

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

April 2, 2022

Business & News

Thank you to **Nancy B.** who hosted the meeting with approximately 35 attendees. The meeting topic was "**How do you build long-range plans with your healthcare team and your family?**" Many longtime AAMMSG members shared their experience and perspective on making informed decisions, lessons learned, and other valuable insights about living with multiple myeloma (MM). Member updates and group questions were also discussed.

Meeting Discussion

Nancy began the meeting recalling a TN MM patient who quoted Mike Tyson that “everyone has a plan until you get punched in the face.” In general, plans during major life events.

- How do we rebuild our plans with health providers and family when faced with MM diagnosis?
- What kind of information do you need from this group or other reliable sources and your healthcare team to help you build a Plan A and Plan B?

It is essential to communicate your plans and goals to your healthcare providers, prepare and update a living will and designate a healthcare surrogate. Additional things to consider when planning include finances, changes in family dynamics, tracking your treatment progress, monitoring labs and testing, ongoing changes in treatment plans, managing side effects, nutrition supplements, and diet.

Long-range Planning Presentation from our Myeloma Experts

Thank you to our longtime members who shared valuable insight about their journey with MM.

Sandy B. is a 32-year MM survivor. Her myeloma journey is inspirational to all of us, and she is always willing to share her knowledge and positive attitude. Sandy is an integral member to both Atlanta support groups (Northside and Southside), and also serves on our board. She demonstrates her belief and commitment to support and motivate others and has spearheaded the support group outreach program for many years. Sandy has a strong faith and knows the power of prayer which she believes has kept her here and for reasons that she enjoys – to be encouraging and supportive for others. Sandy also stays active and enjoys traveling, with many future trips planned and upcoming family events.

Dana D. was diagnosed in August 2000 and has nearly 22 years of MM experience. He cited three main aspects to embrace: *your physical, emotional/psychological, and spiritual well-being*. Ask a lot of questions about treatments and how they will physically affect the body. Dana recommends learning about different treatments and options to stay informed and to make suggestions and quality discussions with your healthcare providers. From his emotional/psychological vantage point, He understands the importance of a good support system from a lot of different areas. Dana shared that when he was a newly diagnosed patient he was invited to attend a myeloma meeting. Although he was really not interested, he attended anyway. He quickly learned the value of being a part of a support group and has remained an active member ever since. He feels very inspired by other group members and enjoys hearing their stories. From a spiritual perspective, Dana has pursued opportunities to travel and share his myeloma story to help encourage people from all over the world and believes that we contribute to the world with our faith and positive

actions. Dana noted that we might not always understand the significance of what we contribute to our world just by sharing our knowledge with others, but it can and does have tremendous impact. Dana appreciates the importance of maintaining close family/friendship ties.

Nancy noted that there are a lot of components that go into this journey - your healthcare team, your family, and your community that are all very important in keeping you moving forward.

Carolyn H. has been on the myeloma journey for 15 years and has been involved with several clinical trials. Carolyn discussed how her spiritual thinking changed when she was diagnosed and forced to think about one's mortality. She also shares her story and experiences to help lift others. Carolyn recommends not being introverted or reserved about myeloma. Reach out to others who are dealing with adverse health conditions to offer advice and information to help them gain knowledge and confidence. Carolyn enjoys spending time with her grandchildren and it helps her to know that future generations will have less of a fear of cancer due to our longevity and the progress that has been made to understand, manage, and cure cancer. Carolyn also touched upon the need for grief planning, as we sometimes lose some of our much-loved group members and others that we meet in our journey.

Jim M. was initially diagnosed with smoldering myeloma (SMM) in 2005, then active MM in 2009. He is a great example of being your own best advocate and he knows the importance of communicating all pertinent information to your entire healthcare team early and often. Jim's advice is to stay informed and pay attention to what your providers are doing to and for you. If something is uncomfortable, tell them right away. Do not wait. Tell them immediately so you get better now and not become worse. Research is ongoing and never ending as treatment plans change rapidly and regularly in the MM world. Jim investigates potential next treatment options in advance, anticipating and staying ahead of his current situation. He regularly researches the IMF website to review different trials and potential side effects for planning how he would manage those options that may occur. Jim stays informed with current research from the IMF, MMRF, and Big Pharma drug websites along with attending lots of webinars. He believes that it is very important to be taking the right drugs at the right time to avoid any kind of effects that could cause harm. Jim consistently monitors his treatment progress and shares personal trends with his healthcare team. He enjoys sharing his story with many different and amazing people that he meets from the infusion lab to his customers, all learning and benefiting from each other. He continues to work full time and feels grounded by his daily career routine. Jim appreciates that he has a great family and stays close to God and summarized by saying that what has led to his survival is the combination of his faith in God, good drugs, and tremendous family support. While it is unfortunate to have MM Jim feels fortunate for what he has learned immensely from having it and how he can share what he has learned.

