

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

February 4, 2023

Business & News

Thank you to **Nancy B.** who hosted the meeting with approximately 25 attendees. The session focused on key points from the American Society of Hematology (ASH) recap session presented by the Emory Winship team in January followed by members' updates during the group open discussion.

ASH 2023 Review discussion

Nancy B. summarized the ASH conference 2023 newsworthy MM abstracts which offers a hopeful perspective of what is going on with multiple myeloma options along with up and coming treatments in MM care. There are a lot of new therapies and research on the horizon. Additionally, doctors and researchers are very excited about CAR-T and bispecific drug therapies.

[Chimeric Antigen Receptor \(CAR-T\)](#) therapy has been approved for MM a couple of years but has not been as available to patients as readily as other therapies because it takes four or more weeks to program a patient's T-cells to identify and attack myeloma. CAR-T treatment is an exciting one and done treatment providing progression free survival (PFS) for an average 10+ months. Unfortunately, the CAR-T laboratories that re-engineer the patient's cells are backed up. Hopefully as [CAR-T Cells](#) side effect challenges such as cytokine *release syndrome*(CRS) and neurotoxicity (*ICANS*) are resolved, CAR-T may someday replace stem cell transplants (SCT) which require a heavy pretreat dose of Melphalan that is highly toxic and have caused negative long-term side effects in some patients.

[Bispecific drugs](#) are a viable treatment alternative but require a lot of staff training for medical administering how to effectively increase the dosage and limit side effects. Patients begin their Bispecifics treatment in the hospital for several days. Three increasing doses are given every couple of days while hospitalized. Doctors aggressively pre-treat for cytokines, nausea, and other expected side effects. Patients are closely monitored for *cytokine storm response (CSR)*, which is a common reaction with the Bispecific drugs, but fortunately not as adverse side effect as with CAR-T therapy. Since Emory conducted Bispecifics clinical trials (CT), it has given them a head start for providing this treatment now that it has been approved, and they are enrolling a couple of patients a week. No one in the meeting has had bispecific therapy.

Doctors are also trying to get the new drugs to patients sooner in the treatment cycle through Clinical Trials (CT) so that they can better understand how effective the newer drugs are for newly diagnosed patients who have not received prior therapies. They are hoping to find much longer remissions for patients whose bone marrow are less affected or immune deficient from prior therapies. An interesting sidebar note that one of the doctors at the ASH meeting reported finding two different variants of clones of MM in the same bone marrow sample.

Patient Update & Open Discussion

Dirk B. stopped treatment of intravenous Dara, Pomalyst, and Dex for three months surrounding the time he was in the hospital and rehab center with pneumonia and acquired fungal infection for 55 days from mid-November to mid-January. He just received his MM test results which were good, despite his drug hiatus. He will consult with his doctor about altering dosages when he resumes treatment, as well as changing to subcutaneous Dara. On a side note, Dirk recently fell and sprained his ankle while crossing the street at a bus stop. His spirits are still high and inspiring.

Jeff W. is currently on subcutaneous Dara and becomes breathless and winded for a couple of hours after receiving it, but then is okay.

Chuck M. also takes Dara and mentioned that after a couple of weeks his white blood cell and neutrophil counts drop and he had to stop for a while. It is early, but Dara seems to be working for him, with light chain numbers dropping significantly, and heavy chain numbers dropping slightly.

Jim M. reported that he is doing well with good results after a recent SCT, and he is glad that he did it. Early post SCT tests still found signs of MM, but now no MM is detected. His biggest side effect post SCT is “chemo brain” which has affected his memory and is making his work challenging and also mentioned that his colon cancer remains in remission after three years. Jim met an MM patient in December who was in poor health and experiencing a very rough time with his MM treatments. The patient is located in rural GA that prevented consulting a MM expert. Jim’s ongoing conversations over several weeks provided valuable information encouraging the patient to consult Emory experts and expedite his MM treatment protocol along with reducing Dex regimen for 40mg two consecutive days. Jim has mentored many patients to help educate them with reliable resources to make educated decisions with their MM journey.

Cappa W. was diagnosed with lung cancer from tests that she had for MM. She is monitored every six months and likes her doctor. **Nancy B.** commented that there are potential secondary cancers from long-term Revlimid use that are low, but it is higher from the high dose Melphalan used in SCT.

There was discussion about the importance of MM patients whose doctors with limited MM experience can affect the outcome of MM decisions (often negatively), treatment plans, quality of life, and all aspects of a patient’s long-term health

Sharon is on a maintenance Revlimid 10 mg/21 day cycle and is experiencing neuropathy in her feet, especially at night when they feel like ice, although they are not actually cold. She takes alpha lipoic acid to help with neuropathy. Sharon is new to the area, just relocating from New Jersey, and is looking for a neurologist. Someone mentioned that her oncologist might be able to provide a recommendation for her. A recent PET scan found nodules in her lungs. **Jim M.** said that he also has nodules in his lungs that are being monitored and have not changed in size. His doctors do not know what they are. **Gail M.** also reported having nodules in her lungs found in a PET scan.

