

Meeting Minutes

Northside Hybrid MM Support Group

May 4, 2024

Next Meeting:

Saturday, June 1, 11 a.m. Carroll Education Center at Emory-St. Joseph Hospital. The guest speaker will be Dr. Sonal Oza, MD. from the Department of Rehabilitation Medicine at Emory Winship Clinic, who will present an overview of services for Oncology patients.

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Business and News

Thank you, Nancy, for hosting this month's meeting in the Carroll Education Center at Emory-St. Joseph Hospital campus. There were 20 members attending in person as well as 18 online via Zoom. The meeting ran smoothly with minor audio glitches, and everyone was engaged in the session. The format is a work in process that will continue to improve as we learn the technology and equipment capabilities. Any input and suggestions are welcome for consideration.

Guest Speaker Presentation

Nancy presented information on two recent developments in myeloma treatment.

First, the FDA (Food and Drug Administration) has approved CAR-T therapy for earlier lines of myeloma treatment. *Abecma* and *Carvykti* were originally available under *conditional approval* two years ago for treatment of myeloma to patients only after **four** lines of therapy which included three different classes of drugs in prior treatments. FDA approval provides access to CAR-T treatment outside of clinical trials. Newly diagnosed Myeloma patients need more options for new treatments sooner as well as patients who relapse after several lines of therapy. This also allows doctors to learn more about the treatment and its adverse side effects. More data has become available on the outcomes of these treatments as a result of expanded FDA approval. The prior conditional approvals showed good outcomes, so the FDA loosened the limitations for patients. *Abecma* is now approved for use after two lines of therapy and *Carvykti* is approved after only one line of therapy. Trends may show better results in patients with less rounds of treatment and stronger T-cells. Having CAR T therapies available for earlier lines of therapy is an important consideration for patients seeking to achieve

excellent quality of life outcomes (QOL) with longer, more durable remissions off all therapy.

The second news announcement was that the FDA held an Oncologic Drugs Advisory Committee (ODAC) meeting to discuss the use of minimal residual disease (MRD) as an endpoint in multiple myeloma clinical trials. This includes considerations regarding timing of assessment, patient populations, and trial design for future clinical studies that use MRD data to support accelerated approval of a new product or new indicator in treatment. There was a unanimous ODAC vote in support of using MRD testing in clinical trials. MRD as an early endpoint for accelerated approvals in MM clinical trials would considerably expedite the development of FDA-approved myeloma drugs and therapies and bring them into the market sooner rather than later. This would remove years from the clinical trial process and get treatments to myeloma patients years sooner.

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Group Discussion

The meeting continued with members updating their myeloma journey, sharing new myeloma treatments, adverse side effects and questions posed to the group including handling slow response times from the myeloma team, accessing physicians for second opinions and tips on less common side effects that can disrupt patient daily activities. Great advice was shared from both in-person and online participants.

The first hybrid meeting of the year was successful, and our goal is to continue this format going forward. The next meeting is on Saturday, June 1, at 11 a.m. Our guest speaker in-person at Emory-St. Joseph Hospital will be Dr. Sonal Oza, MD. from the Department of Rehabilitation Medicine at Emory Winship Clinic, first floor, who will present an overview of their services and quality of life (QOL) benefits for cancer patients.

Submitted by

Nancy B and Sandy W

Meeting Minutes
Southside Virtual MM Support Group
May 25, 2024

Next Meeting: Saturday, June 22, 2024. Topic – Patient/Care Partner Voices (all virtual)

“For Men Only”: Tuesday, June 25, 2024. *What’s on your mind? Let’s Talk.* (all virtual)

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Business & News

The meeting opened with a moment of silence led by Doris; mind centering/breathing exercise led by Gail. Nancy wore her father’s military medals from his 28 years of service to commemorate Memorial Day.

“For Men Only” group will have Dr. Joe Mikhael join them on the 4th Tuesday in July (July 23) or August (August 27). We will share when the date is confirmed. All men are cordially invited to attend.

General Meeting

Thank you to **Gail** for hosting this month’s meeting. Welcome to our newest member, Lonnie R. He was diagnosed about 14 months ago and is on a clinical trial with Dr. Lonial, using *Iberdomide*, an oral drug. Iberdomide is a new class of myeloma drugs. Major side effects are low blood counts (neutrophils) and blood clots. Lonnie is a father of 3. His 4-year-old being among other children challenges his immune system including asthma as a child and pneumonia during his myeloma treatment. He has received IVIG treatments and was in ICC to control infections. He has been through several back surgeries and hip replacement surgery in the past and wonders if the surgeries are related to his myeloma. His doctors have found no evidence. Lonnie’s father was in the military and had leukemia and questions whether genetics or the toxins encountered in the military had any correlation. Nancy noted that the IMF has many special interest support groups including myeloma patients/families with young children.

