ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

August 2, 2025

News & Business

Thank you to Nancy B. who hosted the meeting with approximately forty attendees. Sandy B. reminded everyone that LLS funding is available to multiple myeloma (MM) patients. Those interested should act fast since funds run out rapidly. More information is available on the LLS website (https://www.lls.org/).

Guest Presentation

Thank you to Dr. Nishi Shah from Emory Winship who joined the meeting to discuss MM treatment decisions and respond to questions. When making treatment decisions, Emory considers a variety of items, then discusses with the patient to make treatment decisions together.

For newly diagnosed MM patients, consider the following:

1. **Other comorbidities**
2. **Mobility/availability – can the patient come to the clinic regularly, or not.**
3. **Side effects of treatment and the patient's tolerability**

Recommended induction treatments include a standard of care regimen:

1. **A 3-4 drug regimen for 4-6 cycles**
2. **Stem cell collection for stem cell transplant (SCT) eligible patients (i.e., less than 75 years old and responding well to treatment, with some exceptions). A collection of 6-7 million stem cells is preferred, and the stem cells can be stored for many years. Patients can have a SCT now, later, or never based upon many factors, but it is recommended to collect stem cells as soon as possible after initial treatment while they are at their healthiest. The goal of SCT is to improve progression-free survival prior to requiring additional treatment. Patients can opt to do a SCT after initial induction therapy or as a second line treatment after relapse. It is recommended to proceed with SCT after completing initial induction therapy for high-risk MM patients, or for patients who have not achieved a good induction response. Note: SCT vs. CAR-T front-line treatment is still evolving,**

For relapsed MM patients, recommended treatments include:

1. **Stem cell transplant (SCT)**
2. **CAR T Cell therapy (CAR-T)**
3. **Bispecifics**
4. **Drug Combinations -Immunomodulators (IMiD), Proteasome inhibitors (PI), Monoclonal Antibodies (Mab)**

There are a lot of clinical trial (CT) options for relapsed patients to consider. Benefits of participating in a CT include access to new therapies that work well and ongoing monitoring throughout your treatment with exceptional care.

Questions & Answers

Q: ***If a patient had a SCT and relapses, should they have another SCT?*** **A: If the patient does well for more than 3 years after an initial SCT, then yes, another SCT is recommended. If not, consider other options, and continue to store stem cells for salvage options.**

Q: ***What are recommended post-SCT maintenance therapies?*** **A: It depends on the patient and their MM type, but common therapies include Revlimid, Velcade, and Dara.**

Q: How does one decide whether to participate in a CT or an approved and known working solution?

A: There is no direct answer. Things to consider include other comorbidities, the patient's ability to commit to the CT requirements, prior treatments and responses, expected side effects, doctor's expectation for the patient, the patient's age, and the benefit of participation in the CT now vs. later.

Q*: If a patient had one type of CAR-T with a good response can another type of CAR-T be used later?*

A: Currently all CAR-T has the same target. Note that if a patient does not have a good response to the first CAR-T, then trying another type may respond the same way so consider other options.

Q*: If a patient wants to reduce the dosage of Carfilzomib, due to side effects, how should that occur?*

A: Another option is to reduce the frequency of taking the drug vs. changing the drug dosage. It is recommended to discuss options with your doctor.

Q: How does a patient choose between having a SCT or CAR-T based upon maintenance expectations?

A: Currently, from a standard of care perspective, there is no maintenance recommended after completing CAR-T, as long as the patient is in remission. For some patients, adding Pomalidomide (or some other IMiD) for T-cell activation is used, but it is not considered a standard of care. Maintenance is recommended 2-3 months after completing the SCT.

Q*: As more information is obtained about CAR-T, is it likely that maintenance will be recommended like SCT in the future?* A: Yes, Pomalidomide is recommended for some patients post CAR-T.

Q: *How long have collected T-cells lasted? Are frozen T-cells viable?* A: When T-cells are stored, the quality is affected over time and considered to be out of specification and not meeting manufacturing standards.

Q: *Does the body create more of the modified, manufactured T-cells?* A: They proliferate in the body for the first few months, and then eventually can no longer be detected and do not continue to grow. However, the resultant immune response can be seen over time as the T-cells work in the body.

