

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

September 9, 2023

Business & News

Thank you to **Dirk B.** who hosted the virtual meeting with approximately 35 attendees. The meeting began with our guest speaker discussing multiple myeloma (MM) related sleep issues and solutions; and then moved to an open discussion to share patient updates, treatment details, and helpful tips.

Guest Speaker & Presentation

Thank you to **Sara Scott**, PharmD, BCOP and Multiple Myeloma Clinical Pharmacy Specialist from Emory Winship Cancer Institute, who joined the meeting to discuss sleep concerns for myeloma patients and their caretakers; and answer our questions on this topic. Feel free to contact Sara with any questions that you may have. Sara's email address is: sara.a.scott@emoryhealthcare.org

Sleep is vital for many reasons, including brain performance, mental and physical health, immune system health, and disease/disorders prevention. There are many causes of sleep disturbance including sleep disorders, aging, illness (depression, pain, cancer), stress, and stimulating medications such as steroids. Important sleep components include amount of sleep, sleep schedule and sleep quality.

Healthy adults should have about seven hours of uninterrupted sleep per night; and adults dealing with illness need more sleep to support recovery.

How can we improve sleep? Many MM patients as well as much of the general population experience sleep issues.

There are many non-medical approaches to improve sleep that are effective and preferred over medication as a first step. Practicing a good sleep hygiene routine is very important. Sara discussed non-medical recommendations to improve sleep before turning to medications or supplements. *Relaxation* before bed is something that has shown to help with sleep. *Deep breathing, meditation, and journaling* before bed can clear lingering thoughts out of your brain onto paper and avoid obsessing over them overnight. *Cognitive behavioral therapy* yields helpful exercises to reorient your mind and focus on maintaining a regular sleep schedule. Try going to bed at night and getting up at the same time every day to maintain a regular sleep pattern. Create a cool environment with comfortable bedding where you are not disturbed by people, pets or distracting light and electronics.

There are things we can do during the day to prepare for good sleep as well. Try getting outside in the sun for 30 minutes of walking each day but avoid vigorous exercise too close to your bedtime. Avoid large meals and excessive amounts of alcohol right before bed. When you eat a large meal and go right to sleep, your body is focused on digestion rather than the rest and repair that it should be

focused on. The consumption of alcohol is associated with significant decreases in sleep quality.

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Ways to improve sleep include:

- Practice meditation, relaxation techniques, and cognitive behavioral therapy
- Maintain a regular sleep schedule.
- Create a comfortable sleep environment with minimal distractions.
- Get outside in natural sunlight daily.
- Exercise, but not right before bedtime
- Avoid large meals and alcohol right before bedtime.
- Avoid stimulants close to bedtime (caffeine, nicotine)

If non-prescription modifications do not adequately improve sleep, prescribing medication may be a consideration. The first two options recommended are *melatonin* and *magnesium*, which are both OTC supplements that help your body regulate sleep and wake cycles. With Melatonin there is no concern of drug interactions or toxicities, although it does not work for everyone. Magnesium has been shown to help the brain and the heart and support relaxation; and in theory actually aid in regulating melatonin production. *Ramelteon* is a prescription version of melatonin. *Benadryl* is not recommended for patients over the age of sixty-five since

potential side effects include an increased risk of falls, dry mouth, and urinary retention. *Ativan*, *Klonopin*, and *Xanax* are benzodiazepines that are generally reserved for when nothing else is working to regulate sleep. Trazodone (non-benzodiazepine) is an antidepressant often used for sleep benefits and is sometimes preferred over the benzodiazepines.

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Medications that support sleep include:

- Non-prescription options: Melatonin, Magnesium, Benadryl, and ZzzQuil
- Ramelteon (similar to Melatonin)
- Ambien, Sonata, and Lunesta
- Belsomra
- Ativan, Klonopin, Xanax (benzodiazepines)
- Trazodone (not a benzodiazepine)

There are several herbal sleep aids on the market, but there is not significant related efficacy data available and are not regulated by the FDA. Herbal supplements may also cause side effects in cancer treatments or significant medication interactions, which is the primary reason it is best to avoid them. Always discuss the use of herbal supplements with your pharmacist and physicians. Sara is overly cautious when it comes to herbal supplements and if there is any risk of the cancer therapy not working as well due to supplements, then she does not recommend taking them.