Sandy W. is on a [Phase 1/2 Clinical Trial](#) at Emory for an investigational drug CC-93480 (MEZI) that is the next generation of “IMiDs” class called CELMod5. The 3 drug treatment plan combines Mezigdomide and Dex with Dara, Carfilzomib or Pomalyst. She wondered if anyone else was on the CT, but no one else was in the meeting. Sandy said MM numbers are coming down slowly and she is doing well, but it was very time-consuming during the dosing reduction over the first 6 months. Additional meds are being received for reduced blood cell production and the primary side effect is sleepless nights and mood swings 2 to-3 days a week from Dex.

Kyle reported having Covid in December causing him to stop taking [Pomalyst](#) for about two months. He recommends the EVO face mask to avoid the virus. When he resumed Pomalyst in January it was no longer

effective for him. His third regimen is [Carfilzomib](#) (weekly infusion) and Dex. Kyle's doctor told him after patients have CAR-T therapy, they can retry prior drugs previously effective for them since their immune system has been restarted post CAR-T. He is interested in learning more about the side effects of *Carfilzomib* from other group members.

Mary V. was diagnosed in July 2022 and has been going to the University Cancer and Blood Center in Monroe GA. She is in the process of switching to Emory so that MM experts can treat her. Mary is doing well overall and her MM numbers are improving. She has been very weak, but physical therapy is helping her regain her strength slowly. **Nancy B.** mentioned that Emory doctors will partner with a patient's local oncologist to help build a plan for the patient. There are many in the group who take advantage of this opportunity which allows them to be able to continue to see a local doctor, yet also have the expertise in MM care that Emory can provide. This arrangement helps the doctors as well to build important relationships and share knowledge. The partnership is very beneficial to the doctors as well as the patients.

Glenn I. is doing well and is in remission. He also is recovering from Covid despite double masking (N95 with another mask over that) in public and other precautions. He may have contracted COVID from eating in restaurants (the only times he does not mask in public). Glenn explained that his level of strength is dependent on the amount of exercise that he gets. His energy level decreases when he doesn't get enough exercise. He walks three miles every other day, and on the other days does exercise at home for about a half hour from a TV show called "[Senior Fit with Bradford](#)" on AIB network. Episodes can also be found on YouTube. Glenn mentioned that he started out slowly, then gradually built up to his current regimen, and plans to continue to build up more. He is currently without caregiver support. Additional exercise suggestions in inclement weather are either walking inside the house or public places such as large stores avoiding peak hours when they are busy due to Covid. **Sharon** prefers walking outside but recommended chair exercises for seniors on YouTube for indoor exercise days. **Cynthia B.** recommended drinking zero sugar PowerAde for low energy. When she feels better she wants to walk more.

Lory M. has been taking Pomalyst, [Elotuzumab](#), and Dex for about a year and her numbers are relatively stable. The Pomalyst has caused a lot of issues for her that she does her best to manage. Lori has altered dosages to try to manage heart palpitations and dizziness. Another side effect is the texture of her hair from originally thick and straight to now thin, dry, and frizzy. The Dex is causing some sleepless nights and she is also experiencing restless leg syndrome (RLS) for the first time. Lory has tried taking melatonin for sleep but it made her RLS worse.

This led to a group discussion on recommendations for managing RLS, sleep, and leg cramps, as many in the group have experienced these issues, some before MM treatment, and others as a result of MM treatment.

For RLS: Jim M. mentioned that his RLS has become more pronounced since his SCT, and he uses support socks to help. Chuck's wife recently began a prescription drug called [Ropinirole](#), which seems to help. For better sleep. Mary V. recommended using THC. Other suggestions were Tylenol PM (Chuck and Alison), Unisom or its generic version (Alison), and melatonin (Kyle recommended trying 5 mg. then reducing to 3 mg. if possible).

For leg cramps: Lory recommended drinking pickle juice (which also helps with RLS). Dave O. recommended drinking tonic water, which helps in a couple of minutes. Marilyn M. has found relief by taking one teaspoon of prepared yellow mustard (she uses French's), which works in less than a minute.

