ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

May 3, 2025

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Business and News:

June is the month when myeloma doctors get together to review and discuss research. First at ASCO (American Society of Clinical Oncologists) in Chicago, May 30 – June 3. Then they meet at IMWG (International Myeloma Working Group) which precedes the European Hematology Association (EHA) meeting in Milan June 12 - 15. The IMWG currently consists of 295 myeloma experts from 41 countries working towards improving outcomes for myeloma patients worldwide. After these meetings, there will be webinars available to update patients on the latest research. Equally important are any changes in protocol that may impact patients sooner, such as the use of steroids, maintenance guidelines, or changes in administration of Bi-specifics to reduce or avoid hospitalization. Watch for announcements of these webinars to get the latest news.

Thank you to Nancy B who hosted the open discussion for Northside in May. The hybrid meeting was attended by fifteen people in person at Emory St. Joesph's and fourteen participating online. The session focused on sharing experiences and addressing questions and concerns. Two new patients attended the meeting at St. Joe's which stimulated several questions. The candid discussion serves as a great reminder of how far myeloma advances have come. In the past twenty years, seventeen new treatments have extended the average life span of 3-5 years to 10-15 years for myeloma patients. Nancy B handed out copies of *the Myeloma Discussion Tool* developed by the IMF Nurse Leadership Board to prepare patients for healthcare appointments. It can be downloaded here - Myeloma Treatment Discussion Tip Card

Group Open Discussion

Our first new patient, Nancy Z, was in the hospital last December during Christmas when she was diagnosed with myeloma. She has received four rounds of VRd + Dara and was scheduled for her stem cell harvest on May 3 in preparation for a stem cell transplant (SCT). Her most recent bone marrow biopsy showed the MM was not reduced enough to proceed. Now she is being treated with Kyprolis/ Venetoclax since her FISH test revealed t(11,14). This is an abnormal chromosome in MM cells. Jeff W. also has t (11,14) and was on a clinical trial using Venetoclax which controlled his MM for 63 months. This treatment plan has reclassified t(11.14) to no longer be considered high risk. Jeff did not receive a SCT and has recently completed CAR-T therapy.

Nancy Z and her caregiver were asked how she was doing with Dex. This led to a group discussion on Dex side effects. Cynthia said that Dex reduces pain, but she cannot sleep. Bianca schedules her work around Dex days. When she is on it, she is unable to do any performance reviews or serious interactions with employees. Jeff was on 40 mg of Dex; he would be sitting in a chair and just sweating with a pulse rate of 110. David said that he was on Dex and had no symptoms from it. Frank sleeps fine, but he has had cataract surgery as a side effect of dex. Bianca urged everyone to talk to their doctor about any side effects. Nancy Z asked about the purpose of Dex. Nancy B explained that doctors have learned that Dex aids myeloma treatments to work better by “opening up” the myeloma cells for other drugs. Dr. Harvey, and other CT doctors have compared it to “Dex is like bacon. Bacon makes everything taste better, but you do not want to eat it every day!” Jeff responded, “It’s like one plus one equals four when the Dex enhances the other treatments.”

Dirk B updated the group on his current condition. He was initially diagnosed in 2016 with IgA that switched to IgG after a SCT in late 2017. He started on Dara/Rev/dex maintenance until the MM progressed, then changed to Pom/Dara/dex. There have been a couple of hospitalizations that temporarily paused his treatment. On February 22, Dirk wound up being hospitalized for six weeks, including about four weeks in ICU, which had him and his family worried. He had pneumonia and was intubated a couple of times. He developed trouble swallowing and must ingest all food and medications through a feeding tube every three hours. This put a pause on Pomalyst since the capsules cannot be broken. Dirk has been doing swallowing PT exercises for the last four weeks. He has a swallow test on Tuesday and hopes to pass since he has not been able to eat or drink anything for about two months. Being bedridden in the hospital for several weeks has also caused major immobility and severely weakened his legs. He has been working ferociously with lower body strength training exercises to not wobble when he walks. He hopes that in a few more weeks he will become more stable and cover more ground when walking.