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Herbal sleep aids to avoid include:

- Valerian root
- Lavender – use aromatherapy Lavender oil on a pillow instead of orally to avoid nausea.
- Passionflower
- Glycine
- CBD - using the legal alternatives is all that is recommend.
- Tryptophan
- Gingko biloba
- L-theanine
- Additional herbal supplements that Sara recommended avoiding most of the time include:
 - St. John's Wort
 - Milk Thistle
 - Garlic
 - Kava – can cause liver damage.
 - Black cohosh
 - Goldenseal
 - Echinacea
 - Turmeric - can increase risk of bleeding at high doses.
 - Ginseng
 - Ginkgo biloba
 - Green tea extract – interacts with Velcade.

Presentation Questions & Answers

Q: What are some foods to avoid due to MM drug interactions? **A:** Grapefruit and grapefruit juice, Seville oranges, and starfruit can interfere with Velcade and Venetoclax. **Q:** Why is garlic on the ‘avoid’ list? **A:** Garlic supplements can potentially increase the risk of bleeding. Eating garlic in your diet is fine; that is not enough garlic to cause problems. It is concentrated forms of supplements that can cause problems. Garlic does not have a lot of specific drug interactions other than the concern for bleeding. **Q:** What is the issue with green tea extract, and what about drinking green tea? **A:** Green tea can interact with Velcade. Sara tells her patients that it is OK to drink green tea just not on the days when taking Velcade because it affects how the proteasome inhibitor works. It is best to wait a day or two after your Velcade treatment to drink green tea to allow time for the Velcade to complete its job. **Q:** I am on a clinical trial (CT) which includes 40 milligrams of dexamethasone, and the trial is very specific about taking it all in one day. Do you know if there is any flexibility with CTs? **A:** It depends on the trial, but many do have flexibility. If you cannot separate the doses throughout multiple days, then it is recommended that you take the dexamethasone as early in the day as possible to minimize the effects that it has on sleep. **Q:** Why is dexamethasone used so frequently? **A:** When DEX is used with other drugs, it makes those other drugs so much more effective. Dexamethasone can also help with pain, especially bone pain, so there are a lot of benefits to taking it. **Q:** Are there

any studies that are looking at alternatives to dexamethasone? **A:** Studies are not necessarily looking at alternatives to DEX, but there are therapies that do not have to be given with a steroid. Most of those are in the later lines of treatment. **Q:** Please comment more on the use of CBD. **A:** There is a lot of research data on the benefits of CBD for pain, but not specifically on the use of CBD in combination with cancer therapies. It is an area of growth but may be worth trying the legal CBD alternatives cautiously if you are interested in doing so. **Q:** What new MM drugs/treatments are you (as a pharmacist) excited about? **A:** There are two new drugs approved for MM in the last month, which are both bispecific antibodies. Both are already available at Emory and treated the first patients last week. Also, there are some steroid-free therapies and CAR T-cell therapies that are underway.

Open Group Discussion

We welcomed two new members. **Bianca M.** was recently diagnosed with IgG Kappa MM after being initially diagnosed approximately 5 years ago with smoldering MM. Bianca asked if anyone could recommend an oncologist in the Kaiser network. **Dirk** recommended Dr. Kondapaneni and has been very happy with her for six years. **Karen C.** has had a stem cell transplant (SCT) and has started a CT using Pomalyst and Dex. She would like to learn more, and talk with others about their experiences with high-risk MM. Karen's email address is: cleveland123@comcast.net

Jim M. is starting CAR T-cell therapy in mid-September. During the process, a brain test is administered every four hours. If a test fails, additional drugs are administered to correct problems. Jim mentioned that Cytosan is one of the drugs being used during the process.

There was discussion surrounding **dental issues** related to some of the MM drugs and the importance of taking extra care of teeth and gums. It is essential to find a knowledgeable and competent dentist who understands specific dental risks associated with MM. Many patients who have always practiced good dental care have reported unexpected dental issues with gum-line cavities, gum infections, tooth decay, loosening teeth, and other issues. MM patients mentioned having to see their dentists more frequently than the recommended twice a year for cleanings and fluoride treatments. **Joy** commented that she has had issues with her teeth and is looking for recommendations for a Dental Oncologist. Many dentists are afraid to treat her after X-rays reveal the lesions in her jawbone. There were no recommendations for an oncology dentist, but it was suggested that she see an oral surgeon. They are more likely to have experience with MM patient needs, including monitoring for Osteonecrosis of the jaw (ONJ). **Rick D.** was diagnosed with ONJ, which his doctors believe is associated with his prior quarterly bisphosphonate (Zometa) use for 7 years (2005-2012). **Sandy B.** reported that her ongoing issue with dentures seems to finally be resolved. Her first set of dentures were fitted prematurely before

having all teeth pulled which resulted in poorly fitting dentures. She is currently adjusting to a new set that seems to be working well and much more comfortable. Sandy explained that implants were not an option for her because there was not enough bone to support implants, so she had to opt for dentures.

