

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes Northside Virtual MM Support Group March 2, 2024

**Next Meeting:** The Regional Community Workshop is Saturday, April 13. Click the link for details.

IMF In-Person Regional Community Workshop (RCW) 2024 - Atlanta |  
International Myeloma Foundation

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Business and News

Thank you to Nancy B. for hosting the virtual meeting with approximately 30 attendees. This meeting began with an open discussion in the main forum, and then members split into separate, smaller groups for more personal interactions. These notes are representative of the main forum discussion.

**March is Myeloma Action Month!** The IMF website has suggestions for things that you can do to help raise myeloma (MM) awareness in our communities. Our actions make a difference regularly, and a great example of this is when our support group brochure is provided to newly diagnosed patients by MM doctors at Emory. More awareness leads to more support, funding, and better outcomes. Visit [myelomaactionmonth.org](http://myelomaactionmonth.org) to learn how you can get involved!

**We will not meet on the first Saturday in April.** Instead, the April meeting will be replaced with an in-person International Myeloma Foundation (IMF) Regional Community Workshop on the second Saturday of the month. In the Workshop, there will be topics presented about MM and MM issues. Two couples from our group will share their journey - **Jim M.** and his wife **Lisa**, and **Sandy B.** and her husband, **Joe**. Both Jim and Sandy are long term MM survivors, and they will share what they have learned and how their journeys have evolved. There will also be doctors speaking, mostly from Emory, and a nurse talking about side effects and answering questions. The Workshop is free, but **you must register to attend**. More information, including the Atlanta-area location, will be provided soon. In May and June, we plan to start meeting again in person at the St.

Joseph's facility, while also continuing to have a Zoom session for those who prefer to meet remotely.

### **Open Discussion and Updates**

**Nancy B.** commented that MM treatments are really evolving from clinical trial (CT) data. Nancy interacts with a lot of patients in support groups and is hearing that CAR-T is working very well for many patients. One patient has been MM-free for four years since receiving CAR-T treatment. **Kyle W.** shared that his son is conducting research at the National Institute of Health (NIH) at Johns Hopkins in Baltimore. Kyle attended an in-person research fair recently and learned more about CAR-T and receptors, and what the future holds. CAR-T has become so successful that the focus is now on side effects. There are many CAR-T CTs nationwide and much research is in process. Some of the patients have been on CAR-T CTs for 5-10 years and are cancer-free. CAR-T is also used a lot for lymphoma. T-cells are only one of several types of cells that the body uses to fight cancer. Researchers are no longer only looking at T-cells, but also at the other types of receptors that can be used, which looks very promising. **Kyle** is looking for a good source for finding CTs. **Gail M.** recommended a website for finding clinical trials, which is easier than the NIH site to navigate: <https://sparkcures.com>.

Several in the group have had CAR-T therapy and others are planning to have it. **Sandy W.** reported that **Samantha H.** just had her T-cells collected in preparation for CAR-T treatment and is doing well. **Jim M.** received CAR-T treatment several months ago and reported that he has achieved a complete response (CR) and is doing well. **Jim M.** mentioned that **Lory M.** just had CAR-T treatment and will be staying at Emory for at least another week, which is standard post CAR-T treatment. **Chuck M.** is in touch with Lory's husband, **Ed**, frequently and reported that Lory had a tough time in the beginning since receiving back her T-cells which occurs while the body adjusts, but overall, Lory is doing well. The group wishes Lory and Ed the best, and you can post well wishes to Lory at her CaringBridge account. **Jim M.** said that he suffered from nausea after getting his T-cells back and his taste for food has changed since he had CAR-T treatment. He can no longer tolerate the taste of salt. There are different types of CAR-T treatment and **Joyce** asked which is better. **Jim M.** responded that he asked his doctor about this and learned that both have similar response rates and side effects and both types of treatment work well, but there is a difference in processing time modifying your T cell collection. For

patients requiring treatment as soon as possible, Abecma, which has about a four-week manufacturing time, would be better than Carvykti, which takes about eight weeks for manufacturing.