Nancy B asked Dirk the critical question: “*What landed you in the hospital in the first place?”*

Dirk explained that he had a lower intestinal blockage and had arthroscopic surgery to untwist it that went well. Then things started to go south when he got pneumonia. As a myeloma patient the immune system is compromised so infections are much higher with serious outcomes. Dirk urged everyone to be aware of this risk and to strengthen their immune system through a good diet and exercise. Dirk also noted while on a feeding tube he could not take Pom or Dex. He is interested to see if his MM stayed under control at the next test since he has only taken Darzalex since February. Dirk asked if anyone in the group was treated on Darzalex alone. Carolyn H. was on single agent Darzalex for nine years! Ken wondered about the difference between Dara and Darzalex and Fast Pro. Nancy B explained that Daratumumab is the clinical name and Darzalex is the brand name. When Darzalex became a sub-Q shot instead of an infusion, it was named FastPro. Dara was the first immune therapy that changed the course of treatment for myeloma. Dara is a drug that targets CD38 protein on the surface of the MM cells. It attaches to that target to activate the immune system to come and kill it. Dara works very well with minimal side effects since it is looking for a specific target on MM cells, not the healthy cells.

Alf had questions about IVIG infusions. He has been receiving this for at least a year to improve his white blood cell count. But the last two infusions have caused exceptional chills and shivering during the infusion. An IV of Benadryl and steroids were given to combat the side effects. He asked if anyone else had had any similar incidents. Jim M had it happen on his third infusion of IVIG last year with chills and teeth chattering. It took an extra hour and a half for the adverse effects to settle down. He is getting IVIG weekly. The IVIG infusion is administered at a slower rate and stepped-up intervals to watch for reactions. Jim’s infusion starts with the little bottle drip really slow for about the first hour. Then the big bottle is partially opened. By the last half hour, the IVIG is wide open. Jim hangs around for a while afterwards to watch for side effects. Jeff commented that he is always premedicated with Benadryl and Tylenol ahead of time and Jim agreed. Jeff also gets a step-up dosage for IVIG. Alf got a double dose of Benadryl along with the Tylenol and a dose of Dex to combat his side effects. He normally does not take Dex due to the impact on blood glucose levels. It is now standard of care for CAR-T patients who receive IVIG for at least six months after CAR-T therapy.

Ken joined the SG meeting for the first time. During his wellness check in January, the doctor saw abnormal blood counts and referred Ken to a hematologist for further evaluation. Test results indicated smoldering myeloma (SMM) at the beginning of March this year. Ken went to Emory for a second opinion and the diagnosis confirmed high risk smoldering (HRSMM), which means that his MM levels indicate a 50% chance developing full MM within two years. Dr. Nooka at Emory recommended the Iberdomide Phase II trial to Ken. Iberdomide is a fourth generation Imid drug in the immune-modulatory class (Thalidomide, Revlimid, Pomalyst). There are two arms of the trial: one with Iberdomide alone and the other with Iberdomide with Dex. Ken is on the single agent iberdomide. After the first week, he developed a rash and itching spread all over and he could not sleep. He called the Emory main number and was connected with a nurse who scheduled him into the ICC. Dr. Nooka was consulted and conveyed that oral steroids could not be used on the clinical trial. So, Ken got steroid cream and topical creams. The next couple of days, the rash was much worse, and he was back in the ICC. A six-day steroid pack was prescribed, and there was significant improvement within a few hours. Ken hopes to still be in the trial when he goes back to the doctor. Jeff urged everyone to reach out for appointments at the *Emory Immediate Care Center (ICC)* specifically for Winship cancer patients.

Note to Winship patients! Emory has an Immediate Care Center (ICC) specifically for cancer patients. Be sure to get the number for a referral when needed.

