ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Meeting Minutes

Northside MM Support Group

April 4, 2026

Business and News

Thank you Nancy for hosting the hybrid meeting in April. There were twenty-four people in person and fifteen virtual participants in attendance. Please accept our apologies for the technical issues during the meeting at St. Joe's. The conference rooms were upgraded in March, but there were still broadcast issues. The technical problems have been repaired, and we have a guest speaker for the May meeting. Fingers crossed, everything is resolved and our meeting goes on without technical issues.

Patient Updates and Discussion

Scott N was diagnosed in August of 2025. He is going to Emory for the VRd PACE treatment and asked if anybody has had any experience to learn what else he needs to know. VRd-PACE stands for a combination of the following medications: VRd: Velcade (bortezomib), Revlimid, and dexamethasone with PACE: cisplatin, doxorubicin (Adriamycin), cyclophosphamide, and etoposide. Scott was initially selected for a CAR-T therapy but was rejected. After responding well to Dara/VRd, he was off treatment for 6 weeks, so his recent biopsy came back worse than when he started. The Lambda light chains went up. VRd PACE therapy starts on Monday for a week. He returns home to recover and then back to Emory for standard of care.

Joyce J is from the Southside group. She was diagnosed in 2012 and has received three transplants. She had 10 months induction treatment followed by tandem stem cell transplants at Northside within 6 months which put Joyce in remission for 6 years. Relapsing in January 2020, she had her third SCT with the stem cells originally harvested. She cannot use the remaining stem cells a fourth time since there is a three-transplant maximum and will need to move to a different line of therapy. Joyce is in remission and on DPd (Daratumumab, Pomalyst, dex) maintenance. Nancy noted that if there are stem cells in storage, doctors may use them to boost your immune system like IVIG. Frozen stem cell shelf life is undetermined, but several patients have used them successfully after 15 years. Joyce had recurrent pneumonia for seven

years, so she received IVIG infusions to boost her immune system. Several patients in the group concurred that they were receiving IVIG as well.

Marilyn M has had smoldering SMM for 18 years without any treatment. Her M-Spike is pretty high at 2.5, but she is stable. She is not experiencing much bone pain, high calcium, or kidney dysfunction and is on routine IVIG to help boost her immunity. Marilyn has had her share of infectious diseases. In 2021 she contracted West Nile virus, and since 2024 has dealt with encephalitis, sepsis, pneumonia, blood poisoning, and spinal meningitis, which has put her in the hospital many times. She finally saw an infectious disease doctor who advised that she should be on IVIG. Her hemoglobin has increased to normal range since receiving monthly IVIG infusions. Marilyn has discussed the CRAB criteria with her doctor and whether to start a low dose therapy, but it could create additional side effects from the treatment. Her immunodeficiency infections outweigh any myeloma symptoms. Treating the disease would make her immune system even more compromised. At 76 , she feels very fortunate and acknowledges the support group is important in her journey.

Dirk B noted that he attended his first meeting in a wheelchair. He first noticed back issues while training for a 10K. Within a few months he was admitted into the hospital with severe bone pain. He had surgery on his back and kyphoplasty on 13 fractured vertebrae. By then he was 5 ft. 8 in. and had lost over six inches of height. Dirk was diagnosed with MM in 2016 and received a SCT in late 2017. He responded well and got 19 months' remission. Then his numbers started to go sideways and were wreaking havoc to his immune system that landed him a couple hospital stays. He noted it helps to have a good relationship with your doctors.

Carolyn H has had myeloma for 19 years and only had 4 lines of treatment. She was experiencing back pain. Dr. Lonial asked if she wanted to volunteer on a Phase 1 clinical trial. It was Elotuzumab that lasted 5 years. Her second CT was on Darzalex, which worked for over 9 years. She was very happy with her treatments with no side effects, and no SCT or CAR T. Carolyn started Bi-specific therapy in November 2024 and experienced side effects for the first time. When she brought it up to Dr. Lonial, his response was that she had been spoiled. That never happens for patients to have no side effects. She has attained VGPR (very good partial response) which makes her happy because it means the myeloma is still under control. Medically she has a-fib and got an ablation and has pulmonary fibrosis. As Caroline puts it, she is getting older and getting better.

Jim M started his update by telling the group that he was missing 6 inches and that he had joined the Dirk club. He was 5 ft. 9 in., 180 lbs. now at 5 ft. 2 in. and 133. He was on a clinical trial last year, which worked for a month then stopped. Jim explained that while he was on the clinical trial setting, Emory went to sleep at the wheel. They did not pay attention to Jim at all. They were more concerned about the darn trial. He got really sick, not doing well at all. Jim told

the Emory team, “we gotta do something different.” They did not know what, so that clinical trial was stopped. Jim developed numbness, Influenza A, and pneumonia. He was hospitalized for a week and a half. His brother and sister went to see him. Jim did not know how bad it was but recovered okay.

