

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside MM Support Group

December 7, 2024

News & Business

Thank you to Nancy B. who hosted the Northside virtual holiday meeting with approximately twenty attendees. The first part of the meeting was spent sharing health updates, concerns, challenges, and tips; and then we shared holiday stories and plans.

The American Society of Hematology (ASH) conference occurred in early December 2024 with over 25,000 hematologists attending. The event featured over 1,000 abstracts on myeloma research. Various organizations, such as the International Myeloma Foundation (IMF) and Leukemia and Lymphoma Society (LLS) hosted webinars and presentations based upon these findings to keep patients informed. Staying current and sharing experiences with others is crucial to navigating the complexities of multiple myeloma (MM) treatments, given its rapidly evolving landscape. The next hybrid meeting will be on January 4, 2025, at the Winship Cancer Center, 1365 Clifton Road Building C in Atlanta. In this meeting, the Emory Winship myeloma team will review the December 2024 ASH findings related to MM and treatment options.

Patient Updates

Jeff W. was initially diagnosed in August 2018 and had 63 months of progression-free treatment on a clinical trial using Venetoclax. He has a specific genetic profile (11;14 translocation), which limits some of his treatment options. He is currently using Daratumumab and Dex, which is yielding satisfactory results but with some side effects, especially from the Dex. Jeff is currently preparing for CAR T-cell treatment planned in January. Jim M. and his wife, Lisa, were hit by a car in August. Both are doing okay. Lisa is recovering with physical therapy and injections for her knee. Jim had a broken coccyx and is

now in physical therapy. He developed shingles after missing several doses of Acyclovir during that time and is experiencing burning and tingling in his hands from the shingles. He has struggled with various medications for relief, long wait times for pain clinic appointments, and the general difficulty in managing his neuropathy symptoms. Jim also shared that he was recently hospitalized for chest pain but was cleared of any major heart issues after many tests.

Wendy R. commented that her husband, Rick D., has had satisfactory results from using infrared light therapy for neuropathy in his feet. The treatments have been easily tolerated, non-invasive, covered by insurance, and effective. Eventually, when the results begin to wear off, a touch up is needed, and the touch ups are working. Jeff mentioned that his veterinarian has treated his dog with red light therapy for pain and it has been highly effective for pain management. Glenn I. suggested viewing a YouTube video, ['The Science on Red Light Therapy Benefits with Dr. Michael Hablin'](#) on this topic. There was further discussion regarding shingles prevention and treatment. Many group members are taking Acyclovir or Valacyclovir regularly and have not received the shingles vaccine (Shingrix), which may not be compatible with certain treatments. Glenn I. recommended 'healing natural oils for both shingles' prevention and active shingles relief. Other participants discussed using lidocaine products for relief, although some expressed dissatisfaction with their effectiveness.

Karen C. expressed concerns with managing MM prescription refills while switching to new health insurance providers in 2025, unsure of how the new pharmacy will oversee the requests. Others shared similar concerns, noting the complexity of refilling specialty medications and the importance of starting the process well in advance to avoid gaps in treatment. Tips for managing medication refills include using the message portal at the oncologist's office, setting reminders for when refills are due, and checking and following up regularly to attempt avoiding any delays. Some insurance plans may be harder to navigate, but it is essential to stay ahead of potential issues. It is crucial to understand coverage for specialty drugs and

medical needs as changes in health insurance providers might affect treatments and coverage under new plans.

Doris M. was diagnosed 20 years ago and has far exceeded the initial prognosis that she was given of 3 to 5 years. She started the Atlanta Southside MM support group soon after her diagnosis. She avoided significant side effects from taking Thalidomide and decided early not to have a stem cell transplant. Despite facing health challenges, including pain and treatment with cortisone, Doris is doing well and preparing to celebrate her 84th birthday! Doris provided an update that Gail is recovering in a rehab facility from a MM treatment called DCEP. DCEP is administered in the hospital and is used when MM becomes difficult to control. DCEP involves a combination of older medications and is harsh but effective in controlling MM.

Additional items were discussed in the meeting:

- The *brand name Revlimid vs generic Lenalidomide* formulary is not significantly cheaper. This is due to a legal settlement between the generic manufacturers and Celgene (now owned by Bristol-Myers Squibb), which limits the production of the generic version. The settlement terms are set to expire in January 2026, which may lead to price drops in the future.
- *Insurance and Exception Process:* Some participants noted challenges with insurance formulary coverage for Revlimid and how patients must file for exceptions to receive coverage, which sometimes delays treatment. Once approved, insurance will cover the drug, capping out-of-pocket costs at \$2,000.
- A major topic at the ASH conference is the use of CAR T-cell therapy in MM treatment, with emerging research on a new type of cell therapy using *natural killer (NK)* cells. These cells might offer a new option because, unlike T-cells, NK cells do not get exhausted after repeated use.
- A potential return of *Blenrep*, a treatment that was previously given every three weeks but is now being tested at a lower dose and with longer intervals (every three months). This change could reduce

side effects like blurry vision, which was a known issue with the higher-dose regimen.

