

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes
Northside Virtual MM Support Group
August 5, 2023

Business & News

Thank you to **Nancy B.** who hosted the virtual meeting for approximately 28 attendees. The meeting topic discussion was “*Communicating with Your Healthcare Team.*” What questions have you asked your healthcare team that had the greatest impact on your care decisions? The following questions were provided in advance, as topics for discussion in the meeting:

- How do you prepare and take notes during your routine visits?
- What lab results are reviewed, and questions are most frequently discussed?
- During your appointment, which concerns are not completely answered?
- After your treatment, what do you wish you had asked beforehand?
- How do you manage follow-up questions?

Member Updates & Discussion

The group welcomed a new guest, whose mother was diagnosed (within hours at the ER) with high-risk MM, after experiencing severe back pain in January 2023. Her mother is generally healthy, and her MM numbers look good after

initial treatment of DARZALEX (Daratumumab), Revlimid, and Velcade. She is currently planning an out-patient stem cell transplant (SCT) at Northside (Dunwoody) and is looking for accommodations in the area during this time. Nancy recommended looking into the Hope Lodge as a place to stay during the SCT. The group also recommended considering other options such as having the SCT as an in-patient, or holding off on the SCT, and only harvesting stem cells at this time, since stem cells can be frozen and used later. Many patients harvest stem cells early, and then do well on certain drugs (i.e., DARZALEX) that do not cause a lot of adverse side effects, allowing them to wait to have a SCT later, or even never. There are a lot of variables to consider for the patient and caregivers. **Joyce** was diagnosed with MM in October 2012, and had successful in-patient SCTs (3 times) at Northside and was in the hospital about 14 days each time. She mentioned that in hindsight, she would have waited to have a SCT later since her numbers were already good going into the SCT. Joyce also mentioned that she is allergic to the saline used to flush out ports, which a nurse at Northside discovered, so they had to create special saline for her in their lab.

Jim M. is preparing for CAR-T therapy, with a T-cell harvest date in mid-August at Emory. The T-cells will be sent off site for processing, returned post-processing to Emory, and then re-inserted. Jim expects to be in the hospital for 10-14 days, depending on side effects. This decision was made with assistance from his wife and two of

his children, who attended the doctor's appointment with Jim to hear about the treatment and ask questions. It is important to have someone attend appointments with the patient to make sure that questions are answered and take notes on issues to be discussed later.

Cynthia had CAR-T therapy in 2020 but it only lasted eight months for her due to problems with her immune system recovery. She was not aware of IVIG therapy as an option at the time and in hindsight thinks that IVIG therapy would have helped her. After CAR-T, she was diagnosed with extramedullary MM and had a second SCT, which has controlled the MM so far. Cynthia has been off all drugs for three months while recovering from a lung infection, which has improved, and is working with her Emory doctor on next steps. **Sandy W.** reported great results from two months on Kyprolis, Pomalyst, and Dex (KPD), which are next generation drugs from the same drug classes, RVD, that she has previously taken, which took 4 months to get results.

Marilyn M. was diagnosed in 2008 with smoldering MM (SMM) and has decided (along with her doctors) to not treat it at this time, which is a very critical quality of life type of discussions and decision for her and her healthcare team. Another big issue she discusses with her doctors is diet. She has noticed that changes to her diet affect her numbers, specifically M-spike and anemia numbers. When she adheres to a vegetarian diet her M-spike number goes down, but her anemia goes down too. When she eats even small

amounts of meat, the anemia improves, but M-spike increases, so it is challenging to understand and find the right balance. Someone commented that iron and anemia are a big challenge with blood disorders. **Cynthia** commented that when she adheres to a plant-based diet, her MM numbers are better, but her hemoglobin number is not, and during her first SCT, her doctors encouraged her to eat meat. She commented that her hemoglobin number is what is most important to her. **Mary V.** recommended a plant-based supplement that she uses for hemoglobin support called “Floradix,” which she orders from Amazon. She has had great results with this product. **Nancy** mentioned that diet definitely impacts MM numbers and studies show that a plant-based diet slows the progression of MM and smoldering MM (SMM) and contributes to better MM treatment outcomes. We can expect to hear more about this in the American Society of Hematology (ASH) review in December. She eats 30 different plants each week from seeds, nuts, grains, fruits, and vegetables. Eating from a variety of plants is important because they each contribute different types of nutrients necessary for your body’s functions.