Gail M. was diagnosed with myeloma in 2009. She emphasized how quickly the MM landscape changes with all of the new research and ongoing treatments making it essential to stay connected with a myeloma expert. It is so difficult to keep up with rapidly changing MM advances that even the best general oncologists will not necessarily know what is best for you as a myeloma patient. If you are not seeing a MM specialist already it is recommended that you at least request your oncologist to partner with a myeloma expert to work together on your behalf. Most MM specialists are pleased to work with general oncologists to help guide them and monitor your treatment plan. This allows your own oncologist to continue to be in charge while having access to the best and most knowledgeable MM doctors involved with your treatment plan. The myeloma experts at Emory will help build a plan for you that can be executed with your oncologist. Gail also explained the importance of getting second and third opinions as needed which is a very common practice with diseases that are as complicated as MM. Nancy referred to the IMF site (myeloma.org) for additional information to guide you through the long range planning process: "[Tip Card: Myeloma Treatment Discussion Tool](#)". It can be downloaded and shared with your healthcare providers.

Group Collaboration & Member Updates

We welcomed three new members: Sue, Glenn, and Barbara W.

Sue was diagnosed with myeloma in 2015. She had initial induction therapy with Revlimid, Velcade, and Dex (RVd) and then received a stem cell transplant (SCT) at Northside as an out-patient. She is no longer in remission and is planning for another SCT at Northside near the end of June as an in-patient since she has no caregiver this time. Sue would like to talk to someone who has experience with getting a SCT at Northside as an in-patient, and to learn more about the transplant center protocols.

Glenn was diagnosed in September 2020 after experiencing back pain. He is currently taking Revlimid for maintenance and is in remission, doing well and “feels great.” He has collected stem cells in preparation for a SCT at Emory in June, where he will also be an in-patient without a caregiver. Glenn has been using <https://healthtree.org/myeloma> as a MM resource. Glenn also recommended a procedure that has helped with neuropathy in his feet from Velcade called Sanexas electrotherapy. It is a non-invasive, safe, drug-free, and painless treatment that is covered by Medicare and most other insurances. Glenn said that Medicare covered 24 treatments of the 28 total treatments that fully stopped his neuropathy. Each treatment takes about 20-30 minutes in an in-office visit. The treatments allowed him to greatly reduce his Gabapentin dosage. Some of his neuropathy is returning so he plans to get some touch-up maintenance treatments.

Barbara W. was diagnosed with an aggressive form of MM in October 2020. She had a SCT in May 2021 and there is no detectable MM at this time. She is in the re-vaccination process as she gains her physical strength. Barbara has a “one day at a time” mentality and cited success having a medical team that she trusts, strong spiritual beliefs, and great caregiver, spouse and family support that helps her.

Nancy stressed the importance of attitude which is almost as important as treatment drugs. It has been proven that fear and dread negativity impact outcomes and strong support systems truly help us. Several members mentioned that they have received Evusheld injections for additional COVID protection beyond vaccinations and booster shots. Additional resources mentioned by group members include Facebook groups and <https://www.smartpatients.com/>.

Carolyn H. is experiencing heart-related issues that may be from the use of Dara. **Sandy B.** treatment plan included steroids over many years which has caused her teeth to loosen and resulted in several extractions recently. She has an appointment with an oral surgeon soon to learn more which is her top health-related priority. **Dana D.** has restarted treatment with BLENREP after taking a break due to eye-related issues which is a common side effect with this drug. **Jim M.** is continuing with Selinexor treatments and has a full body PET scan scheduled in May. After treatment completion he will reevaluate and decide if he will have a second SCT. **Rhea** asked if anyone else has been approached by Emory to sign a release of ownership of your tissue in regard to research being performed at Emory. Other members have also been confronted on this topic as well as stem cells and bone marrow. **Sandy W.** asked if anyone had genetic expression profiling testing (GEP) or Next Gen testing performed and if so, did they find it to be useful? **Jeff W.** participated in a MMRF program prior to beginning treatment with Venetoclax and he found the results to be useful. The [FISH](#) test identifies specific genes in human cells with genetic abnormalities associated with cancer. **Gavin** noted interesting and promising research on different targets and combinations with BCMA, CD38, T-cells, B-cells, and natural killer (NK) cells. There also have been group members that have participated in the [Promise Study](#), which is a study related to MM and genetic components but is not specifically genetic testing.

