ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Northside MM Support Group

Meeting Minutes

August 3, 2026

Introduction & Business

Thank you to Nancy B. who hosted the virtual meeting with approximately 25 participants. If you have requests or ideas for upcoming meeting topics and/or guest speakers please contact Nancy. Some topics being considered include dental care, pain management, exercise, clinical trials, Medicare, and safe travelling. The AAMMSG Northside group has been together for 29 years and the Southside group has been together for nearly 20 years. The monthly newsletter has been distributed all of these years. Nancy reviewed sections in the monthly newsletter, specifically the Resources section that contains a multitude of helpful resource links. Thank you to Gail M. and Sandy W. who contributes and maintains the resources information, and Wendy R. for taking notes for the newsletter.

Discussion & Updates

Safe travel tips were discussed. Planning and preparation are key to safe travel. Alf N. schedules his monthly IVIG treatment to best coincide with his travel dates for ultimate protection, wears a mask on planes, and sanitizes surfaces. He also ensures that he is able to access his medical portals as needed and carries a myeloma card in his wallet. Bianca M. suggested tips for international travel, including researching in advance the closest English-speaking hospitals and finding hotels that can assist. She carries a small medical kit with extra medicine such as antibiotics that she gets from her doctor in advance of her travel and verifies in advance that what she is carrying is allowed in other countries, since some drugs are banned in other countries and may require pre-approval. She keeps all medications in original containers and carries them in her carry-on luggage. Sandy W. enjoys traveling in a motor home, which also helps her to stay safe. Nancy B. suggested taking Pepto Bismol daily as a precaution while traveling; and having insurance information available, including evacuation

insurance. An AirTamer is a small personal wearable device that is worn around the neck and purifies the air around you. Lots of patients and caregivers use it in crowded public areas with good results, preventing them from getting sick. AirTamer can be purchased at https://airtamer.com. Nancy recommends getting the rechargeable model.

Benefits of Intravenous immunoglobulin (IVIG) treatment was explained. IVIG treatment can be used to support a weakened immune system by replacing missing antibodies and boosting immune function to help the immune system respond more effectively. It can help myeloma patients with low immunoglobulin (IG) levels, frequent/recurrent infections, and during certain treatments. Some participants reported having adverse reactions to IVIG treatment. Cynthia B. has tried IVIG twice and both times had chills and very painful lower back muscle spasms. Lory M. reported that when she initially received IVIG treatments she did not have adverse side effects, but after she stopped the treatments, then restarted months later she had terrible muscle spasms in her lower back (as Cynthia described). The issue was resolved when the infusion was stopped and then restarted at a slower pace, and she was also given fluids. Jim M. has experienced chills with IVIG infusions, and he takes Benadryl and slower infusion speed which has helped. Sandy W. gets headaches 12 hours after the IV injection. It naturally or she uses a heating pad to warm the IVIG, which makes it easier to tolerate.

Several members of the group have had successful CAR T therapy with others scheduled to start CAR T treatment in the near future. Joe H. had CAR T in April 2025 and has achieved MRD-negative status. He recently had his last IVIG treatment and is doing very well. He is not currently on any maintenance but was taking Pomalyst for his first-year post CAR T to boost T-cells to hopefully extend treatment results. Lory M. had CAR T treatment in February 2024 and also achieved MRD-negative status. She had been on IVIG treatment for over two years and recently stopped in March, however her numbers plummeted and so she has resumed monthly IVIG infusions. Jim N. also just had CAR T and is doing well. He recommends walking and staying active to maintain strength throughout the process. Jim had CMV virus for about a month and has now recovered.

He is getting IVIG treatments and will continue to do so for now. Overall, it was not a bad experience for him. Sandy W. reported feeling great after having CAR T treatment seven months ago. She had joint pain about day 40 which is a normal CAR T side effect that subsided after two months. She recommended self-monitoring and recording of vitals (BP,O2, Temp and HR) throughout the process four times a day during the first month and report any changes or concerns to the medical team immediately. Jim M. added if any subtle changes are identified it is best to notify your medical team and not to assume that you are OK. Let the medical team decide and let them help you. Other participants also recommend doing this for the best possible care and outcome. Sheila is preparing for CAR-T at Emory in the coming month.