Thanks to Ken for participating in a clinical trial. Our local hero is Carolyn H who was diagnosed in 2007 and chose not to have a transplant. Instead, she went on a Phase I trial of Elotuzumab and then a Phase II trial of Daratumumab, both as a single agent. Both trials combined gave her over ten years of controlling her MM. Carolyn was online and said that she was blessed to now be at 18 years as a MM survivor. She is now on a Bi-specific, but not as happy with the treatment. Dr. Lonial told her that she was spoiled with the easy treatment of the first ten years. She gets the Bi-specific once per month and has about a week of side effects with each treatment. Also, she feels very tired most of the time. Carolyn had an easy QOL for so long and is adapting to the current side effects. She is on Elrexfio now which is a shot in the stomach, and she gets IVIG the same day.

Nancy Z asked about the meaning of the light chain numbers. Jeff answered that the first thing a patient needs to know is their myeloma type. Jeff has a Type IgA light chain. An antibody has heavy chains that look like a “Y” with light chains attached on each side at the top ends of the Y. In myeloma, there are too many of these light chains and they are circulating in the blood that can clog up the kidneys. Jeff remembers that his light chain counts were in the 3000-4000 range when he was first diagnosed, but he did not have any kidney issues. His treatment on a clinical trial brought the light chain count way down. Nancy Z had kidney problems that put her in the hospital. Her husband added that Nancy’s kidney function has improved along with the low white cell count, but the percentage of myeloma cells in the bone marrow has not gone down. That is why the stem cell transplant was postponed. David, online, was diagnosed with light chain myeloma, but never had an M-spike. The doctor tracks his MM with the light chain test. Staying hydrated is crucial to reducing the burden on your kidneys. The doctor explained that the sign of good hydration is that your urine is “wheat colored.” Which is very pale, not yellow! So, you must drink and drink and drink! Thus, you have to go to the bathroom frequently.

But this is critical for light chain myeloma. David also watches his light chain ratio to the heavy chains. Doctors look at the absolute value, but it is also about the direction and velocity. Nancy B noted that testing is all about the trend. One test does not make a trend. Is the increase a steep line or just gradually increasing? It can also come down!!

Alf asked if there are Winship clinical trials conducted at the Midtown location or does the patient have to go to Clifton Road? Nancy Z lives in Midtown and schedules three out of four weeks to take place in Midtown. Jeff said that clinical trials are all managed at the Clifton location. Labs for standard treatment can be done at any Emory location.

Jim encouraged taking notes for the new patients. Get a notebook with a calendar in it. Every day, write down what time you got up and how you felt. Note what you ate and drank. Most important, note any new or changed pain and new symptoms. Do not just say it is going to get better. The sooner you get in front of the issue, the better off you are going to be. Do not be a superhero, call the doctor. Especially if you are on a clinical trial, they want to know about any changes. You will get special treatment when you are on trial. Call the number – 888-WINSHIP or 404-778-1900. BMT direct number is 404-778-0519.

Status update from members.

<u>Patient Updates</u>

Chinwe had an SCT transplant on March 21 and is doing well. She is getting good blood test results every month and is still waiting for consultation for kyphoplasty on her compressed disks. She remarked about her first MM support group meeting at St. Joseph when a member told her to not pay attention to all the different side effects mentioned. “If you think about all those possibilities, you will not want to go forward since you will think it will be so bad.” On the first call at home, the pharmacist was going over all the medications and side effects, she remembered crying and saying, “I would rather just die.” Then she remembered what she heard at the meeting and the support group made a difference that it was not as bad as it sounds. Jeff had CAR-T in January, and he is now myeloma free via MRD testing at 10^{-6} level. MRD testing is now done on all CAR-T patients.

MRD (Minimal Residual Disease) testing is performed with a sample from the bone marrow biopsy. One million (10^6) cells are inspected for myeloma and if there are no myeloma cells present then the patient is MRD-neg. If you achieve that milestone, then it has shown that you will be in remission longer. Joe is on day twenty-six from his CAR-T and is at home. He was hospitalized for 14 days since he did not get the CRS fever until day nine. They kept him in the hospital for a few extra days to watch for additional side effects. Joe is doing very well and starts IVIG infusions next week. Carolyn is on a Bi-specific, but few in the group are having Bi-specific treatments. Three approved CAR-T therapies and two of the approved Bi-specifics therapies that target the BCMA protein expressed on the surface of MM cells. Doctors use Talvey when CAR-T or the other Bi-specifics stop controlling MM expressing BCMA protein. Alf has been on Talvey (Talquetamab) since February 2024, Talvey targets GPRC5D protein expressed on the myeloma cell surface. He is also on Dara/Rev along with IVIG and is MRD negative.