**Mary V.** mentioned having issues with getting her prescription drugs on time. Many responded that they have experienced the same problem for various reasons including issues with doctors not calling prescriptions to be refilled into pharmacies soon enough, issues with the Emory portal, pharmacy deliveries, and other delivery services in general. There were recommendations for those that use the CVS home delivery service to have the prescription delivered to a local pharmacy and pick it up, rather than having it delivered directly to your home. Someone else mentioned getting their prescription deliveries via FedEx and using their drop off points, where they can pick up their prescription, versus having them delivered to their home. Others have their prescriptions delivered to their doctor's office or local pharmacy, where they pick them up in person. The Emory portal has known issues and some members have had success with following up with a phone call or text to Emory staff in conjunction with using the Emory portal to request refills.

There was a discussion surrounding the reductions in grants/financial aid that some companies offer to offset the cost of insurance copays, including those from the LLS, and some members have been affected by this. **Gail M.** commented that more organizations plan to reduce their grant amounts per a report from the Financial Director at <https://healthtree.org>. Some of these changes may be related to the Inflation Reduction Act and the Medicare changes this year. Next year, the maximum out of pocket costs will be reduced. Those affected should consider the changes when they select insurance plans. **Barbara** commented that being on a CT does not mean it is free, so be sure to plan for non-CT related costs when selecting insurance plans. **Jim M.** commented that CTs cover the trial drug, and the patient has the responsibility for the costs of standard drugs and service. **Alf N.** is on a Phase 1 CT at Emory for the bispecific drug, Talquetamab, and asked if anyone else has had experience with that drug. No one in the meeting has had experience with Talquetamab.

**Mary V.** recommended a book, '*Fatal to Fearless: 12 Steps to Beating Cancer in a Broken Medical System*' by **Kathy Giusti**, a 30+ years MM patient and founder of the MMRF. The book offers information on how to deal with insurance and related issues from someone with first-hand experience. **Karen C.** has been taking Imodium for side effects from Revlimid but has concerns about long-term use.

**Nancy B.** recommended a cholesterol medication or supplement that is in powder form that you mix in a drink as an alternative to Imodium.

Submitted by Wendy R.

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## Meeting Minutes

### Southside Hybrid MM Support Group

### March 27, 2023

**Next Meeting:** Saturday, April 27, 2024. Patient and Caregiver Voices. Updates on progress, treatment, financing and more. In-person /Hybrid. Details and zoom link sent in separate email.

**“For Men Only – next Meeting: Tuesday. April 23, 2024.** Your Choice, decisions about schedule for meeting with the national group – quarterly or something different?

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#### **Business & News**

This was a hybrid meeting and the technology worked well. The sound was good, but we need to work on using a larger screen for better interaction. Southside was pleased to welcome back **Kimberly S.** and her husband **John** after several years absence. She continued to receive our newsletter and has kept up with our activities and joins again like no time had passed.

March was **Myeloma Awareness Month.** Several members talked about their sharing within their families about what myeloma is and what it has meant to their own lives and that of their caregivers. **Portia** participated in a health fair, **Doris** included a section in her church bulletin, and **Gail** presented to an NPU meeting at the invitation of Doris. **Flora** wore Myeloma education T-shirts to her Zumba class, and she and her daughter wear them with pride to educate others. **Kimberly S.** shares with others that when she was diagnosed, she thought she would not see her son graduate from middle school. He has now graduated with his master’s degree from Georgia Tech.

Keep spreading the word, team!

#### **Group Discussion**

The question of whether family members *could or should get screened for myeloma* came up. More myeloma in families and siblings has been diagnosed over the past several years. General myeloma screening test is not recommended for family members at this time nor is it cost effective. In addition to your genetics, possible causes may include familial experiences – living in the same environment with potential toxins. There is a high-risk group study, called the [Promise Study](#), sponsored by Dana Farber in Boston, which is trying to determine the genetics question and providing free screening for first degree relatives. We will look for additional detailed information to share.

