ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Meeting Minutes

Northside MM Support Group

Hybrid Meeting Minutes

May 2, 2026

Guest Speaker Presentation

This month's guest speaker was Danielle Smith, patient navigator, with the HealthTree Foundation. Her professional background is in health science and oncology-related patient care. The foundation mission is patient support services, research initiatives, and educational resources on multiple myeloma and other blood cancers.

HealthTree Foundation is a nonprofit organization that supports blood cancer patients through education, community support, and medical research. HealthTree helps patients with treatment decisions by connecting medical records, specialists, clinical trials, and myeloma resources. Jenny Ahlstrom, a multiple myeloma patient, started the foundation due to the challenges in finding clear, useful answers during her own journey. HealthTree empowers patients through education, personalized support, and research participation. The foundation's long-term goal is to speed the progression toward a cure for multiple myeloma and other blood cancers by attaining reliable data, sharing patient experiences, and making research opportunities more accessible. HealthTree offers a personalized patient support tool that connects patient medical records to a centralized database that organizes patient information from multiple treatment locations, tracks lab data over time, and matches treatments and clinical

trial options with their medical profile. Patients who register on Healthtree are connected with a patient navigator who helps with guidance, resources, and identifying next treatment steps based on their needs. These tools help patients prepare for conversations with their care teams and make better informed treatment decisions. HealthTree's chat hubs allow open discussion on treatment experiences and feedback from real patients managing issues such as neuropathy, gastrointestinal problems, fatigue, and other treatment-related challenges. Both medical and holistic coping strategies are discussed, allowing patients to see what others have found helpful.

Research studies are not limited to traditional clinical trials. Patients have participated in completing surveys, joining interviews, sharing medical records, or donating biopsy slides for research projects. HealthTree also collaborates with physicians and medical experts to help patients better understand disease diagnosis and navigate difficult treatment discussions. HealthTree's research model video explained the value of patient anonymized real-world data through connected medical records. Major medical institutions and researchers use curated patient data to study disease patterns, treatment outcomes, and diagnostic materials more efficiently than through traditional methods. This highlights how informed patients, shared data, and collaborative research improve progress toward better treatments and a potential cure.

Danielle summarized HealthTree's education and community resources, video library, webinars, newsletters, and topic-specific learning materials. These resources help patients stay current on rapidly changing topics such as CAR-T therapy, bispecific antibodies, minimal residual disease, mental health, and financial concerns. Healthtree offers one-on-one coaching from trained

volunteers who are themselves patients or caregivers. Patients can speak with someone whose experience closely matches their own stage of treatment. There is also a financial advocacy service that helps patients navigate insurance decisions, medication access, disability paperwork, reimbursements, and available grants.

During the Q&A, participants asked about nutrition resources, access to archived webinars, differences between HealthTree and other myeloma organizations, medical record sharing, biopsy slide research, and support for treatment side effects. Healthtree provides educational content, newsletters, and referral guidance. Danielle clarified how patients can choose how much medical information to share and that all research data maintains anonymity before being used. Participants also discussed the importance of specialist care, especially centers with multiple myeloma experts. Several group members have used the HealthTree specialist directory, coaching, Cure Hub, educational content, and community resources. We thanked Danielle for her presentation and providing lunch for those who attended in person. Link Healthtree NS presentation slides.

Group Discussion

After Danielle's presentation, Nancy led a discussion with patients and their status.

Laura R. has concerns about treatment side effects. She had a stem cell transplant (SCT) in July of 2025. Her multiple myeloma was not controlled, so Laura began treatment in November with KPd (Kyprolis/Pomalyst). Her routine lab results were very good, but the side effects have been increasing with new issues appearing every week or two. It has become overwhelming,

knowing that she may be in treatment for several years. Laura's neuropathy has worsened in her hands and feet, and increased burning in her mouth and tongue, which had reduced her appetite and weight loss. She has been treated at Northwest Georgia Oncology, and her transplant was performed at Emory by Dr. Gupta. Laura was receiving Kyprolis weekly along with Pomalyst for 21 days per 28-day cycle. Her doctor has lowered the dose of Kyprolis and is currently on 4 mg Pomalyst. She may ask if her dose could be reduced.

