

# **ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.**

## **Meeting Minutes**

### **Northside Hybrid MM Support Group**

**November 2, 2024**

#### Next Meeting

The Northside group will meet on Saturday, December 7, at 11:00 AM. as a hybrid format at St. Joseph's Hospital and virtual via Zoom session. The meeting will start with open discussion followed by small group breakout rooms for our virtual attendees via Zoom and a pizza holiday celebration at St. Joes for in-person participants. Details and the zoom link will be sent separately.

#### Group Discussion

Thank you, Nancy, for facilitating the patient/ caregiver meetings. The Northside meeting on November 5 had separate patient and caregiver sessions with the patient group in the first hour and the second hour was for caregivers only. Due to the privacy of these discussions, there are only limited notes, but the discussion helped both groups.

The patient discussion was a beneficial meeting with almost 30 attendees that lasted just past the one-hour

time slot. Here are a few of the highlights. One member discussed having [Elranatamab](#) and said it was more challenging than expected. Another person recently completed CAR-T and was doing well, but did have CRS while in the hospital. There was an enlightening, but cautionary, story from someone who “swallowed a spore” some time ago but had an extremely rough time and had to be on oxygen. Someone else, early in the MM treatment cycle was conflicted about whether or not to go to CAR-T next. The group were very concerned about reactions to the treatment and received helpful input from each other. Guidance included to be sure to have a list of questions to review with the doctor. Another patient has been in complete remission for many years and for the past few years completely off Revlimid maintenance – a relief, but always that worry hanging over that myeloma could resurface. Others discussed the dilemma of choosing the next treatment from so many possible options.

One patient has tiny nodules that were discovered in one of the lungs. It is suspected to be [MAC infection](#) – a potentially life-threatening disease. It is an opportunistic pathogen, meaning it is harmless to most people who breathe it in or swallow it. However, it can settle into the lungs and cause disease in people with weak immune systems. MAC organisms are common in soil and water and are easily inhaled during daily activities. Fortunately, there are no symptoms right now, so it is watch and wait because the treatment is aggressive with 3 strong

antibiotics for at least 12 months. This is an important warning/reminder to those of you who have gone through treatments that compromise your immune system - you cannot be too careful - do not garden and be sure to wear a mask when appropriate!

In the caregiver session, participants talked about how unique multiple myeloma is at length. Each patient had a different story about diagnosis, treatment options, treatment response, and side effects. There was a conversation with one caregiver whose spouse's peripheral neuropathy (likely caused by Velcade) was being treated by their longtime/favorite chiropractor. It turns out, the myeloma team at Emory was unaware of this treatment and it emphasized how critical it is for the myeloma team to be the lead on all treatment decisions. The caregiver's session focused mainly on their partners since that is their primary concern and source of stress.

Submitted by Nancy B

Meeting Minutes

## Southside Virtual MM Support Group

November 23, 2024

### Next Meeting:

The Southside group will meet on Saturday, December 28 at 10 AM. This will be a hybrid meeting with both in-person and virtual attendance. We will be celebrating Doris's retirement at this meeting. She is stepping down as the Southside leader since 2006. Her leadership and passion to inform and educate others on the myeloma journey inspires all of us. Let us share our thoughts about her contributions and favorite "Doris" stories.

The in-person meeting and lunch will be at *Evelyn Lowery Library at 3665 Cascade Rd, Atlanta*. Lunch will be provided for in-person participants. Look for the Southside meeting email for RSVP and additional details. The link for the virtual participants will be provided in a separate email.

### News and Business

Nancy B. hosted the virtual meeting with about thirty-seven members attending. Gail continues her recovery from recent myeloma treatment. Thank you, Nancy, for leading the group this month.

The American Society of Hematology (ASH) conference was held December 7-10 in San Diego. Over 30,000 hematologists

and investigators from around the world attended, both in-person and virtually. There were over one thousand abstracts just in myeloma. These abstracts presented information from research, clinical trials, and data studies about myeloma. The information reported at this conference can change the course of treatment plans for myeloma. Key summaries will be available on webinars hosted by myeloma organizations.

The IMF held a webinar on December 18 with three doctors and a nurse. Speakers each discussed what they think will have the most impact on myeloma treatment. The replay can be found here - [IMWG Conference Series: Making Sense of Treatment ASH 2024](#) Each year, the IMF invite patients to ASH to review and report on the abstract posters and oral presentations. These patients will be presenting on a webinar on January 8. Register here - [ASH 2024 Myeloma Updates for Patients & Care Partners | Int'l Myeloma](#). Listen as these ASH attendees talk about what they learned, in plain English! Here is the MMRF webinar on ASH - [Summarizing Key Multiple Myeloma Clinical Advancements from the 2024 American Society of Hematology Annual Meeting - 1689819](#) . You can also watch the replay of Dr. Joe with ASH patients answering questions - [Replay: Latest Myeloma Research at ASH for Patients | Int'l Myeloma Fn](#)

Doris Morgan founded the *Southside Atlanta Multiple Myeloma Support Group* in 2006. She has announced her retirement recently from the management of the group. The Southside

group is so valuable to our patients and caregivers thanks to the care and compassion from Doris. Southside is looking for members to help with the ongoing tasks to continue this group's great work.

