

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

July 13, 2024

Business & News

Thank you to **Nancy B.** for hosting the virtual meeting with approximately 36 attendees, including members from the Montgomery, AL, support group. Our guest speaker, Danielle Doheny, IMF Advocacy Director, had to reschedule her presentation due to her daughter becoming ill. Nancy reviewed some of the information presented at the recent ASCO (American Society of Clinical Oncology) and EHA (European Hematology Association) conferences. An open discussion followed with treatment updates from members.

Nancy will be traveling to Iceland with a fundraising group from the IMF at the end of August to meet with researchers from the [iStopMM](#) study, where 80,000 people are being probed for answers on myeloma. She is anxious to learn more about their findings on the study and tour the iStopMM research facility. Nancy is formulating questions to discuss and is asking you to share any questions you may have and what you want to learn more about. This is an extraordinary opportunity to have your questions. Also consider a donating to mission to Iceland August 29 – September 3 to help raise funds to cure myeloma. You can support her fundraising at [Nancy Bruno's fundraising page for International Myeloma Foundation](#)

Group Discussion

The ASCO and EHA conferences were held in June. Their discussions included minimal residual disease (MRD), CAR-T, four drug combinations, the role of transplants and an updated look at the future in myeloma. Nancy reviewed key points from the recorded webinar, [‘Top Myeloma Presented at ASCO & EHA Webinar 2024’](#) found on the IMF website. Presentation highlights included:

Dynamic Model to Determine Progression (SMM)

A *new dynamic model* is being used to determine myeloma progression for smoldering (SMM) patients, using the following three criteria:

- M-spike increases ≥ 0.25 g/dL in 6 months
- Free light chain increases ≥ 5 mg/dL in 6 months
- Hemoglobin (Hb) decreases ≥ 0.5 g/dL in 6 months

If an SMM patient has no signs of these criteria, the likelihood of further progression is 50%. As patient risk factors increase, or if patients have all three factors, progression

to myeloma is expected to happen within two years. The dynamic model helps to identify disease progression earlier before damage occurs.

Dara-VRd vs. VRd PERSEUS Trial Update

In this trial, Daratumumab (Dara) was combined with Velcade, Revlimid, and Dex and compared against the current 3-drug frontline standard of care (Velcade, Revlimid, and Dex). At 36 months:

- 64% of Dara-VRd patients were MRD negative with progression-free survival status.
- 31% of standard VRd patients were MRD negative with progression-free survival status.

Blenrep (Bela) Update

Blenrep is once again being used successfully with less side effects (especially keratopathy) when adjusting the dosage, dosing less frequently, and combining with other drugs in CTs. Some findings include:

- Blenrep, Velcade, and Dex is better than Dara, Velcade, and Dex
- Blenrep, Pomalyst, and Dex is better than Velcade, Pomalyst and Dex

FasTCAR Update

The FasTCAR process was developed in China and purchased by AstraZeneca, who is trying to obtain FDA approval. The product offers faster autologous CAR-T cell therapy delivery, reducing manufacturing time from months to days. When used as frontline treatment, the T-cells are received earlier, are younger, and stronger (less damaged from previous treatments). A clinical trial of tested newly diagnosed, high-risk patients who received VRD as initial induction therapy followed immediately by frontline FasTCAR (CAR-T) therapy was conducted in China. Outstanding results (100% MRD negative, and well-tolerated, but there is not enough data available yet.

There is evidence from studies that indicate that measuring MRD can be used as a guide to determine when to stop clinical trials (CT) and length of maintenance treatments. In CTs, if MRD negative status is achieved and a patient is not expected to progress, MRD can be used as a valid endpoint to end the trial which could shorten some CTs by years. Maintenance therapy can also be guided by MRD numbers, allowing patients to reduce the time that they need to continue on additional drugs. Doctors are trying to limit maintenance to 2-3 years. MRD is also being used to assess if a patient should have a stem cell transplant.

In summary, a lot of myeloma studies are being conducted to control myeloma better and longer. The future is bright when we can intervene early. There is a push for both prevention and a cure.