Sandy W. had also been treated with KPd. Her doctor had decreased dosage and frequency of Kyprolis to once a month. Nancy Y. recalled that while taking Kyprolis, she had needed two naps a day. After talking with her doctor at Kennestone, Kyprolis was paused for a few weeks so she could regain her energy to resume treatment. Members suggested that Laura write down all of her symptoms and concerns to send to her Emory healthcare team through the patient portal. She could arrange a video visit with Dr. Gupta rather than driving because of the long distance to Emory. The group encouraged her to keep a detailed list of questions in front of her during the appointment, so that no concerns would be forgotten. It was important to explain that her quality of life was declining and that the side effects were causing anxiety. Jeff W. added to ask whether she had high-risk multiple myeloma and how that might affect treatment options.

Phyllis P. had been experiencing cramps in her hands and wanted to know what might help. Joyce J. suggested that low potassium may be the cause. Marilyn M. said that her hands cramped severely and fingers sometimes overlapped during the cramping. She had taken potassium for many years and now her potassium levels were normal. Marilyn added that she had suffered from very bad leg cramps and was told to use mustard,

which worked very well and quickly. Scott N. mentioned that athletes often use pickle juice for muscle cramps. Phyllis likes dill pickle juice and would try it.

Scott N. reported that he had initially responded well to treatment with Dara-VRd, but after being off treatment for six weeks, his multiple myeloma had become worse than it was at diagnosis. He had recently been admitted to Emory Hospital for four days of VD-PACE, a high-dose treatment intended to reduce disease burden, with nausea and hair loss as the primary side effects. Scott was feeling fine and returned to the hospital the following week for a transplant. Three weeks after the transplant, he was scheduled to receive CAR T therapy. Members expressed surprise at how aggressive the treatment plan was, but it was explained that this level of treatment was needed to bring his disease under control. Other patients observed that transplant was common and that some people had undergone SCT two or three times. Jeff said that his own CAR T treatment had caused minimal side effects and that those side effects had been treated promptly. Karen added that during her inpatient transplant, the nurses were very responsive when nausea occurred, and Joyce agreed, noting that the nurses consistently encouraged patients to eat in order to maintain their strength.

Nancy B. noted that multiple myeloma patients who had participated in clinical trials for CAR T therapy were still in remission five to six years after treatment. The patients in those trials had received an average of five lines of therapy, with some having as many as ten. CAR T showed a very high rate of effectiveness and excellent treatment results. Jeff had recently spoken with Dr. Kaufman about a clinical trial for a new CAR T approach in which T cells would be developed inside the patient's body rather than harvested and sent to a lab. Laura asked

whether CAR T or stem cell transplant offered longer survival. Nancy replied that outcomes were currently about the same and that clinical trials were underway to compare them directly. Laura asked whether Emory provided CAR T treatment, and Nancy confirmed that Emory performed both CAR T and SCT. She added that Northside Hospital also offered both treatments.

Nancy Y. shared that she had undergone CAR T therapy at Northside Hospital in early February and that it had been successful. She also received tandem transplants at Northside and was very satisfied with her treatment there. Nancy has good energy and was not taking any medication. Karen asked whether a patient had to relapse after a transplant before becoming eligible for CAR T. Jeff W. never underwent a transplant and has been in remission for a year and a half after CAR T without additional multiple myeloma treatment other than acyclovir for shingles prevention. Jeff has felt better than he had in years.

Karen had been in remission for three years since her transplant and was feeling well. She remained on Revlimid maintenance and took Colestipol for gastrointestinal issues, which she found effective when taken consistently every day. Phyllis said that the hardest part of dealing with myeloma was fatigue, and several members agreed that this was a common issue, especially in the early afternoon. Joyce said that fatigue had to be managed because it remained present from both the disease and treatment. Whenever Joyce felt negative or discouraged about the fatigue, she identified the feeling, changed her attitude, and did something that made her happy. Jeff noted that Revlimid causes fatigue. He agreed that it was important to recognize the issue and take action. Karen remarked that she had not realized her afternoon naps might be related to Revlimid. Glenn stopped Revlimid four months ago and his blood counts were recovering. He had been

in remission for five years, and his doctor had told him he could stop Revlimid. Nancy explained that the recommended length of Revlimid maintenance had changed and that if a patient remained in remission after three years, treatment could be stopped and the patient could be simply monitored. Revlimid had previously been given indefinitely, which had led to more secondary cancers. Phyllis' doctor had told her she would likely remain on it for two years before reevaluating her disease status. Joyce was taking 2 mg of Pomalyst and would be evaluated to determine whether she needed to continue. She explained that she had previously taken 4 mg, but that dose had been too much for her.

