

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Northside MM Support Group

Hybrid Meeting Minutes

July 11, 2026

Guest Presentation

The Northside July meeting welcomed Dr. Hong De Sa, MD of the Northside Blood, and Marrow

Transplant Group of Georgia. Dr. De Sa joined the Northside transplant and cellular therapy program last year. Her professional emphasis on myeloma and transplant medicine was influenced by the loss of her father to multiple myeloma in 2007, before many of today's highly effective therapies were available. She started the meeting with a review of current and emerging treatment strategies of Northside's transplant and cell therapy program for multiple myeloma. Northside is one of only eight transplant programs exceeding expected survival outcomes for 17 consecutive years in the United States.

The presentation focused on the evolution of immune-based therapies for multiple myeloma. Dr. De Sa reviewed the major treatments currently available:

- Autologous stem cell transplantation (your own stem cells)
- Allogeneic stem cell transplantation (donor stem cells)
- CAR T cell therapy (re-engineered T cells target BCMA on MM cells)
- Bispecific antibody (targets BCMA or GPRC5D on MM cells)
- Emerging Trispecific immune therapies (targets multiple protein antigens on MM cells)
- Clinical trial opportunities targeting novel antigens and patient populations

These therapies rely on directing a patient's immune system toward specific targets found on myeloma cells, improving treatment effectiveness while reducing the broad toxicities commonly associated with conventional chemotherapy.

Dr. De Sa spent considerable time discussing CAR T therapy, one of the most rapidly advancing areas in myeloma treatment. She explained how CAR T treatment involves collecting a patient's T-cells, genetically modifying them to recognize myeloma cells, and then reinfusing them as a personalized therapy. Unlike traditional treatments, CAR T is administered as a single infusion that can continue expanding and functioning within the body after administration. Currently approved BCMA-targeted CAR T products for myeloma include Abecma ([idecabtagene vicleucel](#)) and Carvykti ([Ciltacabtagene autoleucel](#)).

CAR T can cause common adverse effects (AE), Cytokine Release Syndrome (CRS), and Neurologic toxicities (neurotoxicity) shortly after infusion. Dr. De Sa noted that Northside generally does not use preventive treatments before symptoms develop but instead monitors patients closely and intervenes early if any side effects occur.

Several active and emerging clinical research efforts were highlighted:

- CAR T therapies targeting GPRC5D
- Trispecific T-cell engager therapies
- Investigator-initiated cellular therapy trials
- Industry-sponsored studies
- A trial designed specifically for patients with moderate to severe kidney impairment

Dr. De Sa explained that these studies aim to expand treatment options, particularly for patients whose disease has become resistant to currently approved therapies.

The [International Myeloma Working Group](#) (IMWG) guidance regarding treatment sequencing has recently been updated. Key concepts regarding immunotherapy include:

- Antigen Selection: Myeloma cells can lose or alter treatment targets over time, called antigen escape which affects cell proteins like BCMA, GPSC5D, and FCRH5. Changing therapeutic antigen targets after relapse may improve outcomes.
- T-Cell Fitness: The effectiveness of CAR T therapy depends heavily on the health and quality of a patient's T-cells. Certain chemotherapy agents, particularly Bendamustine and alkylating agents, (i.e... Cyclophosphamide, Melphalan) may negatively affect T-cell fitness and therefore influence treatment planning.
- Treatment Timing: emphasizes the importance of washout periods before T-cell collection to maximize CAR T effectiveness and allow the immune system to recover.
- Choosing Between CAR T and Bispecifics: While CAR T may provide durable responses, bispecific antibodies can often be started more quickly. Dr. De Sa noted that disease status, urgency, prior therapies, and patient-specific input all influence which approach is most appropriate.

Participants asked how physicians monitor treatment response and whether CAR T therapy remains active and effective. Dr. De Sa discussed several monitoring treatment methods.

- Flow cytometry testing to detect CAR T cells in circulation.
- Bone marrow biopsies to evaluate disease burden.
- Measurement of BCMA expression
- PET imaging
- Routine blood work

She explained that follow-up schedules vary by patient but often include quarterly laboratory monitoring along with periodic imaging and marrow evaluations.

Another important topic was clonal evolution, the process by which treatment-resistant myeloma cell populations emerge over time.