Sandy B. was initially diagnosed with smoldering myeloma 36 years ago in 1989 and began treatment in 1994. She took high doses of Thalidomide in 1999, which caused peripheral neuropathy, which still persists. She currently has mobility issues but remains active using a cane and walker as needed. Overall, she is doing well and contributes to staying active, positive, and supporting others. Many in this group have benefitted from Sandy's help and experience! Bianca M. was diagnosed three years ago. She had a stem cell transplant and had an aggressive maintenance protocol using Velcade and Dara. She has not yet achieved a MRD negative status. This led to a discussion about minimal residual disease (MRD) negativity and what it could mean when a patient does not achieve a MRD negative status despite adhering to treatment protocols. Nancy commented that studies show that maintaining a consistent, stable disease status is as good as being MRD negative. Sandy W. commented that it took her 13 years to achieve MRD negative status.

Jim M. reported that he has relapsed and the myeloma is back aggressively. He also has heart failure issues and has been hospitalized several times in the past two months spending four days in ICU. He is considering starting back on Talvey, which he has taken before and that controlled the myeloma very well but with severe toxicity and side effects – he couldn't eat, lost a lot of weight, became very weak and his nails were

peeling and falling off. His last dose of Talvey was December 2025 and went six months until he relapsed. Alf N. noted that he has taken Talvey for 2-1/2 years and is doing well. It works well for him, but he also experienced tough side effects including CRS, loss of taste, and loss of skin on his hands during the first year. His dose was reduced and is now on a monthly infusion and all prior issues have disappeared. His sense of taste returned after about a year, and he has achieved a MRD negative status. Barbara W. is taking Pomalidomide. At the end of May she thought she had a cold with a low fever and cough. Those symptoms went away but then she had difficulty breathing so she went to her doctor. She was hospitalized for four days with pneumonia and human metapneumovirus. She cautioned the group to be cautious of contracting infections with the compromised immune system. Marilyn M. warned everyone to also beware of mosquito bites. She was bitten by a mosquito in her own backyard, which led to contracting West Nile virus. It took her 18 months to get better, and she is still not fully recovered. The experience was very debilitating she wanted to warn everyone to be very careful and avoid getting bitten.

Submitted by Wendy R.

Southside MM Support Group

Hybrid Meeting Minutes

Saturday, August 22, 2026

Next Meetings:

Southside Meeting: Saturday, **September 26, 2026@ 10:30 AM. Hybrid.**
Guest speaker - Joseph (Joe) Maakaron, MD, Northside Hospital. Leukemia/Precision Immunology. Topic: *How to Decipher Your Oncologist: Doc Lingo 101.* Please plan to attend in-person to meet our guest, if at all possible.
For Men (with Myeloma) Only: Tuesday, **September 22 @ 6:00 PM**. **Virtual Only.**

New members

Southside welcomes new members **Arletha** and **Partho.**

Arletha went to her primary care doctor at Kaiser after losing range of motion in her arm from gardening. She was initially diagnosed with a muscle strain or tear. An MRI showed several lesions. A follow-up bone marrow biopsy confirmed her myeloma in May. Kaiser referred her to Northside where she is scheduled for a stem cell transplant on September 9. Arletha has high risk (17p deletion) myeloma. She is a part of a prayer group and has a good support system.
Partho has a double high-risk myeloma, t(14;16)-chromosomes 14 and 16 swap places and gain (1q)- extra copies/gain of a small section of chromosome 1. High risk myeloma cells can grow faster and be more difficult to control than standard risk.