Submitted by Sandy W & Nancy B

Meeting Minutes

Southside MM Support Group

Hybrid Meeting Minutes

May 23, 2026

Next Meetings: General - Saturday, June 27, 2026. Sebia will host our Support Groups at the Sebia location in Norcross – learn about testing and importance of SPEP. Our host will be Aigars Brants, PhD, Director of Scientific Affairs. Arrival time is 9:45 AM. Hybrid meeting will begin at 11:30 AM.

"For Men (with Myeloma) Only" – Tuesday, June 23, 2026. Virtual Only.

We started our meeting with a moment of silence – and deep breathing exercises to help center us and learn more about correct breathing for optimal benefit. We had one new member, Yvonne, who goes to Kennestone for her treatment. Linette was diagnosed in 2022 with smoldering myeloma and is being treated by Dr. Nooka at Emory Winship.

We had two guest speakers, Dr. Ajay Nooka from Emory Winship and Dirk, one of our patient members.

Joyce and **Portia** shared with us their experiences at the **Path Church Health** Fair on March 28. This is our second time attending this event. There were lots of vendors with health information and services. Many community members came out to participate. Joyce's highlight was meeting a newly diagnosed patient who had not heard of our Support Groups. Portia thought the event was very informative overall and that raising awareness at community events is something we need to continue. There are still so many who have never heard of Multiple Myeloma and so many who are shocked with the diagnosis. Portia also urged us all to continue sharing this information with our **church congregations** and requested that we participate in the **Fayetteville Juneteenth Event** on June 19, from 10 AM. We commit to try to find volunteers for this worthy event.

Dirk provided us with information and a tour of the IMF-sponsored **"Smart Patients"** website – smartpatients.com. "Smart Patients" is a monitored website where patients and care partners can share experiences and concerns about their myeloma journey. They share through conversations about medications, side effects, options for treatment, and access to medications. Comments come from all over the world. You can learn what treatments are available in other countries – and that many over the world do not have access to some medications that we do. **Teonna** shared that in 2023, she used Smart Patients as she researched the experiences of others to help with her decision-making on a procedure after a hip fracture. One option was an intramedullary nail procedure and the second was hip replacement. She got lots of advice from others who had received the nail procedure and what to expect. The advice was very helpful in her decision to go with the 'nail' procedure and she is doing well. It was good to be able to hear from those who have gone through the procedure alongside the

recommendations from the doctors. Teonna says this can be a great resource for those who are newly diagnosed and those who are making decisions on changing regimens after relapse or for some other reason. Others may have made similar decisions. Both Teonna and Dirk say that it's easy to navigate. Dirk demonstrated searching for a specific topic, like CAR-T or daratumumab, and tuning in to conversations of others to start.

For Men Only: Anderson and **Ted** reported that the Men's Group continues to provide a safe space where men can share their journey and be supportive of each other, even when they are not related to myeloma. They look forward to the opportunity to share that one hour of virtual fellowship. They encourage all men with myeloma to join them on the 4th Tuesday of each month at 6 PM virtually. David joined this meeting from his hospital bed. Some lessons learned include that we should take nothing for granted, that you might be able to help someone else based on your experiences, or learn from others. They had one new member, **Daniel,** join during their May meeting.

David shared his recent personal journey with the general Support Group – that he had shared with the Men's Group recently. He had a biopsy for prostate cancer in Atlanta then he returned to his home in Savannah. On returning to his usual busy schedule of work, family, and his regular life, he started to feel unwell. He went to Emergency Room and collapsed at sign in. They found after much research that he was bleeding from two separate places where three arterial vessels been punctured during his biopsy. His blood pressure went down to 55/30 (Standard reading average – 120/80). He had lost massive amounts of blood by the time they had him fully diagnosed. He is doing well, and the other good thing is that biopsy showed he is clear of cancer.

Though this was a life altering experience, David says 1. Do not be discouraged from getting prostate biopsies; 2. It was good to have the men to share this adventure with. Many he spoke to says they had never seen this in their career; 3. If you see ***any*** signs of blood, be sure to communicate it to your medical professional as soon as possible (don't try to "tough it out"); if you feel that something is not right in your body **, please let the doctor know. Even routine procedures can go wrong sometimes. Dirk** shared that a few years ago, he had a routine colonoscopy and developed **sepsis** (a medical emergency that is the body's response to infection -- a life-threatening situation where the body's own immune system causes damage to its tissues and organs) as a result. Please follow all the doctor's instructions for any procedures you have – routine or new procedures. They do these procedures all the time but because it's new to you, you may want to know reasons for taking antibiotics before procedures or other questions. David emphasizes that we "err on the side of caution."