Patient Updates

We discussed treatments and changes in treatments. **Jeff W.** was in a clinical trial (CT) using Venetoclax for 63 months, but recently stopped the CT when his paraprotein level started to rise. He is now using Kyprolis, Pomalyst, and Dex to get his myeloma numbers down, and in preparation for both a T-cell collection and a stem cell collection. T-cells can be frozen for up to a year and stem cells can be stored much longer. Jeff mentioned that his doctors have some concerns about his ability to collect stem cells due to being on Daratumumab for five years. He plans to continue with the current drugs for a few months and then decide on any new treatments after that. **Tom H.** has been on Venetoclax for 25 months and is doing well. **Joe C.** is currently on a CT at UAB, under Dr. Costa's care, taking a Bispecific drug, along with fourth generation Revlimid ([IMid](#)) drug. Joe was diagnosed 9.5 years ago, and started on Revlimid, Velcade, and Dex (RVd) which worked well for him. Four months later he had a bone marrow transplant at UAB with very good partial remission (VGPR) for about 5-6 years before his M-spike began to rise. Joe began taking Daratumumab which worked well for 2-3 years before his M-spike began to rise again rapidly. He was eligible for the current CT and explained that there was another option for a CAR-T cell trial, but it would not be available for several months. He and his doctor decided that it would be better to begin the Bispecific trial available right away. Prior to this CT his bone marrow biopsy results were 30% plasma cells, His recent biopsy detected 0% plasma cells. Joe commented that he had very few side effects and was in the hospital for the first 10 days of the CT as the dose was gradually brought up to the level he is at now. There was some nausea and diarrhea, and he had a bad rash, but that was attributed to an antibiotic prescribed with the treatment. **Nancy** commented that it was interesting that his doctor thought it was more important to get treatment started sooner than risk waiting. Some doctors and patients opt for bridging therapy, short-term treatment is provided while the patient waits for CAR-T to be ready, although it does not always work well. **Stephen W.** was diagnosed with myeloma in March 2023 and received a stem cell transplant in October 2023. His recent lab test results show no myeloma and his MRD number was very low. He is expecting to start a two-year maintenance regimen soon and will learn more at his next doctor appointment. **Sandy W.** asked if it is known if the different types of myelomas (i.e., IgG, IgM, IgA, etc.) determine myeloma risk levels. For example, if type IgG is considered standard risk, are other immunoglobulin types associated with higher or lower risk? Nancy will ask the experts when she meets with researchers in Iceland. Be sure to send your research questions to Nancy for clarification.

Submitted by Wendy R

Meeting Minutes
Southside Hybrid MM Support Group
July 27, 2024

Next Meeting: Saturday, August 24, 2024. Hybrid, in-person – Atlanta-Fulton County Library – Cascade Drive. **LLS** – Light the night.

New Patients

We welcome a new member, **Henry L.**, who was diagnosed in September 2020. He had a transplant in February 2021. He was in remission until December 2022, after which Dr. Kaufman placed him on Darzalex Faspro, dex, and Kyprolis. He had a biopsy in June and is waiting for the results on August 13. He is doing well now, except for swelling in his feet and legs. He does elevate them when sitting. We asked him about staying hydrated because our weather has been so hot. He assured us he was.

Karen recently had her Stem Cell Transplant (SCT) at Emory and was in the hospital for two weeks. She said everything went smoothly. She feels well – except for the compressed spine she had prior to the SCT. Asked what her advice would be to someone who was about to undergo a SCT, she responded, “Stay hydrated, eat healthy, exercise, i.e., try to be as strong as you can physically and mentally – and do the same after the process.” **Gail** also recommended that she consider a referral to the oncology exercise specialist, Dr. Oza. Her information should be included in our June newsletter.

(We need more extension cords to work with our remote/hybrid equipment).

We then shared the passing of Jack Aiello, a strong patient advocate who enjoyed about 30 years of survival with myeloma. Jack was extremely active as a Support Group leader in San Francisco, and nationally, testifying before congress about the importance of myeloma drugs, as a committee member with the FDA, interviewing doctors for Patient Power educational series, and attending national and international meetings on

behalf of IMF and patients. Jack provided some of the most detailed, comprehensive notes from the annual meeting for the American Society of Hematology, and raised money through his wide network of family and friends to advance the cause and a cure for MM. **A link for more information is in your July AGENDA.**

Another major announcement was the retirement of Dr. Brian Durie, co-founder of IMF and Chief Scientific Officer, after 35 years of service. He will remain on the IMF Board of Directors. Dr. Durie discovered one of the staging systems for myeloma, the Durie-Salmon system.

