ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

February 1, 2025

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News & Business

Thank you to **Nancy B.** who hosted the hybrid (virtual and in-person) meeting with about forty members present. Welcome Johnson City, TN support group who joined us along with new members for the February meeting. Congratulations to **Nancy**, who announced that she is retiring after 12 years as Director of Support Groups from the International Myeloma Foundation (IMF) at the end of March. She will continue to lead the AAMMSG support group, as she has since 2006. Nancy joined the group in 1998.

Mark your calendars for the IMF-sponsored Regional Community workshop (RCW) in Atlanta April 5. This will replace the Northside April meeting and will provide a larger discussion with doctors, nurses, and other patients. Additional details will be provided.

Updates & Discussion

There is a new MM chatbot on the IMF home page of https://www.myeloma.org called ***"Myelo"***, which provides reliable information from trusted sources on multiple myeloma (MM). **Sandy W.** has copy/paste her lab tests into the chatbot for further explanation of the results. Sandy also gets bloodwork done a couple of days before the appointment so that she can discuss the lab results in real time with her doctor.

Keisha was diagnosed in 2019 and had a stem cell transplant (SCT). She takes maintenance Revlimid, Dex, and Velcade and is still in remission and doing well. **Chinwe** and her niece also joined the meeting for the first time. Chinwe was diagnosed in September. She is planning for a SCT in March. She wanted to hear more about what to expect during the SCT. Many members in the group have had SCTs (some more than one).This led to further discussion on what to expect and helpful tips such as chewing on ice chips while Melphalan is administered and using mouth rinse to prevent mouth sores, taking anti-nausea medication, and avoid letting the medical disclaimers scare you.

Joseph S. reported that he was taken off the Fentanyl patch and another medication that worked to control neuropathy and pain management. Current medication is not controlling his pain. It was suggested that he escalate the issue by contacting a patient advocate to be able to get the prescription renewed.

Jeff W. had CAR T-cell therapy in January and is recovering well. On January 9, he developed Grade 1 Cytokine Release Syndrome (CRS) response with a high fever, which was controlled within two hours. Other side effects were a sore arm from the PICC line and loss of appetite, but the side effects are being controlled, and he is feeling good. He has stayed active by walking. He spent 11 days in the hospital and then moved to a hotel with plans to return home soon. **Jim M.** has been fighting shingles since October 2024, with itchiness that feels like neuropathy. He is using a slow-release version of Gabapentin that causes less drowsiness to help control symptoms. Sandy recommended acupuncture treatments for neuropathy at Emory Oncology – Acutherapy Center . **Jim C.** had a SCT at Emory in September 2024. He has some neuropathy but otherwise is doing well with no other side effects. Questions on preventative IVIG treatment to boost the immune system was addresed. **Jeff W.** and **Marilyn M.** get regular IVIG infusions (monthly/2.5 hours) which have helped prevent ongoing respiratory illnesses.

There was discussion concerning patients who cannot drive and do not have a dedicated caregiver. There are some charities that can help with rides such as the American Cancer Society, although they may require a caregiver to accompany the patient. Also suggested was Uber, and shuttle services. Ask your medical team if you need help with rides to/from medical appointments.

Are there natural remedies for maintaining good health? Maintaining a good diet and regular exercise was discussed. **Nancy B.** commented that a plant-forward diet is recommended and noted researching the work of Dr. Urvi Shah, with articles available on the IMF website. Also, a reminder to stay informed of anything that should not be consumed while on treatment such as green tree while taking Velcade.

Nancy B. recapped the Top 5 items of interest related to MM from the December **American Society of Hematology (ASH)** conference:

1. High risk smoldering MM (SMM) and important measurements used for controlling it.
2. Frontline treatment using four drugs vs. three drugs, which can produce deeper and longer responses, even for those who are not eligible for SCT. Also using CAR T-cell therapy and bispecific drugs earlier.
3. Using Minimal Residual Disease (MRD) in treatment decisions and trying to get away from treatment for life.

4. New CAR T-cell therapies and bispecific drugs are showing great results, especially in patients who have had many lines of therapy. Newer versions may get approved later this year that have less side effects and great results.
5. Less is more when it comes to Dex. Studies are showing that Dex may only be effective during the first few months of new treatment, and the plan is to get away from long-term Dex.

Submitted by Wendy R.

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Meeting Minutes

Southside Virtual MM Support Group

February 22, 2025

March is Myeloma Action Month. Tell at least one person about Myeloma!