Q: *Does Emory manufacture CAR-T cells onsite?* A: Currently Emory does not manufacture CAR-T cells in-house, but there are CTs being conducted to determine if T-cells from someone else (a donor) will work for a patient.

Q: *As CAR-T becomes more common, is there a risk insurance companies will limit use, given high costs?*

A: It is hard to know but there could be more scrutinization and may depend on prior therapies.

Q: *For a patient in remission for 5 years, decide whether to stop maintenance drugs?* A: Review results of bone marrow biopsy and MRD tests, along with risk vs. benefits with your doctor.

Q: *What is your opinion of Teclistamab?* A: There is a high risk of infection when taking this drug, but it is a good drug for treating MM.

Q: *Can umbilical cords be used in SCTs for treating MM?* A: No

Patient Updates & Discussion

Carolyn H. is doing well after recovering from pneumonia. Jim M. is participating in a Phase 1 CT and doing well, with a zero M-spike after two rounds. The CT drug, CFT7455, is a next generation IMiD and the primary side effect is nausea. He is still experiencing bone pain which is being managed with a combination of Tylenol, Fentanyl patch, and muscle relaxants. He has already returned to work. Kyle has had MM for 20 years. He is doing well and is starting CAR-T therapy tomorrow!

Sandy B. has had MM for 35 years and is doing well. She is on Revlimid – 21 days on, and 7 days off. She has just begun physical therapy (PT) to help strengthen her legs and hopes to be able to stop relying on a wheelchair and walker. Sandy explained that she was on Zometa (a bisphosphonate) for 6-8 years which resulted in dental issues. Every time she has oral surgery it results in her getting a new set of dentures and she is currently on her third set. It is now recommended to keep bisphosphonates use to less than three years for MM patients. Sandy also reported hearing from Vanessa F. who is doing well and still in remission after 15 years. Cynthia B. was diagnosed with extramedullary MM and has added Pomalyst to her TALVEY regimen, which is working well. She has a lesion in her upper eye area which is being treated with radiation. The treatments last 15 minutes each, with seven sessions planned. She is experiencing some fatigue from the treatments but is tolerating it well and can see the nodules decreasing. Cynthia mentioned that she was recently admitted into the hospital because she was having trouble speaking and remembering words, which lasted for about 15 minutes; tests that were run were inconclusive. Joseph is in remission and doing well. He mentioned that he had been using a Fentanyl patch for pain but had to stop using it after 6 weeks due to the risk of potential addiction. Jim M. commented that he is working with his palliative care team to help him reduce his Fentanyl patch dose as he begins to wean from it, but he wants his MM controlled with less pain before getting off it entirely. Jeff W. is in remission with MRD-negative test results and doing well after CAR-T earlier this year. He reported that he is feeling the best he has in years! Sandy W. commented that it is important to review long term trends (over time) with lab reports, not only the current set of lab results.

There was discussion about being approved for SS disability benefits. Some patients are not getting timely, or any approval, and some report obtaining approval easily. Gail M. recommended Triage Cancer archived webinars on how to make appeals to insurance companies, as well as videos on Medicare, Medicare advantage, etc.

Submitted by Wendy R.

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Atlanta Southside Multiple Myeloma Support Group

Abbreviated Meeting Minutes **Saturday, August 23, 2025**

Next Meetings: Saturday, September 27, 2025 – Meeting cancelled for those who wish to attend the Atlanta Myeloma Roundtable at the Atlanta Marriott Marquis, 8:00 AM – 2:30 PM. To sign up: https://healthtree.org/myeloma/community/events/atlanta-myeloma-roundtable-2025

For Men (with Myeloma) Only. Tuesday, September 23, 2025, 6:00 PM – 7:00 PM.

