

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

November 4, 2023

Business and News

Next Meeting: Saturday, December 2, 2023, at 11:00 AM, VIRTUAL Group Discussion and Breakout session

Guest Speaker Presentation

Charise Gleason, MSN, Nurse Practitioner /Multiple Myeloma Program joined our November meeting. Her topic presentation: Treating myeloma *Do We Have a Plan?*

Charise started the program by reviewing treatment backbones for MM in frontline and early relapse. Combination therapy using two drugs and a corticosteroid is the “backbone” for newly diagnosed and early relapsed patients. Immunomodulatory agents (IMiDs -Rev/Pom), Proteasome inhibitors (PIs- Velcade/Ninlaro/Kyprolis) and Monoclonal antibodies (MABs- Dara/Sarclisa/Elotuzumab) are the drugs prescribed for triple regimen (2 drugs and DEX) for induction and initial relapse settings. The term *early relapse* is considered 1-3 prior lines of treatment. There is a preferred regimen of when to prescribe these drugs. Patient sensitivity and drug availability will determine the treatment sequence. Side effects and drug sensitivity symptoms have a huge impact on drug dosage, timing, and monitoring. Your physician and healthcare team will ask questions on your status with what may seem monotonous. Be mindful that it helps them determine your drug tolerance and the effectiveness of the treatment. Be honest with your answers and always tell them about any new symptoms or concerns on every visit. You are the first line of defense.

Clinical Trials establish the parameters of promising new drugs.

Phase 1: First use in humans (20-80 patients)

- Determine tolerance, ID adverse effects, early data on drug effectiveness

Phase 2: Evaluate effectiveness for specific type cancer (up to 100 patients)

- Monitor treatment closely for adverse effects (AE)

Phase 3: Further data collected on Effectiveness and Safety vs Standard of care (SOC)- 100s of patients

- Trial may be single or randomized at multiple locations
- Trial includes standard of care arms or placebo if no SOC available

Charise spent time explaining specific drugs.

Venetoclax is a BCL-2 Inhibitor used specifically for patients with t (11:14) translocation. It is on Clinical trial for newly diagnosed or relapsed MM patients. Side effects are closely monitored. **Selinexor** is a XPOI inhibitor that prevents cells from transporting suppressing and abnormal proteins from the cell nucleus. It is used after MM progression from PI-IMiD therapy. Premeds for nausea, anorexia and dosage are closely monitored.

CAR T cell therapy is a process of using a patient's T cells which are genetically modified in a lab to express antigens on malignant tumor cells which promote attack and kill myeloma. CAR T cells are harvested from the patient, modified in the lab (4-8 weeks), then returned to the patient. A bridging therapy may be needed during the wait time making aggressive and high-risk myeloma a determining eligibility factor. FDA approved *IdaCel* and *Ciltacel* are currently available in some cancer facilities, but CAR T manufacturing facilities are still limited.

Bispecific Antibody is a manufactured antibody with two targeted regions with a linker that binds to different types of antigens (t-cell and malignant cell). The linker brings the two cell types together causing the t-cell to kill off the tumor cell. Current bispecific available are *Teclistamab*, *Talquetamab*, and *Ebranatamab*. Dosing regimen varies by drug. Both CAR T and Bispecific require 4 prior lines of therapy or clinical trial to be eligible for treatment. T cell mechanism of action is to target and kill myeloma cells expressing BCMA. Patients are monitored closely for several weeks during treatment to minimize adverse effects and toxicities from Cytokine release syndrome (CRS), neurotoxicity (ICANS) and infections.

Charise noted that new treatments in development will be addressed at this year's ASH conference in December. There will be more information at the ASH review session in January.

Submitted by Sandy W.

Meeting Minutes
Southside Atlanta MM Support Group
November 25, 2023

Next Meeting: December 23, 2023 (Virtual) at 10:00 AM. Patient and Caregiver Voices

Next Meeting: “For Men Only.” Tuesday, December 26, 6:00 – 7:00 PM

We opened the meeting with a moment of silence and gratefulness for the Holiday Season led by **Doris. Dirk** shared that the Men’s Only group finds fellowship to be a special time to share and bond over their journey with others with myeloma in common. Hearing from other men informs those present on a different level.