If you want to make a difference, here is where assistance would be appreciated:

- Planning committee
- Outreach to members
- Writing notes from meetings
- Coordinate on-site meetings at the library
- Help with food and refreshments
- Promoting the group at clinics and health fairs

Your help and support with small tasks will help keep the group running smoothly.

### Patient Updates

Geraldine had CAR-T two years ago and is now on SOC treatment Talvey with Dex since February 2024. She has experienced side effects with her nails, but her myeloma is gone! Alf has been on a clinical trial being treated with Talvey since February and is now receiving it monthly at a reduced dose. He will be getting a bone biopsy to test for MRD (minimal residual disease). He is holding off on a CAR-T as a back-up for

now. Alf was diagnosed with smoldering MM in 2020 and has been active MM since 2023. Jeff has changed treatment to Kyprolis with Cytosan. On his second cycle, the M-spike went way down. He was originally diagnosed eight years ago and was on Dara + Pom (pomalidomide) for five years. Sandy W. is currently on Kyprolis with Pom and Dex (KPd) and her M-spike is down to zero. Cynthia changed treatment plans from Cytosan + Pom to just Pom.

Gail was able to join the meeting. Gail has started a new regimen following her second relapse. She was initially diagnosed in 2008, 16 years ago. She started induction treatment with traditional standard Velcade-Revlimid-Dex (VRd) and was in remission after a SCT transplant for 7 years. After first relapsing, she was treated on an all-oral regimen; Ninlaro [ixasomib] -Pomalidomide- Dex. Gail relapsed a second time after 5 years. After intense research and consulting with her team, she has decided on her next regimen to be Selinexor-Dara-Dex (SDd). This can only be used when myeloma cells are knocked way down with intense chemotherapy- DCEP minus Velcade since Gail has neuropathy. Her platelets dropped dangerously low 2.2k (REF: 150-400k). She is climbing back...platelets are currently at 30. Before starting the new treatment, her platelets must reach more than the 150 REFerence level.

Submitted by Nancy B.

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## Educational Information/Opportunities

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### Healthtree Foundation

All oral triplet drugs for older patients are on the horizon.

New all-oral treatment combinations like Iberdomide, Ixazomib, and dexamethasone offer a promising option to improve quality of life with fewer hospital visits.

### What Are the Benefits of All-Oral Treatments?

1. Convenience and quality of life: Oral treatments allow patients to manage their therapy from the comfort of their homes, reducing the need for hospital visits. This is an advantage for elderly patients who may face mobility issues or live far from treatment centers.
2. Fewer hospital-based infections: By reducing the intravenous or subcutaneous therapies, patients are less exposed to potential infections, which can be a serious concern for patients with a weakened immune system.
3. Consistency in dosing: Oral therapies help maintain consistent drug levels in the body, which may improve treatment outcomes in myeloma cases. This also empowers patients to adhere to their treatment plans more effectively.



- Kappa/Lambda Myeloma – 3:20 – [What kind of myeloma do I have?](#)
- [Motivation/Inspiration – Rich Armstrong](#) – 4:20
- [Managing the Unique side effects of Talquetamab](#) - ~ 7 min.
- Nutrition and Myeloma. Urvi Shah. 65.40 [Dietary Research in Blood Cancer](#)

Meditation and myeloma, mindfulness, mental Health.

56.11 [Benefits to Meditation](#)

International Myeloma Foundation - IMF

- Meet Myelo at [myeloma.org](https://myeloma.org): The First AI-Powered Responsive Chatbot to Provide Compassionate Myeloma Support for Patients, Care Partners, and Healthcare Professionals. IMF Partners with ZS Associates, AWS, and SparkCures to Develop Groundbreaking First-of-its-kind Gen AI Companion
- IMF welcomes Dr. Sagar Lonial, Multiple Myeloma Program at Winship Cancer Institute of Emory University, on [IMF Board of Directors](#) and Scientific Advisory Board member
- Myeloma Minute: [What is Immunotherapy in myeloma treatment? What is its role?](#) Dr. Joe Mikhael. ~ 7 min.

- SMART

Patients: <https://www.smartpatients.com/partners/imf>

LLS – [lls.org](https://lls.org)

- Empowering Myeloma Patients: [Managing Side Effects](#).
- MEDLIVE/BD.org/LLS Educational Series
- Nutrition Consultations – FREE – LLS. Schedule appointment. Call: (800) 955-4572. Monday to Friday, 9 a.m. to 9 p.m. ET

#### Patient Empowerment Network

- Bispecific Antibodies – [How long will therapy last?](#) Video ~1:49.

[How do Race and Ethnicity Impact Side Effects of Car-T Therapy?](#) Video ~ 4:00.

#### Patient Power

- [Myeloma Patient Advocate Shares Her Tips for Success](#). Valerie Traynham. Founder of Blacks and Myeloma on Healthtree. Video - ~5:20. Lessons Learned.
- [Answers Now: Improving Communication with your Multiple Myeloma Team](#). ~ 40 min video. Dr. Andrew Schorr.