**“For Men Only” update.** Ted reported that the national meeting with the Men’s Only Group and **Dr. Brandon Blue** (Moffitt Cancer Center) was exceptional. **Anderson** gave it high praise and said the comfort and sharing was like being in the Barber Shop. They reported that in this first meeting, more than 30 men from around the country were in attendance. Men attended from Colorado, Virginia, North Carolina, and California. All pitched in and shared. **Dirk** underscored what Ted and Anderson said and added that the meeting was well-run. Dr. Blue was down to earth in his presentation and was like one of the fellas – just an expert in myeloma. He did a brief presentation with many charts and graphs and talked about the significance of the kappa/lambda ratio. He agreed to share his slides with the Group. The Atlanta Men’s Group will decide the frequency of inviting the national group going forward. The next time may be May 2024.

We debriefed the presentation delivered by JNJ representative, Kim Burney, RN, MSN, given in February. She discussed three JNJ products; Darzalex, Bispecifics-Teclistamab and Talvey. Several members have experience with Darzalex. Members in the group were able to provide input and feedback on their experience with the JNJ drugs. **Joyce J.** is on Darzalex treatment with Dr. Carr of the Georgia Cancer Specialists. **Gerri** had a negative experience while on Darzalex dealing with tooth and bone pain issues. She was able to share much of what Kimberly discussed to have a conversation with her doctors. **Geraldine** has had two Stem Cell transplants, CAR-T, and now Talvey Bispecific).

### **Patient/Caregiver Voices**

**Kimberly S.** has developed neuropathy and osteopenia/osteoporosis that may be connected to [Bisphosphonates](#) (Aredia, Zometa, Xgeva, Prolia [last 2 contain denosumab]). It is prescribed to reduce loss of bone and/or bone fractures. Bisphosphonates can contribute to problems with necrosis of the jaw ([ONJ](#)).

Kimberly was hesitant to take Bisphosphonates because of potential side effects. She has decided to take a supplement instead called Q -Absorb (Which contains Co-Q-10). She took it to her doctor for approval and was given the green light. She bought it through Health Limited (~\$46). **Gloria** has been taking [Alendronate](#) as a bone strengthener – a low dose, oral medication since 2010. Alendronate is *used to treat and prevent osteoporosis (a condition in which the bones become thin and weak and break easily)* in women who have undergone menopause ("change of life," end of menstrual periods). Alendronate is also used to treat osteoporosis in adults who are taking corticosteroids (a type of medication that may cause osteoporosis in some patients). Note: Alendronate is different from bisphosphonates **Dan M.** has smoldering myeloma (SMM) at age 40 and will follow its progression with his doctors. **Kimberly S.** had a Stem Cell Transplant (SCT) in 2009 and now has neuropathy. She shared that she got a leg and foot massager from Amazon that is very helpful. She will send us this information in a separate email. **Glenn** also shared a resource on neuropathy and directed us to [www.neuropathyga.com](http://www.neuropathyga.com). The [TENS](#) (Transcutaneous electrical nerve stimulation) is also used as a pain management system. The treatment is two visits and in combination with B-12 therapy. **Gail** shared that increased walking is also helpful to activate the nerves in the feet. **Linda** was newly diagnosed with myeloma in December 2023. She also has Lupus and Raynaud's syndrome. She is a patient at Emory and wondered how to differentiate the symptoms of neuropathy from Raynaud's as she communicates them with her team. We will share some specific resources from IMF, MMRF, and others to help navigate this journey.

**Aluen B.** wants to know when we will have another in-person meeting, like pre-COVID and sponsored by 57 Fighter Group and pharma companies. Gail reminded Aluen that the current meeting was hybrid with some members attending in-person. **Nancy** shared that while lunches have been provided for in-person participants, the funding from 57-Fighter Group has gone away due to a change in how pharma companies will fund Support Group meetings. Nancy also just got over five weeks of COVID, and it was not fun. COVID is still with us. Remember that myeloma patients have a compromised immune system and are at high risk of infections.

**Bridgette** shared that myeloma and Support Group Leader (North Carolina), **Thomas Goode**, reached out for support in a bike ride fundraiser. This is an IMF-sponsored fundraiser taking place in Iceland, where the [iSTOP](#) myeloma

research project is being conducted. Nancy is also participating. The fundraising bike ride will be 50 miles/day for three days. *Go Nancy!*

We adjourned the meeting at 12 noon.

Respectfully submitted,

Gail