Mary V. was diagnosed a little over a year ago and is doing very well. She started treatment with Daratumumab then added Revlimid to achieve what her doctors call a “dramatic response.” Mary explained that she has always been health conscious and is interested in exploring different types of options to stay healthy. **Marilyn M.** had sinus issues for

years and has been on strong oral antibiotics frequently prescribed by her general practitioner (GP) for recurrent sinus infections that have not helped and knew that she should not continue the same path that was not working. Because she was persistent in getting the issue resolved, her GP referred her to an ENT doctor, who found a pocket of pus in her sinus, which was treated with a nebulizer containing an antibiotic and resolved the issue. She feels much better now and no longer has the fatigue that she experienced with the constant infection. Additionally, before she went to the ENT doctor, her IGG kappa numbers were “off the chart.” After treatment prescribed by the ENT, her IGG kappa numbers are normal again. It is important to be persistent and communicate with your doctors when something they have prescribed is not working for you.

Barbara W. is recovering from a recent bout of e-coli, which was a big surprise to her, as she does not know how she got it. She is on antibiotics and feeling much better. She is very careful about preparing food, washes her hands often, does not share towels, etc. and expects everyone in her household to do the same. She still adheres to the guidelines from when she had her SCT in May 2020. In general Barbara stays updated on all of her vaccinations and knows that she is her own best patient advocate, including when she interacts with her healthcare team. She uses MyChart to communicate with her doctors when not in person, which works well for her. Whenever she has an

issue, she lets her doctor know right away so that it does not go on for too long where it may progress to the point where they cannot treat it as easily. She asks her doctors a lot of questions because she is aware that her doctors, especially MM specialists, have done so much research, that they can't tell her everything that they know, so it is her responsibility to ask the right questions that are relevant to her situation to be able to draw out the response and answers that she needs. You have to ask the right questions to get to what they know. She likes to stay involved with both Northside and Southside Atlanta MM support groups to share experiences and information. **Cynthia** asked if mRNA is considered a possible cure for MM, and if anyone has heard anything more about this. **Nancy** responded that currently there are no good results reported from studies, but we expect to have more information provided at the American Society of Hematology (ASH) review in December. **Glenn** mentioned a drug called Ivermectin, which has been around since the 1980's and originally used to treat malaria and can also treat and cure a lot of different things, including COVID and potentially MM (there are some limited studies). It is inexpensive and is not promoted for that reason. **Mary V.** commented that a drug called Panacure (Fenbendazole) has also been used to treat MM.

There was discussion surrounding the need to not feel rushed when signing important, complicated healthcare documents related to procedures, treatments, clinical trials,

insurance, etc. Patients and caregivers frequently feel overwhelmed with the many pages of documents containing medical terminology that is not well understood. Read and understand what you are signing – do not allow anyone to rush you. Ask for clarification if you do not understand something. There may be times when you need someone from the medical team to review documents with you step by step before you sign. Make sure that you understand how what you are signing may affect your quality of life. It is your healthcare team's responsibility to ensure that you understand what you are signing.

Some tips in preparing for appointments include:

- have someone go with you to your appointments to help you take notes.
- prepare in advance by conducting research.
- organize your questions before your appointment.
- study medical terminology
- ask for a contingency plan in the event that the treatment does not go as well as expected.

There was mention of how negative stress can affect your body and the extent of the damage that it can do. It is very important for everyone to have ways to control and recover from stress in order to stay as healthy as possible.

Monitoring and controlling your stress are very important. Everyone is reminded to be careful about COVID and flu. It is advised to wear masks in hospital and clinical settings. COVID cases are spiking again, and flu is also in the area. The newest COVID vaccinations are expected to be

available in the September/October timeframe. COVID vaccines may be combined with the seasonal flu vaccine and should also be available separately, along with RSV vaccinations for adults.

Submitted by Wendy

Meeting Minutes
Southside Virtual MM Support Group
August 26, 2023

Business and News:

Southside Next Meeting: Saturday, September 23, 2023 @ 10:00 AM. This will be a **hybrid meeting**. The guest speaker will be **Kendelle Miller, MSW, LCSW, ACM**, Emory Clinical Social Worker. The **Zoom meeting link** will be sent in a separate email. For those attending in-person, the location is the Fulton County Library off Cascade Road (near 285).

For Men Only. Next Meeting: Tuesday, September 26, 2023, at 6:00 PM (Virtual Meeting).

Meeting Discussions:

In August Southside held a successful hybrid meeting. Since the library does not open until 10 AM, there is a short delay

until the in-person group can join the virtual meeting. We may consider changing the future meeting's start time to 15 minutes after the hour (10:15). Thank you to Doris M and her son, Nancy B and Sandy W for their help accessing the technology available to run the hybrid meetings.