Gentle reminder: The **LLS/Blood Cancer United "Light the Night"** at Piedmont Park, October 4 is fast approaching. Only two weeks to go! Please make your desired contributions using this link: https://pages.lls.org/ltn/ga/Atlanta25/southsidemultiplemyelomasupportgroup

Our guest speaker for August was Mrs. Diahanna Vallentine, Healthtree Foundation, Financial Advisor. Her topic was "*Navigating the Complex Costs of Cancer Treatment in Times of Uncertainty."* Her PowerPoint presentation will come through your email. She covered many considerations we should take during our upcoming open enrollment period. Diahanna conducts **bimonthly (Every other month) sessions on Blood cancer financial literacy Q & A** for myeloma through the Healthtree Foundation. The **next session is October 7.** To register: https://healthtree.org/myeloma/community/events/oct25-blood-cancer-financial-questions

Topics covered during Diahanna's presentation include 11 Mistakes in Medicare selections that can cost you thousands of dollars; How to navigate devious sales tactics and protect your insurance options; Things to consider when Medicaid is your only or dual insurance option; Understanding changes to Medicaid and how these changes can impact your coverage.

Some highlights include:

· Legitimate Medicare representatives do not make home visits, and they do not solicit by phone.

· If a representative tells you that "enrolling in a Medicare Advantage Plan does not affect your Medicare" do not believe them. A Medigap or Supplement Plan may be best.

· If a representative tells you to switch plans at any time -- it is not true! They are trying to make a commission.

· Lots of Medicare insurers are dropping certain providers. Comparison shop through Center for Medicare and Medicaid Services (CMS.gov) and the expertly trained staff at SHIP (State Health Insurance Plans).

· Beware of plans offering extras, like gym memberships and groceries. Most of your medical costs do not come from these areas.

· Companies/agents need to have your express permission to contact you. Beware of entering your contact information on pop-ups, websites, etc.

· Do your homework! Be sure to check to see if your current and/or projected medications and providers, and coverage for pre-existing conditions are included in the Medicare option you are considering. Anticipate what specialists you may need to see over the coming year.

· Agents must represent *All* Medicare programs that are available to you.

· 10 Potential traps you can avoid and why:

o Consider using GoodRx or other discount cards.

o Review closely the medications that will be covered (e.g., Many insurers dropped Revlimid last year, and you have to use Lenalidomide instead).

o Use the Medicare Plan Finder for the best rated plans in your geographic area.

o Find more information about Medicare, Medicaid, and Medigap at websites Medicare.gov. cms.gov, and SHIP (GA State Health Assistance Program).

o Look for potential penalties for not adhering to schedules to sign-up by assigned deadlines for Medicare Parts B, C, and D.

o The rumored $2,000 limit on costs for medications may go away.

o Review of Big Beautiful Bill and changes in Medicaid – the costs shift to the state for funding. Many rural hospitals and their programs are closing because of changes in Medicaid.

o Several organizations that financially support cancer patients are reducing the amounts they provide in order to cover more patients. Some examples include LLS, Healthwell, Patient Advocate Foundation, and Cancer Care.

o Experienced Financial Coaches at Healthtree Foundation (healthtree.org – under financial connect) can assist you with your specific year.

o Contact information: diahanna@healthtree.org

Q & A:

Question – Deborah. After retiring at age 66 from a federal employer, I did not sign up for Medicare, Part B (outpatient services). Will I be penalized for not signing up for Part B, if I still have coverage from my employer? **Answer: No.**

Question - Lori is still working and plans to retire in three years. I was considering Medicare Advantage because I need glasses and dental issues. Is there something else I should consider? **Answer:** Stay vigilant in reviewing best plans through cms.gov – looking for a 5-star rating for Medicare advantage and all other insurance plans. Plans can change throughout the year, so nothing is guaranteed**.** Consider Delta Dental and other providers for this service. Myeloma treatments can affect dental and vision.

Question – Linda. I have recently retired and currently have Medicare, Part A. My former employer is completing paperwork for Medicare Part B. I have blood work scheduled next week, to determine my treatment. Will I have to pay for the blood work out of pocket? **Answer:** You may have to pay out of pocket and submit paperwork showing your application was in process for reimbursement. Work with clinic staff who work with insurers all the time to help with this.

Question - GM: What are some additional financial resources you provide through Healthtree? **Answer:** There is a huge amount of information on the website on financial resources. They can include travel costs like Uber and Lyft, plane rides to get second opinions, help with paying mortgage, utilities, car maintenance, cleaning your home, and more. Look for archived webinars for those recently diagnosed and other topics. 2-1-1 can get your local resources, and Catholic charities including St Vincent de Paul is another resource.