Jim had CAR-T about 18 months ago and it has stopped working. He is looking at two clinical trials. One is a CAR-T that targets GPRC5D and the other is a “super IMID” which is a next generation immune modulator, the “ultimate Pomalyst”. It is a pill, like the other IMIDs which would be easier for Jim’s work schedule. Bianca has changed treatment. She looked at clinical trials but was not keen on the potential side effects on the eyes. She is now on Dara + Vel/Pom. She goes into the clinic once a week and has integrated the treatment into her work schedule, making calls and sending emails from the chair. Bianca has high risk MM and on the three drugs as maintenance to keep her MM under control. Nancy Z was interested in how Bianca has a good quality of life, allowing her to continue working while in treatment. Jim recommended getting regular treatments at one of the remote Emory locations, like St. Joseph or Johns Creek. They are not as large as the main Clifton campus, and you are able to get in and out quicker.

Nancy B closed the meeting with a big thank you to those who attended online and in person. With two new members, we made a big difference for them and will continue to impact each other in future meetings.

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Submitted by Nancy B

Meeting Minutes

Southside Virtual MM Support Group

May 24, 2025

Open Group Discussion

The meeting opened, wishing all a Happy Memorial Day and thank you for being available to attend during the holiday celebration weekend. Gail led a centering/deep breathing activity and moment of silence to start the meeting.

Ken O., a new member, attended the Northside meeting in May, also joined us at the library. He was diagnosed in February 2025. He had no symptoms, but his labs at the PCP office showed many indicators over several years for myeloma. His diagnosis has been defined as high-risk smoldering (SMM). He is currently on a 2-year/2-arm clinical trial of **Iberdomide** only versus Iberdomide and dex and is physically doing very well. Ken has experienced side effects. A rash, low blood counts causing fatigue, and does not sleep well. The rash sent him to the ER twice (Note: Iberdomide is a novel oral immunomodulatory drug being developed for the treatment of multiple myeloma and other cancers. It belongs to a class of drugs called cereblon E3 ligase modulators {CELMoD) which are structurally similar to immunomodulatory drugs (IMiDs) like lenalidomide and pomalidomide).

Ken was reminded not to minimize or downplay any side effects, report them to his team, and not compare himself to others. He can provide valuable information about this drug with the group as a clinical trial participant. Ken was also encouraged to join the "Men's Only" group on June 24th.

Discussion of Invitations to participate in surveys/studies

We received a request from **IMF** to complete a survey from a medical student. We also received an invitation from **Polygon Health/Massive Bio** to join them for guidance through the clinical trial process. **Nancy B**. shared that through her research, Polygon Health was a new organization. Massive Bio is also a new biotech organization that partners with seventeen pharma companies and has received some awards for their work. After reviewing their info and their websites, we decided not to respond to them. The SG leaders will do an initial vetting. Please remember to do your own research before sharing your personal or medical information. Also be cautious when offered financial incentives to share medical information. **Georgia CORE** (Center for Oncology Research and Education) asked that we complete a survey on survivorship. Gail is a member of their Survivorship Workgroup. She shared some background about GA CORE, including their funding from tobacco settlement funds and advocate work each year during the GA legislature session to maintain funding. They support the GA Cancer Plan and partner with many Cancer organizations including GASCO (GA Society of Clinical Oncologists). Under the leadership of Lynn Durham, EdD/CEO., GA CORE helped with passage of two major pieces of legislation this past session. One was for more screening for **colorectal cancer**. The other closed gaps in cancer screening and treatment for all Georgians. GA CORE provides funding for community-based **breast cancer** organizations from funds generated through the breast cancer car tag sales. Look for organizations that will share results on CT studies once they are completed. **Healthtree** does a good job in this regard. Gail showed an example of sharing results on the Healthtree website.

