

AAMM Meeting Minutes  
Northside Support Group  
May 6, 2023

Business & News:

The Northside group *will not meet on Saturday, June 3* and will instead attend the IMF Regional Community Workshop (RCW) on Saturday, June 24, 2023, from 9:00 AM - 3:00 PM, at National Center for Civil & Human Rights – The Glenn, 100 Ivan Allen Junior Blvd. NW. Atlanta, GA. 30313. The workshop will include sessions from Emory experts Dr. Nooka, Dr. Hofmeister, Charise Gleason and myeloma journey perspective from patients and caregivers.

**Member Updates & Group Discussion:**

Thank you to Nancy B. who hosted the first hybrid (combination in-person and online) meeting at the new location at Emory-St. Joseph Hospital. There were twenty-eight in-person and twelve remote attendees present. The meeting was an open group discussion. Members shared their multiple myeloma (MM) journey history, treatment updates and helpful tips. Lunch followed the in-person meeting.

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Carolyn H. was diagnosed with multiple myeloma (MM) 16 years ago. She participated in the first Daratumumab ([Darzalex](#)) Phase I Clinical Trial for 8.5 years at Emory. She changed treatment plans to Elotuzumab, ([Empliciti](#)) with Dex for 5 years at Northside Hospital which is closer to where she lives in Canton. She is currently considering next-step treatment options for when the time is appropriate. We are thankful to Carolyn for participating in the Phase 1 clinical trial (CT) for Dara, as well as other CTs. Frank M. was diagnosed in 2008 with myeloma and initially treated with Lenalidomide ([Revlimid](#)) and Dex for 7.5 years. He had a stem cell transplant (SCT) in 2016 and was in remission for 2 years. His treatment following relapse was Pomalidomide ([Pomalyst](#)) which was not a good option for him. Frank has since been taking Dara which is working well with minimal side effects. Jeff W. was diagnosed almost 5 years ago with myeloma with translocation of chromosomes 11& 14. He is enrolled in a Phase 2 CT of Venetoclax ([Venclexta](#)), Dara, and Dex. He has not had a SCT and is not a suitable candidate for a SCT due to his type of MM. Jeff started intravenous immunoglobulin (IVIG) therapy 3 months ago, which has helped tremendously. [IVIG therapy](#) helps to normalize a compromised immune system. Venetoclax was originally developed as an antagonist drug inhibitor for Leukemia, but also works well for MM patients with t(11;14) abnormalities. Lory M. was diagnosed with myeloma 12 years ago. She is currently taking Elo/Pom/Dex and is doing well. Lori noted that the Pom has made her hair curly. Sandy W. was diagnosed with myeloma in 2013. She received four cycles of RVD induction therapy at Emory followed with a SCT at Mayo Clinic in Rochester, MN. She was in remission for 6 years without maintenance before relapsing in 2019. Sandy achieved a very good response (VGPR) on an oral treatment of Ixazomib ([Ninlaro](#))/Revlimid,/ Dex (IRd) for 2.5 years before relapsing a second time. In March 2022, she began a clinical trial at Emory Phase I Infusion Center on CT-Dara/ CC-92480 /Dex treatment. CC-92480 ([Mezigdomide](#)) is a potent, Novel Cereblon E3 Ligase Modulator (CELMoD). After a year of treatment, Sandy is not getting as good of a response as expected but is enjoying a good quality of life. Jim M. was diagnosed in 2005 with smoldering MM. He has had 3 SCTs, the most recent being as part of a CT that uses a reduced [Melphalan](#) dosing protocol. He recovered well and was able to go home after 14 days. He is currently taking maintenance of Carfilzomib ([Kyprolis](#)) and Dex and is doing well. The side effects from Carfilzomib are fatigue, and some shortness of breath from infusion. Jim had been on Selinexor ([Xpovio](#)) prior to his most recent SCT, which was a very tough drug to tolerate, but worked for him. Nancy mentioned that Blenrep ([Belantamab mafodotin](#)) is another drug with challenging side effects, but the approval from the FDA has been pulled after a review of the data. This drug continues in combination trials and should return to the list of available treatments. Doctors have a lot of flexibility on drug timing and dosage which can help patients stay on drugs much longer.

*If the drug is working for the patient, stay on it for as long as possible.* Libba was diagnosed with myeloma 16 years ago and had two stem cell transplants 12 years apart. She is doing well. Glenn I. was diagnosed with MM in September 2020. He is on Revlimid and doing well. He has harvested and stored stem cells but has not had a SCT. Jeff R. was recently diagnosed and was surprised and overwhelmed by his diagnosis. He is currently on Dara, Revlimid, and Dex. Kyle was diagnosed in 2005 with smoldering MM. He had a SCT in 2014, but the myeloma relapsed in 2022. He is now taking Kyprolis, which works great in getting his MM numbers down, but has caused other issues including heart failure in March. Kyle went to nursing school while in remission and is now a nurse at Emory. Rhea P. was diagnosed 5 years ago with myeloma. Her peripheral neuropathy limits her mobility. Last summer she was also diagnosed with Parkinson's disease. Rolf H. was anemic and was diagnosed with MGUS in 2009. He is currently taking RVD combination for treatment.