Featured Item

We emphasized again the great resources for myeloma provided by the many myeloma-focused organizations, including Healthtree, IMF, LLS, MMRF, Patient Empowerment Network (PEN), and Patient Power. We watched a 20-minute video from Patient Power on “How Myeloma Effects Your Kidneys” featuring Dr. Brandon Blue, hematologist/oncologist of Moffitt Cancer Center, Tampa, FL. Symptoms of kidney problems can include increased urination, impaired filtering, and limited urination. Our bodies can become more sensitive to dehydration due to the medications we take. Teas and coffee can make us hydrated. Water is much better. We monitor kidney function by creatinine levels on our lab reports. If kidneys stop working, we can do dialysis, but naturally functioning kidneys is better. Several shared that the video was very helpful to them. There are two additional videos in this series – “How myeloma effects your cardiovascular system” (11 min) and how myeloma effects your nervous and gastrointestinal system” (15 min). Links to these videos can be found on your monthly “agenda” or information document. **Nycole** shared with us a cardiovascular oncologist. **Dr. Lalitha C. Medepalli** at Northside is a cardio-oncologist. Her clinical interests include noninvasive cardiology, **women’s heart health and cardio-oncology**. An active member of the local community, she promotes women’s heart health awareness and the early detection and treatment of heart disease.

Please also look for videos on bispecifics and medication side effects. More of us are already taking or having to learn more about bispecifics as we consider new regimens that work. **Alma** is happy to speak with you about her experiences so far with a bispecifics regimen. (Healthtree Foundation – “New therapies, New Side Effects” 24 min - <https://www.youtube.com/watch?v=ocpojo8S0hc&t=57s>).

We took time during our November meeting to get to know each other a little better – beyond myeloma. It was a little difficult at first for some members to separate their

myeloma life from who they are/were outside of their myeloma journey. As we thought, we have an exciting group – individually and collectively. We have world travelers, musicians, techno-geeks (my word), master gardeners, volunteers and more. Below is just a sample:

Meet your members.

Wanda P. is a long-time member of a Book Club; **Dirk** jams with his acoustic guitar and entertains his wife and daughter among others; **Nycole** has taken her furthest trip this far to Australia and loves spending time with her mom. She enjoys being a “resource person” and helpful to others....she enjoys finding videos featuring the enduring human spirit, for example the blind man and woman living well into their 90s and providing care for others; after being diagnosed with myeloma, **David** and his now extended family took a several times postponed trip to Tanzania (East Africa) and like Nycole, witnessed “the great wildlife migration”. **Gail** enjoyed her first safari in Tanzania a few years ago; **Doris** enjoys her time with her neighborhood planning unit/organization – one of the first groups with which she shared her myeloma diagnosis and subsequently started the Support Group – she exercises at the Ben Hill Recreation Center and swims at the Bowden Center – she stays connected to family and friends; **Denise W.** is retired from IT, where she worked with **Jeff W.** She loves to travel with Brazil being one of her favorite trips so far. Her sister, **Janice**, is about 70-days post-transplant and enjoys being creative.

Bernard has a “helping spirit.” He makes calls to check on members, shares his knowledge and resources as a retired plumber, and shares other resources (financial, for example), as he learns about them; **Barbara W.** finds joy in her 3-year-old granddaughter – she enjoys family and recently celebrated her 50th wedding anniversary! She retired from the Georgia Dept of Revenue, teaches Sunday School, and can join **Dirk** in our entertainment hour, as she loves to sing in her church choir. She enjoys helping others and joins a coat giveaway project each year. She does Tai Chi and dancercise at her Senior Center. She loves watching butterflies and hummingbirds in her back yard that are nurtured by her husband; **Tom** loves spending time with his grandchildren and counts as one of his great life’s experiences the 2016 World Series, where he witnessed his beloved Chicago Cubs become victorious over the Cleveland Guardians!; **Jeff** calls himself an audiophile – he has over 1000 CDs in his collection! (*What’s your filing system?*). He loves to bike and walk – still working full time.; **Sarah** was diagnosed Mar 2022 and is doing well. She is an avid gardener and is a Master Gardener – she has published a blog in the UGA- My Community Garden; **Wanda P.** is also a Master Gardener, and though they do not know each other, spend time at the Hershel Road Georgia Cooperative Extension facility. She enjoys landscaping and creating updates on her home. Both Sarah and Wanda must complete about 200 hours of teaching to maintain their certification; our friend and Group nurse-consultant **Deborah T.** is retiring from her 40-year nursing career at the Veteran’s Administrative Hospital on January 2, 2024. She has been a member of the Southside Atlanta MM Support Group since 2005, and her patient Lonnie introduced her.

Congratulations, Deborah!; **Joyce J.** enjoys swimming and cooking some of her favorite dishes. She has one son and is retired from the Army –still working full-time.

