology) annual meeting. This is an international meeting of researchers, clinicians, and others to share information on the current status of all blood diseases – including sickle cell, leukemia, lymphoma, as well as myeloma. There were over 8,000 abstracts (research reports) accepted for this conference. Myeloma was represented in over 1,500 abstracts (25%) that is very significant and speaks to the many advances in myeloma.

The IMF supports patient representatives from Support Groups to attend this meeting. This is an example of the patient-centered philosophy of the IMF. Patients/Care partners have been central to the IMF from its inception – as the founding members were a patient, a care partner, and a physician-scientist, Dr. Brian Durie. Dr. Joe Mikhael leads a December 17th online seminar sharing many of the updates from ASH 2025. There is great information for all of us to consider in this presentation. Please listen to the recording available for you at myeloma.org, the IMF website. In one of our short, selected videos from this month, Dr. Brandon Blue (Moffitt Cancer Center, Tampa) explains how patients/care partners can benefit from these big medical-scientific meetings.

Experts can differ on their approach to myeloma questions. It is a way to view how they can respectfully disagree and what those differences might mean to you as a patient/care partner.

We had three **selected videos** this month. They included: How Patients Benefit from Major Medical Conferences. March 2025 – 7 min/30 sec. Dr. Brandon Blue and Cindy's Story: From Passive Patient to Powerful Advocate – 2025. To get these links, see your Agenda from November 22, 2025.

After viewing Cindy's story (video), **Marcia s**hared that she had an issue with her provider regarding the IVIG injection to improve her immune response. Because her veins are difficult to access, she requested the Sub-Q (subcutaneous/under the skin) procedure and was told that it was only available for children. Because she had learned about the sub-q availability, she approached her insurance providers herself. Marcia worked with her case worker through CIGNA and was able to save her veins and an uncomfortable/painful procedure. Case workers will often reach out and check on you on a regular basis. **Jean** encouraged others to use their insurer's case manager. That case manager can advocate on your behalf within the company. She is a nurse with Anthem, and they help patient/care partner navigate the services of their Health Plan. They are often underutilized. Each Health Plan member has a dedicated case worker. Medicare/Medicaid might also have these services through dedicated social workers or nurses.

**David shared information on three ASH myeloma research updates with the Group.**

**Article 1-** The **MMyCAR** study was a phase I study with three patients. This is a what seems like "science fiction" study where the T-cells are treated inside the patient: in vivo. This process would replace the current 4-6 weeks of removing, treating, and re-introducing T-cells into the patient. This was considered a favorite abstract of ASH for many due to its innovation and success. All patients achieved MRD negative (no myeloma detected) in the first month of treatment. All patients had high-risk cytogenetics. There was no progression of the disease at the third month. **https://firstwordpharma.com/story/6686446.**

**Article 2**- The founders of the **CRISPR-CAS9 technology** (gene-editing tool) (J. Doundna and E. Charpentier) and 2020 winners of the Nobel Prize in Chemistry will apply this innovation to myeloma, B-cell malignancies, and various other cancers with an $82 million grant. Myeloma reaps the benefit of this innovative tool. https://firstwordpharma.com/story/6515769 .

**Article 3**- The **MajesTEC-3 study** (LBA-6) is a phase III randomized trial with 260 patients comparing teclistamab plus daratumumab (**Tec-Dara**) with standard regimens of **darat**umumab and **dex**amethasone plus either **pom**alidomide or **bort**ezomib in RRMM after at least one prior line of therapy. The Tec-Dara combination showed an 83% vs 30% in Progression Free Survival (PFS) in remission in two groups after three years. This can be a dramatic change in the ability to treat after first relapse and can easily be applied in both community and academic settings. J&J is looking at this – it would compete with their own CAR-T (Carvykti) profitable technology.

Lots to think about. Thanks David! Gail reported that in many of discussions, the risk of infection was a real concern – something for patients to be vigilant about.