There was some discussion about **vaccinations and re-vaccinations post stem cell transplant (SCT)**. The latest Covid vaccine BXX.1.5 is now available and there were many comments from those members planning to get it. Several members intend to get the flu, RSV, pneumonia, and Covid vaccinations separately (not in combination with any other vaccines) due to prior side effects that they experienced when combining vaccines. **Donna R.** had a SCT, and when it was time to be re-vaccinated, she had a very bad experience going through the Kaiser network. She explained that Kaiser medical personnel did not understand the post SCT vaccination process for MM patients.

Thankfully, she was finally able to be re-vaccinated, but it was a very long (over a year) and quite stressful ordeal. Donna mentioned this to warn others and hopes that no one else has a similar experience. **Susan C.** had all her re-vaccinations post SCT in one day and was sick for a week. She will not do that again and wanted to recommend to others to not do this either.

Several people suggested helpful tips for **relieving cramps** in legs, feet, and hands, which is a common side effect of MM drugs. The tips included

taking *magnesium* supplements, increasing *hydration*, drinking *pickle juice*, eating *yellow mustard*, and a bar of *Irish Spring soap* in bed near your feet.

Open Discussion Questions & Answers

Q: Is there a website or another resource that helps you interpret FISH test results? **A:** **Jim M.** recommended using the IMF website and/or calling the IMF helpline and leaving a message. They will call you back and help you.

Q: Does the Northside group attend the LLS Light the Night walk? **A:** **Doris M.** commented that these events are very good and many people from the Southside group attend. Others commented that they have also participated in prior walks and recommend them.

Q: What are some financial assistance options? **A:** Multiple group members suggestions:

- Leukemia & Lymphoma Society - LLS.org
- Contact the drug manufacturers for any of the MM drugs that you take (Genentech was mentioned for Venetoclax and Janssen for Daratumumab)
- Consult with a social worker where you are treated.
- IMF – myeloma.org
- MMRF – themmrf.org
- HealthTree Foundation

Submitted by Wendy R.

Meeting Minutes
Southside Hybrid MM Support Group
September 23, 2023

Next Meeting (VIRTUAL): Saturday, October 28, 2023 at 10 AM.

Speaker – **Kendelle Miller**, MSW, LCSW, ACM-SW, Oncology Social Worker, Winship Cancer

For Men Only: Tuesday, October 24, 2023, 6:00 – 7:00 PM

Business & News

Our hybrid meeting in September was more successful with audio to hear each other than in the past. Since the library opens at 10 AM, we may shift the start time of the meeting to 10:15 AM going forward. Stay tuned. Thank you, Veronica P., for your help with in-person technology. This month's meeting is virtual due to the library being closed for renovation.

Group Discussion

We had one new member; **David H.** joined us in September. David was diagnosed in May. He is asymptomatic and his MM findings were from a routine CT scan. The radiologist noted some scattered lesions that were of concern. He sees

Dr. Lonial as his myeloma specialist. It helps that his wife of 35 years is a nurse with this new diagnosis. David resides in Savannah and has a community oncologist there. (There is also another member, John Z, from Savannah.)

September is the month to celebrate/raise awareness for all blood diseases, including blood cancers and sickle-cell disease. We encouraged everyone to participate in the annual fundraising event for **LLS, Light the Night**. We surpassed our goal of \$2000 this year. Thank you to all who contributed to this endeavor. LLS helps many of our members financially with different buckets of funds. There were issues on our site in trying to donate funds correctly attributed to our Support Group. We are working with Samantha of LLS to help us get this fixed. Thanks again everyone for your support.

Teonna shared with the group that she has a fractured femur and was given two surgical options: 1- intramedullary nail procedure or 2- a full hip replacement. Veronica shared that she had a hip replacement. Her biggest problem was finding a reputable orthopedic oncologist. She was with Kaiser, but ultimately had surgery with **Dr. Jonathan Michael Morris** at Emory (orthopedic surgeon specializing in musculoskeletal oncology). None of the rest of the group has expert knowledge of these procedures. Teonna was advised to call the nurses helplines at LLS and IMF for assistance.

Sandy W. reminded the group that there are COVID home tests available by mail once again. The new variants are more contagious than previous ones, so please remain vigilant.

