ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

November 1, 2025

Open Discussion and Updates

Thank you to Dirk B. for hosting the virtual meeting with approximately twenty-five attendees. This meeting was an open “sharing and caring” session. There was discussion relating to members attending both Northside and Southside Atlanta Area Multiple Myeloma Support Group (AAMMSG) meetings and enjoying the flexibility and convenience that hybrid meetings provide. It offers a virtual option for many with long drives and for those who cannot drive. David H. is from Savannah and is new to the group. He has been treated at Emory and attends both Northside and Southside AAMMSG meetings virtually and finds them invaluable. Ken O. began joining both group meetings both in person and virtually approximately six months ago. They are both the same distance for him. He appreciates having both groups available to him with multiple sources of information and two different groups of people to hear what people are experiencing, and being able to ask questions is incredibly helpful. Marilyn M. mentioned that she began attending AAMMSG meetings in 2008 when she read that people with cancer that attend support group meetings live five to 10 years longer than those that do not. She said that this support group reminds and encourages her to take the best care of herself. Dirk B. commented that he has been surprised at the number of MM patients who are not aware of the two AAMMSGs in Georgia and has concerns about the information those patients are missing. He noted that in general, not everyone is interested in, or recognizes the value of support groups. Jim M. commented that the people in our meetings are not average patients, in that we are very educated and want to learn as much as we can about multiple myeloma.

This led to a discussion about the importance for MM patients to have access to healthcare professionals that specialize in myeloma disease. It is highly recommended to have an MM doctor as part of your care team. Gail

M. commented that this is important for all MM patients; especially for newly diagnosed multiple myeloma (RDMM) patients to establish a relationship with an MM specialist early. The only physicians that specialize solely on multiple myeloma in the state of GA are at Emory Winship Cancer Institute. Emory MM doctors are available to collaborate with other oncologists to help myeloma patients get the best care that is available to them. So, for patients who see an oncologist or hematologist who is not an MM specialist, it is advised that they find an MM specialist to be a part of their care team that will collaborate with their healthcare team. This is extremely important because MM specialists understand myeloma better than other doctors. There are so many ongoing discoveries and changes happening with myeloma research that only doctors specializing in MM can realistically keep up and stay informed with current information. Several people commented that their doctors will naturally partner with MM specialists if the need arises. Dirk's doctor is an oncologist/hematologist and will defer to an MM specialist whenever necessary. Scott M. also expressed that his oncologist works closely with Emory MM physicians and does not make decisions without guidance from them.

Gail and Jim M. commented that they have met new MM patients recently who felt they were not getting the best, most updated treatment advice for myeloma. Both noted a variety of reasons such as not consulting with myeloma specialists, or not knowing how to do so, and not having good MM-specific education and support. They have tried to steer those patients in better directions, but it has been disheartening for them to experience this. Gail commented that when you work with an MM specialist you are far more likely to get the right treatments with the best outcomes and not having to wait for appointments. Sandy B. was diagnosed 36 years ago and joined the support group in 1998. She is grateful and humbled to be able to share her story to help others. She hopes her journey helps provide joy and contentment on their own journey and find reasons to support other patients. Sandy has been on Revlimid since 2016 after a relapse and is not in remission but is remarkably close and in a good M spike range. She accepts each day as it comes, both good and bad, and says that the longer you are here, the more likely you are to encounter unexpected things.

Barbara W. was diagnosed in 2020 when her sports medicine doctor saw lesions and sent her to an oncologist who performed a bone marrow biopsy and CT scan. It was determined that she had blood cancer and she was referred to Emory Winship. Emory performed the same tests a second time along with a PET scan to determine that she had MM. She was in pain and frustrated to have the same tests run again, but now she is glad that she went to Emory. She has been in remission for three years and feels good and stays active physically and socially. She currently takes Pomalyst and may be able to get off it soon. She is currently trying to reduce stress and mentioned that this group really lifts her up. Barbara really appreciates the stories and knowledge shared. She recommends this group to others and shares information from the group with others frequently. Jeff W. asked if anyone that has taken Zometa had a successful dental implant. He has been off of Zometa for a year. Dirk B. said that his doctor would not make an implant for him. He had to have a molar pulled with no implant. Jim M. was off Zometa for almost six months before having a tooth pulled. He commented that root canals and bridges can also be troublesome for patients who have been on Zometa. Jim M. commented that he visits his dentist three times a year for cleaning and exams. Gail M. reminded everyone to keep all preventative dental maintenance appointments.