News & Business

March Meetings: Southside - Saturday, March 22, 2025, (VIRTUAL), 10:30 – 12:30 PM. Dr. Craig Hofmeister of Emory Winship will discuss *Interpreting Lab Results and Self-Advocacy in Navigating the Myeloma Maze.*

"For Men (with Myeloma) Only" – Tuesday, March 25, 2025 (Virtual), 6:00 – 7:00 PM

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Group Discussion

Gail opened the meeting with a deep breathing and centering exercise and a moment of silence.

There was discussion on what we as a group or as individuals could take as action steps during Myeloma Action/Awareness Month in March. Some suggestions from the group included:

- **Tell just one person about multiple myeloma.**
- **Share the information with church groups, organizations, health ministry, or chaplain.**
- **Advocate for medical research dollars through IMF, LLS, or American Cancer Society.**
- **Send letters to elected officials at federal and state levels.**

February was *Black History Month* and *Heart Healthy Month.* We discussed the disproportionate number of myeloma cases in black versus white patients and the need to give special attention to co-morbidities like heart disease or diabetes, as we focus on myeloma.

M-Power is an IMF initiative designed to increase the awareness of myeloma in communities of color and providers treating MM in the community. IMF's M-Power Initiative aims to achieve its vision by creating awareness about myeloma and by empowering healthcare professionals, community leaders, neighbors, and families to break down cultural and diversity barriers in healthcare.
"For Men (with Myeloma) Only": Anderson updated that the men had a great gathering in January. They have learned that many of the attendees are former athletes, which is a common thread for bonding with each other. It is often hard for men to talk about personal matters, so this time together provides an opportunity for each to share, if they choose to. The group provides great feedback to each other, and it makes a difference. Ted says they will continue to gel as a group. Dirk expressed that the men are accepting of each other's status and are kind to each other. David and Jeff concurred.

<u>Patient/Care Partner Updates</u>
Jeff had CAR-T on January 8. His Mom is his care partner. Chinwe was diagnosed in September 2024, being treated at Emory Winship and is preparing for a SCT (Stem cell transplant). She has compressed discs in her spine and damage to her ribs. She is very independent but has many side effects. She is working with Dr. Parikh (*new hematologist*) and *Social Worker*, *Rebecca Connel* at Emory. Dirk also had collapsed vertebrae during his journey since 2016. He lost about six inches of height, had spinal stenosis, and lesions in 15 (of 33) vertebrae and 13 kyphoplasty procedures. Henry lives in Macon and was diagnosed in 2020. He had a SCT and relapsed in 2022. He is on Darzalex, Kyprolis, and dex (dexamethasone) and is in remission. *Dr. Kaufman* is his hematologist. Sarah R. developed symptoms of swollen gums following 4 days of chemo. *Dr. Nooka* said myeloma cells had moved into her gums causing swelling. She will get IVIG to boost her immune system. Other myeloma numbers were good. Sarah is moving better and using a cane. Pat M. now lives in two cities – diagnosed in 2014 and is enduring excruciating back pain. Karen had kyphoplasty. She is undergoing PT at Emory Winship and plans to get injections and acupuncture that is offered there. There is physician-led PT for myeloma patients at Midtown and on Emory Winship campus. Carolyn H. now lives in Houston, but joins us, when possible, because of the information we continue to offer. Thanks, Carolyn!

For Myeloma Action Month, IMF encourages patients/care partners to talk with or send a letter to their primary care doctors (PCP), reminding them to watch for myeloma symptoms and lab results with their patients. Here is the link to the letter -- <u>Share the Patient Action Letter | Myeloma Action Month</u>

The IMF Regional Community Workshop (RCW) in Atlanta is Saturday, April 5, at the Sheraton – Cobb Galleria near Cumberland Mall. More details on registration and parking here -- IMF In-Person Regional Community Workshop (RCW) 2025 - Atlanta | International Myeloma Foundation

Featured Videos for February meeting.
What is prognosis for Multiple Myeloma? with Dr. Joe: Myeloma Minute or less J
Frontline therapy Advances in MM: Using less Dexamethasone. Dr. Joe - ~3 min.
Essential Monitoring Following Bispecific Antibody Therapy for Myeloma.
***What should care partners know*? PET: Dr. Craig Cole -- ~4 min.**
What are the Pros and Cons of CAR-T therapy? ~ Patient Power: Dr. Joshua Ritcher ~ 9 min

Respectfully submitted, Gail.