The August meeting focused on three topics of interest.

- **LLS speaker Samantha Candless:** *September is Blood Cancer Awareness Month. LLS Financial assistance, and Light the Night event on October 7.*
- Open discussion on patient updates and the importance of remaining physically active and engaged in the myeloma journey
- **Myeloma resource updates**

LLS resources and Light the Night Event:

Samantha McCandless from the Leukemia and Lymphoma Society (lls.org) spoke to our group. **September is Blood Cancer Awareness Month.** She shared some statistics on blood cancers. More than 1.2 million children and adults are living with Leukemia, Hodgkin's disease, and Myeloma. LLS provides many resources and financial support for those living with MM. Explore the website or call an information specialist at 800.955.4572. **The annual LLS Southern Blood Cancer Conference will be held on Saturday, October 14 from 8:30-2:30 PM** at the Renaissance Waverly Hotel off Cobb Parkway. Dr. Lonial

will be presenting at the conference. Please go to the website to register.

Samantha also provided details on Light the Night event on Saturday, October 7 at Piedmont Park in Atlanta. She shared the webpage for Southside fundraising. Watch your emails for links to the website and updated information. We hope each person will contribute in gratitude for all LLS does. (Samantha.mccandless@lls.org – 330.715.7030)

Group discussion and Patient updates:

Jeff reported for the Men's Only group. They have a great time discussing myeloma and how the journey is impacting them, how it has changed their lives, communication styles with health care providers, and more. They also talk about “guy stuff” and life away from myeloma.

While waiting for the in-person group to join, the virtual group patients discussed updates. **Carolyn H.** shared that after 8-1/2 years on Darzalex, it is no longer working and she must look for another regimen. Since she has moved to Canton, getting to Emory is a hardship. She went to Northside but returned to Emory after finding a tumor on her skull. With a travel grant from LLS, she took an uber to Emory. The cost is prohibitive, costing \$100 each way. **Jeff** made some suggestions that he has used from the north part of the state. The **Georgia Xpress** bus travels from Bolling Park to the MARTA Arts Station. Transfers can take you to Emory. Others shared that she should check possible

Medicare contracts with transportation support and with Uber. **Alisha B.** advised checking with AARP, and your insurance company, particularly United Healthcare. **Barbara W** suggested other bus transport systems from north GA into Atlanta and Emory. Connections may be in Cobb County. Check for **Express Georgia** and **GRTA** (Georgia Regional Transportation) was suggested by **Marcia W.**

Janice W. joined us as a new member. Her sister, **Denise W.** reached out to us. Thanks Denise! Janice was diagnosed in April and will be harvesting her cells in October. So far, the myeloma journey has not been too bad. Unfortunately, her primary care doctor did not diagnose her myeloma...an Emergency Room visit helped with the diagnosis. The cardiologist listened to her symptoms, suspected myeloma, and referred her for a CT scan, which provided her diagnosis.

Mary F. was recently diagnosed with MM. The stress of her diagnosis has been compounded by a divorce which set into motion all the financial issues of a cancer diagnosis, applying for Medicare, and being told that the Social Security Administration (SSA) had overpaid her in disability payments that she must repay. Several people in the group have experienced errors on the part of SSA that have caused extremely stressful situations. Members advised Mary that one labor intensive strategy is to call SSA on different days and different times – to get different people. One of them should be able to help her resolve this situation. **Gail** reminded the group that at one time MM was on the expedited list of health concerns for receiving

disability. Group members especially encouraged her to take deep breaths, try to remain positive even with all these crises in her life. Excess mental and emotional stress can have a negative effect on one's health. (From Gail: *There was a story on Good Morning America on Monday, September 18, 2023, in the 7:00-7:30 AM hour. "Social Security Warning." The report encouraged people to file an appeal and to plead hardship in repayment. SSA has made many errors in payment and wants to make the clients responsible.*) Stay strong, Mary!

Review of Meeting Agenda Resources:

Gail conducted an overview of the "Agenda" we share each month at our meetings. It is much more a list of upcoming educational opportunities and resources from a variety of myeloma organizations. We encourage everyone to take time to mark their calendars for "real time" events and to circle archived educational videos in which they have an interest to view. This month, Gail added additional resources including a Financial Resource Page and for increasing physical activity. In our minutes, we include the website for each of the organizations also – Healthtree, IMF, LLS, the Patient Empowerment Network, and Patient Power.