Submitted by Wendy R.

Meeting Minutes
Southside Virtual MM Support Group
April 23, 2022

Business & News:

Next Meeting: Saturday, May 28, 2022. Our Guest Speaker will be Udaan Dozier, Patient and Caregiver Voices. The discussion Topic will be MMRF CoMMpass Study and Myeloma genetics.

Group Discussion:

Thank you to **Gail** for hosting the meeting with welcome to the group and a moment of silence led by **Doris**. One new member joined us from the Tampa Bay area in Florida. **Mary M.** is being treated at the Moffitt Cancer Center. She connected with **Doris** through the *LLS Peer-to-peer program*. Doris has volunteered with this program for many years. When Mary was asked how the myeloma was discovered she explained that it started with four hip operations in four years. She was told she had aggressive bone cancer and has lost 6 inches of height during that time. There is a lot of anger from being misdiagnosed. She initially contacted the American Cancer Society (ACS) but was unable to reach anyone who could assist her. It took another four months to get to hematology. Mary was diagnosed about 10 weeks ago. She started her oral regimen at Moffitt Cancer Center in Tampa and her myeloma numbers are down. **Debra T.** joined us again after many months of absence. Welcome back, Debra! Debra shared she had also lost 5 inches of height. She was diagnosed in 2004 and is on a chemo vacation. Lesions were found on her femur (the longest and strongest bone in the body) and her humerus (upper arm). She now has a rod. Both lesions were on the same side and dominant side of her body. Fortunately, she is able to drive again—since July 2021.

The group talked about *Light the Night*, the annual fundraising event for LLS. The LLS representative had to postpone her presentation. **Doris** shared that we have joined as an online group -- and we will have a link that folks can follow to donate. Our pledge is \$2,000. Of course, members are welcome to join and raise funds independently. LLS has been very supportive for so many in our group. This year's celebration will be in Centennial Park on Saturday, October 1. **Alma** described some of her experiences at past Light the Night events. It is a great family-oriented event outside in the fresh air. Lots of colorful balloons representing blood cancer patient status. Music, food, and fellowship are at the center. There is a featured walk at dusk – all the balloons light up against the night sky.

The group then discussed future in person meetings, as COVID becomes less of a threat. Our old meeting place inside Macy is no longer a meeting option, as Macy at Greenbriar has closed. Doris is checking two libraries for a possible “central” meeting place, one at Cascade, and the other at Metropolitan. Future meetings will need to maintain adequate social distance inside. There is favorable interest in some kind of in-person meeting. Local libraries are being checked out as possible in-person meeting locations. Several Members are some distance away. The East Point/College Park location is an easier meeting place for those from Fayetteville (Emma), Griffin (Debra T.), Stockbridge (Barbara W.) Cascade would be more suitable meeting locations for many (Ted, Mattie, Doris, and others). Meeting locations should also consider an outdoor venue, like a park. Westside Park is newly opened and might be a good place. We may consider one meeting with a limited agenda to meet in-person and outside. Marcia suggested that we could use our hotspots to engage the group from an outdoor location. Glenda encouraged hybrid meetings (in-person and via Zoom) so that as many people as possible can attend no matter their distance, physical condition, or other reasons, more people can participate without barriers.

The *For Men Only* Group is seeking the best day and time for the majority of men to attend meetings. **Ted** and **Anderson** encouraged all the men to look for the next invitation to a meeting and be ready to participate.

Gail spent some time online to navigate websites for important information: myeloma.org, lls.org, themmrf.org, [Patient Power](#), and the Patient Empowerment Network (PEN). Each month there are important topics highlighted on the agenda. We showed a nutrition video – for those with no appetite.

Patient Updates:

Tom H. will begin Venetoclax in a few weeks and was seeking information. **Gail** researched and was able to provide information on Tom's inquiry. **Sandy B.** has also lost 5 inches of height during her journey. She updated the group on her current status. She is receiving dental care for her teeth and will have a consultation regarding the sudden loosening of several teeth. Sandy B. also talked about applying for financial support from LLS after twenty years on her myeloma journey. She thought that since her husband had good insurance, she would not be eligible for support. LLS approved her request and is providing co-assistance for her insurance premium of \$314/month which is a real saving for her family. Sandy noted that Doris was responsible for encouraging her to apply for LLS assistance funds that are there to assist families with blood cancers.

Advocacy is an important part of getting us to affordable treatment and to research that leads to a cure. Gail encouraged everyone to take 5 minutes to complete letters of support that might come from LLS or IMF directly to you, or messages from Paulette.

Respectively submitted, Gail