# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

## Northside MM Support Group

## July 12, 2025

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### Business and News:

**Thank you to Dirk B. who hosted the virtual, open discussion Ice Cream Social meeting, with approximately twenty-five attendees.**

### Welcome New Patients:

**The group welcomed some first-time attendees. Kathryn N. was diagnosed in May 2025 with smoldering multiple myeloma (SMM). She has had cancer before and knows the value that support groups can provide and found this group through an internet search. Steve D. was diagnosed with multiple myeloma (MM) four years ago. He has attended some Southside meetings, and this was the first time he joined the Northside meeting. John S. was diagnosed with MM this spring. John mentioned that his wife attended a meeting previously and she learned a lot. Donna G. attended a Southside meeting, and this was the first time joining the Northside meeting. She was diagnosed with MM in January 2025 and is currently doing a second stem cell collection at Emory in preparation for a stem cell transplant (SCT) in August. She explained that she did not collect enough stem cells the first time and so she is going through the process again. Her doctor wants to have 6-8 million stem cells collected prior to proceeding. Donna mentioned that she found the support group to be very encouraging.**

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### Patient Updates:

**Jim M. was recently hospitalized for 17 days. His MM numbers suddenly jumped, and he experienced terrible pain in his chest that was related to broken ribs. Jim described the pain as the worst he has ever had. He did two rounds of**

**radiation, had kyphoplasty to repair broken bones; and is currently managing pain with a Fentanyl patch, Tylenol, and Oxycodone. He was unable to walk and had to relearn to walk. He is currently not driving and is taking a break from work as he recovers. He is also experiencing a loss of appetite. He has been very much disrupted and is learning to manage all the unexpected and sudden changes on a day-by-day basis. Jim also mentioned that he had been on a Phase 1 clinical trial (CT) but had to stop for a while. The Dex that he was on from the CT has triggered a resurface of diabetes. He plans to resume the CT again soon. Jim had a lot of praise for his doctors and the palliative care team at Emory. Jeff W. reminded Jim to be careful not to get pneumonia due to shallow breathing caused by broken ribs. Others mentioned how painful broken ribs are and that there is not much that can be done other than to manage the pain as they heal. Sandy B. is experiencing compromised mobility and is starting physical therapy (PT) to strengthen her hips and legs and hopes to stop needing to use a walker at home and wheelchair when out. She is still taking Revlimid and a low dose of Dex which continues to work well for her. Marilyn and Dirk recommended always opting for PT when a doctor recommends it, and to take advantage of working with a professional. Marilyn M. was diagnosed with SMM in 2008 and has not had any MM specific treatment. It is possible to have SMM and not need treatment. She did, however, begin getting IVIG infusions last October to help build up her immunity and prevent infections which had become frequent for her. She gets an IVIG infusion every 28 days, which takes approximately 4 hours including lab work. Marilyn never had infections until she was diagnosed with SMM, but the IVIG infusions are working, and she feels good.**

**Several members have recently completed CARVYKTI CAR T-cell therapy:**

- **Jeff W. completed CAR T-cell treatment earlier this year and is doing well.**
- **Scott M. is on Day 12 and was just released from the hospital on Day 10. He is doing well and mentioned that he experienced a low-grade fever and the hardest part for him was the lymphodepletion and nausea around Day 3. He coped with the side effects by eating small meals and staying hydrated. He currently goes to Emory ICC daily for lab work. He said his neutrophil count is currently at zero, which he also experienced after a SCT 11 years ago.**

**- Joe H. is on Day 97 and is doing well. His m-protein level is not at zero yet, but all other counts are good. On Day 100 he will get a PET scan and bone marrow biopsy.**

