# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

## Northside MM Support Group

## April 5, 2025

## Notes from IMF Workshop - April 2025

**The International Myeloma Foundation (IMF) workshop was held on April 5 at the Cobb Galleria Sheraton. About sixty people attended the educational session benefiting both patients and care partners. The workshop provided information for both newly diagnosed patients as well as patients on a longer myeloma journey.**

**Robin Tuohy, VP Patient Support, was the host for the day. She started the workshop with a shout-out to the support groups in Atlanta that connect patients. She acknowledged Nancy Bruno's retirement from the IMF after 12 years, and Doris Morgan's retirement from leadership of the Southside MM Group after starting the group and leading for 18 years. Nancy noted that she was not retiring from the Northside ATL Support Group!**

**Robin talked about the Special Interest groups listed on Myeloma.org. These groups provide additional support for: high risk MM, patients with young children, patients without full time care partners, smoldering MM, care partners group, and a veteran's MM group coming soon. She also mentioned the availability of the IMF InfoLine during business hours at 800-452-2873, and the online AI assistant "Myelo" at Multiple Myeloma Information | International Myeloma Foundation. Myelo is available 24/7 on the IMF website and provides research for MM authenticated information. Check out the website for all these educational tools as well as future workshops and seminars.**

**Dr. Nisha Joseph from Winship Cancer reviewed the basics of multiple myeloma. The number of estimated new myeloma cases in**

2024 is 35,780, which is 1.8% of all new cancer diagnoses. A MM diagnosis can be challenging due to non-specific symptoms such as fatigue (32%), bone pain (58%), or anemia (73%). These symptoms can be linked to other conditions. Dr. Joseph talked about how MM disrupts the cellular balance in the bone marrow by making just one abnormal protein and crowding out the normal plasma cells. She talked about the diagnosis criteria and necessary testing. Staging in MM is different from cancers with solid tumors, like breast, prostate, lung, etc. The staging is to determine how advanced the MM is and if there are high risk factors. It is also used as a baseline to guide therapy and measure responses to treatment. For initial treatment, Dr. Joseph reviewed the drug classes and the drugs within each class. She reviewed the terminology for response to treatment. Below is low response to high response, in order:

- PD – Progressive disease
- SD – Stable disease
- MR – Minimal response
- PR – Partial response (at least 50% reduction in MM protein)
- VGPR – Very good partial response (90% reduction in MM protein)
- CR – Complete response (no more than 5% plasma cells in bone marrow)
- mCR – Molecular CR
- sCR – Stringent complete response
- MRD negative – No MM cells by NGF (next generation flow), sensitivity at least 1 in 100,000, which is $10^{-5}$

Not every relapse requires immediate therapy. Each patient case is different. If there are no symptoms, two consecutive tests will show the trend of MM disease increase. If symptoms present such as high-risk marker, or extramedullary disease, then treatment must be initiated quickly.

Then Dr. Joseph talked about MM immunotherapies:

- **Monoclonal antibodies – Darzalex (daratumumab), Empliciti (elotuzumab), and Sarclisa (isatuximab)**
- **CAR T-cell therapy – Abecma (ide-cel) and Carvykti (cilta-cel)**
- **Bi-specific antibodies – Tecvayli (teclistamab), Elrexfio (elranatamab), and Talvey (talquettamab)**

**Each of these drug treatments connect to targets on the myeloma cells and cause cell death using your own immune system. They are providing longer control of the disease with less side effects. New tests are being developed to identify which targets are present on the myeloma cells within a patient. There are many CAR-T and bispecific therapies in clinical trials, showing even higher efficacy and lower side effects. The new bispecifics have less hospital time and are easier to administer at smaller clinics. This improves access for more patients. The evolution of myeloma therapy is amazing and so many new options are extending life spans and quality of life.**

**Lastly, Dr. Joseph talked about communication with your healthcare team, which includes getting a second opinion from a myeloma expert. A general oncologist or hematologist treating multiple diseases cannot keep up with the research, new therapies, and changes in the standard of care for myeloma. Talk to a specialist who only treats MM to understand all your options. If the expert is part of a research institution, they can introduce you to clinical trials and will work with your local healthcare team.**

**Dr. Joseph Mikhael (Dr. Joe) was not able to attend the workshop but prepared a brief video about Health Disparities in Myeloma. Myeloma is the most disparate cancer within the African American community. A Black man or woman diagnosed with MM today is expected to live half as long as the same-aged white man or woman. That is certainly unacceptable, and the IMF is working extremely hard towards reducing that disparity. The *M-Power program* is designed to improve the short and long-term outcomes of populations that have historically been underrepresented and have had health disparities in multiple myeloma. About 14% of the general population is African**