Sandy only had congestion and a sore throat. She took a precautionary COVID test which was positive since she had an appointment at EMORY that week. Gail reminded all that we should ask for Paxlovid as soon as possible with COVID symptoms to reduce potential impact and keep us out of the hospital. As myeloma patients and being older, our immune systems are not as strong as they could be. “Long COVID” is a real thing. Having COVID symptoms persist for months and even years is now a part of our COVID experience. Our lungs, heart, kidneys, and other organ systems can be permanently affected. There is a disability code with the Social Security Administration for Long Covid.

Patient Updates

Alicia shared that she was not working. She has been on Teclistamab since after Labor Day. **Joyce J.** is not high risk. She is deemed a CAR-T cell therapy candidate. **Pat C.** came to the in-person group with her husband, her sister, and her daughter. Her sister, **Bert**, (from Fort Wayne, IN) was Pat’s first caregiver. Twenty years after her own diagnosis, her husband, **Mike**, has been diagnosed with myeloma this past March. Mike is also being treated at Northside and is currently on Velcade, Revlimid, and Dex (RVd). **Jeff W.** reported he had gotten three vaccines at the same time flu, COVID booster, and RSV. He was told by his medical team it was okay.

We discussed the SSA’s requiring members of our group to repay funds they were granted. From August to September, we heard in the news

that these “overpayment” errors are very widespread. There will be investigations by congress and others into this and how to address the problems with the SSA. Stay tuned.

Last month, a Food and Drug Administration advisory panel found that phenylephrine — an ingredient found in medications like Sudafed PE, Sinex, Dayquil and other oral formulations of the drug are ineffective at treating cold and flu symptoms. Jeff shared that in Europe, they have had effective medication since 1978. He said that medications take a very long time to be approved through several randomized clinical trials.

Announcements, Educational Information/Opportunities

U.S. Food and Drug Administration (FDA) recently granted accelerated approval for two **bispecific antibodies**. On Aug. 10, the **FDA approved talquetamab** (Talvey) for adults with relapsed or refractory multiple myeloma. Days later, the agency granted approval for **elranatamab (Elrexfio)** for adults with relapsed or refractory disease.

COVID Updates – from Dr. Durie’s blog. Several new COVID-19 variants are currently circulating, with EG.5/Eris as the dominant variant (24.5 percent of U.S. cases); FL.1.5.1 following at 13.7 percent of U.S. cases; XBB.1.16.6 at 9.9 percent; and BA.2.86/Pirola as a variant under monitoring (VUM) due to its concerning several

mutations. The good news is, updated Pfizer-BioNTech and Moderna COVID-19 vaccines are now available and have been tested to be effective in fighting against XBB lineage of omicron variants, including EG.5 and BA.2.86. Currently, the U.S. government is still going through some supply issues and issues in health insurance coverage for the new COVID-19 vaccines. “I also highly recommend the use of high-quality masks in high-risk situations of COVID-19 exposure. Avoid crowds and indoor gatherings as much as possible and be proactive if you test positive for COVID-19.

- **Music therapy and Medicine –**

<https://www.youtube.com/watch?v=oCHZw11RUoI> Anthony Arant, Certified Clinical Musician, ajja87@hotmail.com

HealthTree Foundation

- First innovation in stem cell mobilization for multiple myeloma was approved on September 11, 2023. BioLineRx announced the FDA approval of APHEXDA (motixafortide) in combination with Filgrastim (G-CSF) to mobilize stem cells for autologous stem cell transplants of multiple myeloma patients.

- Launch of HealthTree 2.0 “Using Technology and Revolutionary Approaches to Cure Blood Cancers” – October 23

- Neutropenia and neutropenia diet – Short video

IMF

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

- Can Nutrition improve quality of life and outcomes of Myeloma? Dr. Urvi Shah. Replay available here. Dr. Shah shows how a change of lifestyle can impact MM outcomes and survival.

LLS – lls.org

- LLS. New Portal – One stop shop for 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

- Dollar For – Agency working with LLS to help you complete applications to have your hospital bills forgiven.

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

Patient Empowerment Network (PEN)

- Myeloma Combination Therapy. 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

- How Does Multiple Myeloma Cause Hypercalcemia? – article
- Cancer Dietitian Explains What to Eat During and After Treatment.
 - Can I eat sugar? Cancer diet tips from an oncology nutritionist – video
- Should smoldering myeloma be treated or not?
- What is neutropenia?
- Women, Cancer, and Sex: Why you should ask for help
- FamiliarTreasures.com – Therapeutic Music
- Developing Research /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?

SMART

patients - <https://www.smartpatients.com/partners/imf>

Respectively submitted, Gail.