**Cynthia B. recently started using TALVEY, a bispecific drug, and it has been challenging for her. She wondered if anyone else in the group had used it and what their experience had been. Gail commented that there are a couple of others in the group using it, but they were not present at the meeting. Cynthia reported side effects of peeling skin, itching, and loss of taste/appetite. She has been able to maintain her weight despite her loss of appetite. Gail mentioned that others that she knows that have taken TALVEY have experienced the same side effects as Cynthia, plus more, including issues swallowing and peeling nails. Gail recommended finding a nutritionist and staying well hydrated; she also suggested considering discussing a lower dose of the drug with her doctor. Dirk and others suggested a skin lotion that contains urea: https://en.wikipedia.org/wiki/Urea-containing_cream. Cynthia uses a urea cream as well as steroids to help with itching and she also commented that the MM has spread to portions of her brain, and she will start radiation soon. Despite all this, she is not feeling bad and is doing her best to manage drug side effects. She explained that she has done well with MM treatments for 12 years and hopes that it will continue.**

**Dave O. joined the meeting after having been absent for a while. He was diagnosed with bladder cancer approximately 2.5 years ago. The bladder treatment did not work and so two months ago he had his bladder removed, which went well, and he is feeling back to normal again. Dave went off his MM treatment two years ago to focus on treating bladder cancer. He has not resumed MM treatment, and his numbers remain stable. He is enjoying a break from the twice a week Dara treatment which he had been on for four years. Molly asked if the bladder cancer might be a secondary cancer due to prior MM treatments. Gail commented that there is no way to know definitively if secondary cancer is from MM, but that secondary cancers are definite risk factors for MM drug therapy. Dave explained that he has had four types of cancer, with MM being the third and bladder cancer the fourth. He thinks that it would be more likely that the bladder cancer might be a secondary cancer from the first type of cancer that he had, which was non-Hodgkin's lymphoma over**

**20 years ago because a drug he took then had a side effect that could affect the bladder. He has submitted his story, which will be published on the bladder cancer network. Dave also mentioned that last November he fell off a ladder and fractured his pelvis, shoulder blade, and ribs from which he recovered. Dirk B. asked if any others have taken a break from MM drugs due to hospitalizations or other conflicting treatments. He stopped Pomalyst and Dex recently during a hospital stay and is doing well without them. Mary V. recently went off Dex and is doing well. Gail and Jeff mentioned that researchers are trying ways to reduce Dex and other MM drug dosages to see if the efficacy remains with a lower dosage. There is continuous research happening on this topic. The researchers are listening to patient feedback, and many MM drugs are not being used in ways or dosages as originally intended due to the feedback of the MM community. Vanessa F. reported that she has been having some struggles and is planning to meet with her doctor to consider a new treatment protocol. She plans to provide another update at the next meeting.**

## Open Discussion:

**Steve D. will be participating in a Leukemia and Lymphoma Society (LLS) scenic 150-mile bike tour in Wisconsin soon. This led to further discussion about physical activity and e-bikes, recumbent bikes, and folding bikes that several members plan to begin using.**

**Additional items were discussed in the meeting, including the following:**

**Many commented on the value of being a part of a support group. Marilyn commented that patients who have a strong support network have better outcomes and live longer than those who do not. Several in the group have encouraged others to join with good outcomes, benefiting all. Jeannie B. commented on how a single conversation can change the direction for others significantly. Mary V. mentioned that what she learns from others helps empower her to have more meaningful conversations with her doctors. Jeff and Dirk commented that it is good to hear how others are doing and knowing that you are not alone on your journey.**

**Gail spoke about the importance of seeing an MM specialist regularly or seeking a second opinion if you are not already seeing a myeloma specialist. The reason for this is because with the vast amount of research and new MM treatments, it is hard for doctors to keep up with all of the changes when they are not specialized in MM. Good doctors will work together as partners to find the best treatments for their patients, and prefer that their patients get second opinions and location should not matter. Dirk B. commented that Atlanta is a good place for MM patients, as there is good care locally. There was discussion about the differences between Northside and Emory facilities. Northside is a treatment facility, and Emory is a research medical center. Steve D. commented that Emory offers CT options, and he was glad to be able to participate in a Phase 2 Dara/VRD 4-drug CT when he was newly diagnosed 4 years ago and very sick with kidney impairment. The 4-drug combination worked well for him, and quickly, and has now become the standard of care. Donna G. commented that she initially started working with a hematologist who treated her and then sent her to an MM specialist at Emory. She expects to continue to collaborate with both doctors, as it has been a good experience for her. Mary V. was initially treated at a medical facility in Athens, which was a good experience with the best treatment available at the time. She then went to Emory where they made modifications to her treatment plan that helped her feel much better.**

