

**Meeting Minutes**  
**IMF Regional Community Workshop**  
**April 13, 2024**

**Next Meeting:**

Northside Meeting: Saturday, May 4, at 11 AM. The Northside MM support group is hybrid which offers an in-person meeting at St. Joseph's Hospital and a Zoom session at the same time. More details to come.

**Business and News**

The May Northside MM support group will be hybrid this month at St. Joseph's Hospital and a Zoom session simultaneously to connect those members at home to the members via the website. The meeting will be an open discussion to learn from each other as we share experiences. Be sure to review your current MM status, treatment plan with drug dosage level. It provides comparison with others. The IMF regional community workshop will also be discussed. Watch your email for details on the location and zoom link connection. The Northside Atlanta group meeting was not held on the first Saturday this month. Instead, everyone was encouraged to attend the IMF Regional Community

Workshop on April 13. 60+ attended the workshop and lots of information was shared.

### IMF Regional Community Workshop Recap

Thank you, Nancy Bruno, for hosting the RCW workshop. The first speaker was Dr. Johnathan Kaufman who presented **Myeloma 101**. He started with the basics of our blood and what the myeloma cells do to our immune system. The discussion continued on the types of myelomas, symptoms, and lab tests that track MM and other functions impacted by the disease. Then Dr. Kaufman reviewed the different classes of drugs along with an explanation of immunotherapy – their processes and targets. The Good News is the increased survival rates for MM patients. There are now so many new treatments making a difference for patients and their families. It is important that all patients stay informed and empowered to seek the best treatment.

Next, Charise Gleason talked about “Taking the Reins of Your Multiple Myeloma Care.” She discussed a wide variety of treatments and combinations currently available for patients, including the latest immunotherapy. CAR-T and Bispecifics treatments have a unique set of side effects that patients need to be aware of. Charise went into the side effects of SOC treatments

and ways to reduce their impact. Communicating with your healthcare team is important if there are any changes or increases in your side effects. She also talked about important steps that can help with side effects: *hydration for kidneys, sufficient sleep, pain prevention/ management, and exercise*. All and any new side effects should be discussed with your team, including *depression and anxiety, financial stress, and any impact on your quality of life*. You are central to the care team and communication is key to arriving at timely treatment decisions together.

“If you want to go fast, go alone, if you want to go far, go together.”

Dr. Nisha Joseph was the next speaker who talked about Frontline Therapy. The depth of response in early treatment is important along with the increased use of MRD testing to quantify the response. The frontline approach is changing with *quadruplet therapy before stem cell transplant*. If the patient is not eligible for transplant, the options for continuous therapy need to be reviewed. The decision for stem cell transplant is usually made early so treatment can be determined for a deep and durable response. Do not “*save the best for last*” because early therapies have a long-term effect on overall survival. Dr. Joseph displayed data following

patients for four or more years when Darzalex was added to first line Induction treatment prior to SCT. It showed a 58% reduction in the risk of early MM progression.

Conclusions on frontline therapy:

- Transition to quadruplets in frontline therapy. (Optimal length of quad treatment is still TBD.)
- Transplant still has a vital role in MM, even with long term use of novel agents.
- *Consolidation* may deepen responses and should be considered in patients who have not achieved at least VGPR (very good partial response).
- MRD guided discontinuation may be possible in lower risk groups, but not high-risk patients.
- Transplant eligibility is determined by a number of factors: *age, fitness, comorbidities*, etc. In many cases, continuous maintenance therapy has resulted in better outcomes.

A panel discussion by Patient Advocate and Care Partners, Sandy B and her husband Joe, and Jim M and his wife Lisa, shared their MM experience and admiration of their partner's strength on this journey. Thank you for sharing your stories.

Then Dr. Joseph returned to discuss maintenance therapy. Important terms:

- **Induction:** Intense first-line therapy with the goal to achieve rapid remission.
- **Consolidation:** Intense shorter-term therapy with the goal of deep remission.
- **Maintenance:** Less intense longer-term therapy with the goal of better PFS and OS outcomes.