This past December everything started coming back. Jim did well on the three step-up doses of Talvey. Then was given a full dose on December 23. He was released on December 27 and the adverse reactions started. He lost his taste buds along with his appetite. It has been pure liquids for a while. Solid food is coming back slowly. Dr. Kaufman told Jim, “You are going to get better.” Jim is back to eating, but not a lot, His family is pushing food, feeding tubes and all sorts of stuff along with Dr, Kaufman. Jim is battling and is getting better.

Jim stated he is not going to be like this 30 days from now. He works with palliative care for pain control to reduce the narcotic drugs and physical therapy with Dr. Oza, Jim had a serious conversation both He had to come to the support group meeting. Jim needed to see new faces and wanted everyone to see him as he is today. He thanks everyone for being there today. It means a lot. We are all here to help each other.

Joseph S has been experiencing side effects from treatment for the last four months. The chemotherapy is causing brain issues, chest pain, difficulty breathing, and gastric reflux problems. All these conflicting symptoms are agonizing. Every morning Joseph wakes up with pain and has to decide if its acid reflux or a heart attack. It is mostly reflux so medication helps it subside. If the asthma flares up, he hates the inhaler with high dose steroids that cause chest pain. This has become a regular routine. He takes his treatment pills, supplements, heart medications. Joseph goes to the VA for his appointments. He asks for a community care referral to a specialist in whatever area that you're having issues with. And that is important.

Frank M had CAR T therapy in October 2024 that was successful. He started IVIG infusions three months ago and is doing great. Prior to infusions, Frank had pneumonia every year and sinus infections that would last for 8 weeks. It was miserable and a quality-of-life issue. IVIG is a plasma blood product, not a medicine. It works like a booster shot to your system. IVIG is expensive, but it works to keep you out of the hospital and feeling great.

Submitted by Sandy W

Southside MM Support Group

Hybrid Meeting Minutes

April 25, 2026

Next Meeting:

Southside Meeting. Saturday, May 23, 2026 @ 10:30 AM. VIRTUAL only.

Speakers – Patient and Care Partner Voices.

“For Men (with Myeloma) Only. VIRTUAL. Tuesday, May 26, 2026 @ 6:00 PM. One hour.

Thank you Gail for hosting the hybrid meeting. The session opened with a moment of deep breathing and centering, followed by a welcome to all attendees and new member Yvonne. She was initially diagnosed with smoldering myeloma and received a diagnosis of active myeloma in 2025. She has been treated at Kennestone Hospital in Marietta. After speaking with Nancy, Yvonne sought a second opinion from myeloma specialist Dr. Lonial at Emory. She found the support group through the Internet since she appreciated the benefits from breast cancer support groups several years ago.

Guest Speaker Presentation

The guest speaker was Katie Atkins, Associate Director of Support Groups for the International Myeloma Foundation (IMF). Her presentation covered IMF resources as well as palliative and hospice care. Katie explained both palliative care and hospice focus on patient comfort, dignity, and quality of life.

Palliative Care

Palliative care is not end-of-life care. Its focus is on symptom management, including pain, stress, and practical concerns such as access to financial resources. The term comes from the Latin word meaning to *lessen pain or discomfort*. Palliative care is available at any stage of a serious illness, whether the condition is curable, chronic, or terminal and may be offered alongside curative or life-prolonging treatments such as chemotherapy, radiation, dialysis, or surgery. Its purpose is to improve patient and family's quality of life (QOL) physically, emotionally, and spiritually. QOL differs from person to person and may include goals such as gardening, traveling, playing tennis, or spending time with grandchildren. Palliative care is typically provided by a team that may include physicians, nurses, social workers, and other specialists. Anyone with a serious illness may qualify, including individuals with cancer, COPD, heart disease, heart failure, or dementia. Katie noted that access in some regions, such as Asheville, NC, have outpatient palliative care clinics and many specialists. Palliative care access in this area may be more limited. Members were encouraged to ask their provider or local social worker for referrals and to inquire about services at Emory. Alma shared that she received palliative care at Emory during COVID, when anxiety interfered with treatment and found the experience helpful and supportive.