We spent a few minutes with Group members sharing their in-patient stem-cell transplant experiences with David, who will travel from Savannah to Emory Winship in one week to get his transplant. His wife has been a nurse for more than 25 years. Janice has had the most recent SCT of the group (September), and shared tips, as did others in the Group. Some practical advice tips were to 1- listen to all the nurses advised him to do, and 2- bring his computer or books. There will be some down time.

Announcements/Educational Sessions

A market research company conducts patient research. Currently working with a team to understand treatments of Multiple Myeloma. The study is being conducted via an hour-long online interview where participants will give their opinions on medication brochures, how they look, how they are worded, what it communicates, etc. **Participants receive \$145** for their feedback, paid through Tremendous.com. We were asked for some additional information and will share that and links with you.

November is National Family Caregivers Month (NFCM).

- Tip cards for Caregivers - Tip card for Caregivers (IMF)

Did You Know That Medicare May Cover Some Dental Services for Cancer Patients?

For the first time ever, Medicare will cover dental services that are necessary before or during certain cancer treatments. Some examples of these cancer treatments with tandem dental services covered by Medicare include CAR T-cell Therapy and stem cell transplant, among others. The button below provides further details to share with your dental provider.

<https://www.cms.gov/medicare/coverage/dental>

Cancer Coach Live/LLS

- Bispecifics – Who it effects. Video – 9 minutes: from BlackDoctor.org. Who it effects – Bispecifics -Video -Who it affects.
- **Healthtree Foundation**
- **Twelve common classes of drugs/treatment options used to treat myeloma.**
 - 12 Common MM Treatment classes
- **Dexamethasone and Cataracts** (4 min video). Dex and Cataracts

- **Side Effects of some new medications.** Medication Side Effects - 24 min video
- **Free Light chain ratio** – Explained. 4:18 min

IMF – myeloma.org

- Info Line - 800-452 CURE (2873)
- **M-Power makes an impact.** Myeloma Made Simple: **Disparities Made Simple | What Health Disparities Do Minority Patients Face?** Dr. Mikhael, 6:21, [Myeloma Made Simple: Disparities Made Simple | What Health Disparities Do Minority Patients Face? \(youtube.com\)](https://www.youtube.com/watch?v=...)
- **Two bispecifics approved by FDA in August.** Talvey™ (talquetamab-tgvs) targeting the G protein-coupled receptor family C group 5 member D (GPCR5D) and accelerated approval to Elrexfio™ (elranatamab-bcmm), a bispecific B-cell maturation antigen (BCMA)- directed CD3 T-cell engager, for adult patients with relapsed or refractory myeloma who have received at least 4 prior lines of therapy.
- **Advances in myeloma research from ASH 2023.** Dr. Durie and doctors. December 14 @ 2:00. Replay available – [IMWG Conference Series 2023: Making Sense of Treatment \(myeloma.org\)](https://www.myeloma.org/conference-series-2023)
- Dr, Shah - [Living Well With Myeloma: Can Nutrition Improve Quality of Life and Outcomes in Myeloma?](https://www.myeloma.org/living-well-with-myeloma)
- **High Risk MM Support Group** - HRMM.support.myeloma.org
- **SMART patients** - [Multiple Myeloma | Smart Patients](https://www.myeloma.org/multiple-myeloma-smart-patients)

LLS – lls.org

- **New! Online Chat About Nutrition** – December 14 from 6-8 pm ET and January 11 from 6-8 pm ET
- **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
 - **Caregiver Workbook.** The Caregiver Workbook comes in a tote with a journal and pen Caregivers may order a copy of the full workbook by calling (800) 955-4572.
 - **Worksheets.** [Caregiver Support | Leukemia and Lymphoma Society \(lls.org\)](https://www.lls.org/caregiver-support)

Patient Empowerment Network

- Managing Side Effects of Car-T Cell Therapy

- **About Clinical Trials** – w/patients. Clinical Trials - Jack A. and Thomas G
- **Myeloma Combination Therapy. Classes of Drugs.** What Patients should know – Recorded - 3:25
- **How can myeloma patients cope with fatigue** – Recording – 1:37
- **What are the common issues that CAR-T Care partners face?** Recorded - 5:49

Patient Power

- **In three parts – videos. MM and your kidneys; MM and the GI and neurological systems; How does MM affect your CV system.** How MM affects your kidneys - 20 min
- **Patient Power – REGISTER. Answers Now: How to Have a Safe Holiday Season With Cancer.** Thursday, November 2nd, 2023 from 11:00-11:45am ET/ 8:00-8:45am PT
- **Developing Research and New Myeloma Treatment Options** – Brandon Blue. 5:40
- 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?

Respectfully submitted, Gail.

Join us at AAMMSG monthly meetings: