ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Northside MM Support Group

Meeting Minutes

September 12, 2026

The Northside group meeting on Saturday, September 12, was held at The Olive Garden on Cobb Parkway in Smyrna. It was a social luncheon and the food was tasty! The setting gave us time to catch up and connect. There were 22 people attending including some long-term patients: Sandy B – 36 years: Vinnie – 23 years smoldering using curcumin (turmeric) to suppress it; Carolyn H. – 19 years that included clinical trials but no transplant; Joyce J – 14 years and three transplants. There were also several recently diagnosed patients who enjoyed hearing about the variety of experiences.

The upcoming programs for the Northside group include:

- **October – GA SHIP (State Health Insurance Assistance Program) Medicare Outreach Specialist. This program will be on Zoom only since there is so much information provided.**
- **November – Dr. Richa Parikn from Emory Winship.**
- **December – Holiday Party meeting**
- **January – Winship presentation of the ASH (American Society of Hematology) review of abstracts from clinical trials. This will be on Saturday January 9.**
- **February will be open discussion about ASH and treatment options.**

- **March – Dr. Nisha Joseph from Emory Winship**

Let us know if you have any suggestions for meeting programs or discussion topics that you may find challenging. The depth of experience and knowledge within the group and myeloma speakers is a valuable resource; both are available and willing to help you on your MM journey.

Southside MM Support Group

Meeting Minutes

September 26, 2026

Announcements

Upcoming events happening on Saturday, October 24 include Southside's 20th year celebration at 2 PM and the Blood Cancer United Southern Blood Cancer Conference at Loews Hotel on the same day, starting at 9 AM. The Men's Group is energetic and informative on the 4th Tuesday of every month. Their next meeting is on September 27 at 6 PM for one hour. All men with myeloma are encouraged to join the group.

This month's speaker was Dr. Joe Maakaron from the Blood and Marrow Transplant Group of Georgia whose patients are seen at Northside Hospital in Atlanta. Northside Hospital has a robust transplant program and hematological research program with national recognition[BW1] . His topic was entitled: Deciphering your oncologist: Dr. Lingo 101.

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Guest Presentation

Dr. Maakaron started with a review on the building blocks of myeloma. White blood cells (WBC) produce antibodies, proteins that stick to the germs that cause infections, bacteria, viruses and foreign substances, and signal to destroy them. 'B' cells are a type of white WBC that originates in the bone marrow and travel throughout the body through the spleen and lymphatic system to support immune response. When a B-cell encounters a germ, it transforms into a plasma cell to produce quantities of targeted antibodies to fight infections and foreign invaders. In myeloma, plasma cells go awry, and become cancerous, making multiple copies of itself over and over again.

Plasma cells produce immunoglobulins (Ig), another name for antibodies, to fight germs. It is the Y-shaped graphic. Each Ig antibody has– 2 light chain and 2 heavy chain pairs. The two long "heavy pieces decide the Ig classification as G, A, M, D, or E. IgG is the most common family of antibodies. If the lab report states IgG Kappa, the heavy chain is 'G.' IgG includes about half of myeloma cases, and IgA represents about 20% of the heavy chains type myeloma. In myeloma, large amounts of one type of immunoglobulin crowd out the others. This is called the M-protein or M-spike. Light chains are named with the Greek letters, kappa, or lambda. Plasma cells can make 'extra light' proteins that can travel freely in the body. They are called 'free light chains. On lab tests, the ratio of kappa and lambda is reported. The normal K/L ratio range is about '.26 – 1.65'. Light chain myeloma disease only happens in about 1 in 6 people. It means there are no heavy chains, like IgG, IgA present. Light chain myeloma is hard on the kidneys. There is a less common type of myeloma that produces very

little protein at all – too little protein to detect called oligosecretory. Special testing for this includes free light chains, bone marrow, and scans, like PET scans and MRIs. There is also non-secretory myeloma, where there is no protein secreted in the blood or urine. This is relatively rare – about 1-3 in 100 myeloma cases. In these cases, there will be frequent scans and frequent bone marrow biopsies (BMB) needed to diagnose and monitor.

Myeloma Treatment Process

Remission in myeloma does not have the same meaning as in remission of solid tumors like breast or lung cancers. Remission is not a cure; it is a level of control. Response to treatment defines the level and duration. PR indicates partial remission, VGPR - very good partial remission, CR - complete remission, and sCR - stringent complete remission is referring to the amount of myeloma that can be detected in your blood during and after treatment. Minimal residual disease (MRD) refers to a state where the test cannot find one myeloma cell in over 1 million bone marrow cells. The more common test is called clonoSEQ. In clonoSEQ, an early sample from a BMB must be available for comparison. MRD-negative means no cancer cells are detected. MRD-positive means a few cells are still present.

Induction is the very first type of myeloma treatment a patient receives. Induction means "to induce remission," to knock down the disease. Consolidation is the next phase of treatment to push the disease down even further, i.e., Stem Cell Transplant (SCT) after cycles of chemotherapy and/or continue more cycles of chemo to consolidate the treatments. Maintenance means a lower dose of medications than one receives after induction and consolidation to keep the cancer under control. The goal is to dampen the cancer into

a longer and deeper remission and prolong the disease from coming back so that patients resume a more normal life.

Relapse is when the cancer comes back. This is an expectation for myeloma because we currently do not have a definite cure. There are numerous treatment options in myeloma when relapse occurs, including: SOC (standard of care) combos; bispecifics; CAR-T; and CELMoDs (next-gen lenalidomide and pomalidomide, but more potent); and antibody conjugate therapies available. Refractory means that the current treatment and medications are no longer working, and the myeloma has returned and increased during treatment. New treatment therapies and drug classes are introduced to battle the progression of myeloma. Clinical trials may be recommended to provide novel drugs and treatment options. The term Cure general means the cancer is gone for good. We are not there yet for myeloma, but a new term is being discussed- functional cure. This means that patients with no treatment or setbacks showing no sign of disease for at least 5 years can be considered functionally cured. Treatments in the last few years have definitely improved and more people are going into remissions longer and deeper towards the functional cure goal.

Smoldering myeloma (SMM) is an earlier form of myeloma. Labs show some myeloma precursors below 10%, no evidence of damage to kidneys or bones, etc. This needs to be monitored, but there is current research to determine if it should be treated. For high-risk smoldering myeloma, there is evidence that using Darzalex can be used to control it.

Well tolerated treatment regimens can mean different things to different patients. People experience side effects in very different ways. Issues for nausea, fatigue, etc. can be medically addressed, but

it is very important that you report any and all side effects – what, when, how much. The treatment plan can change dosages, the schedule, or medications if needed. Patients can develop adverse events that require immediate medical attention. Complications can come from the disease itself, from the treatment, or a combination of the two. Side effects are rated by levels of 1-5, with 1 being more mild side effects.

Understanding your myeloma

What does high-risk mean? The definition of high-risk has changed over time. Prognostic refers to 'what is likely' to happen, based on FISH test, MRD, etc. Predictive is more certain. It can predict the outcomes. What was high-risk 20 years ago is no longer considered high-risk. For example, if someone's FISH test shows a translocation of chromosomes 11 and 14 [t (11;14)], the myeloma can be treated effectively with Venetoclax. This is not yet an FDA approved regimen.

Palliative versus curative. In palliative care we just want the patient to feel better. Palliative care is not hospice. More attention is given to side effects and to quality of life. Curative means just wanting the cancer gone. More aggressive treatment may happen with more side effects, with the plan to have the cancer gone in a shorter period of time.

Lifestyle modifications are another quality of life (QOL) term. Fatigue is a very common side effect/symptom for the cancer journey. Exercise and nutrition, stress reduction, reducing or eliminating tobacco and alcohol are lifestyle changes that have proven to be helpful.

Ask about your Risks, Benefits, and Alternatives during every visit to the doctor.

- **What could go wrong and how likely is it to occur with the treatment?**
- **What are the treatment benefits? How likely and long will I benefit from this plan?**
- **What is the alternative including waiting or no treatment? Are there options to consider?**

Keep a journal of questions and responses discussed from every appointment. It can help you to make a more informed decision or give informed consent to a clinical trial.

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<u>Clinical Trials 101</u>

For any drug to be approved, it must go through an extensive 3 Phase clinical trial.

- **Phase 1: 20-100 patients volunteer to participate to assess drug safety and dosage.**
- **Phase 2: 100 -300 patients participate to determine drug effectiveness and side effects.**
- **Phase 3: 300 to over 3000 patients are enrolled to confirm overall effectiveness, monitor adverse reactions, and compare the new treatment against standard-of-care treatment (SOC) myeloma. No placebos are used.**

After Phase 3, *a successful* FDA approval is granted if the clinical trial is successful. Clinical trials can provide information about Progression Free Survival (PFS) and Overall Survival (OS). PFS means how much

time until the cancer returns, spreads, or the person dies. OS is the time people live, from any cause – the gold standard.

Q & A

Q- Gail: Please define FISH and cytogenetics. A: These tests look at the gene mutations of myeloma. A BMB (bone marrow biopsy) looks at DNA or chromosome cytogenetics called next generation sequencing.

Q-Glossie: Diagnosed with myeloma with SCT in 2020. Recent BMB showed biomarkers were increasing. Northside recommended CAR-T. My financial assistance program will not cover the product for CAR-T. What options are available? A: BMT of GA works closely with Northside sharing many of the same resources. Ask your oncologist to refer you to the BMT team at Northside. There is another CAR-T option on the horizon for approval along with clinical trials for CAR-T that do not have to go through insurance. Other members recommended the financial counseling department at Healthtree Foundation.

Q- Cynthia: is on linvoseltamab, which does not seem to be working. She is refractory and the physician is considering Mezigdomide. Your thoughts? A: It's a new pill in the Imid family. Ask the risk/benefits/alternatives questions discussed earlier to help make your decisions.

Dr. Maakaron reminded us that your healthcare team only has about 20 minutes to review test results, explain your treatment plan, and answer your questions, which is not nearly enough time to share everything in a comprehensive manner. Be sure to address your three questions of risks/benefits/alternatives and any specific concerns.

Patient and Care Partner Updates

Dirk participated in his first 5K in years with his wife at his side. It was a real challenge, especially compared to pre-myeloma days, but they completed it. Congrats to them both! Sandy B., who has been living with myeloma for 37 years provided an update on her dental challenges. Since all her teeth were extracted, she continues to struggle to find properly fitted dentures, due to many complications. Her dental issues are suspected to be from taking Revlimid for years. Sending prayers for success.

Selected Videos

- ***From Exhausted to Empowered: Using Movement to Fight Cancer-Related Fatigue. RECORDING. https://healthtree.org/myeloma/events/sep26-cancer-related-fatigue-solutions**
- ***Beating the Insurance Clock: Using Your Data to Fight Prior Authorization Delays. RECORDING: https://healthtree.org/myeloma/events/sep26-cancer-financial-insurance-authorization**
- ***Monthly Cancer Financial Q&A: Expert Answers to Your Treatment Costs and Support Questions. RECORDING: https://healthtree.org/myeloma/events/sep26-cancer-financial-q&a?utm_source=&utm_medium=email&utm_campaign=eventpromo&utm_content=general**

Upcoming Educational Opportunities

Blood Cancer United (formerly LLS)

- **September is Blood cancer awareness month. #Know Myeloma. Do you KNOW myeloma? … or NO Myeloma**
- **Southern Blood Cancer Conference, Saturday, October 24, 9:00 AM– 2:30 PM. Loews Hotel, 1065 Peachtree Street.**

CURE/Cure Connections

- **Educated Patient® Survivorship Summit | Saturday, February 6, 2027.**

Healthtree Foundation

- ***From Exhausted to Empowered: Using Movement to Fight Cancer Fatigue.**
- ***Beating the Insurance Clock: Using Your Data to Fight Prior Authorization Delays.**
- **Bridging the Gaps in Multiple Myeloma:**
- ***Financial Q&A: Expert Answers to Your Treatment Costs and Support Questions.**

IMF (myeloma.org)