Question -Ken: If my Medicare Advantage Plan decides mid-year to discontinue providing certain medications, does that void the contract and allow me to go to original Medicare? **Answer:** Unfortunately, not. You have to make choices within your plan until the next Open Enrollment period.

Ted and Anderson encourage all men on the myeloma journey to join the **For Men (with myeloma) Only** group virtually on the 4th Tuesday of each month for one hour, 6:00 – 7:00 PM. Anderson shared that his LLS co-pay assistance has dropped from $12,000 per year to $8,000/year.

Respectfully submitted, Gail

Resources, Announcements, and Educational Opportunities

· **Triage Cancer Conference.** Saturday, October 18, 2025, 10:00 – 6:30 PM. Registration - https://triagecancer.org/conferences/october-2025

· **Triage Podcast/webinars.** https://triagehealth.org/triage-health-podcast/ . Episode 1: About Triage Cancer and Triage Health. Episode 2: Advocacy in Action. Episode 3: Medicare 2025: What's New and How It Affects You. Episode 4: Managing Work and a Health Condition: Your Legal Protections Explained. Episode 5: What is in the "Big Bill" & How it Impacts You.

Healthtree Foundation

· **Blood Cancer Patients:** Avoid Medicare Advantage Traps and Medicaid Eligibility Pitfalls. **52 min**

IMF (myeloma.org)

· **Blood Cancer Awareness Month** – September. **Do you use social media?** Post your experience with myeloma on social media with the hashtag #KnowMyeloma. Try answering questions like "What is something you wish people knew about myeloma?" or "What's one piece of advice you have for someone on the myeloma journey?" Sharing your stories and advice with others builds the myeloma community up stronger. Do not forget to tag us so we can see! Share your experience online.

· Blood Cancer Awareness Month. Q & A. **Tuesday, September 30**. IMF Nurse Leadership Board Member Beth Faiman, PhD, MSN, APN-BC, BMTCN, AOCN, FAAN, FAPO on myeloma. Facebook Live.

· **Get the facts about MM. Watch videos. Get involved for Blood Cancer Awareness Month. Ways to help.** Blood Cancer Awareness Month - Sep 2025.IMF

· **Top Myeloma Questions Answered with Dr. Joe**. /Smoldering vs Double-hit/Supplements and Myeloma and more… Myeloma Questions Answered-Dr. Joe

· The FDA has issued a complete response letter (CRL) for the supplemental Biologics License Application (sBLA) of Darzalex FastPro (daratumumab and hyaluronidase-fihj), **declining its approval for the treatment of newly diagnosed, transplant-ineligible multiple myeloma**. In a news release, Johnson & Johnson clarified that "the CRL is based on observations from facility inspections and is not related to the robust safety and efficacy data submitted for this application. No new clinical studies were requested. [Johnson & Johnson is] committed to resolving outstanding observations in a timely manner, with the goal of advancing this indication as soon as possible."

· In a press release, Dana-Farber Cancer Institute announced the unveiling of a **groundbreaking blood test for multiple myeloma. Researchers have developed SWIFT-seq, a blood-based single-cell sequencing test that profiles circulating tumor cells in multiple myeloma** and its precursor conditions. This test offers a **more accurate and less invasive alternative to bone marrow biopsies.** https://www.eurekalert.org/news-releases/1093817

· **Advocacy.** Bill Introduced to Restore Myeloma Research Funding. The International Myeloma Foundation has officially endorsed a bipartisan bill in Congress that could help restore critical federal funding for myeloma research. The Medical Research for Our Troops Act (H.R. 3906) aims to reverse significant cuts made earlier this year to the Department of Defense's Congressionally Directed Medical Research Programs, which fund innovative studies on diseases like multiple myeloma that disproportionately impact veterans. The program recently faced a 57 percent cut, which could hurt progress on research. If passed, H.R. 3906 would restore funding to previous levels and protect research efforts from further disruption. The International Myeloma Foundation will continue to advocate for the bill and keep the myeloma community informed. **Want to get involved?** Interested in learning more or taking actions about our federal and/or state priorities? **Email the IMF Advocacy Team**, advocacy@myeloma.org, to find out ways you can help and make your voice heard. Find us on Twitter and Facebook! We will be sharing the latest news on legislation and policies we are tracking.