**Gail mentioned the Emory Immediate Care Center (ICC) that is available to Emory cancer patients as an alternative option to going to an ER. An appointment is required, and the ICC phone number is: 404-778-0519. Several people commented that they have gone there with good results. Refer to notes above.**

**Submitted by Wendy R.**

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## Meeting Minutes

# Southside Virtual MM Support Group

### July 26, 2025

## Next Meetings:

**Southside** meeting is this Saturday, August 23, 2025 @ 10:30 AM. Virtual Only**.**

Guest Speaker, **Diahanna Vallentine, from Healthtree, Finances and Cancer Care** will present an information-packed session on what financial pitfalls to avoid, considerations for myeloma patients during healthcare open enrollment and estate planning.

**For Men Only:** Tuesday, August 26, 2025, 6:00 – 7:00 PM. Virtual Only.

## News & Business:

Information was shared about **Personal air purifiers** for a compromised immune system that is worn around your neck. It was highly recommended by a patient at a recent IMF conference. To purchase this necklace, go to "**airtamer.com**" and use the Discount code – myeartamer for a 30% discount. **Veterans Myeloma Support Group** meets virtually the fourth Wednesday of each month from 6 to 7 PM. Next meeting is Wednesday, August 27, 6:00 PM. Sign up for emails and Zoom link here - The Veterans with Myeloma Special Interest Group | International Myeloma Foundation

## Group Discussion:

Thank you, Gail, for hosting this meeting with 30+ attendees. Members have requested more sharing on the specific experiences and expectations from the group during their MM journey regarding **Stem Cell Transplants, Bispecifics, and CAR-T therapy.** Scheduling a Stem cell (SCT) or CAR-T therapy or starting a bispecific regimen with all the unknowns and possible side effects can be scary. We hope you find these notes, vocabulary, and shared experiences helpful. Use additional resources and discuss with your providers to gain a deeper understanding of each procedure. Please be sure to journal detailed notes in your personal Cancer Care Plan.

***<u>Stem cell Transplants:</u> (SCT).*** For those who are eligible, the actual procedure is more like a blood transfusion than what we usually think of as "transplants." The patient goes through several rounds of treatment to reduce the number of diseased (myeloma) cells. For those who can use their own cells, they will harvest healthier cells after induction treatment and will receive their own cells back in an *autologous stem cell transplant* **(ASCT) or bone marrow transplant.** Others might receive cells donated from another person. This is called an *allogeneic stem cell (Allo) transplant***.**

**Nancy B**. emphasized that SCT is still standard of care and there are discussions about moving CAR-T up to first-line treatment. **Wanda** (diagnosed in Jan 2023) was able to harvest only a bare minimum after six tries. She worked closely with Dr. Lawrence (now retiring from Northside) with her unusual response to harvesting and treatment so far. She is looking for a new myeloma specialist at Emory, though most have full patient loads. Wanda has had a unique journey for her myeloma and needs a specialist. **Jeff** shared that CAR-T harvests different cells – T-cells vs stem cells for transplant. He has harvested both types. **Lory** is a new patient and was able to get immediate appointments with Dr. Lonial. She had a Bone Marrow biopsy in July, and things are moving well in her treatment schedule**. Nancy Z** had her SCT two days ago and is doing well, reported Sandy W**.**

***Quick ASCT Facts:*** aka bone marrow transplant involves replacing damaged or diseased bone marrow with healthy stem cells.