Molly reminded everyone to be careful about touching their eyes as COVID can enter the body through the eye which masking will not prevent. **Gail M.** commented that COVID impacts the entire body and we

do not know yet how it impacts those with compromised immune systems. Gail also commented that a lot of drugs cause deficiencies in electrolytes such as sodium, magnesium, potassium and calcium. Gail remarked on the importance of staying hydrated. She carries a calcium supplement with her and when her body spasms she puts it under her tongue which helps. Several people also commented that they have had some issues with the new portal at Emory. They are not seeing their test results as quickly as before and some results are lacking the details that they used to see. Note that the Southside group will host a session on **My Epic Patient Portal / Physician Communication** at this month's virtual meeting on Saturday, February 25..

Submitted by Wendy R.

Meeting Minutes
Southside Virtual MM Support Group
February 25, 2023

Business and News

Next Meeting: **Saturday, March 25, 2023**, at 10 AM. Presentation topic: **Front and Center**. Myeloma Awareness Month Reports -*How did you celebrate?*

Reminder: **"For Men Only" Group** meets on Tuesday, March 28, 6:00-7:00 PM.

March is Myeloma Awareness /Action Month! Please do something to spread the word about myeloma. There may be others who need to know about the same resources you do. There is a 31-day Fitness Challenge, give a talk to your church or social/civic club. Submit your story with a picture so others can learn from you. IMF theme: What's your Myeloma Story? <https://mam.myeloma.org/>

Guest Speaker Presentation

Thank you to **Gail M.** who hosted this month's zoom session with 30+ attendees. The meeting opened with a moment of silence by Doris. We welcomed guest speaker, Rosie Pruitt, PA-C of Emory Winship. Her topics were **Effective Patient-Physician Communications: Navigating care teams** and the **Patient Portal (EPIC)** to improve your overall healthcare experience. Rosie shared that Emory Winship strives to achieve patient-centered care. This healthcare model emphasizes the patient as the most important member of the healthcare team. She displayed a Venn diagram graphic of all our care providers with the patient in the center of the circle. The **Immediate Care circle** of providers includes *nurses, PAs, physicians, social workers, pharmacists, nutritionists, and medical assistants*. The **Extended Care** set of providers is an extension to the core diagram to include *Rehab medicine, based on interventional radiology, psychiatry, spiritual health, reproductive health, integrative oncology* and more.

The *Immediate Care team* is all available to you, so seek the medical staff as needed. The Emory healthcare model is also beginning to assign a Medical Assistant to each Physician team. This allows the entire team to know their patients they serve. Routine patient care reviews ensure the best medical outcomes. Rosie noted that two of the most underutilized healthcare team members are the *pharmacist and the dietician*. **Dr. Kathryn Maples, PharmD**, an oncology pharmacist, specializes in myeloma. She can review your medications, potential interactions and side effects, dosages, and current research. **Stephanie Boyea, Dietician**, can also help you with weight loss or gain, nutrition needs and the effects of *Dex* on blood sugars (medication induced diabetes).

Winship's **Clinical Trials (CT) program** coordinator and advisors can explain the CT opportunities for you to consider and consent. **Social Workers** are another underutilized resource. They can help with locating patient subsidy programs for cancer care to reduce the cost to very expensive cancer medications, transportation, and more. It is comforting to know that all these experts can provide valuable support. To ensure the success of personal healthcare the *patient/caregiver must still be his/her own best advocate*. Be aware of medical mishaps with blood draws and medical appointments can occur based on a miscommunication between the provider written orders and the performed labs and testing. It is important that the patient pays attention to standard lab draws, be engaged in routine care and report any issues or concerns to their providers. Other changes made to improve the *Quality of Life (QOL)* for the patient is the amount of time the patient has to wait in the clinic following the five minute DARA subQ injection. The patient no longer needs to sit for hours in the infusion center if there is no negative effect from the injection.

Rosie emphasized the **Mission of the Emory Winship** team which includes the final phrase *"...to improve the patient experience by centering care around the patient in an environment that nurtures trust, hope, courage, and compassion*. The benefits of communication include *patient satisfaction, empowering patients as decision-making members of the care team, allowing a better understanding of one's condition and care plan, and facilitating efficient exchange of information*." The new **Emory Winship Tower in Midtown** is scheduled to open in May 2023. The facility design and medical practice will be a continuation of the *patient-centered care philosophy*.

Patient-Physician Communication can take place face to face or via telemedicine appointments. Regardless of format, please bring a list of your concerns. Ask questions. You should have at least two questions for each visit. Study the lab values your provider deems most important for your condition, i.e. *Any side effects? Why was this medication or clinical trial chosen for you over other treatments? Better communication can mean more comprehensive care. Your provider should know about any non-medical issues that may compromise the best outcomes. Is transportation an issue? Can patients only drive during daylight hours, attend appointments around work / kids' schedules, driving long distances a problem? What are some of the medications contraindicated?*

Whether your physicians are from Emory Winship, Kaiser, Northside or your personal provider, be sure to have all your important numbers for your care on file in advance.