There were comments about MM patients having immune system deficiencies. Marilyn M. was diagnosed in 2008 with smoldering MM (SMM). Her numbers are increasing and over time she began getting more frequent infections and serious illnesses such as West Nile virus in 2021, pneumonia, blood poisoning, spinal meningitis, encephalitis, epilepsy seizure, and sepsis in 2024. She was frequently sick, on antibiotics, and sometimes hospitalized. About a year ago she began getting regular IVIG infusions every 28 days, which has not entirely prevented her from getting sick, but has kept her out of the hospital. Instead of being on antibiotics every six to eight weeks, she has only been on antibiotics twice in the last year and has not been hospitalized since beginning IVIG treatments. She also mentioned having some issues with her eyes related to glaucoma and pressure that results in it taking a long time to adjust to light and dark conditions with her eyes not working together. Cynthia B. has had vision therapy and recommended Dr. Janna Iyer OD FCOVD, 678.256.3990 at the Vision Care & Therapy Center. Rhea P. shared that she was experiencing falls and having lots of physical therapy. Her two neurologists said that there was not anything more they could do to help her, so her MM doctor got her an appointment at the Emory disabilities clinic, where she was diagnosed with Parkinson's. She has moved to an assisted living facility that offers weekly Parkinson's exercise classes, including boxing. Although she is living with two serious diagnoses, Rhea said that she is happy to report that she is doing fine.

The importance of staying active and maintaining balance was discussed. Maintaining balance and balance exercises can help prevent falls. Stay alert and aware of your environment and slowing down the pace of movement can help to prevent falls. David H. recommended strength training for legs so that if you stumble, you will be more able to catch yourself, rather than falling. Molly L. recommended Nordic walking, which she also teaches, as a great overall exercise which is also great for balance. For Nordic walking instructions, email Molly at nordicwalkingatlanta@gmail.com. Dirk B. suggested core training and lunges using dumbbells. Rhea P. recommended physical therapy to help with balance issues. Cynthia B. recommended FYZICAL Therapy & Balance Centers. Gail M. suggested that for anyone experiencing falls, make sure you collaborate with your providers to identify the root cause and then work on prevention from there. Providers can determine the root cause of balance issues and provide physical therapy if needed.

There was some discussion and concern about the cost of healthcare insurance. Cynthia B. posted information related to the Patient Advocate Foundation (PAF). Funds are open to MM patients, and PAF will make payments monthly for insurance premiums and drug premiums.

Submitted by Wendy R.

Meeting Minutes

Southside MM Support Group

November 22, 2025

Next General Meeting: Saturday, December 27, 2025. Virtual Only. Voices of Patients and Care Partners.

"For Men Only" Meeting: Men's group is not meeting in December.

We had two new patients/four total new members join us – Thomas (wife Natasha) and Jenai (daughter Jayni). Thomas is a veteran and was diagnosed in February 2024 and had an ASCT in the summer of 2024. He has pain in his hips and has had to learn to sleep on his back. He sees Dr. Hofmeister at Emory Winship. He works in healthcare and has a very supportive care partner. Jenai goes to Kaiser (Dr. Kumblah?) and was told in past six weeks there was no more treatment for her. She is currently looking for a vehicle that will accommodate a wheelchair. Several Group members thought that "…no more treatment" advice was unusual, at best, even those with 15-20 years as patients. Carole O. who also goes to Kaiser agreed to connect with Jenai and her daughter to recommend a different myeloma physician. Wanda P., who sees Dr. Kimbrough at Kaiser, was supportive of this strategy.

For Men (with Myeloma) Only

Ted and Anderson reported a lively meeting with about a 50% increase in the number of men who attended. There were a couple of men (veteran) who joined from the Savannah area, and they were looking to start a support group there. When we get the contact information, we will be sure to support their efforts in whatever ways we can. David (Savannah) was not familiar with the new members. The meeting was energetic and informative with lots of sharing and fellowship as usual. There is an online Veteran's Support Group through the IMF. IMF Veterans

Special Interest Group - https://www.myeloma.org/support-group/veterans-myeloma-special-interest-group.

Our general meeting was held during the Thanksgiving Day weekend, which was all about reducing holiday season stress and expressing gratitude for all the blessings we enjoy. We shared a few select videos on proper breathing techniques and shared some of the benefits of being able to practice those techniques, whether in a high stress situation or just a daily health practice.