- ASCT is the current standard of care for MM.
- Stem cells can be autologous (own cells) or Allogeneic (donor).
- Pre-transplant conditioning reduces level of myeloma cells present (induction therapy)
- Patient's stem cells are collected (harvested) from their blood.
- High dose chemo/melphalan is given to kill remaining myeloma cells prior to transplant.
- ASCT is like receiving an IV for blood transfusion.
- Infused stem cells travel through the bloodstream back to the bone marrow to begin blood cell production again.

**Side effects**. Common side effects of SCT include fatigue, nausea, vomiting, mouth sores, hair loss, and increased infection risk due to an extremely compromised immune system.

Blood counts (white blood cells, red blood cells, and platelets) will be closely monitored as the new stem cells start to function. It is crucial to communicate openly with your healthcare team about any symptoms, concerns, or questions you have during your recovery.

Questions to ask: *What about home preparation and care partner?*

**Resources:**

**IMF-** – Understanding Stem Cell Transplants – Understanding Stem Cell Transplant| Intnt'l Myeloma Fnd

**Healthtree -** Stem Cell Transplant (SCT) Educational Guide

***Bispecifics*** … aka BsAbs are antibodies designed to engage the patient's immune system to target and destroy cancer cells.

- These antibodies have two binding arms: one that attaches to a protein on myeloma cells, like BCMA or GPRC5D, and the other attaches to T cells, bringing them into close proximity to kill cancer cells.
- Binding protein targets for bispecific antibodies include BCMA, CD38, CD138, FcRH5, GPRC5D.
- Patients who are not eligible for CAR T-cell therapy may be eligible for bispecifics.
- Bispecific antibodies are typically administered as subcutaneous injections.

Bispecific Action

## Key Bispecific Antibodies:

**Teclistamab (Tecvayli) by JnJ:** The first bispecific antibody approved for multiple myeloma, targeting BCMA on MM cells and CD3 proteins on T-cells.

**Elranatamab (Elrexfio) by Pfizer:** bispecific BCMA antigen directed CD3 T-cell engager.

**Talquetamab (Talvey) by JnJ:** Targets GPRC5D on MM cells and CD3 on T-cells.

Bispecific T-cell engagers help your immune system to attack the myeloma cells. Bispecific T-cell engagers damage and destroy myeloma by bringing T cells close to the myeloma cells. For **Trispecifics (new)**, two arms bind to a myeloma cell, and one engages the immune system by binding to an immune cell (a T cell or *Natural Killer* cell). Alternatively, one arm may attach to a myeloma cell while the other two bind to the immune cells.

***Important Considerations**:* Initial doses are administered in a hospital setting to monitor any potential side effects, such as cytokine release syndrome (CRS). Bispecifics have shown promising response rates in *heavily pretreated patients*. These are MM patients who have had 5 – 12 or more lines of therapy.

## Patient experiences with Bispecifics:

Carolyn H, Alf and Cynthia B. shared their journeys on Bispecific treatment with the group.

**Alf** started Talquetamab (Talvey) in a Phase 1 clinical trial with Dr. Hofmeister about 18 months ago. He spent 17 days in the hospital and developed a hemorrhaging lymph node. Alf always had access to providers, especially the nurse practitioner. He initially experienced a rash on his torso and fever. He also lost his fingernails and toenails along with his taste but has since regained it back. He is now on Dara/dex/Rev and IVIG and is ‘officially’ MRD negative. He does not wish to have CAR-T.

**Carolyn H**. started Elrexfio in October 2024. She had a bad CRS reaction shivering/shaking during the night. She receives IVIG once per month. Dr. Lonial says she is spoiled from being pampered on clinical trials through her 19 years of myeloma treatment. He also told her that this was her only option at this point, and would have to wait for a future treatment, if she declined this one. She is now in remission with a VGPR (Very Good Partial Response).

**Cynthia B**. has started Talvey and reported side effects of peeling skin, itching, and loss of taste/appetite. She has been able to maintain her weight despite her loss of appetite. She had an event and was hospitalized for something that appeared to be a stroke, with her being unable to recite her usual daily prayers/scriptures. It came out as gibberish, or she could not remember the next line. She does not yet have a diagnosis.