- Therapies may eliminate sensitive cancer cells while resistant myeloma clones survive.
- Chromosomal and genetic changes may signal evolving disease biology.
- Myeloma can shift from marrow-based disease to extramedullary disease, which is often more difficult to treat.
- This concept reinforced the need for changing treatment approaches and targets as the disease evolves.

Dr. De Sa also revisited stem cell transplantation, a longstanding component of myeloma care.

- Autologous transplants continue to demonstrate very strong outcomes, with success rates exceeding 90%.
- Stored stem cells can remain viable for at least 15 years.
- Multiple transplants may be considered in select circumstances if stem cells remain available.

There was extensive audience participation. Patients shared personal experiences involving:

- CAR T therapy
- Stem cell transplantation
- Long-term remission monitoring
- Maintenance therapies
- Relapse management
- Quality-of-life considerations

The group discussion emphasized the importance of staying informed, maintaining open communication with healthcare providers, and considering clinical trials when appropriate. Participants exchanged practical insights about living with myeloma while navigating an expanding array of treatment options.

The meeting underscored several Key Takeaways.

1. Increasing use of immune-based therapies such as CAR T and bispecific antibodies.
2. The growing importance of treatment sequencing and antigen selection.
3. Continued value of stem cell transplantation within modern treatment pathways.
4. Expansion of clinical trial opportunities targeting new antigens and patient populations.
5. The need to preserve T-cell fitness and carefully plan therapy timing.
6. Personalized treatment decisions based on disease characteristics, prior therapies, and patient goals.

Overall, the session provided both a practical update on current standards of care and a look at promising future developments in multiple myeloma therapy.

Submitted by Nancy B & Sandy W

Southside MM Support Group

Hybrid Meeting Minutes

July 25, 2026

Next Meetings: General Meeting – Saturday, August 22, 2026 – Care Partner and Patient Voices. Hybrid meeting. In person at the Evelyn G. Lowery library. 3665 Cascade Road, ATL 30331

For Men (with Myeloma) Only. Tuesday, August 25, 2026 (Virtual Only).

Thank you, Gail, for hosting the Southside meeting and leading the group in deep breathing/ centering exercise. Welcome two new members, Parthos and Rose attending with her mother, A special thank you was expressed to Sebia (SPEP testing) for hosting our June meeting. “*Light the Night*,” the annual event/fundraiser for Blood Cancer United/LLS will be in Piedmont Park again this year on October 3. Look for more details in the coming weeks. There will be a 5K (3.1 miles) sponsored by Emory Winship on October 3. Please click that you want your donation to go to multiple myeloma. Official website “2026 WINSHIP 5K”: https://secure2.convio.net/emory/site/TR?fr_id=1360&pg=entry

Patient and Care Partner Voices

Rose and her mother (also Rose) attended the meeting in person to gather more information on myeloma. She was diagnosed with myeloma in May 2026 and admitted being in denial. Rose is 39 years old with a 10-year-old daughter. She broke her ankle a few months prior while playing with her nephew on the floor. Her primary care doctor referred her to Northside Hospital for further testing. Rose got a second opinion at Emory Winship with Dr. Nooka. She has not started treatment yet, since she wanted to do more research before moving forward. Portia shared the importance of staying positive for mom and daughter. This is advice for both the care partner and the patient. There are support

resources for caregivers and for myeloma patients who have young children (Myeloma in the middle) at myeloma.org. Deborah, a retired nurse from the VA Hospital, volunteered to speak with Rose and her mom after the meeting to answer questions from a nurse's perspective. She emphasized the importance of having a 'village' of just a few people who you can trust, and people who can help you get to your appointments and be able to support you in your regimen. When people ask if they can help, allow them to help.

Partho S. introduced himself to the group. He was misdiagnosed for about a year before being diagnosed with high-risk myeloma. He started treatment at Emory with Dr. Lonial in February. Partho is concerned with overall survival rates (OS) and is interested in speaking with others in the group about high-risk myeloma. There are SG members who are at high risk that will contact him. The IMF has a Special Interest SG for high-risk patients. He was also encouraged to sign up for the IMF-Myeloma Minute for myeloma study reviews on high-risk myeloma.