About the IMF

We did a review of who the IMF is and what resources are available through IMF. The International Myeloma Foundation supports over 150 Support Groups around the country, including ours. We shared a two-minute video on the organization.

Stress, Distress, and Your Health -- Breathe

The three YouTube videos were entitled: 1- How can I manage my stress and fatigue over the holidays?, 2- The Biology of Stress, and 3 – Proper Breathing. The links can be found in your November Meeting Agenda. We sent a fourth link for practicing your breathing to the ocean and wind chimes in a follow-up email -- https://www.facebook.com/reel/1091790259817119.

Stress hormones can protect the body by releasing hormones like adrenaline and cortisol to boost heart rate, blood flow, and alertness for "fight or flight," but chronic stress activation damages systems, leading to issues like high blood pressure, weakened immunity, and anxiety by disrupting the brain, heart, and metabolism. See the graphic below for all the body's systems impacted by stress—whether it's good or bad stress. (Not available).

To the question of "What works for you to reduce your stress?", There were many and varied responses, like go to services and fellowship (Doris), exercise (Several), spending time and drawing energy from others, cooking favorite dishes (Joyce), coloring (Jala), "I live for stress" says my husband (Sandy W.) so I have to remove myself from the situation, and Dirk's perverted sense of relieving his stress by annoying others about their politics, watching holiday movies (Karen), like Hallmark, cleaning (Lori), music (listening to (Gail) or playing (Dirk).

The practice of deep breathing techniques can support you throughout your life in general, and in your myeloma journey whether overthinking the disease itself, the treatment, or related financials.

Highlights of Myeloma Progress – -

Nancy B. shared that over 25,000 hematologists are meeting in December at the annual ASH (American Society for Hematologists) Conference in Florida. Over 2,000 of the 8,200 research projects to be presented are about myeloma. Some of the discussions will include the progress of CAR-T cell therapy and CAR-T vs SCT.

…from the International Myeloma Society in September 2025

- **Smoldering MM** – Hot topic. Small study with new bispecific antibody linvolseltamab (Lynozyfic) as monotherapy for High Risk SMM
- **Frontline therapy** – Quadruple therapy for most patients is the way to go. Can it be improved upon? Clinical Trial MajesTIC using bispecific Tecvayli in frontline therapy before ASCT…in several combinations including Darzalex, Velcade, Revlimid, and dexamethasone (DVRd).
- **HRMM** – ongoing research and new classification. So far, any remissions are short term, and cytogenetic abnormality deletion 17p is especially difficult.
- **Immunotherapies** – Focus on optimizing CAR-T and bispecific antibody therapies – assessing T-cell health through treatment and determining the sequence of treatment…how cells are impacted by disease and treatment.
- **To bridge or not to bridge?** If disease is well-controlled, patients less likely to experience side effects like CRS and neurotoxicity, like Parkinson’s.

Resources

The Patient Advocate Fund and ACS have a $200 grant available for nutritious foods and anyone who applies as long as funds are available (844) 216-7520). **Marcia** shared this resource with the group. LLS/Blood Cancer United has funding for specific CAR-T travel funds. There are also funds for co-pay assistance and insurance premiums. **Sandy B**. reminds us that funds do run out, and at times you have to keep calling, so have patience. **Doris** also reminded us that Healthwell has funds available for blood cancers. Insurance information and assistance can be found at Healthtree and at Triage Cancer. **Sandy W.** shared that funds might be available for CAR-T, but being successful means using the proper terminology. For example, with CAR-T, calling it a transplant versus immunotherapy. Check to see what your insurance company calls the procedure.

There are free nutrition consultations available for patients and care partners through Blood Cancer United/LLS. This resource is being underutilized.

Patient and Care Partner Updates

Diane reports she has been doing much better since our last meeting. She has had five treatments – pain has substantially improved. She will be connected with group members who have had kyphoplasty. This procedure may be in her future.

Karen shared she is having blurred vision/watery eyes. Could it be a side effect of Revlimid, myeloma, or something else? Her eye doctor did not know anything about an association. Gail shared that there are a number of medications with side effects that are related to eye health, including increased risk of cataracts. **Jayni** shared that her mother, Jenai, was having double vision and the suspicion is that it’s due to gabapentin and opioids. She has used Systane for dry eye which seems to help. **Carolyn H**. shared she also had watery eyes that were thought to be from her Velcade injections. Gail shared that the gabapentin/opioid connection also popped up in her news feed. Her P.A. shared that it may be a risk for dementia.

Please check your November agenda for more information and resources.

Respectfully submitted,

Gail