Dr. Nooka consented to attend our meeting over this Memorial Day holiday due to concerns of several Emory Winship patients that they never see their physician, but Physician Assistants and Nurse Practitioners. While they respect the training of these PAs and NPs, there are times when they feel they need to see the physicians. Even asking specifically several times to see the doctor, they feel they are put off – or treated as if they have offended the other staff. Dr. Nooka was invited to address these concerns. He started with the background of myeloma at Emory. Each year, there are 35,000 patients diagnosed in the U.S. – 1,500 of them in Georgia. Half of those (750) newly diagnosed patients are seen at Emory each year…there are over 5,500 myeloma patients seen at Emory. Myeloma patients are living longer and are at varying stages of their myeloma. Since 2008, when there

were just 3 physicians to see patients, there are now 12 myeloma specialists. The training of the support clinicians (all with over 10 years of experience) is more than that of general oncologists. For patients who may be in remission or do not need special intervention (e.g., change of medications or dosages, changes of regimen), they might be seen by non-physician staff. The physician-led team discusses the status of each patient to be seen each week. In the past, they saw about 20 patients each week – now that number is 65 patients per week for three people.

Carolyn expressed her gratitude for the explanation of the practice, and that she did not know of the large volume of myeloma patients being treated at Emory. She was diagnosed about 20 years ago, and rarely sees Dr. Lonial, but sees Charise most of the time. **Carolyn H**. described her concerns – she had a SCT late last years and was given a cadence for her visits post-transplant. She was concerned she had not seen Dr. Kaufman and asked to see him. She was not given an appointment with the doctor and did not receive a future appointment scheduled. It seemed that she was being ignored or as if she had offended other clinicians. Dr. Nooka explained the cadence of visits post-transplant depends very much on lab results and determining next steps. He further explained for all present that it is the patient's right to see their physician – and to ask (politely of course). If their requests are not filled, they should reach out to him personally. Nancy and Gail emphasized the importance of setting expectations – so that when the team is introduced, the patient receives the information about who they will see going forward, and what the process for physician-engagement will be. **Question/David:** For further clarification of the roles of NPs, PAs, and MDs. When would be the appropriate time to request a consult with the MD. **Response:** In addition to newly diagnosed patients, when the labs show significant differences of

concern, when considering a new regimen – all these are reasons to request the appointment with your MD. He asks that patients and care partners prepare for their appointments, and to please write their questions down. If patients have questions after the appointment, and for example, send the question through MyChart, the way the question is written can be open for interpretation. **Question /Concern from Alf:** I am on a clinical trial and feel as though I have been left to the CT team – as if I am being used as a guinea pig. I would like to know some of the results of the CT. Did it work? What's the next step for that treatment? **Response:** We consider our CT patients as some of the bravest patients, because they volunteered for this effort with no real proven results of the outcome. You only have to ask – send a note in MyChart, and we are willing to share results with you. On this matter, Gail mentioned previous discussions among researchers of sharing the results (in common language, not peer reviewed articles) with all CT participants when results become available. Dr. Nooka said he would take the ideas we have given back to the teams of clinicians and researchers. He also mentioned that updates to these CTs are provided during annual meetings of ASH (American Society for Hematology) in January, and other meetings ASCO, and IMF.

Other comments: Alf is very happy with their NP and comes in with a prepared list of questions that are addressed immediately with follow-up. They request a meeting with Dr. Hofmeister twice a year and have never encountered any difficulties. **Alicia** had a concern about what might be "an attitude" from clinicians when she asked to see the MD. Alicia loves her team and is mostly satisfied but wants to resolve any bad feelings. **Question/concern from Mary**: Mary offered that she had requested a bone marrow biopsy, which was not scheduled when she was told it would be. Subsequent to getting the biopsy, she received a

MyChart message about the biopsy results but was not sure of what they meant. She sent a message to Dr. Kaufman, asking for explanation/clarification, but never heard back after two weeks. Should she continue to request through MyChart? *"I think it might be good news, but I don't really know."* **Response:** For the first time, we are talking more about "cure" for myeloma. There is a test called MRD (Minimally Residual Disease) testing which can detect one myeloma cell in 1 million calls (10^{-6}). This test is applicable to about 90% of the population. There is only one company that conducts the test. The time we get the results can vary from a couple of weeks to three months. We are using these tests to change treatment, so you can wait to discuss your appointment in three months or send another message and be persistent in your requests. **Wanda** shared that her strategy was for communication: in MyChart she says her message is for anyone on the team to respond. She also fills out all the surveys and includes any comments on her treatment services.