Follow-up on IRBs

Update on a question from the group in April on "What's an IRB?" Gail did a brief presentation on the mistrust of the medical care system, the origin of IRBs (Institutional Review Boards), and how patients became protected from harm during Clinical Trials. She included a *history of medical experimentation in the US*, and what we learned from it.

She provided a brief explanation of **informed consent**, and the three principles of human research."

§ Respect for people

§ Beneficence (minimize harms/maximize benefits), and

§ Justice (fairness in the distribution of benefits and burdens of research).

"For Men (with Myeloma) Only" Group Report

Anderson shared that the men's group is strong and a great place for one hour each month of fellowship and sharing. He emphasized, as Dirk and Jeff did, that it is a safe place to talk about their lives in general, not just myeloma. All encouraged the men in the group to join them this month.

Patient/Care Partner Voices

Dirk was in ICU for 42 days with an intestinal blockage. He is getting better, building strength, and undergoing PT 1-2 times weekly. He had issues with swallowing as a part of his journey. Gail wondered about whether there was any relationship between this swallowing, what happens with swallowing difficulties as a side effect of Talvey with Geraldine, and her own diaphragm spasm issues since her myeloma diagnosis in 2008. She has been prescribed a muscle relaxer, **baclofen**, for times when the spasms are most concerning**. Joyce** shared that she also had a swallowing issue when she was diagnosed with GERD (gastrointestinal esophageal reflux disease), pre-myeloma. A gastroenterologist suggested that a bulging disc in her neck might be related. She also had a series of swallowing tests. **Barbara W**. shared that we should build on what we already know. Barbara was diagnosed in October 2020. She has high risk myeloma and is doing very well after a Stem Cell Transplant (SCT) and rounds of carfilzomib, dex and Pomalyst (KPd). **Gloria** is doing well.

Barbara tries to keep up with all the information to maintain a high quality of life. Diagnosed in 2020, she is doing a virtual art class (national bone marrow org) and regular exercise classes. She knows how important social connections are and may do in-person or virtual. **Dirk** found an article on Facebook Myeloma Private Group **"The Price of Remission"** through **ProPublica.** The cost of treating myeloma and how the industry works is something we should all be aware of. **Ken** heard about the same article on **NPR's Fresh Air.** Gail talked about the importance of having an awareness of not only myeloma, but the policies that inform and govern cancer treatment. She reminded us to maintain our own **Cancer Plan** in a journal or three-ring binder with lab tests over the years, cost of treatment, side effects, etc. **Sandy B**. is sharing her longevity story with more people when asked – MMRF and her church were two occasions. Revlimid, which contributed to her dental issues was the catalyst for sharing more about her personal struggles so that others might benefit.

__Some questions to consider…__

Ø Have **you visited any new websites/information in the last month?**

Ø Have **you interacted with Myelo, the AI assistant on IMF, any other resources?**

Ø Do **you have ideas about other ways we should share information>**

Ø Is **it too much information? Alma** and others said they read the newsletter, use resources on the agenda, and that it is not too much information.

Nancy talked about the **Myeloma Minute** – IMF newsletter that comes out every Thursday evening. The most recent issue included info on high-risk smoldering myeloma. Skim through the blog for topics of interest. **Sign up here -** Latest Myeloma News | Int'l Myeloma Foundation

__Selected Videos__

***** Mitigating Neuropathy During Cancer**:** Video - <6 minutes :

Dr. Joe…What Really Causes Multiple Myeloma? What Doctors Know So Far, in 60 Seconds. Why do some people develop multiple myeloma while others do not? In this sixty-second video, IMF Chief Medical Officer Dr. Joseph Mikhael breaks down the top risk factors for MM, including obesity and environmental exposures.

Respectively submitted,

Gail