**American and yet only 6% of physicians are of African descent. If you look at the historic clinical trial accruals in multiple myeloma, and cancer in general, the proportion of minorities has always been low. That trend has been changing in myeloma because many have recognized this and are elevating the level of the playing field. So, if you give patients the right treatment, you should expect better outcomes for those patients. It has been shown that there are no differences in overall response rates, depth of response in Caucasian, Black myeloma patients or Hispanic versus non-Hispanic patients.**

**The next speaker was Dr. Manisha Bhutani from Levine Cancer Institute in Charlotte, NC. She talked about advancing treatment options through clinical trials. She first clarified some myths about clinical trials:**

- **Cancer patients do not get a placebo. They get the standard of care vs the new regimen.**
- **Patients can withdraw from clinical trial participation at any time.**
- **Risk is involved with any treatment, but medicines in clinical trials are used only after they have gone through extensive testing to indicate that the drug is likely to be safe and effective.**

**Every patient is unique, but there are benefits of trials:**

- **early access to the newest therapy.**
- **delay use of standard of care.**
- **contribute to the myeloma world – present and future.**
- **financial access to certain agents.**

**The benefits must be balanced with potential risks: toxicity of side effects; lack of efficacy. It is important that people from racial and ethnic minorities and other diverse groups are represented in clinical research. Discuss with your physician if you are eligible for a clinical trial. Discuss the trial with the coordinator and carefully review the Informed Consent. Ask about how often you must visit the clinic; additional tests; benefits and side effects; can I get treatment locally;**

**what is the cost of the trial to the patients? Find resources to find clinical trials through the SparkCures link on the IMF website - Clinical Trial | International Myeloma Foundation**

**Workshop attendees then broke out into two groups – newly diagnosed and relapsed/refractory MM. The newly diagnosed group learned about the new 4-drug treatment and that Emory data shows the median progression free survival (PFS) is 80 months for standard risk and overall survival is over 11 years. This will continue to grow with new treatments coming. The relapsed/refractory group discussed the treatments based on patient, disease, and treatment characteristics. They also discussed the approach to late relapse and the use of new therapies such as CAR-T and bispecific. Consideration of treatments include risk, amount of disease, previous therapies and adverse effects, previous responses, and cost. Other patient factors are other diseases, general health, preferences, support, access to treatment center, and insurance coverage.**

**Sylvia Dsouza, VP of Development, spoke next about the ways to engage and support the IMF. If you choose, you can designate your gifts to a specific area that is meaningful to you: Research, Education, Support, or Advocacy. The Iceland trip is now an annual event to raise awareness around the world. The documentary about the 2024 ICE trip is winning awards at film festivals globally which will increase connections. The IMF Advocacy team is following any policy changes that could impact patient access to care. IMF Research includes a Scientific Advisory Board, which Dr. Sagal Lonial along with other global experts guide research priorities and clinical trials.**

**Kevin Brigle, PhD, NP presented guidance as a member of the IMF Nurse Leadership Board. Kevin, a long-time myeloma nurse, presented an overview of treatment options, side effects, and quality of life for patients and care partners. With seventeen new treatments in the last 20 years, there are so many choices and combinations**

**available. Stem cell transplant remains the standard of care for eligible patients. This is an important decision to have a transplant in your first line of treatment or wait for the first relapse. Patients and care partners need to be fully informed and have a discussion with their healthcare team. CAR T-cell therapy is an option on first or second relapse or even later. CAR-T involves harvesting T-cells, much like stem cell harvest. CAR-T patients do not get maintenance, so the treatment is considered "one and done" until there is a relapse. Bispecific antibodies are also an option, either before or after T-cell therapy. Both CAR-T and bispecific treatment are highly effective, even after many lines of therapy. Patients and care partners need to be informed about side effects and what symptoms to monitor. Cytokine Release Syndrome (CRS) occurs in both of these treatments as well as neurotoxicity, which is rare. Myeloma centers are learning all the time about monitoring and treating side effects, so be sure to be fully aware of monitoring factors. Side effects can occur from disease or any treatment. Your team may be able to help, but only if they know how you feel. Proactively discuss common side effects and what to do if they occur. Keep a symptom diary and bring it to appointments. Steroids enhance the effectiveness of myeloma therapies but have their own set of side effects. Have a discussion with your doctor about the length of treatment and if the dosage can be reduced if steroids are impacting quality of life for the patient or the care partner.**

**Preventing infections is paramount. Infection remains the leading cause of death in patients with multiple myeloma. Several factors account for this infection risk, including the overall state of immunosuppression from myeloma, treatment, age, and comorbidities. This is according to the IMWG consensus guidelines. Report fever of more than 100.4° F, shaking chills even without fever, dizziness, shortness of breath, or low blood pressure. Talk with your team about infection prevention actions, including medications to reduce risk. Kevin also talked about GI issues. Fluid intake can help with both diarrhea and constipation and helps kidney function. Discuss GI issues with healthcare providers to identify causes and make adjustments to medications and supplements. Pain can**

significantly compromise quality of life. Tell your healthcare provider about any new bone or chronic pain that is not adequately controlled. Be an empowered patient. Ask questions and participate in the treatment decisions. Speak up if something seems different or unusual. Develop a support network beyond the care partners.