- For **urgent, same day issues, weekends** -- new chest pain, concerns about infection, symptom management with medications, uncontrolled bleeding, you need to go to the Emergency Room or urgent care.
- For **non-urgent issues**, use the EPIC PATIENT PORTAL. You should receive a response within 48 hours at the latest. Do not hesitate to follow up on earlier contacts.

- Call the clinic. Emory has a dedicated hematology/oncology clinic number – **404.778.0519** (Dept. of Hematologic Malignancies and BMT).

The main Emory Winship contact number – **404.778.1900 (Emory Triage line)** may have long hold delays and is understaffed. Messages to the clinic via patient portal can include mild symptoms, follow-up questions to your visits, Rx refill requests and other general questions. Personal emails for your providers are on a case by case basis. – and by provider.

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Signing up for Epic – MyChart Patient Portal

You will first need an activation link. You can sign-up through self-service or work with tech service at Emory Winship. Have Emory Healthcare send an activation link. Call **404.727.8820, Monday-Friday, 7:30 – 5PM**. For self-help, go to <https://mychart.emoryhealthcare.org/>. There is a **MyChart app** on Androids and I Phones. Creating passwords, you will remember and with requirements from the provider can be a challenge. MyChart is no different, but here are the requirements. The My Chart Patient Portal password must be 8-20 characters and must contain at least:

- One lowercase
- One uppercase
- One number

There are still some problematic “growing pains” with MyChart. For example, if you see that you cannot request refills on your medication list, it means the medication needs to be ‘reconciled’ in MyChart by the staff. Type the medication into the box at the end of the list. Rosie also demonstrated how to get a look at your labs with comparisons over several months. **If you need help with your first steps to setting up**

MyChart, let us know.

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Group Discussion:

Vena asked about communication across healthcare facilities about medical issues. She is a member of Kaiser. If the system uses EPIC to maintain medical records, there should be the capacity to communicate. Kaiser has EPIC and can communicate with Emory.

As a patient/caregiver, know as much as possible about your myeloma. Every patient is different, including medications and progress. Know which labs are most important to your care and what values are optimal. At each visit, find what labs are being drawn for the next appointment. Follow up in MyChart, so you can discuss your progress with your provider. Gail suggested that if you have not had your Vitamin D level assessed recently, please request it for your next labs. Vitamin D has been shown in studies to have an essential role in myeloma.)

Flora wants to discuss having a “Women’s Only Group. She feels we should be able to share among ourselves experiences that are unique to us. **Rhea** is a patient of Dr. Lonial coordinates her care with community doctors in Marietta. Rhea’s practice model is not unique. We are fortunate to have a premier Myeloma Research Center at Emory Winship with researchers/practitioners who study the latest treatments, treatment combinations, and clinical trials. With Georgia so large geographically and many practitioners in the metro area, Emory Winship collaborates and coordinates care with many practitioners all over the Metro area and State.

Extended Care Team – it is best to get a referral from your immediate oncology care team.

Thank you, Rosie, for researching these Emory Winship resources and sharing them .

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| Interventional Radiology – minimally invasive treatments – 404.778.4747 | Interventional Pain – cancer pain management – 404.686.2410 |
| Integrative Oncology – Mindful approach to symptom management – 404.778.0600 | ICC – Immediate Care center. Not a walk-in clinic – 404.778.0519 |
| Psychiatry – Mental Health Services – 404.778.1900 | Radiation Oncology – Radiotherapy technologies/Treatments – 404.778.3473 |
| Rehabilitative Medicine – Rehabilitation of cancer-related impairments – 404.778.1900 | Reproductive Health – Fertility health, sexual health: Females – 404.686.8114; Males – 404.778.3401 |
| Spiritual Health – Counseling and Spiritual Support. Winship – 470.446.7844; Midtown – 470.808.2580; SJH/JCH/Buford – 470.487.2457 | Supportive Oncology/Palliative/Hospice – Symptom Management. Supportive Oncology – 404.778.1900; Palliative care - 404.778.7777 |

“For Men Only” AAMM Support Group meets every month on the 4th Tuesday at 6PM . Join the Men’s group to share your experiences and concerns with others on the same journey. Hear about resources and ways to navigate the myeloma care maze. If you are a male myeloma patient, please mark your calendar to attend our Group, “For Men Only” at our next meeting in March. We just meet for an hour, but we are able to speak freely and share issues that might be unique to us as male patients.

Ask Dr. Durie: Is CAR T-cell therapy being used to treat newly diagnosed multiple myeloma? **Yes.**

New study presented at ASH 2022 Conference. New development of CAR-T cells. Mostly for High-risk myeloma patients. All patients have achieved MRD negative status.

Respectively Submitted, Gai