

Atlanta Area Multiple Myeloma Support Group Newsletter

June 2025 Edition

Northside Meeting – June 7, 2025

The Northside group gathered both in person at St. Joe Hospital and online, with heartfelt thanks to Nancy B. for hosting. Twelve attended on site and eighteen joined virtually. The open discussion gave space for new and long-time members to share their myeloma journeys, questions, and hard-earned wisdom.

Patient Journeys & Insights

- **Nancy Z.** – Diagnosed in early 2025 with t(11;14) high-risk myeloma, Nancy shared how Venetoclax has started working after a rocky start. She was encouraged to hear from **Jeff W.**, who's own Venetoclax treatment kept his M-spike low for over five years.
- **Kim S.**, caregiver for her husband John (diagnosed April 8), recounted their determination to keep a long-planned France trip. John's myeloma was found after recurrent sinus infections and a PET scan revealed spinal lesions. Both Kim and Nancy Z. discussed the challenges of sorting fact from misinformation online.
- **MaryAnn H.**, diagnosed at 31 in March 2024, detailed her treatment path—DRVd induction, ASCT, and now KRd with a strong M-spike reduction. Side effects have been rough, and she looks forward to connecting with younger patients like Jameca from the Southside group.
- **Sandy W.** reminded the newly diagnosed not to panic: “You’re only two steps behind the doctors who are learning every day.”
- **Nancy B.** reflected on her husband's diagnosis in 1998, when treatment options were scarce. Today, with 17 new drugs in the past 20 years and 4 just in the last year, life expectancy for newly diagnosed patients can be 10–15 years—with a cure on the horizon. She encouraged members to grow their knowledge and use trusted resources like **myeloma.org**, **themmrf.org**, and **healthtree.org**.
- **Jim M.** described his latest “roller coaster” of pain management, radiation, kyphoplasty, and a new clinical trial showing early promise.
- **Scott M.** prepares for CAR-T with Carvykti and welcomed advice from Jim and Jeff.

- **Lori M.** celebrated 16 months of remission after Carvykti but cautioned that kidney health can suffer silently during treatment. She now has Stage 3 chronic kidney disease and urged regular nephrologist visits.
 - **David H.** offered perspective on balancing gratitude for extended survival with the emotional weight of a shortened life expectancy.
 - **Sandy B.**, living with myeloma for 35 years, closed with wisdom: focus on the positive and on living well—no one knows your timeline but God.
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Southside Virtual Meeting

June 28, 2025

Twenty-five attendees joined the Southside meeting, opened by Gail with a moment of silence and guided breathing. The group honored **Selina B.**, a devoted member of 17 years, who passed away June 17. Selina's contributions included identifying little-known side effects of Revlimid.

Resource Update:

The **Emory Immediate Care Center (ICC)** now offers urgent appointments for Winship patients—available at both Emory University Hospital and Emory Midtown. These are not walk-in facilities; call **404-778-0519** to schedule.

New Members:

- **Steve** (diagnosed 2021) is on Revlimid maintenance after 4-drug induction.
 - **Donna G.** (diagnosed Dec 2024) has high-risk myeloma, on DVRd, and scheduled for SCT Aug 4.
 - **Donna MS** (diagnosed 2021) is in remission after SCT and a long recovery.
 - **Jala W.** (diagnosed 2023) is regaining mobility after severe back pain and is eager to connect with others.
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Guest Speaker: Brian McMahon, Founder of SparkCures

Brian, a four-time cancer caregiver, explained how SparkCures helps patients match with myeloma clinical trials nationwide. Key points:

- **Awareness & Participation:** 90% of attendees knew about CTs; 60% had participated—well above average.
- **History & Progress:** In 1844, average survival after myeloma diagnosis was six months; today, transplant-eligible patients are often alive at 4+ years.
- **Trial Types:** Treatment trials (testing new approaches) and observational studies (collecting data on existing treatments).
- **Patient Rights:** You can withdraw anytime; protections include IRBs and Data Safety Boards.
- **Cost:** The study drug is usually free, but SOC-related procedures may be billed to insurance—ask in advance.
- **Study Phases:**
 - Phase 1: Safety & dosage (12–60 patients)
 - Phase 2: Effectiveness
 - Phase 3: Comparison to standard of care

Brian stressed that CTs should be considered at any stage of the myeloma journey, and finding the right one is a personal decision.

Helpful links:

- [Myeloma.org SparkCures](https://myeloma.org/sparkcures)
- [Promise Study](#)
- SparkCures: (888) 828-2206, support@sparkcures.com

Next Meetings:

- **Saturday, July 26, 2025 – 10:30 AM** (All Virtual, Patient/Caregiver Voices)
 - **Tuesday, July 22, 2025 – 6:00–7:00 PM** (Men Only, Virtual)
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