ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP INC.

Northside MM Group Meeting – The date is changed to Saturday, July 11, due to the July 4 holiday. We will meet hybrid (both in person and virtual) at 11:00. We will have a guest from Northside Hospital to talk about their programs.

Northside MM Support Group

June 6 Meeting Minutes

Introduction & Meeting Synopsis

Thank you to Nancy B. who hosted the virtual meeting with approximately 25 participants; and to Katie Atkins, MSW, LCSW, LCAS, CCS, OSW-C, Associate Director, Support Groups for the International Myeloma Foundation (IMF) who joined the meeting to present on the topic of 'The Unseen Impact of Myeloma: Taking Care of Your Emotional Health', an insightful topic for patients and caregivers traversing the many phases of the myeloma journey. After the presentation we shared updates from meeting participants.

Guest Speaker

Katie Atkins opened by commenting that she is aware of the strength of our support group and that it is well attended. She joined the International Myeloma Foundation (IMF) last year. She's been an oncology social worker for about eight years, working as a therapist in an oncology setting in Asheville, NC, helping patients and their family members deal with all types of cancer. Since she has joined the IMF, she has been specifically

focused with myeloma patients and caregivers. She has also been leading the Asheville Multiple Myeloma Support Group for about five years and created the presentation deck that she shared with us. Katie explained that some of the topics might feel uncomfortable and that her entire team is available for support, and to remember that you're not alone. It’s important to recognize that every patient and care partner's emotional response to living with myeloma is different, but her team’s goal is “to be steadfast in our support to this entire community, no matter where you are on the spectrum.”

The presentation provided emotional support strategies, common reactions, and resources for individuals diagnosed with myeloma and their caregivers. Topics presented and highlights:

- Common Emotional Responses & the Spectrum of Emotions
- Coping with Emotions
- Grounding Exercises
- When & Where to Seek Help
- Wellness Tips & Resources

Common Emotional Responses & the Spectrum of Emotions

Getting a cancer diagnosis can feel like getting the wind knocked out of you. Patients may experience a wide range of emotions, from grief and sadness to moments of gratitude and hope. It is important to understand that all feelings are normal and that recognizing emotional responses helps in managing mental health effectively.

- Patients often experience shock, disbelief, anger, fear, and worry after diagnosis.

    - Shock & Disbelief: Many patients feel numb, confused, or disconnected after diagnosis, sometimes experiencing denial.
    - Anger: It is common to feel anger towards doctors, oneself, or even a higher power.
    - Fear & Worry: Fears may include concerns about death, pain, treatment, loneliness, the future, and practical issues like finances or career.
- Feelings of grief, identity loss, and relationship challenges are common.
    - Patients may grieve the loss of their previous identity due to physical changes (fatigue, hair loss, cognitive changes) and withdrawal from social activities, work, or relationships.
    - Loss of independence and routine can be demoralizing.
    - Myeloma can strain relationships with partners, family, friends, and coworkers. Some people may not know how to offer support, leading to distance or discomfort.
- Caregivers may experience emotional exhaustion, guilt, and helplessness.
- Anxiety and depression frequently affect patients, requiring awareness and support.
- Anxiety: Symptoms include persistent worry, sleep disturbance, restlessness, irritability, fatigue, and difficulty concentrating.
- Depression: Symptoms include sleep issues, loss of interest in activities, guilt, fatigue, and appetite

changes. Over 56% of patients with blood cancers experience anxiety and depression, much higher than the general population's depressed mood, and sometimes suicidal thoughts.

Some individuals find meaning and strength through adversity.

- Post-traumatic growth includes increased appreciation, spiritual beliefs, and inner resilience.
- Emotional healing is possible even if the disease cannot be cured.
- Hope and empowerment are vital for coping and finding purpose.

Coping with Emotions

Emotional healing is possible even if a physical cure is not. Patients can find agency in how they spend their time, share their experiences, and support others. Helping others (advocacy, volunteering, and support groups) can provide a sense of purpose. Techniques such as grounding exercises, mindfulness, and creative outlets (journaling, music, art) are recommended. Support groups offer a sense of belonging, connection, and hope.

- Acknowledge and accept all feelings without judgement.
- Use grounding techniques like breathing exercises and mindfulness.
- Share feelings with trusted people and seek professional help when needed.
- Carry both grief and gratitude to foster compassion and resilience.

Emotional Awareness and Acceptance:

- Practice Mindfulness or Meditation.
- Spend time each day focusing on the present moment.
- Physical Activity: Move your body daily—walking, yoga, or gentle stretching can boost mood.
- Creative Outlets: Engage in journaling, music, art, or other hobbies to express yourself.
- Healthy Habits: Prioritize quality sleep, eat a balanced diet, and break big goals into smaller, manageable tasks.
- Celebrate Small Victories: Recognize and celebrate progress, no matter how small.