The final speaker was Stephanie Boyea, MS, RD, CSO, LD, clinical oncology dietitian for Winship Cancer Institute. Her topic was: Optimizing and protecting the immune system: a nutrition approach. The immune system is a complex network of immune cells, proteins, receptors, antibodies, and organs. It acts as the body's law enforcement, providing a line of defense and responds to any threats. It works to defend, prevent, and limit infection. Multiple myeloma's impact on the immune system decreases white blood count, reduces antibody production, and increases inflammatory cytokines. The treatment also has similar effects on the immune system. You can fuel your immune system with an adequate amount of the right diet for your body. This includes adequate amounts of energy, protein, micronutrients, fiber, hydration, gut microbiome support, and minimize inflammation through lifestyle. A whole food, plant-based diet has been associated with a decreased risk of MM. A supported gut microbiome has been correlated with sustained MRD. Studies are continuing to show that improved nutrition makes a significant difference in MM outcomes. Lastly, Stephanie talked about supplements for immune support. Patients should be cautious and talk with their doctors.

Submitted by Nancy B.

## Meeting Minutes

## Southside MM Support Group

## April 26, 2025

**Next Meeting:**

**The Southside MM group will meet hybrid format on the 4th Saturday, May 24, 2025 @10:30 AM. in person and online. Patient and Care Partner voice discussions.**

**"For Men (with Myeloma) Only." 4th Tuesday, May 27, 2025 @ 6:00 PM–Virtual. Networking, sharing, and check-in.**

## Group Discussion:

**The meeting opened to the sounds of Motown and Vivaldi in the background. There were no new members. Gail led the group in a moment of silence, prayer, centering, and guided breathing.**

### Myeloma Action Month Updates:

**Pat C. and her husband Mike, who also has myeloma, shared their MM journey during the IMF Regional Community Workshop in April. Their daughter was also there in support. It was a time of reflection about the origin of our myeloma, especially when it happens in families. Is it genetics or is it the environment where siblings are diagnosed with myeloma? Sandy B. presented at the Palm Beach, FL support group meeting on her journey over 35 years with myeloma. It was a positive experience, and she received a gift card for her favorite treat from Wendy's – their Frosty. Portia made a $250 donation to "Every Color Matters" foundation March for myeloma. Every Color provides support to all the different cancers. Karen posted information on Facebook about myeloma. Alma worked with Dr. Joe in filming her experience for a "*Diversity in Clinical Trials*" project with other MM patients in ATL. It was a great experience for her. Indeed, Georgia made its contribution to the more than 53 million MM patients touched by messages of myeloma in 52 different countries. Flora has many myeloma awareness T-shirts. She wore one for her physical therapy appointment and was able to discuss myeloma with others.**

**Triage Cancer: Flower purchase fundraiser. Purchase flowers from Triage Cancer – donate to the cause. About 60% of purchase costs go to Triage Cancer.**

**"For Men Only" Report: Anderson, David, and Dirk shared that the Men's Only group continues to be a great support and networking opportunity. They shared that it is a safe, caring, and insightful place for men with myeloma to come together each month. Dirk added that sometimes what others share is surprising and would never have been on his radar. They keep each other's confidence, try to help with solutions, if appropriate, and check in on each other if they go missing from the meetings.**

## Topic Discussion on Research/Survey promoting recruitment through Support Groups

**Several different invitations to participate in research or complete surveys related to cancer or myeloma specifically were sent to SG members in March and April to recruit participants. They included Syncscript and Georgia CORE. Some had associated incentives for as much as $165 – others were for free. The time it takes to complete a survey varies. Support Group leaders try to do a cursory vetting of the sponsoring agencies/organizations before sending them out but want the members to decide for themselves whether to participate. Gail had conversations with Syncscript to share concerns about the pre-screening questions, the video required, and the lack of information on the company for recruitment. She decided to participate and will report back on her experiences. She is a member of the Georgia CORE Survivorship Work Group with a goal of determining the needs and status of the almost 450,000 survivors of all cancers in Georgia.**

**Discussion questions/concerns about research participation included:**

- ***What are your general thoughts about getting surveys from SG leaders, or being sent directly to you?***
- ***Do you want us to continue sending you survey opportunities/requests?***
- ***Are the monetary incentives of concern?***