**https://www.oncologypipeline.com/apexonco/ash-2025-jjs-multiple-myeloma-juggling-act**

**Patient/Care Partner Check-in**

**Cynthia** is stable now. She is on bispecific Talvey and IVIG, and pentamidine (which helps with prevention of pneumonia when the immune system is compromised). She has had serious side effects with Talvey and is not willing to remain on the drug. Gail offered that J&J might be able to assist with side effects – Kim Burney (Johnson and Johnson (J&J) representative presented at Northside SG recently). Side effects of Talvey include mouth problems (change in taste, sore throat, dry mouth), fingernails (cracks, peeling), skin (rashes, redness), and weight loss (get nutritional consultation). This is because the target is the GPRC5D protein on myeloma cells and this same protein is found on epithelial cells. These epithelial cells form a protective barrier in skin, lungs, and mouth. J&J provides patient kits with a recommended cream/lotion and lozenges to each patient. Contact J&J patient care navigator [*jnjwithMe.com*] at 844-94-8463.

Unfortunately, sometimes the information from J&J does not get to patients through providers, e.g., information on numbness around the mouth, loss of fingernails/toenails, rashes, etc. Cynthia's question is, "Is there anything beyond Talvey?." Nancy suggested she and others listen to the ASH updates online seminar on *myeloma.org* from December 17th. **Wanda P**. will have CAR-T next week at Emory. She works with Dr. Joseph who was recommended by someone from this support group and is very pleased with the Emory team. She came from Northside and the doctor she worked most closely with has retired. She is most nervous about the 7–14-day hospital stay. **Marcia** recently had CAR-T and was told she was a boring patient: She had none of the CRS (cytokine release syndrome) and never had a fever. She asked, "What causes CRS?" and was told about inflammation. She decided to go in with as little inflammation as possible. She feels her healthy eating (plant-based) may have been a factor. Wanda P. is 69 years old and has followed a plant-based eating lifestyle since age 18. We wish her good luck!

Gail shared that **Dr. Jennifer Rooke,** a preventive medicine physician at Morehouse School of Medicine, came a couple of times to talk to our Support Group about the health benefits of whole-food plant-based (WFPB) eating. For more than five years, she has offered free sessions over 10-12 weeks on Wednesday evenings. Several of us attend those Wednesday sessions that often have over 100 attendees from across the country. If you are interested, The **Optimal Health Lifestyle Intervention Workshops** are virtual! Starting January 14, from 6:00 PM to 8:00 PM Eastern Time. Register in advance to join the classes in this series of workshops: https://msmedu.zoom.us/meeting/register/4Zky_9u1QnazIt_kldSRVA . **Jala** asked about information on Caregiver/Care Partner resources. Nancy shared that IMF (Myeloma.org) has resources for Care Partners. **Carolyn** shared that she was told that green tea and grapefruit can interfere with certain medications. Wanda shared that Oolong tea can interfere with Velcade effectiveness.

The Patient Advocate Foundation (PAF) and American Cancer Society (ACS) partnered to provide a **$200 grant** to myeloma patients. Marcia shared this information from last month and once approved, you will receive the check within a week. **Call 844-216-7520** before funds run out. There is an opportunity to join an advocacy group with Blood Cancer United on January 29. If interested, please ask an information specialist at 800-955-4572.

**David** asks that we all please write/call our congress representatives and ask that they restore National Institutes of Health/National Cancer Institute (NIH/NCI) funding. Emory and others have been hit by a reduction of over $100 million in research. He provided ways for us to locate and reach out to our representatives.

https://www.house.gov/representatives/find-your-representative

https://www.senate.gov/senators/senators-contact.htm

https://www.congress.gov/members/find-your-member

Wanda suggests we consider writing as a group to show power as a group. She volunteered to work on this: It is something she has done previously. **Alicia** also suggested working with Blood Cancer United on advocacy. For IMF advocacy, it is advocacy.myeloma.org.

We talked about **Myeloma Action Month**. The IMF has a plan to identify places where we can raise awareness about myeloma by “lighting” their buildings with “red” for blood cancers. Some ideas for Georgia would include downtown ATL Bank of America, Mercedes Benz, Truist Park. Other sites could include Savannah and Macon. It was pointed out that February is heart month – which would also be red. If you have ideas about other possible sites, please email us and we will share with the IMF team.

Please be sure to review your resource list on your agenda from December and your Support Group Monthly Newsletter for more information you can use.

Respectfully submitted,

Gail.