· **Smart Patients:** https://www.smartpatients.com/partners/imf

LLS – lls.org

· The Leukemia & Lymphoma Society (LLS) is becoming **Blood Cancer United** in September to represent all 100 blood cancers**.**

· **Light the Night – fundraiser**

· **The Future of Myeloma Treatment. What's Next**. Replay. Future of Myeloma Treatment. LLS-Replay

· **Health insurance open enrollment will begin this fall. LLS wants to help you to prepare.** Whether you are renewing coverage or exploring new options, having the right healthcare plan can help you prevent future medical debt. Contact a case manager who can help you prepare:

Call: 1-833-507-8036; Visit: www.LLS.org/MedicalDebt

MMRF - https://themmrf.org/

· **Managing Symptoms & Side Effects patient webinar:** Wednesday, September 24, 2025

Patient Empowerment Network

· Decode. AI and cancer care, diagnosis, health education**,** and more.~28 minutes. AI and cancer care-diagnosis-problem solving. Patient Emp Network

· **AI and Cancer Care** – AI and Cancer Care. Vocabulary-Resource Guide. Patient Emp Network

· **Advice for Care Partner. Being Prepared for Patient and Bispecific Antibodies**. Bispecific Antibodies. Care Partner preparation. Patient Emp Network

· ***Strengthening the Patient-Provider Partnership in Myeloma Care** **- Roundtable. 44 min**. https://powerfulpatients.org/2025/06/18/hcp-roundtable-strengthening-the-patient-provider-partnership-in-myeloma-care/?utm_source=PEN+Connect+List&utm_campaign=7f9ea80c46-EMAIL_CAMPAIGN_2025_06_24_07_47&utm_medium=email&utm_term=0_-16df1fc5fa-540581198

Patient Power

· **How Does Myeloma Affect the Brain?** Myeloma and the Brain

· **What is Neutropenia**? What is Neutropenia? Your body's count of neutrophils (a kind of white blood cells is abnormally low. Learn more…

· **Extramedullary Myeloma**. MM.Extramedullary Myeloma. Patient Power

· **What is Serum Protein Electrophoresis?** SPEP and myeloma. What is it?

M protein, also called paraprotein, monoclonal protein, or M component, is an abnormal immunoglobulin (antibody) that appears when plasma cells multiply uncontrollably, Dr. Pozdnyakova explained. In multiple myeloma, these plasma cells produce excessive amounts of identical proteins, creating a distinctive pattern that SPEP can detect.

· **U.S. Food and Drug Administration (FDA) granted accelerated approval to linvoseltamab-gcpt (Lynozyfic) for the treatment** of adults with relapsed or refractory multiple myeloma who have been treated with at least four previous lines of therapy, including a proteasome inhibitor (PI), an immunomodulatory agent (IMiD), and an anti-CD38 monoclonal antibody.

· **CAR T on the Frontlines: Is Earlier Use in Myeloma the Future?** Earlier use of CAR-T therapy…most people with multiple myeloma are not candidate for chimeric antigen receptor T-cell therapy (CAR T) until the fourth line of therapy. But new clinical evidence is showing that CAR T might be effective much sooner than experts previously thought. There are currently two FDA-approved CAR T products for treating myeloma: Idecabtagene vicleucel (Abecma) (BMS), or ide-cel; Ciltacabtagene autoleucel (Carvykti), or cilta-cel (J&J).

· **Multiple Myeloma Bone Lesions and Pain.** "Almost any bone in the body can be attacked by myeloma and result in lytic lesions. This includes the skull, spine, ribs, pelvis, and the bones of the arms and legs," said Nitish Prayani, MD, an assistant professor of radiation oncology at the University of Central Florida. Natural treatments include physical therapy, exercise, massage, and acupuncture. These are often complemented with supplements to assist with managing pain and overall health, though their value is under debate. Common supplements used include fish oil and magnesium. Fish oil contains omega-3s, which can improve peripheral nerve health and

help alleviate inflammation and pain. Magnesium plays a role in strengthening bones, preventing pain, improving nerve health, and regulating calcium levels, which are too high in multiple myeloma.

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

Southside Meetings: **11/22/25, 12/27/25**

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

For information, contact: Website: **ssatlanta.support.myeloma.org**

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