**Some concerns include strangers collecting medical information about you, the lack of information on the agency/organization or on the purpose of the research; a reluctance to share medical information with strangers and knowing how information will be used and the desire or duty to help with myeloma research, whether for clinical trials or observation or something else. The sharing of results of research was also a concern. Healthtree and Patient Power have begun to report the results of studies for whom they recruit on their websites. Dr. Shah (oncologist/nutrition researcher) recruited most of the nutrition and myeloma research study participants through Healthtree.**

**Cynthia asked if others knew the definition of "IRB." Gail shared that it is an Institutional Review Board designed to protect 'human subjects' in research. It is a committee who reviews the applications of those who wish to conduct research and provide oversight for its safety. It came about from historically dangerous and unethical medical research conducted in the past. Cynthia asked about a clinical trial she received an email about to participate and asked if anyone had heard of CT-AZD0305. Jeff looked it up on the clinical trials.gov website that lists clinical trials for all diseases/all cancers. He found that the study is Phase I/II and has been recruiting since 2023, is an Antibody Drug Conjugate (ADC – same category as Blenrep) targeting, GPRC5D which has been around for more than five years. IMF also lists information on myeloma CTs and has partnered with Sparkcures organization that provides information on trials. AstraZeneca sponsors the research. MMRF also offers information on CTs. You can call and ask questions from the IMF/Sparkcures and MMRF websites. IMF website - What Is a Clinical Trial | International Myeloma Foundation We benefit greatly from CTs and other research and need to be informed and safe about participation. Gail suggested an available checklist of questions for patients to determine if the CT is a good fit for them. Questions to ask include:**

- **What is the Phase of the CT?**
- **What is the time duration of CT required to participate?**

- **Transportation/parking, insurance coverage concerns?**
- **What is the class of drugs and how does it work?**

***Do not forget to use Myelo, the IMF AI guide, to help answer your questions.***

## Patient and Care Partner Updates

**When Alicia (diagnosed 3 years ago) talks with newly diagnosed people during her infusion, many are surprised that she is doing so well. Many patients do not know about the MM Support Groups. She learned about the SG about three months after her own diagnosis. Alicia encourages others to go on and live their lives even with an MM diagnosis and shares that she learned much from long term MM survivors. Gail encouraged Alicia and all group members to keep information about the MM SG on them so they can readily share phone numbers and email addresses with people they meet. Contact information is found in the monthly newsletter. The AAMMSG flyer attached below provides meeting information to myeloma patients and can be distributed to Dr. offices and infusion clinics.**

**Alicia also inquired about an MM educational session held last year by the MMRF at the Lou Walker Center in Dekalb County. Portia said there are many opportunities to gain MM information, and we should all take networking opportunities seriously and share with each other. David shared some information about CAR-T cell therapy. There is a new approach for manufacturing the immune CAR-T cells needed for transplant being used in the UK and at the University of Wisconsin. The cells are manufactured on site over 8 days versus 4-6 weeks wait time for the patient’s cells to be modified and made ready for infusion. This could make CAR-T less expensive and potentially more accessible than the current process. Vena shared that she is doing okay. She was diagnosed with lung cancer recently after her myeloma diagnosis several years ago. Her myeloma was quiet for a few years, so she focused on the lung cancer. Vena never smoked; even in high school she hated being around smokers. She drove a school bus for many years. She has several new lesions that are**

**currently being addressed. Vena tries to do her part to stay healthy by keeping appointments with doctors, taking medicines as prescribed along with vitamins, eating right, etc. She is tired and rests when needed.**

**Vena offered part of her formula for remaining happy and hopeful. –**

- ***Be positive. Stay away from negative people.***
- ***Take time to look your best when you go out into public.***
- ***Make others smile and give compliments that can lift your spirits.***
- ***Be grateful/show gratitude*... words to live by.**

**Financing myeloma costs. Bernard shared that he has an additional diagnosis of Parkinson's Disease. Like myeloma, the medications can be tens of thousands of dollars each month. There are organizations like LLS and the Patient Advocate Fund (PAF) for myeloma. Through his research he found that Parkinson's also has organizations that will help with financing. co-pays and medication costs. Cynthia reminded us that LLS and PAF have funds that will be available during short periods of time. One can easily miss those windows of opportunity. We have members like Alma and Pat C. who will let us know if funding is available. Be on the lookout for email notices and respond as soon as possible. Unfortunately, there is not another system. Please be sure you have completed all the necessary paperwork, so you can be notified of available funding.**

**Featured Videos: Each month we try to choose a few selected short videos that you will find of interest. Here are the ones for this month.**

**How Can a Specialist help a Patient choose the right therapy for them? Dr. Blue – 1:45 min.**

***STRONG! Living with Multiple Myeloma Paris, is a young Black male independent film producer who is diagnosed with myeloma and documents his journey with family and friends.**

**Respectfully submitted,**

**Gail**