Hospice Care

Hospice care is end-of-life care focused on helping patients live as comfortably as possible for as long as possible. In many cases, people live longer than expected. Hospice teams may include a physician, nurse, social worker, chaplain, and sometimes lifestyle therapists. Hospice addresses pain and symptom management, emotional support, and bereavement care to both the patient and the family for the

duration of the service. Generally, two physicians must certify that the patient has a life expectancy of six months or less for eligibility. *Curative treatment is not provided under hospice care*.

Medicare covers hospice through a set payment structure and determines how those funds are allocated. Patients choose whether to enter hospice care, and they may change that decision at any time. For those with private insurance, requirements may differ. Hospice begins with an initial 90-day period, followed by recertification approximately every 60 days. The care team is generally led by a physician with nursing visits once or twice a week. Personal care services, such as bathing assistance, are not covered by Medicare and may require a certified nursing assistant paid for by the family. Hospice covers equipment such as a bed, wheelchair, and incontinence supplies, along with 24-hour on-call support. It may also provide at least five days of respite care in each quarter to give family members a break. Medicare covers home hospice, while hospice care in a facility is managed differently. Those without insurance were encouraged to contact a hospice agency directly to ask what support may be available.

Getting to know IMF…myeloma.org. Katie continued her presentation with an overview. The International Myeloma Foundation (IMF) is a 36-year-old organization founded by patient Brian Novis, and his wife Susie Novis and physician Dr. Brian Durie, MD. The IMF mission is to improve the quality of life for every myeloma patient. Its four pillars are research, advocacy, education, and support, with a focus on treatment, prevention, and a cure. More research and discussion about a cure now more than ever before. The IMF supports more than 150 regional support groups across the continental United States. It also offers many special interest groups that meet virtually each quarter.

These groups include MM Families for patients with small children, MM in the Middle, Veterans, Smoldering, Living Solo, a Spanish-speaking group, Care Partners Only, and High-Risk Myeloma. The IMF SG staff offers MM presentations to support group meetings. *Myelo* is an AI assistant search tool on content from the myeloma.org website with evidence-based information rather than Internet results. Katie provided an overview of the website features and current publications that can be read online or ordered free of charge, as well as searchable videos. Members may also call 800-452-CURE (2873) with questions about myeloma or contact Katie at katkins@myeloma.org.

Group Discussion

Joyce and Portia attended a health fair in March sponsored by a church. They reported that it was a very successful event with many vendors, resources, and services. Numerous community members stopped by and received information about myeloma. Joyce noted that one highlight was meeting a newly diagnosed patient who learned about the support group at the event. Portia also announced the Juneteenth Celebration sponsored by the Historical Society in Fayetteville on Friday, June 19th. The celebration will be held from 10:00 AM to 4:00 PM, with vendors arriving earlier. Volunteers are needed for this event.

Portia reminded members to share myeloma information with their churches, whether through the bulletin or on an information table. She noted that people are being diagnosed all the time, but many others, like her uncle, may live with pain and discomfort without receiving a diagnosis. Members were reminded that materials can be ordered from the IMF website, including tip cards on MM signs, symptoms, questions to ask.

Gail shared that a webinar sponsored by Morehouse School of Medicine on AI risks and benefits for community health was held on April 30. Members were encouraged to look for flyers in their email. She also announced that the Southside meeting in June will be held at the Sebia offices in Norcross, where members will be able to observe the organization's SPEP lab operations. Details will be emailed in advance.

Anderson and Ted reported that the Men's Only Group had a productive, informative, and supportive meeting in April. Each participant shared as much or as little about his myeloma journey or any other topic. All men with myeloma are encouraged to join the group, which meets on the fourth Tuesday of each month at 6:00 PM.

Beatrice reminded the group about her fundraising effort for myeloma research through a long-distance trek across Spain with the HealthTree Foundation. Her letter requesting support has been shared by email. Dr. Hofmeister of Emory is also raising funds with the IMF for myeloma research through the Iceland Cycling Expedition in August. Members were encouraged to contribute if able and to share these efforts with their networks. All funds raised support the search for a myeloma cure.

Yvonne, a new patient, shared concerns about not being able to see a physician when she wanted. Carolyn H. and others expressed similar concerns. Gail agreed that patients should be able to see the physician. She also noted that meeting with a nurse practitioner or physician assistant can sometimes allow for more time and discussion. Gail will follow up with the Emory team regarding concerns about access to support staff and physicians.

Flora asked about financial assistance for dental care, noting that this question arises frequently. Katie said this is an important question for social workers and encouraged members to ask them for available

resources. Alma is celebrating her 20th year as a myeloma survivor in conjunction with her May birthday.

Respectively submitted, Gail