(**Geraldine** did not attend the meeting but had both CAR-T and Bispecifics (Talvey) therapy. She had severe problems with swallowing and received OT therapy to assist. She also reported in the past rashes and loss of fingernails/toenails. Geraldine could only consume liquids for a while. She was not pre-warned of these possible side effects which compounded the fear and pain. She was not given (or recommended) a cream for the rashes and created one herself.

**Resources:**

**IMF – Tip** card for bispecifics. Find Multiple Myeloma Information & Support | IMF

“Ask Mylo” any questions or clarifications you may have.

**Healthtree - Educational guide to Bispecifics** –

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**CAR-T*: Chimeric*** Antigen Receptor T cell treatment is a cancer immunotherapy that helps the body’s own immune system find and attack cancer cells. CAR-T cell therapy starts with a process called leukapheresis. During leukapheresis, immune cells called T cells are taken from your blood. Blood is drawn through an IV line into a machine that removes the T cells. The remaining blood then returned to your body.

· T cells are then frozen and sent to a lab. At the lab, the T cells are genetically altered so they have specific receptors (called chimeric antigen receptors, or CARs) on their surface. These receptors help the T cells attach to proteins on cancer cells. The T cells are then multiplied in the lab, which typically takes several weeks.

· Once the CAR T cells are ready, you will get chemotherapy for a few days to help prepare your body for the treatment. Then the CAR T cells are infused back into your blood, where they can seek out the cancer cells and help your immune system attack them.

· There are currently two CAR T-cell therapies that target the BCMA protein, which is found on myeloma cells – (1) Idecabtagene vicleucel (ide-cel, **Abecma** by BMS**)** and (2) Ciltacabtagene autoleucel (cilta-cel, **Carvykti** by J&J**)**

· Tocilizumab (Toci) is an anti-IL-6 antibody designed to interrupt the inflammatory process that causes cytokine release syndrome.

· *Cytokine release syndrome (CRS):* CRS can happen when T cells release chemicals (cytokines) that ramp up the immune system. CRS most often happens within a few days to weeks after treatment, and in some cases it can be life-threatening. Symptoms can include High fever and chills*;* Trouble breathing*;* Severe nausea, vomiting, and/or diarrhea*;* Feeling dizzy or lightheaded*;* Headaches*;* Fast heartbeat*;* Feeling very tired.

**Patient experiences with CAR-T therapy**:

Frank M. (Oct 2024), Joe H. (110 days), Jeff W, (Jan 2025), Scott (21 days) are all at different places in their journey after having received CAR-T therapy. They received LCD chemo for three days prior to the CAR-T infusion and developed a fever on day nine. Their progress was monitored, and they continued routine labs, ongoing observations and regular IVIG* infusions to boost their immune systems.

**Frank M.** has IgA myeloma. He developed Bell's palsy that persisted for two weeks. He is getting labs about every two months. He decided on a CAR-T after Dara had stopped working for him. **Joe H**. had no problems until day nine when he developed a fever. He has High risk 17p deletion myeloma. After just over three months, his M-protein was increasing again. His team will continue to monitor closely. **Jeff** has IgA (11,14) translocation myeloma and participated in a

Venetoclax trial. He has taken IVIG for years. He is now MRD negative and feels better than he has in years; **Scott** had the day nine fever that he addressed with Tylenol. He was given *Toci* on day five as a preventative measure. He did go to the ICC (Immediate Care Center-Emory Winship) for 5days in a row/3 hour each time. He gets IVIG to boost his immune system once/month. Scott also reports that his labs – WBCs, platelets have fluctuated over the weeks and was told this is normal – to be expected; **Rosalind** was diagnosed in 2019 after being rushed to the hospital on New Year's Eve – when most of the regular staff was on vacation. She had SCT at the VA Hospital, developed sepsis, and went into a coma for three days. On three different occasions, they told her she would not make it, but thankfully, she is still here. She had CAR-T at Emory Winship December 18, 2024, with Dr. Joseph as her lead. She is also with the Georgia Cancer Specialists, as they partner with her care. Her experiences were much like the others, with side effects of headaches, nausea, and vomiting. She takes IVIG and is still weak. Rosalind was exposed to Agent Orange and was diagnosed with lymphoma and leukemia. So far, she is in remission from myeloma, and there is no evidence of leukemia or lymphoma. She gets IVIG. She is still weak and has read that side effects can last up to a year. She continues to get better each week. Nancy B. shares that IMF now has a Special Interest Support Group for Veterans.