Paulette sends out a 'new member packet' with reliable MM organizations, a video and helpful educational materials like the myeloma vocabulary guide. It includes a list of questions to ask your care team. i.e., "What type of myeloma do I have?" Be aware of the information and diagnosis seen on the internet, it can be overwhelming. Take your time to learn about the disease and continue to ask others for support. Get a three-ring binder or 5 subject notebook for notes and writing down questions on general information, lab tests, finances, personal thoughts, and important papers. The group's longtime MM survivors of 16, 18 and 37 years reassured the new members that myeloma is not a death sentence. Stay positive and lean on those who continue to walk this journey for comfort and support.

Sandy W. was diagnosed in May 2013 and has learned so much on her myeloma journey. She received a stem cell transplant (SCT) with complete remission (sCR) for over 6 years. When the first relapse occurred in 2019, she was treated at Emory with 3 different lines of therapy and eventually relapsed. Sandy received CAR-T therapy in December 2025 at Mayo and attained *MRD- status for the first time in year 13!!!* She remains free of active myeloma disease but has .0003% MM cells preventing her from being declared MRD negative. She is currently being monitored and is getting monthly IVIG infusions. Since June, Sandy has traveled through 13 states in 40 days via motorhome from Arkansas to North Dakota. followed by her 6-month CAR-T check-up in MN... taking full advantage of QOL opportunities.

Doris M., who is 85 with MM, started the Southside SG 20 years ago because she had never heard of myeloma. She knows the importance of getting the message out about myeloma through health fairs and community groups. She raises funds for BCU every year for Light the Night which is coming up in October. Chinwe was diagnosed in August 2024. Never hearing of myeloma before, she came to meet others who have myeloma face-to-face. There is a wide range of knowledge and experiences learned from attending the support meetings. Laurie is a nurse who was diagnosed in July 2025, after losing her job two days prior. She had heard of myeloma but did not have a single symptom. She had a stem cell transplant in January, is pain-free and knows to ask lots of questions. Wanda added to block out others' opinions that may not know anything about the disease. Since being diagnosed in 2023, she is 'blown away' by the many new treatment regimens being offered. There is so much information – so much to be hopeful for. Myeloma is just another facet of life. Flora advised continuing to be encouraged and stay connected. Dr. Nooka is her doctor and is awesome. Joyce was diagnosed in 2012 at age 50, after suffering a broken rib, and was told she had 5 years to live. She takes care of herself and walks 6.2 miles of the Peachtree Road Race every year to celebrate her health. Gloria shared that if the care team offers a clinical trial, please consider them. Living 16 years with myeloma, she can testify that myeloma is not a death sentence.

Meeting Presentation

There is a clinical trial called “*Nutrivention*” for newly diagnosed MM patients. Its purpose is to determine the relationship between whole food plant-based eating and MM. The study is led by Dr. Urvi Shah of Memorial Sloan Kettering (MSK) with Emory Winship is one of the clinical sites. If interested, contact shahnutrivention@mskcc.org. To see Dr. Shah's discussion of her program and amazing results, click here – [Nutrition benefits](#).

A 5-minute video, [Good options for Myeloma](#), was shown that emphasized what is being said about new studies and treatments consistently being available.

Another video was shared to end the meeting – [Dr. Joe answers your questions on Anito-cel, Blood tests for MRD status](#).

Joyce attended her first IMF Support Group Leadership meeting held in Minneapolis, MN. She enjoyed interacting with others who were familiar with the myeloma journey and so involved in helping others to navigate it. It was exciting to hear about new treatment options on the horizon, like self-administered injections at home (Sarclisa). She also visited the Mall of America!

Additional highlights: Recent study results indicate that patients may no longer need Revlimid past two years as a maintenance drug. There are ongoing studies that will compare SCT to CAR-T as front line therapy. A promising new class of oral medications called CELMoDs (Iberdomide and Mezigdomide) has been approved for treatment. Look for more information in coming weeks and months with presentations at the December annual ASH (American Society of Hematology) meeting where cutting-edge myeloma research from around the world is presented.

“For Men (with Myeloma) Only” Group Report

The July meeting was robust with sharing about myeloma and other topics of interest. They issued an in-group friendly challenge to participate in the Saturday, October 3 run/walk at Emory Winship at 8:30 AM.

2026 WINSHIP 5K

Website: https://secure2.convio.net/emory/site/TR?fr_id=1360&pg=entry

All men with myeloma are invited to mark their calendars for the 4th Tuesday of each month for one hour, starting at 6:00 PM. It's a virtual meeting with the same link each time.

Respectively submitted, Gail