Dirk B. was diagnosed in September 2016 during an ER visit when he was very sick. He had back pain and lost eight inches in height, due to broken vertebrae, which kyphoplasty surgery repaired. He started taking Velcade/Dex which caused heart failure. Dirk received a SCT in 2017 and relapsed soon afterward. He is now taking Dara/Pom and Dex. Dirk was also hospitalized for over 40 days recently for a fungal infection. Glossie was diagnosed with MM and received a SCT in 2020. Her treatment plan included Velcade/ Dex, Dara/ Dex and most recently Kyprolis. Jeff B. was diagnosed in November 2016 and had a SCT in 2017. He was on maintenance RVd for 1.5 years. He was in a CT with Ninlaro (only), but it did not work for him. Now Jeff is treated with Pomalyst, Dara, and Dex for 4 years and doing well. He enjoys taking 5-mile hikes in the mountains near his home in Hendersonville, NC. Chuck M. was diagnosed with MM approximately 3 years ago when he broke a rib while playing golf. Doctors found lesions on his hips. He started with RVd regimen for 2 years, which eventually stopped working. Then Chuck received treatment with Pomalyst and Darzalex. He is currently on a drug break after being hospitalized for dehydration and heart issues two months ago, but he is feeling well. Ted A. was diagnosed in 2019 and started a 4-cycle induction regimen of RVd which resulted in no response. He changed to Velcade, Darzalex, and Dex, which worked for him, but Chuck developed AFIB from the drugs. Currently he is taking a lowered dose of Revlimid, Darzalex, and Apixaban ([Eliquis](#)) and the AFIB is now under control. He follows a regular exercise routine, works with a dietician, and has adopted a plant-based diet. These lifestyle changes are contributing to his good quality of life. Anderson F. was diagnosed with smoldering MM in 2016. His numbers started increasing in 2021 and he had a SCT in late 2021. He is now on Revlimid, with side effects of constipation, and some neuropathy in his feet. He was also getting leg cramps at night and found that putting a bar of dial soap in his bed helps. He is also on a bone strengthener that he started in February and his numbers look good. He walks 1.5 – 3 miles / day, listens to his body, keeps a positive attitude, and has good social support. Anderson mentioned that he is part of the *Men's Only* MM support group along with Ted and Dirk. Vanessa reported that she is doing great. She has regular acupuncture sessions in the new Wellness Clinic which has reduced her neuropathy pain. She also reminded the group that the Leukemia & Lymphoma Society (LLS) has funds that may be able to help with Co-Pay Assistance. Additional information on the myeloma drugs referenced in the meeting notes is available online at [IMF Current FDA-Approved Medications](#).

There was some discussion about collecting and freezing stem cells for reasons other than having a SCT, as your stem cells can help your body in other ways. For example, doctors can inject stem cells into the body for an immune system boost if a patient becomes run down or struggles with infections from treatment. We expressed gratitude to our members who participate in CTs, which helps the entire MM community!

Submitted by Wendy R

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**Meeting Minutes**  
**Southside MM Support Group**  
**May 27, 2023**

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**Business and News**

**Next Meeting:** Southside group will attend the Atlanta Regional Community Workshop this Saturday, June 24, 2023, from 9am to 3pm at the *National Center of Civil and Human Rights – The Glenn in Atlanta, GA*. The event is an in-person event from 9 AM to 3PM. For details and to register see attachments below.

Doris has been very busy during the month of May spreading the word about MM. She and her team attended three Health Fairs reaching hundreds of community members about myeloma. MM tables were set up at health fairs for the annual Delta Sigma. There were events at the Adamsville Recreation Center, the Path Church on Bolton Road, and the Bowden Senior in East Point. The events were well-organized and were COVID- conscious. Please applaud our volunteers for spreading the word -- Bridgette, Nancy, Deborah T, Portia, Carolyn W, and Deborah from Griffin at all 3 events. Doris also sent myeloma information to churches through our members. Kudos! Doris and all for getting the word out.

As you might remember, one of our members, Montine Wilburn, passed away suddenly in May. Her family asked that in lieu of flowers, people make a donation to the MM Support Group. Several of her friends and family generously donated \$238. Thank you.

**Group Discussion**

For our May meeting, we attempted our first hybrid in-person and virtual sessions. Doris, Nancy, and Sandy W. were on site at the Cascade Fulton County Library and Gail handled the Zoom session with the virtual group members. We lost the internet at the library and could not connect to the Zoom link even online or on the hot spot. Doris proceeded with the library in-person group meeting. Gail remained on Zoom with the remaining group members. We will continue to work on solutions for the next meeting.

**Zoom Session**

We had two new members to join us. John Z. from Woodstock was diagnosed on April 4, 2023. He is seeking all he can about Multiple Myeloma (MM) so he can work along with his doctors to control his myeloma. He wants to remain physically active at 71 and loves kayaking several times a week, fishing, and boating. John's treatment plan is Revlimid and Dex(amethasone). There is no longer anemia, and MRI and blood tests indicate no bone involvement or kidney issues.