Group Discussion
David H. reported on results from a 7-year study, ENDURANCE, which were published in July on drug combination Revlimid/Lenalidomide and Iberdomide, specifically for patients with standard-risk, newly diagnosed multiple myeloma. The study showed that ***Revlimid maintenance after two years may no longer be necessary.*** The mortality rate for those who continued Revlimid versus those who stopped taking the medication was similar. Secondary cancers (11% vs. 8%) and side effects, like fatigue and infections (48% vs 31%) were higher for those patients who continued on Revlimid after 2 years. *Talk with your doctor if you have been on Revlimid maintenance for 2 or more years.*
In August 2026, FDA granted accelerated approval for **Iberdomide (Zenbexus™)** the first in a class of drugs call cereblon E3 ligase modulator **(CELMoD**). Iberdomide is an oral drug designed to modulate cereblon, a key protein target in myeloma, and is taken in combination with Daratumumab (Dara) and dexamethasone (dex). There is ongoing research in the CELMoD class of drugs, including its more potent partner **Mezigdomide (Mezi)** in relapsed/refractory myeloma. Researchers believe the drugs may also help stimulate the **immune system's ability to recognize and attack cancer cells**. FDA's approval was based on results of the phase 3 EXCALIBUR clinical trial. In the study, 41% of patients receiving the Iberdomide combination achieved a complete response with no detectable evidence of disease, compared with 21% of patients receiving standard treatment. Side effects from Iberdomide are much less than other therapies. **Alma** participated in clinical trials in 2018 – 2020 for Iberdomide. Also, **Sandy W** participated. Neither Alma nor Sandy are officially 'high risk', although Sandy was told she had 17p-deletion when she participated in a clinical for 'Mezzi' in 2023.
These new drugs offer more opportunity to personalize and sequence patient treatment plan.
High-risk multiple myeloma is defined by the presence of del(17p), p53 mutation, or bi-allelic del(1p); t(4;14), t(14;16), t(14;20) in combination with gain(1q) or del(1p); or gain(1q) plus del(1p). *Dr. S. Vincent Rajkumar. American Journal of Hematology. August 18, 2026.*

Patient updates
Joseph enjoys the Tuesday Men Only meetings. He is in remission and is feeling well. He volunteers as a crossing guard – no money, but it brings him joy and gets him out of the house.
Caroyn H. shared her Stem cell transplant (SCT) experiences at Emory Winship with **Arletha.** What she wishes she had known was about the self-injections needed to harvest her cells. The hardest part was with the hospital stay. The SCT itself is much like a blood transfusion.
Veronica had her SCT at northside Hospital where the treatment is totally outpatient. Someone needs to take you back and forth to appointments for about a month. **Joyce** J received three SCTs at Northside. The first time was tandem (2-SCT within 6-month period). She received a third SCT in 2020 after a relapse. Joyce requested an in hospital stay, stayed for 14-days, and

continued working from the hospital. **Diane** also had a Northside SCT in April 2026. She did her own injections collecting 10 million cells over 2 days. She stayed at the Hope House for 42 days (American Cancer Society) for the follow-up, arranged by her BMT coordinator. She lives in Fayetteville, more than 20 minutes away from the hospital. **Dirk** took his acoustic guitar to entertain himself and found other ways to break the rules and monotony.
Jim M. was able to visit his new grandchild in Savannah and started his first round on a new bispecific, **Linvoseltamab**, human B-cell maturation antigen (BCMA). He is dealing with severe side effects; we will keep him in our thoughts; **Cynthia B.** has been on linvo for 5 cycles and is also having a difficult time. Her para protein is 0, but her doctors are monitoring her light chain, lambda. She has to have a PET scan every 2 months, David was diagnosed with light-chain myeloma through a CT scan and bloodwork. He has never had an M-Spike.

Selected Videos

***Iberdomide and the Rise of CELMoDs in Multiple Myeloma.** Dr. S. Lonial. Video – 1:12.

***Defining "cure" really in multiple myeloma|.MRD and long-term Remission.** 5:46 min video with Dr. Joe and Beth Faiman.

***Health Disparities Explained about Myeloma** (in a minute). Dr. Joe - <1 minute.

Calendar of Myeloma-related events – September-October 2026

Myeloma-related events – September-October 2026	
Date	**Event**
September 19	Health, Hope, and Hip-Hop. 330 Marietta Street. Dr. Joe (IMF) and 2 myeloma patients seek to raise awareness through mus3ic
October 3	Emory 4 Walk/Run event/fundraiser. Can be virtual (registration closed).
October 3	Morehouse School of Medicine annual Health Fair. Need Volunteers.
October 3	Blood Cancer United fundraiser. *Light the Night in Piedmont Park*.
October 24	Blood Cancer United. Loews Hotel. 9:00 AM – 2:30 PM
October 24	Southside ATL MM SG *20th Anniversary celebration*. Details to follow.