Several videos and resources were reviewed by the group during the meeting. Gail shared that she had recently learned about **Artificial Intelligence (AI)**. There are multiple platforms for AI, depending on the purpose. Gail shared that *ChatGPT* was user-friendly. This ensued a discussion on how it is being used and the relevance to medical research and practical application. A video from the Patient Empowerment

Network was shown with Dr. Ola Landgren on *AI: What Are the Latest Artificial Intelligence Advancements for Myeloma?* Recently a research study was published “*Individual Risk predictors for patients with MM*” in the Journal of Clinical Oncology in collaboration with myeloma specialists across the world, AI was able and will continue to develop databases to help teach the computer in greater detail about the best next treatment. The IMF) is also working on ways patients have their concerns better addressed with AI, including what the best therapy might be for them, whether newly diagnosed, at relapse, or when certain medications do not work well for them. The technology is not yet ready for predicting outcomes. Nancy noted that when doctors get more comfortable with the new technology myeloma will begin to be diagnosed earlier. Gail added that patients can use AI to gather information to help make decisions about next medications or therapies. Dirk suggested that AI should more appropriately be referred to as “Large Language Model” not AI since it has been around for a very long time. Dirk spent much of his professional life as a technical writer – providing clear and concise instructions and procedures.

Is Myeloma genetic? (2 min video). Although there is no definitive response to help answer the question, *The Promise Study* is ongoing and hopes to answer questions related to genetics and myeloma. Dr. Ghobrial is the Principal Investigator of the Promise Study. Go to the website, [SPARK CURES](#) or Call 888-828-2206 if you have any questions.

Another selected video was from Dr. Urvi Shah (hematologist-oncologist), who has an interest in nutrition and myeloma. She has several studies going on and is developing a partnership with Emory to make the studies more accessible for patients with MGUS. The **Myeloma Living Well** series features *Triage Cancer* presentation (recording) on “Medicare changes in myeloma for 2024 and beyond”. You can find this video on [myeloma.org](#). Please go to this site to find what things you and your family need to consider before its time for annual enrollment. There is information about prescription drugs, Medicare Parts A, B, and D. In 2025, there will be a cap on drug care costs of \$2,000. Example: What will be your highest “out of pocket” maximum for medical costs in the next year? There are several examples during the video to help with making choices that are better for you --- and you can watch the video in ‘bite size’ pieces.

Nancy asked if anyone had undergone CAR-T. Only Geraldine (of those on the call) had the experience. She has since relapsed and is on the bispecific, *Talvey*. She has struggled with many side effects – losing fingernails and toenails. **Joyce** shared that her doctor had discussed the option with her. She gets information from the Support Group, IMF, and other myeloma resources. Nancy shared that CAR-T is available earlier than in the past and there are two CAR-T treatments: *Abecma* and **Carvikti**. Gail is happy to see more helpful videos for care partners on what to expect from the CAR-T journey. She also cited a 5 min video “Is CAR-T for everyone?” (Patient Empowerment Network), focused on disparities in how CAR-T therapy is offered to

Blacks vs Whites. **Sandy W.** has many family members with blood cancers. She asked this question 28 years ago, before the Promise Study was introduced. At the time her doctor said, “there is no evidence.” Her Mom had “primary” amyloidosis, her siblings and other relatives have been diagnosed with myeloma, MGUS, amyloid chronic leukemia, lymphoma, and other blood diseases. The doctor said he flagged her chart with recommendations that all her relatives be tested when they reach age 40. She works to ensure that relatives are tested at the appropriate times.

Pat C. was diagnosed with myeloma many years ago. Her husband was diagnosed about three years ago. Is it familial (runs in families) – so people who live in the same environment can experience similar health issues. The Multiple Myeloma Research Foundation (MMRF) has also collected data for research in the genetic arena of myeloma research. We reviewed many of the resources from various MM organizations in the Announcements section of this newsletter.

Please consider a donation to our own Nancy B., who will travel to Iceland in August to help raise funds for a cure for myeloma.

Respectfully submitted,

Gail