For Men Only

Ted described their meeting as very energetic and informative. Their speaker was Dr. Joseph Michael, medical director for the IMF. He shared that Dr. Durie was very engaging and entertaining. There were about 33 attendees (about half from the Atlanta group. Dr. Joe did about 30 minutes of an overview of myeloma and 30 minutes just to chat and see what issues were concerning those present. There were lots of questions and we learned a lot. Dirk and others shared it was good to know more about who was at IMF, and how much they care about patients across the country. He was thankful for the good participation from our GA group. There were 45 registered for the meeting. We will work to increase attendance at our quarterly national meetings. Anderson called in from Urgent Care. We wish him a speedy recovery.

Garth H. was looking for some information to help him prepare for the procedure. Nancy mentioned that two Support Group leaders, Linda H. in Chattanooga, and Jim M., from Northside ATL groups have had CAR-T therapy. She suggested he call them and have a conversation about their experiences. Linda had to travel to Emory, as will Garth (from Athens), so there will be some similarities in what they will require. Gail will point out links in the resources for videos on what to expect from CAR-T for patients and care partners.

Dirk shared a situation with Zometa and his providers. He asked if he should still be taking it. Sometimes they forgot to give him the Zometa. These bone strengtheners, while essential at some points in treatment, they can be harmful if given too long. **Bernard** shared they talked in the

Men's group meeting with Dr. Joe that you must ask questions – about what the medication is for, and how long you should take it. We, as patients and caregivers have to help monitor our own health. Bernard also shared that he was on a high dose of Revlimid, but after hearing from others in the Support Group, he asked his doctor, and they reduced his dosage.

It is important to be monitored by a myeloma specialist. Bernard shared that in the Men's Group, they learned about the different types of remission. Nancy talked about one patient in Florida, who has had myeloma for 24 years, had never had her indicators go down to "0", but she is stable and is doing well. Bernard's doctor told him that he has the "highest" level of remission. Of course, we all cheered for and congratulated him. The doctor also reminded Bernard that there is no cure for myeloma. His doctor is Dr. Andrews who works with Dr. Nooka at Emory Winship.

It is so important to remember that myeloma can be so different in each of us. We must remain vigilant as we continue our journey.

Veronica shared that she had hip replacement surgery just three weeks ago! She is doing well – and working with our technology for a smooth meeting.

After much hesitation, **Vena** shared with us that she is not doing well. She was told that her myeloma has returned. She was already struggling with lung cancer and the myeloma was in remission. She has an appointment at Emory on August 12 to look at possible clinical trials. She asks only for our prayers – and she has those and our virtual HUGS. *“Again I say to you that if two of you agree on earth concerning anything that they ask, it will be done for them by My Father in heaven. For where two or three are gathered together in My name, I am there in the midst of them.” Matthew 18:18.*

Featured Videos

Healthtree was featured on **ABC news**. The link did not work for us during the meeting...we will send another one that works. On your AGENDA,

there are links to several videos, including separate one-hour ones on **sexual health and myeloma** from BMT InfoNet.

Dirk and Gail encouraged others to visit **SMARTPatients.com**, a resource supported by IMF. It is a much-underutilized resource, where you can interact with other patients about your experiences, or just read about their experiences to help you better understand your own. Dirk is very bullish on this website and encourages others to try it out. Dirk says the Facebook myeloma page is also very good.

We shared 10-minutes of a 1-hour long Palliative Care video for patients and caregivers. At least two people in the group shared that they had been on palliative care. It is not the same as hospice. Many shared they would go back and view the entire YouTube video. **The link is in your July AGENDA.** **Alma** received palliative care services during her monthlong stay in the hospital for COVID.

Light the Night with LLS will be October 7 in Piedmont Park. Doris would like someone else to lead our group in these efforts. If you are interested, please contact Doris or me.

Bridgette shared that a senior group at her church is sponsoring a trip to the Biltmore in Ashville, North Carolina in **December 2025**. Diamond Tours is the company for the trip. She will send more information for those who might be interested.

We went through our list of events, resources, and websites.

We were pleased to have **Vermell, Vena, and Deborah** join us after long absences from the meeting.

Respectfully submitted, Gail.