Dr. Nooka, in speaking for the entire myeloma team at Emory Winship, stressed that sometimes any 'relationship' might be challenging. But if you have the same goal, issues can be resolved with clear (and respectful) communication. Patients/Care Partners should know they are most important in this relationship, and the team together will work to resolve any concerns. You have put your health and your trust in us, and we do not take it for granted.

Patient Updates: Diane is on Day 31 after her Stem Cell Transplant and is doing well. The team at Northside is pleased with her progress. Alicia is looking for a free Yoga class near Decatur or Conyers/Covington area. Northside has many different activities for cancer patients. Some

suggested Senior Centers might have some classes. Others suggested virtual free classes – Healthtree, AARP, Emory (in-person), or local TV stations. Linda suggested Emory in their Alternative/Complementary Medicine area.

Resources, Updates, Educational Opportunities

Blood Cancer United (formerly LLS)

- **Looking for a clinical trial?** BCU has partnered with Carebox to help you find a match for your condition. You can also work with their Nurse Navigators to use this resource**. https://connect.careboxhealth.com/en-US/partner/bloodcancerunited?utm_source=sfmc&utm_medium=email&utm_campaign=CT%20Day%20-%20May%202026%20non-gmail%2024%20months&utm_term=https:%2F%2Fconnect.careboxhealth.com%2Fen-US%2Fpartner%2Fbloodcancerunited&utm_id=840603&sfmc_id=344642147**

CURE/Cure Connections

- **Where Care partners find hope and information for myeloma.** Video ~ 5 minutes. https://www.curetoday.com/view/where-care-partners-find-hope-and-information-for-myeloma?ekey=RUtJRDo4QkVBNzMxMy0zM0Q2LTRBNDEtQTg5N

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- **Iberdomide and the Rise of CELMoDs in Multiple Myeloma.** Dr. S. Lonial. Video – 1:12. https://www.curetoday.com/view/iberdomide-and-the-rise-of-celmods-in-multiple-myeloma

Healthtree Foundation

- **Medicare Coverage Confusion? Understanding Preferred Pharmacies and Prior Authorization Rules**. Tuesday, March 3 @ 1:00 PM. https://healthtree.org/blood-cancer/community/events/mar26-blood-cancer-ginancial-medicare?utm_source=intercom&utm_medium=email&utm_campaign=eventpromo&utm_content=general

IMF (myeloma.org)

- **What happens after CAR-T Therapy?** 12 min video with Dr. Joe and Beth Faiman**. https://www.myeloma.org/videos/happens-after-car-t-cell-therapy-myeloma-experts-answer-common-questions**
- **How are you using AI today?** Take an anonymous survey – less than 10 minutes**. https://www.surveymonkey.com/r/QX5Z9WQ**
- **The New "Normal" in Myeloma. A Blog by Dr. Joe.** The myeloma norm is radically changed by these five developments: 1. Treatment of high-risk smoldering multiple myeloma, 2. Quadruplet (4-drug) therapies for frontline treatment, 3. CAR T-

cell therapy at first relapse, 4. Bispecific antibodies at first relapse, and 5. The reintroduction of antibody-drug conjugates. **The Amazing New "Normal" in Myeloma Is Here for Today's Patients! | International Myeloma Foundation**

- **Can cancer be cured?** Key takeaways from Dr. Lonial's March 2026 Facebook Live presentation. Narrative**. https://www.myeloma.org/blog/facebook-live-summary-dr-sagar-lonial-answers-myeloma-questions**

- **What "Cure" Really Means in Multiple Myeloma | MRD & Long-Term Remission Explained. 5-minute video – Dr. Joe and Dr. Beth Faiman. https://www.myeloma.org/videos/cure-really-means-multiple-myeloma-mrd-long-term-remission-explained**

- **Understanding ELREXFIO & Bispecific Antibodies for Multiple Myeloma. 12 min Video. https://www.myeloma.org/videos/understanding-elrexfio-bispecific-antibodies-multiple-myeloma**

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

MMRF - https://themmrf.org/

- The Multiple Myeloma Research Foundation® (MMRF®) has just launched its agile, next-generation **Translational Research Umbrella (TRU)** program to answer some of the most pressing questions facing multiple myeloma patients now. Its first sub-study will focus on important unknowns about two of myeloma's most innovative immune therapies: CAR T-cell therapy and bispecific antibody treatments (bispecifics).