

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group December 3, 2022

Business & News

Thank you to **Nancy B.** who hosted the meeting with approximately 20 attendees. *Please note the next Northside meeting will be a virtual workshop on the second Saturday, January 14, 2023.* This meeting will recap the ASH American Society of Hematology (ASH) conference held in December 2022. Emory physicians and staff members will review conference highlights regarding multiple myeloma (MM). This workshop is always a valuable and highly informational meeting for our AAMMSG members and myeloma patients. Watch for additional information to be provided prior to the January recap meeting. The Northside February meeting will continue the discussion on what we learned from the January ASH workshop.

The AAMMSG Board of Directors are discussing options to meet in person again next year and are looking for locations to conduct a hybrid meeting— both in person and virtual Zoom simultaneously. The Presbyterian church where meetings were held before the pandemic is no longer available. The group brainstormed several different locations and a few members volunteered to check into some facilities. Monthly programs for next year's meetings were also discussed. Nancy asked for topics that would be of interest to the group. Meeting topic presentations mentioned include Free lite Binding Site, Medicare, VA-PACT/environmental dioxins exposure, life-style programs on exercise, physical therapy, and nutrition. If you have recommendations for places to meet in a hybrid setting and/or programs topic ideas for meetings, please reply to **Nancy B.** at the email for the newsletter.

Updates & Discussions

Important news and information can be found on <https://myeloma.org>. Dr. Durie's team posted updates on his blog during ASH on over 750 other posters, myeloma sessions and expert reviews; there is so much happening in the MM arena! Research updates from the Iceland iStopMM initiatives are available in addition to immune therapy, bispecific and trispecific drug research studies. Conference highlights included CAR-T patients getting longer lasting results, advances in targeted immune therapy drugs that focus on different clones of MM to help patients get into better remissions and help prevent relapse.

Group members recommended IMF "*Living Well with Myeloma*" webinars include:

- “Ways to improve your bone health as a myeloma patient.” explains differences between X-ray, CT, PET, and MRI

- “Psychosocial Care.” help with coping skills for MM patients and caregivers during the phases of the myeloma journey.

Significant medical updates include:

- 1) The FDA pulled Blenrep, which had been approved for treatment from the market. Blenrep was working well for many patients and had been conditionally approved based on Phase 2 clinical trial results, with good results from Phase 3 in process. This news has been disappointing to a lot of doctors and patients who have experienced good results from Blenrep. Blenrep can still be provided as a compassionate use treatment for patients who qualify.
- 2) A bispecific drug Tecvayli (Teclistamab) was conditionally FDA-approved but it will require myeloma centers to become certified in order to dispense it and is expected to take about six months before it becomes widely available.

Nancy reported that **Dirk B.** has been hospitalized for 10 days and may be in the hospital for another week with a fungal infection. Dirk warned everyone to please be careful and wear your mask. **Chuck M.** just began taking Daratumumab (Dara). A side effect was a lot of sneezing that he is treating with Benadryl. **Cappa** suggested getting gamma globulin treatment when on Dara. **Jeff W.** has been on Dara for about 4 years and noted that he gets winded for a few hours after receiving Dara treatment, but then it subsides. **Sandy W.** has been on a Phase 1B clinical trial for nine months investigating a 5th generation drug CC-92480 that is in the same IMiD class as Revlimid, along with Dara, and Dex in combination. She currently receives Dara once a month intravenously along with Dex weekly and clinical drug 21 on/ 7 off rotation. She mentioned that intravenous Dex is better tolerated by her than in pill form. **Sandy B.** is recovering from having 11 teeth extracted in November. She is experiencing difficulty with speaking and pain during the process since the denture set was measured prior to the extraction. Sandy B. mentioned that she has been taking generic Revlimid for two months. There was discussion surrounding the *generic Revlimid* and its cost. There appears to be a lot of differences between drug costs depending on insurance companies, and some members have found that the generic version is not significantly less expensive than the name brand version. Some insurance companies are forcing the generic version. **Jim M.** suggested researching and comparing the ingredients, including the carrying agents and inactive ingredients between name brand and generic drugs to make sure that the generic version will work for you and that it does not contain ingredients that you may be allergic, or sensitive to. It is also a good idea to check with your pharmacist when considering a generic version of a drug. Several members commented that they have had some issues using the new patient portal at Emory. Some drugs/ procedures have not been properly ordered or are not getting to the pharmacy timely. Patient messages are not being routed to the Healthcare team and some test results are not posted. Be sure to follow-up during the transition period.

Small group breakouts

Following the patient updates the participants were assigned to breakout rooms to meet in smaller groups to exchange updates and stories of their holidays as a child. This was a great way to learn more about our fellow members and fellowship with each other.