Grounding Exercises

- Practice exercises such as butterfly hugs, mindful walking, and aromatherapy.
- 5-4-3-2-1-Grounding Exercise: Identify 5 things you can see, 4 you can touch, 3 you can hear, 2 you can smell, and 1 you can taste to anchor yourself in the present moment.
- Butterfly Hug: Cross your arms over your chest and tap your shoulders alternately to self-soothe.
- Mindful Walking: Focus on the sensation of each step and your surroundings.
- Square Breathing: Inhale for 4 seconds, hold for 4, exhale for 4, hold for 4, and repeat.
- Other Techniques: Hold a piece of ice, use aromatherapy, or eat a small bite of food mindfully.
- Engage in activities like journaling, art, or spiritual practices.

- Seek practical help for daily needs and emotional support.
- Join support groups for connection and shared understanding.
- Join a Support Group: Connect with others who understand your experience.
- Support groups provide a sense of belonging, acceptance, and hope.
- Lean on Trusted People: Ask for help and be specific about your need.

When & Where to Seek Help

It's important to seek professional help if symptoms of anxiety or depression are preset. Therapy, counseling, and sometimes medication can be part of a treatment. Prioritize mental health as part of overall well-being.

- Communicate with healthcare providers about emotional struggles.
- Resources include clinical social workers, support groups, and mental health platforms.
- Seek Counseling: If you experience persistent anxiety or depression, ask your healthcare team for a referral to a counselor or social worker.
- Therapeutic Approaches: Consider therapies such as Cognitive Behavioral Therapy (CBT), Dialectical Behavioral Therapy (DBT), Acceptance and Commitment Therapy (ACT), or meaning-centered psychotherapy.

- Medication: Discuss with your doctor if medication might be appropriate as part of your treatment plan.

Know When to Seek Immediate Help

- Crisis Support: If you have thoughts of self-harm or suicide, call 988 or reach out to a crisis professional immediately.

Reliable Resources:

- Online Platforms: Headway, Better Help, Talkspace, CaringBridge, Psychology Today.
- Organizations: National Alliance on Mental Illness (NAMI), Association of Oncology Social Workers,

American Cancer Society, Cancer Support Groups, Counseling, Education & Financial Assistance, and 988 Lifeline.

<u>Wellness Tips & Resources</u>

- Maintain a balanced diet, regular activity, and good sleep.
- Practice mindfulness, connect with loved ones, and set small goals.
- Use reputable sources for information and support.
- Explore community and online resources for ongoing assistance.

Finding Meaning and Purpose

- Help Others: Volunteer, share your story, or support someone newly diagnosed. Turning your experience into advocacy can provide a sense of direction and fulfillment.
- Spiritual Practice: If meaningful to you, engage in prayer, meditation, or attend religious services.

Discussion & Updates

Some members commented that they will soon begin new treatments. Sheila is preparing for CAR-T and had some specific questions about it. Jeff W. is doing well after having CAR-T about a year ago and is currently not taking maintenance drugs. Jeff answered Sheila's questions and described his experience, which was relatively easy for him to tolerate and was much easier than having a stem cell transplant.

Thyra Z. is preparing for DTPACE, which is an aggressive treatment that can present some challenges. She will be hospitalized and receive four days of chemotherapy. After the initial DTPACE treatment she will be released from the hospital and then be on a tri-specific clinical trial (CT). She explained that although she feels that she has good doctors and family support she is scared about the initial DTPACE treatment especially after reading about side effects that will occur after she leaves the hospital. Nancy B. commented that DTPACE is a treatment that provides a very strong chemotherapy hit to bring the myeloma down so that the patient can move on to another treatment with the myeloma under control. Another group member also recently received the DTPACE treatment and they recovered quickly. Jeff W. commented that patients in CTs get very specific and focused care and it is very important to let the doctors know immediately if you are experiencing any type of discomfort. CT medical staff are known to be very responsive and that is one of the benefits to being on a clinical trial.

Laura R. has experienced problems with antidepressant medication. She is being treated for anxiety and depression, and the medication has made her very weak and fatigued. She has stopped other treatments temporarily and her bloodwork is good.

She is currently working with her doctors to get the medication dosage corrected.

Beatrice R. reported that she recently had metapneumovirus and warned the group to be aware and careful of this, as it can be very debilitating. She explained that it can give you pneumonia and she ended up in the ICC hospitalized overnight. She warned the group that it is common right now and there are a lot of cases at Emory currently. It is an upper respiratory infection, and she experienced coughing, headache, weakness, and a fever. For cancer patients who are immune compromised the ICC considers it to be an oncologic emergency that must be evaluated to ensure that it doesn't get worse. For people who are not immune compromised it feels like a cold and they can generally get over it on their own without treatment. For Beatrice it was serious and her monthly myeloma treatment has stopped as she recovers.

There was some discussion about hydration drinks and being aware that many of them contain large amounts of sugar. For anyone consuming a lot of these drinks, be aware and careful of the sugar content.

An AirTamer is a small personal wearable device that is worn around the neck and purifies the air around you.

It's like a very small air purifier. A lot of cancer patients use it, especially on airplanes or in very crowded public spaces. It is quiet, rechargeable, and is considered a good infection prevention device. Nancy B. commented that she knows a lot of patients and caregivers use it with good results, preventing them from getting sick when others around them are sick or become sick. Anyone interested in purchasing an AirTamer can find one at

https://airtamer.com and can receive a 35% discount using this code provided by Katie A. ‘myeairtamer’ (note: “mye” as in myeloma).