- **: What's Next? - Managing Myeloma at Relapse. RECORDING:**
- ***Myeloma has always been incurable, as the vast majority of patients relapse after initial therapy and have shorter life expectancy. However, due to outstanding advances in the field, this is changing. Leading experts, including members of the IMF's International Myeloma Working Group (IMWG), proposed a working definition of cure. The IMS media brief adds, "Myeloma remains incurable for most patients. Relapse is still common. High-risk and ultra-high-risk disease continue to resist even the most intensive therapies."***
- **What's New in Myeloma. August - September 2026.**

- **Clinical Updates. Multiple Myeloma: 2026 Update on Diagnosis, Risk-Stratification and Management — American Journal of Hematology (August 2026). Diagnosis, risk, Therapy/maintenance - Initial and Maintenance Therapy**

  - **Initial therapy generally uses an anti-CD38 monoclonal antibody plus VRd, followed by ASCT in eligible patients.**

Selected standard-risk patients may delay transplantation until first relapse.

  - **Frail patients who are not transplant candidates may receive an anti-CD38 antibody plus lenalidomide and dexamethasone or VRd.**

- ***What "cure" really means in multiple myeloma|MRD and long-term Remission**

- **Updated NCCN (National Comprehensive Cancer Network) Myeloma Guidelines include NDMM treatment updates, changes to treatment strategies for RRMM, and MRD testing for frontline therapy, the updated NCCN guidelines for newly diagnosed multiple myeloma (NDMM) have added Sarclisa (isatuximab-irfc) plus Kyprolis® (carfilzomib), Revlimid® (lenalidomide), and dexamethasone as category 1 recommendation for both transplant-eligible and transplant-deferred candidates. Guidelines recommend annual MRD testing during maintenance therapy and testing after later lines of treatment, including after CAR T-cell therapy. This positions MRD as a longitudinal measure that can track changes in disease status over time rather than relying on a single assessment. The updated guidelines state that MRD negativity and sustained MRD negativity may help inform treatment escalation, de-escalation and maintenance therapy as part of shared decision-making between**

clinicians and patients. Conversely, rising MRD positivity may lead to closer monitoring and clinical evaluation.

- **Q&A. Ask me anything about myeloma. Dr. Saad Usmani. Video - 32 min.**
- **Health Disparities Explained about Myeloma (in a minute). Dr. Joe - <1 minute.**
- **Trispecific Antibodies Explained. 1 min video with Dr. Joe.**
- **Smart Patients: https://www.smartpatients.com/partners/imf**

MMRF - https://themmrf.org/

- **(MMRF®) has launched its next-generation Translational Research Umbrella (TRU) program to answer most pressing questions. Sub study will focus unknowns on CAR T-cell therapy and bispecific antibody treatments (bispecifics).**
- **TRU builds on the CoMMpass Study and Immune Atlas, two landmark MMRF data-generation initiatives that changed our understanding of multiple myeloma.**

Patient Empowerment Network

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

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

Patient Power

- **Your eyesight and myeloma.**

Dexamethasone/Steroids - fluid retention, leading to swelling in the back of the eye; can increase the risk of developing cataracts – cloudiness in the eye's natural lens.

Proteasome Inhibitors (Velcade…) - posterior reversible encephalopathy syndrome (PRES). PRES is a condition where the small blood vessels in the brain become inflamed. It can cause a sudden decrease in vision, double vision, changes in color vision, or blindness.

Immunomodulators (Revlimid/Lenalidomide) - blurred vision and an increased risk of cataracts

Antibody Drug Conjugates – (Blenrep) - can also affect vision, though these effects are often reversible. Common ocular side effects include dry eyes, blurred vision, and damage to the cornea – the outermost layer of the eye.

- **We have good options for Myeloma - ~ 5 min video. Dr. Abounour @ASCO, 2026**
- **Cancer related nausea. Narrative.**

Respectfully submitted,

Gail

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

Southside Meetings: 11/28/26, 12/26/26

The Southside group meets at 10:30AM on the fourth Saturday of each month.

Website: ssatlanta.support.myeloma.org

Gail McCray 770-996-4964, mccrayg@aol.com; Joyce Jones 404-606-2734, jajonesatl@aol.com

Northside Meetings: 11/7/26, 12/5/26

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