Respectfully submitted, Gail

Upcoming Events, Resources, and Educational Opportunities

National Bone Marrow Transplant Link

Multiple Myeloma: Immunotherapy, Sequencing and Updates. 57 min video.

Blood Cancer United (formerly LLS)

September is Blood cancer awareness month. #Know Myeloma.

Making Your Voice Count: The Power of Patient Advocacy. 55 min video.

Light the Night Journey. Sample narrative. Subject: Will you support me this year?

Hi [Name],
I'm reaching out because I'm participating in Light the Night this year to support Blood Cancer United. This cause means a lot to me because [share your personal reason, connection, or

motivation]. I would be so grateful if you could support my fundraising by making a donation of any size. Every dollar helps fund research and patient support for families affected by blood cancer.

CURE/Cure Connections

Cancer patients – stay active. "Take it easy" may not be best message for anyone exposed to surgery, chemotherapy, or radiation and is at **high risk for loss of musculoskeletal, cardiopulmonary, and functional strength** — so everyone should **get a rehab consult.**

***Iberdomide and the Rise of CELMoDs in Multiple Myeloma.** Dr. S. Lonial. Video – 1:12.

Healthtree Foundation

Monthly Cancer Financial Q&A: Expert Answers to Your Treatment Costs and Support Questions. Recording from Aug 18 available.

Relationships, Intimacy, and Life After Cancer Diagnosis. Thursday, August 27 @ 2:00

Understanding your Myeloma Labs, What they Mean, and when to ask Questions.

Safe Strength and Endurance Exercises for Myeloma. 45 min Video.

IMF (myeloma.org)

***Deifne "cure" in multiple myeloma|MRD and long-term Remission. 5:46 min video**

The definition of **cure** remains in draft form, consensus on the key aspects of the definition:

Patients must be off therapy for at least 5 years.

there must be no evidence of disease, as noted by the following criteria:

- Patients must be in complete remission (CR).
- Testing for minimal residual disease (MRD) must be negative at least 4 times, a year apart, in the 5 years of no treatment.
- Advanced functional imaging shows no evidence of disease at the start and end of the 5 years (with no activity in between).

This can be applied to patients with newly diagnosed or relapsed multiple myeloma.

Q&A. Ask me anything about myeloma. Dr. Saad Usmani. Video -32 min.

Key Takeaways from Dr. Lonial's (IMF/IMWG) Facebook Live Q&A. March 2026.

Multiple Myeloma: 2026 Update on Diagnosis, Risk Stratification, and Management. Dr. S. Vincent Rajkumar. American Journal of Hematology. August 18, 2026

Sarclisa (isatuximab) SC — the first anticancer therapy (EU) to be administered through an on-body injector (OBI) June 8. Sanofi.

Safe Exercise and Multiple Myeloma. Video in 1:37.

***Health Disparities Explained about Myeloma** (in a minute). Dr. Joe - <1 minute.

***Dr. Lonial: MRD Negativity to guide maintenance in myeloma.** Video~2 minutes.

Patient & Care Partner Conversation on Myeloma Research from ASCO. 90 minutes.

High Risk Smoldering MM Treatment Explained…in a minute or less. Dr. Joe.

Trispecific Antibodies Explained. 1 min video with Dr. Joe. **Smart Patients: https://www.smartpatients.com/partners/imf**

MMRF - https://themmrf.org/
Patient Empowerment Network

What to expect during and after CAR-T. Video – 4 Min. Dr. Ciara Freeman. Moffit

Elevated Expert Advice | Myeloma CAR T-Cell Therapy. Video~ 4 min.

Care Partner Advice | Questions to Ask the CAR T-Cell Therapy Care Team. ~ 4 min.

Join us at AAMMSG monthly meetings: (in-person or virtually)

Southside Meetings: 9/26/26, 10/24/26
The Southside group meets at 10:30AM on the fourth Saturday of each month.
Website: ssatlanta.support.myeloma.org
Doris Morgan 404-346-1372, dorismorgana@aol.com, Gail McCray 770-996-4964; mccrayg@aol.com

Northside Meetings: 10/3/26, 11/7/26
Northside group meets at 11:00AM on the 1st Saturday of each month.
Nancy Bruno 404-374-9020; Sandy Brown 404-630-6155 email: aammsg@gmail.com