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Educational Information/Opportunities

- Volunteer **Opportunity** – Health Fair at Word of Faith – September 30 – any interest?

- **COVID Updates**

WHO has classified BA.2.86 as a “variant under monitoring”. The CDC has released a risk assessment report indicating the presence of BA.2.86 in a U.S. wastewater sample. Amid these ongoing developments, Dr. Durie strongly advises myeloma patients to practice caution and due diligence—to stay updated on COVID-19 community levels, wear reliable masks in situations of risk, and get tested if symptoms emerge. The IMF will be closely monitoring updates and relaying important information on new COVID-19 variants and sub-variants, as well as updated vaccines and boosters.

Healthtree Foundation - <https://healthtree.org/myeloma>

- **Neutropenia** and neutropenia diet – Short video
- Know Your Myeloma Immunotherapy: Teclistamab and other Bispecifics – Listen to this one hour recording from Aug 16.
- **Talquetamab**, first-in-class bispecific antibody, was approved on August 10, 2023, by the Food and Drug Administration of the United States for myeloma patients with four or more lines of previous therapy.

- **Nutrition, myeloma, and generating evidence-based advice.** Be a part of cutting-edge research. Dr. Urvi Shah, MD oncology. (4:45)

<https://healthtree.org/myeloma/community/articles/dr-shah-nutrition-study-report>

Ø To participate (survey takes about 15 min and is anonymous): Go to Healthtree Cure Hub
- <https://healthtree.org/myeloma/curehub>

- **Bispecifics.** ASH 2022: Elranatamab Bispecific Shows Promise in Multiple Myeloma.
<https://healthtree.org/myeloma/community/articles/ash-2022-immunotherapy-research-is-exploding>

IMF – myeloma.org

- Info Line - 800-452 CURE (2873)

Blood Cancer Awareness Month - Throughout Blood Cancer Awareness Month, the IMF will be hosting a series of 30-minute sessions covering research, education, fundraising, and advocacy:

September 1, Friday: "Ask Me Anything About Myeloma Research" with Dr. Joseph Mikhael.

September 12, Tuesday: "Ask Me Anything About Myeloma" with IMF NLB Member Beth Faiman.

September 19, Tuesday: "How to Host a Fundraiser" with IMF Director of Development – Events Ilana Kenville.

September 26, Tuesday: “Ask Me Anything About Advocacy” with IMF Director of Public Policy and Advocacy Danielle Doheny.

- **Financial Assistance Page** – IMF – see addendum and myeloma.org

LLS – lls.org

- **LLS. New Portal** – One stop shop to access the Co-Pay Assistance Program and our other financial assistance programs in one place. Going live – late May. Questions? Email: FinancialAssistance@LLS.org. **Phone: (877) 557-2672**

LLS Financial portal. If you are not already registered, please do so while you are not competing for funds. They are working hard to streamline their various pools of funding... co-pay assistance to travel funds. Keep down anxiety by being prepared.

- **Blood Cancer Awareness Month. VIRTUAL. Sat. September 9. REGISTER.**
- **Resource – Survivorship Plan...** 93 pp during and after diagnosis
- **New educational materials** – Myeloma Guide: for patients and caregivers (easier to read). www.LLS.org/booklets. New educational materials for download include **Mental Health, Stem cell transplantation Guide, and Hospice Care.**

- **LLS Information Specialist to order copies:**
(800) 955-4572
- **Nutrition video series** – 4 videos under 4 minutes each

**Patient Empowerment
Network** - <https://powerfulpatients.org/>

- **How Is Bispecific Antibody Therapy Changing Myeloma Care?** Video-1:13
 - **A series of on-demand videos-** Making treatment decisions; how lab tests help to determine prognosis and treatment plan.; Myeloma combination therapy – what patients should know. PEN-Powered Activity Guide.
 - What testing is appropriate for smoldering myeloma?
 - Bone-building therapies recommended for myeloma patients. (Recording, 3:18)
- **Therapies (~7:15).** Newly Diagnosed or Relapsed/Refractory, Which medications are best for you and in what combination). What class of drug?

<https://powerfulpatients.org/2023/05/05/making-treatment-decisions-understanding-common-myeloma-therapies/>

Patient Power - <https://www.patientpower.info/>

- Exploring **natural remedies for cancer control**;
Nutrition and cancer; How financial toxicity affects cancer care; Advice for patients undergoing CAR-T therapy.
What Do High and Low Neutrophil Counts **Mean?**

Respectively submitted, Gail.