Most patients who shared their CAR-T experiences had Carvykti therapy and Jim M. had Abecma. We spoke about the cost of these procedures – from SCT to CAR-T to Bispecifics they cost into the millions of dollars. There are grants from pharma and other programs that work with insurance to alleviate the high costs. Jeff shared that he took advantage of a Carvykti grant that paid for his (and care partner) hotel and meals while he was being monitored at the hospital after his CAR-T. The clinic support staff will help you navigate the finances.

*IVIG – Intravenous Immunoglobulin – a solution of antibodies made from the plasma of healthy cells. It is delivered intravenously. It boosts the ability of the body to fight infections and regulate immune response.

**Questions from presentation:**

**What does the care partner need to know?** Carolyn H. did not have a Care Partner when she started on Bispecifics. She was in the hospital when most of her CRS and other major side effects occurred. Patients are prohibited to drive for at least 30 days after their CAR-T. Scott shared that he is on an anti-seizure medication and this could be part of the reason. He advised patients to NOT critique their care partners driving! RE: **Patient Empowerment Network. Care partner advice for CAR-T – Video ~6 minutes.**

**Marcia asked if anyone changed their diet or routine in preparation or during CAR-T therapy?** No one made any major changes. Scott said he usually maintains a healthy eating and exercise regimen. Alcohol is not allowed during 30-day intense monitoring period for CAR-T.

**Resources:**

What is CAR-T therapy? Ask Dr. Durie – 4 minutes.

What are differences between CAR-T therapy and bispecific antibodies? - *Video~ 4 minutes*

Contact J&J for a patient for Talvey which includes cream for expected rashes, a bracelet, and ID card indicating your care (in case of emergencies).

## Additional Highlights

- **For Men Only** – David reported the small group had a good meeting in July. He encouraged any other men to join them on the 4th Tuesday each month for one hour of fellowship and sharing.

- **Open enrollment**. Insurance coverage. Consider myeloma medications you are taking now and may plan to take. Healthtree and LLS have financial coaches to help.

- **New CAR-T** *Anito-cel*: look for more information on clinical trials and treatment.

- **New Bispecific** – *linvoseltamab/lynzozyfic*.

- **Peripheral Neuropathy (PN)**. Exercise may help, according to a Patient Power study. shared **Nancy B**. has PN and was prescribed a B-complex vitamin supplement that really lessens her symptoms. There are over the counter (OTC) supplements, like Nervive, also available. **Linda** has IgG Kappa myeloma, and PN in her hands and feet. She was referred to getting acupuncture

(Emory/Hofmeister), also takes OTC B-complex, and has noticed a difference. For acupuncture, patients must commit to weekly treatments over time. Other potential remedies and dosage from Emory's pain clinic have included alpha-lipoic acid and turmeric.

o ***Watch the Replay: IMWG Conferences Series 2025.** short videos by topic: Screening for Myeloma, Smoldering Multiple Myeloma, Frontline Therapy, Early Relapse, Late Relapse, New Definition for High-Risk Myeloma, and a word from the IMWG Committees.

· Top Takeaways from the 2025 IMWG Conference Series: Making Sense of Treatment (Part 2 of 2)

o OBI: Innovative delivery method for Isatuximab with potential for home use

o Belantamab: Promising triplet results; likely to re-enter treatment landscape.

o Cilta-cel: Strong performance in early relapse and high-risk subgroups

o Bispecifics: Growing role, with linvoseltamab leading upcoming combinations.

o New Drug Type: Trispecific Antibody

*Submitted by Gail*

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