Submitted by Wendy R.

Meeting Minutes Southside Virtual MM Support Group December 24, 2022

Business and News:

Next Meeting: Saturday, January 28, 2023. **Managing Side Effects of Multiple Myeloma Treatment.** Speaker: Tara Roy, MS, NP, Takeda Patient Advocacy Liaison

“For Men Only” AAMM Support Group meets every month on the 4th Tuesday at 6PM. Come and share your experiences and concerns with other men on the same journey. Hear about resources and ways to navigate the myeloma care maze.

Group Discussion

The Southside group convened for an abbreviated final “Counting Blessings” meeting of the year on Saturday, December 24, Christmas Eve. Doris opened our meeting with a moment of silence and included a thank you to all who attend the Support Group meetings throughout the year. Doris started the MM Support Group when she was diagnosed 16 years ago in 2006.

Patient/Care Partner Updates

Joyce J. talked about her current dentist and his practice. She stated that the technician did not practice good hygiene in handwashing. Joyce shared these concerns with the dentist and emphasized that she was a myeloma patient with an immune deficiency. The dentist did not appear to know much about myeloma. **Gail** responded that after not being satisfied with the doctor’s response and since she was not satisfied with the dentist or his practice it would be best to relieve her stress in that area and find another dentist. Dental referrals were given by **Sandy B.** and **Carole O.** who were both impressed with the myeloma knowledge of their dentists. Referral information will be sent to Joyce. Gail also shared additionally that this situation was very concerning. Dental offices were some of the first practices to come back after the pandemic with full pandemic-protection equipment and training criteria. Since all dental procedures can have a high infection potential, dentists need to protect themselves and their patients. For some invasive dental procedures, myeloma patients and dentists must have clearance from their Hema-oncologist before proceeding. **Bernard** shared that he also was having some difficulties with his dentist. Patients and caregivers should have a discussion with all their health professionals-providers about the importance of why certain precautions are vital and necessary. Hopefully, candid conversations will come to a satisfactory way to move forward. If you do not trust your healthcare providers to make the best decisions for your health, please look for another provider.

Carolyn E. reported that she has now been in remission for 5 years. She had a bone marrow biopsy confirmation on November 2. Congrats Carolyn! **Barbara W.** shared that she is having some side effects from her Pomalyst. Twice, she has found herself out of breath when doing normal activities. The second time while grocery shopping, she had to sit down to catch her breath. Gail advised her to report this immediately to her doctor. Do not wait for her next scheduled appointment but go through the portal or call directly if she gets no response. The side effects need to be addressed. A treatment adjustment or dose reduction may be needed too. Barbara W. also completed all her immunizations

recently. **Barb M.** had an adjustment in her meds and is now in remission. She advised us to watch out for the Holiday Blues. It is real. Be sure to eat right and continue to exercise over the holidays. **Emma S.** shared that her sisters, *Mildred, and Mary*, were wonderful and attentive caregivers. Mildred came down with a sore throat and it turned out to be COVID. One of them will usually stay with her overnight since she lost so much of her independence over the last 6 months. Emma is able to go to physical therapy closer to home in Fayetteville, but must still make several visits to Emory Winship on Clifton. Her son also came from Texas and spent some time with her. Emma is blessed and asks for your continued prayers.

Gail shared a short video on Bispecifics. This is a new drug category that was discussed in many sessions during the recent annual ASH (American Society of Hematologists). This drug works by attaching to two sites simultaneously – a T-cell and a site on the myeloma cell. This allows a more focused way to target and destroy the myeloma cells. Bispecifics will be discussed much more in the coming months and at the January ASH update from Emory physician-researchers. Ted invited other men with Myeloma to join the “For Men Only” Groups every 4th Tuesday evening for an hour. They have lively, spirited discussions, share ideas and resources, and concerns about their diagnosis – from a male perspective. Please share the information widely and join them in January.

We are in the midst of some of the coldest days in decades in Atlanta. Be advised to protect water pipes from these sub-10-degree temperatures. Gail asked Bernard, a retired plumber, for any pearls of wisdom. Some hints were to cover water lines with insulation. He explained that hot water freezes first, so only allow the cold water to drip. Also, protect the outside water faucets with an insulated cover. Know in advance where the cut-off for your water line is so that if your pipes do burst, you can minimize any water damage.

Gloria encouraged everyone to be safe in this crazy world – be vigilant in all areas, including being protected from the COVID-19 and virus. Anderson closed the meeting with some reflections on this past year. He just celebrated his first anniversary with myeloma and has learned a great deal. He continues to encounter many other men who have myeloma. We have to take care of ourselves and find others who might also benefit from the information we share. Happy Holidays!

Respectively submitted, Gail.