Mary F. from Decatur was diagnosed in 2017 and had a Stem Cell Transplant (SCT) in 2018. She had an early relapse and is working with Dr. Lonial, Charise, and the healthcare team to

control her myeloma. Currently, she is on Revlimid. Mary is undergoing some major life challenges (divorce) and needs to change her insurance to Medicare and pay out of pocket. Suggestions that Mary F. talk with her providers about her change in insurance status and discuss her status with the staff Social Worker. Also inquire with LLS regarding many different grants from \$500 travel grants to over \$10,000 for insurance co-pays and many others in-between. Marcia shared a couple of new resources. One of them assists with free educational resources on legal issues of cancer patients. Thank you, Marcia! <https://trriagecancer.org/>. The other two resources are related to each other and include educational information on all cancers. (PatientResource.com and <https://secure.patientresource.com/>).

Patricia and other group members said in addition to Medicare, one might qualify for spousal benefits from Social Security. There is an extra \$500 for widowed spouses. Sandy B. encouraged Mary F. and any others who might hesitate about applying for grants to reconsider. Cancer is a very expensive disease, and many have gone bankrupt from medical expenses. It took Sandy years before taking Doris' advice to apply. She felt because her husband had good insurance and she retired from Hewlett-Packard that she might not qualify. Alma has had the LLS grant for years and thought she might not qualify. The grant has reimbursed her \$600/month copay for insurance premiums for many years. LLS has several different kinds of grants that are available at different times. You can subscribe to the website to get alerts about when funds are available. In addition to the funding are many different kinds of patient education materials. For finances, go to <https://lls.org/support-resources/financial-support>. To speak to someone, please call (877) 557-2672. Southside Group participates in the annual LLS fundraising event "Light the Night." You can make donations to LLS at any time through their website.

Anderson and Ted extended an invitation to John Z. and other men who are on the MM journey to join them for one hour each month. It is an opportunity for men to share their unique positions as men *and* patients, and interactions with the medical care system. The "For Men Only" group meets every 4<sup>th</sup> Tuesday of the month from 6:00 – 7:00 PM. They shared that the group has lively discussions and shares experiences and resources.

### **In-Person Meeting**

There were 19 people in attendance at the library. Doris and Nancy facilitated the session. Everyone introduced themselves and discussed their MM journey. There was one new member present among members who had not seen each other in two years. **Glossie** is a new member to the group and myeloma. He was diagnosed in 2020 and he received an SCT later that year. His father was diagnosed with SMM at age 96. Glossie is active and researching the whole-body approach to treating myeloma. He is currently on KDD maintenance. **Carol** was diagnosed in 2016 and had an SCT transplant for her myeloma. She is currently taking 5mg REV for maintenance.

**Bernard** retired in 2017. He was diagnosed with myeloma and received his SCT in 2018. He is on REV maintenance. Bernard has dealt with being misdiagnosed, several side effects and medical issues including Parkinson's disease. He is currently having trouble with his Kaiser insurance not paying for his Revlimid and changing it to a generic formula which is not as effective. **Celina** developed myeloma in 2009 and received an SCT in 2010. She was on REV for

5 years before experiencing muscle cramps. Celina had a second SCT in 2020. She started taking Pomalyst but stopped due to increasing creatinine levels.

**Pat C.** was diagnosed with myeloma in 2004. She started with Thalidomide induction and received a tandem SCT transplant in 2005. She was in remission for 12 years without maintenance before the myeloma returned. She collected a second round of her stem cells to transplant in 2019. She is currently on POM maintenance. Her husband was recently diagnosed with MM. This is not a common occurrence. Pat's sister also attended the meeting. **Veronica** learned of her myeloma in May 2019. She started with RVD induction for 3 months followed by high dose chemo and a stem cell transplant in October 2019. She is single and being treated by Dr. Holland at Northside. She is taking Rev brand and generic for maintenance.

**Barb** was diagnosed with high-risk myeloma in 2020 and received her SCT in September 2021. She started on POM for maintenance during remission through 2022. Kyprolis was added but she has cramp joints and shortness of breath as side effects. **Joyce** discovered her myeloma from an exam for a broken rib in 2013. She received a tandem SCT in 2013 at Emory followed by REV maintenance. She broke her collarbone in 2018 and received a third SCT in 2020. Joyce is in remission and taking DPd. She developed pneumonia from allergies and is receiving annual skeletal exams.

**Karen** learned of her myeloma in June 2022 after breaking her humer bone in her right leg. Dr. Kaufman has been treating her with Dara/Dex since October 2022. Her insurance stopped paying. She is now back on REV for maintenance. **Vena** has been on her myeloma journey since 2007. She started on Velcade /Dex causing many side effects that landed her in a mental rehab facility for a short time. She has not had a SCT. Vena has developed secondary cancers including Stage 4 -Liver, Stage 4-lung and a brain tumor. That has not stopped Vena from being her best with a positive attitude.

Many remained after the meeting and continued to fellowship with their lunches from Jason's Deli. Overall, this first try at a hybrid meeting was a successful one, though it was two separate meetings. Thank you, everyone, for your patience.

Respectively submitted, Gail.

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