- There are reports about a clinical trial using *Minimal Residual Disease* (MRD) as an endpoint, which would be an exciting development in assessing treatment effectiveness.
- **FAST CAR-T:** Researchers reported a breakthrough in the manufacturing of CAR T-cells, reducing production time from six weeks to just a few days. This technology was purchased by a pharmaceutical company, indicating potential advancements in CAR T-cell therapy.

The group discussion was followed by a breakout session in smaller groups to give attendees time to meet new members and share their myeloma journey and personal stories.

Submitted by Wendy R

Meeting Minutes
Southside Virtual MM Support Group
December 28, 2024

Next Meeting:

The Southside group will meet on Saturday, January 25 at 10 AM. This will be a *hybrid meeting with both in-person and virtual attendance*. “For Men Only” meeting will be held virtually on Tuesday, 27 from 6 to 7PM.

Guest Presentation

Thank you, Nancy Bruno, for meeting with the Southside support group. Her discussion focused on the findings on myeloma at 2024 ASH in December. ASH is an annual conference of 33,000+ hematologists from around the world, meeting to present and examine over 8500 research abstracts on blood disorders. A record 1200 research reports related specifically to myeloma. IMF published

a recap video. Nancy showed the members many features on the IMF website clicking.

myeloma.org > *Publications and Video* > IMWG Conference Series
> [Making Sense of Treatment ASH 2024](#)

Nancy demonstrated how to maneuver the video timeline to locate where topics of interest can be found. Cc can be added for “closed caption.” Nancy also pointed out how to access the “Ask Myelo” icon and contact the IMF info line with your questions.

Dr. Joe broke down the video into main topics to explain the changes and updates in myeloma over the past year. Each topic provides details of many findings from the conference.

- Whether SMM be treated or monitored based on risks factors
- Frontline Therapy changes from 3 to 4 drug combinations with immunotherapy.
- Multiple use and treatment options for Daratumumab
- Use of newer drug classes sooner in myeloma treatment for maximum response
- Targeting BCMA for greater response rates with T-cell and bispecific antibodies
- MRD testing to determine maintenance endpoint and QOL options.
- Approving Blenrep for treatment every 3-4 months for late relapse
- Reduce Dex to less amounts and duration “Down with Dex.”

Be sure to review the video for more information and questions to discuss at the next meeting.

“Patient Voices” on [Facebook Live](#) provides personal perspectives on the myeloma process. Know the essential questions to ask and

discuss with your healthcare provider. These questions help you focus on the present concerns of your myeloma as well as providing insight on new treatment options that relate to you.

- The most important treatment to me is the one I am on right now.
- What would be the next one I potentially would be on?
- Explain how you help patients think about the next treatment.
- How do we get to that next line?

Gail M. provided some insight on the importance of being active in your myeloma journey. Her protein levels were rising, and the doctor offered a clinical trial along with standard treatment. Gail also listened to several people from the group about their experiences. She discussed [Selinexor](#) with Dr Nooka and reviewed several research papers on the drug. Gail liked the possibility but was not initially approved since she had not been through three prior lines of therapy. She and Dr. Nooka worked through the appeal process to get the drug approved for treatment which took several months. Her persistence emphasizes the importance of being knowledgeable on the newest treatments to make the best-informed decisions throughout your myeloma journey.

Patient updates

Nancy E. is currently on Dara-Kyprolis (KDd) and is doing well. She was originally diagnosed in 2007 and received a tandem transplant after induction in 2009. A brain lesion was found more recently that was treated with radiation, followed by KDd therapy. Nancy is very active in her garden. Nancy B. noted that Darzalex is a powerhouse myeloma drug since its approval in 2015 being used as a 4-drug induction treatment DRVd for newly diagnosed MM patients as well for maintenance.

Gail M. updated the group on her treatment journey. She returned home from rehab and had her third round of Dara-Selinexor. She had a trying recovery with blood and platelet transfusions, low

magnesium levels, and medical mix ups, physical and emotional difficulties since October. Recovery is even harder for patients without immediate family to provide personal care partner support. Patients discussing their journey concerns, successes and hardships help all of us. Gail spent several months researching her options before deciding on her current therapy.

Carol O. discussed side effect issues and financial concerns dealing with brand name Revlimid vs generic lenalidomide. She has experienced many problems from the inactive filler ingredients in the generic version, most recently causing unexpected fainting. She has taken seven different generic lenalidomide versions in the last 2 years. Insurance providers do not automatically cover Revlimid brand since the cost is greater than \$22,000 compared to around \$13,000 for generic lenalidomide. Since so many patients have reported significant side effects from the generics, physicians can work with pharmacies to get brand name Revlimid for their patients. It is important to let your healthcare team know of any new or increased effects from your drugs or treatment.

Submitted by Sandy W.