Submitted by Wendy R

Southside MM Support Group
Hybrid Meeting Minutes
June 27, 2026

Next Meetings

Southside Meeting: Saturday, July 25, 2026. Voices of Patients and Care Partners. HYBRID

For Men (with Myeloma) Only. Tuesday, July 21, 2026. VIRTUAL Only.

Guest Presentation and Sebia Tour

The June Southside meeting was a combined site visit to **Sebia** in Lawrenceville, GA, and followed by a hybrid session. **Sebia** is an international company based in France which manufactures SPEP testing equipment. Dr. Aigars Brants, Director of Scientific Affairs and a supporter of the IMF MPower Program, invited the group to tour the facilities. The staff were very welcoming and engaged with our group of about 20 members.

Dr. Brants led off with a presentation about SPEP basics. The **Serum Protein Electrophoresis** (SPEP) is a **vital diagnostic blood test** that separates and measures proteins in the blood based on their size, shape, and electrical charge. It is primarily

used to *detect monoclonal proteins (M-spikes)* linked to blood cancers like multiple myeloma. The SPEP test focuses on the two primary protein types in the blood: **Albumin** and **Globulin.** He shared slides to show monoclonal gammopathies (immunoglobulins -heavy and light chains, IgG, A, M, etc. and kappa/lambda) and described the advances in technology from gel electrophoresis to fully automated capillary electrophoresis. Dr. Brants also explained the significance of the test throughout the myeloma journey from increase/decrease in the M-spike peak to when there is no change. There was discussion about the role of SPEP testing detecting Minimal Residual Disease (MRD) and the future of a myeloma cure in research and treatment with staff members. Some group members toured the labs during lunch.

Group Discussion

Joyce reported on the Juneteenth Health Fair in Fayetteville. Alongside 50-75 other vendors, Southside members set up a table with information tip cards, brochure, flyers, and AAMMSG banner. There was a steady stream of people from 10 a.m. to 2 p.m. who listened to our information about myeloma, its possible signs, and symptoms, who is at risk, and the hope for a cure in the near future. It was a successful event.

Ted reported that the June “For Men Only” meeting went well with about 11 people present. It was an upbeat meeting with both good myeloma reports and some challenges, which is to be expected. Some reported on their Father’s Day celebrations, which were good to hear. As always, all men are encouraged to meet with them virtually for an hour every 4th Tuesday at 6:00 PM.

Care Partner and Patient Updates

David reported that he is back to normal following a ‘hemorrhagic shock’ experience. His labs have recovered well, hemoglobin and iron levels are normal, and he is back on Revlimid after being on

pause during his illness. In March, **Gloria** had a break in her right arm that was due to a lesion from her myeloma. Her doctor said even a sneeze could have caused a fracture or break in the bone. Gloria did not have radiation but needed surgery and now has a rod in her arm. She has just completed physical therapy and has begun to drive again. She also started a new treatment plan with Venetoclax and dex that is going very well. **Jala** has pain in her leg and groin area and is in a wheelchair. She is taking medication for pain, has completed therapy, and is now exercising with Silver Sneakers giving her some relief. Jala goes to UCBC in Athens. Her doctor stated, “when you have cancer, you have pain.” Several patients felt that the doctor’s response was woefully inadequate. Recommendations were given to seek other specialists, orthopedic oncologist, neurologist, or urologist, since there is so much bone involvement in myeloma. **Gloria** recommended the oncology orthopedist who performed her arm surgery from Emory Orthopedics and Spine Center. **Joyce** shared her experiences with having to probe further for answers to get relief. She was having breathing issues and was referred to by a pulmonologist. The pulmonologist noted there was an obstruction but did not treat it to solve the problem. She had to seek a different specialist to resolve her issue. This is another of many examples of having to *‘advocate for yourself.’*

David H. updated *In vivo CAR T*. This is a procedure where the T-cells are reprogrammed while still in the body versus the current practice of extracting the T-cells, sending them to the lab for cell remodification taking 3-6 weeks while using a bridge therapy , before reintroducing the cells into the body. This could mean a CAR T that is cheaper, more efficient, quicker, and more accessible to more patients. This was a Phase 1 clinical trial of only 18 patients. All 18 patients achieved and have maintained an MRD negative status at least 10 months. The therapy is known as KLN-1010 and was conducted by a Center in Australia. Emory Winship will be the lead Center in a Phase 1 study in the U.S. to conduct a similar Clinical trial enrolling about 70 patients. (*Phase*

1 Clinical trials represent the first time a therapy is used with humans, helping to establish the safety of new therapies in a few patients, identify side effects, and determine a safe dosage.)

There was discussion on recent IMF updates from national and international annual meetings on myeloma progress. Archived recording includes information on CAR T, Bispecifics, Trispecifics, and other information on research giving us hope for a myeloma cure. Please review your Resources and Upcoming events for recordings from past meetings, information on movement/exercise and myeloma, CAR T for patients and care partners, and your myeloma labs.

Respectfully submitted, Gail