*What does Ideal Maintenance therapy look like?* A deepened remission with prolonged duration over time. It should also be easy to administer with minimal toxicity. These goals are still being improved. Revlimid is the standard for maintenance, but the [Forte Trial](#) shows adding Kyprolis improves the progression-free survival (PFS) from 73% to 90% in standard risk patients. High risk patients showed similar improvements – 69% vs. 56%. Dual maintenance drugs may increase side effects and need to be discussed with your doctor.

*How long should maintenance be continued?* Data suggests ongoing PFS benefit from Revlimid beyond at least 4-5 years in the overall patient population. Even patients with sustained MRD negativity, there is benefit from continuing Revlimid for at least 3 years.

Dr. Kaufman returned to discuss Relapsed Therapies and Clinical Trials. He explained that the approach to relapsed/refractory myeloma (RRMM) is not a simple algorithm of successive treatments. Consideration of

next line treatment is made based on prior treatment success and experience and patient preference as well.

RMM Definitions:

- **Relapsed:** disease recurrence (reappearance of myeloma) after a response to therapy.
- **Refractory:** disease continues to progress despite ongoing therapy.
- **Progression:** change in M protein/light chain values.
- **Line of therapy:** a need to change in treatment due to either progression of disease or unmanageable side effects. Note: initial (or induction) therapy + stem cell transplant + consolidation/ maintenance therapy = 1 line of therapy

Therapy selection considerations:

*Disease-related* – the nature of the relapse, whether the relapse is Biochemical vs Symptomatic, your Risk Stratification, whether you have high-risk chromosomal abnormalities: del(17p), t(4;14), t(14;16), and additional disease burden.

*Therapy-related* – Previous therapies taken, a prior treatment-related adverse event, Drug regimen related toxicity, depth and duration of previous treatment response, cost to patient.

*Patient-related* – Renal insufficiency, hepatic impairment, comorbidities, personal preferences, social issues

concerning a support system, accessibility to treatment center, insurance coverage.

*General Principles* to consider- mechanisms of action not previously used, do not continue to use lenalidomide if disease is progressing on Len maintenance, triplets are preferred over doublets.

These concepts apply to subsequent relapses as well. The doctors have studied clinical trials, but it is important that patients be educated about options and understand the impact of each treatment.

Then Dr. Kaufman focused on CAR T-cell therapy and Bispecifics. He explained the process of harvesting the T-cells and sending them to a lab to create engineered T-cells by expanding them to generate hundreds of millions of these cells before sending them back to be infused into the patient. This manufacturing process can take 4-6 weeks and the patient may need *bridging therapy* during that time. The side effects from CAR-T therapy include cytokine release syndrome (CRS), neurotoxicity (ICANS), cytopenia, and infections.

There are currently three approved Bispecific antibodies: *Tecvayli*, *Talvey*, and *Elrexfio*. These treatments are showing response rates of 63% to 73% in patients following multiple lines of therapy. Bispecific antibodies can target two cell surface molecules at the same time (one on the myeloma cell and one on a T cell).

Availability is off-the-shelf, allowing for immediate treatment. This is an on-going treatment with side effects similar to CAR-T therapy. There are many different Bispecific antibodies in clinical development and information about them is expected at the next few conferences.

Dr. Kaufman provided an overview of clinical trials. Here are some of the important principles:

- The drive of clinical research has brought us to where we are today.
- No one is expected to be a “*guinea pig*” with no potential benefit to participants.
- Research is under very tight supervision and research protocol standards.
- Open and clear communication between the physician, research and patient is vital.

#### *Clinical Trials – Is it for Me??*

- Every patient is unique and must be viewed that way.
- Benefits of trials are numerous and include:
  - Early access to “new” therapy
  - Delay use of standard therapy
  - Contribution to myeloma world – present and future
- Financial access to certain agents
- Must be balanced with potential risks.



- “toxicity” of side effects
- Possibility of lack of efficacy

Clinical trials translate results of basic scientific research into better ways to prevent, diagnose, or treat cancer.

The more people that take part, the faster we can answer critical research questions, find better treatments and ways to prevent cancer.

*Benefits of Participation in clinical trials:*

- Patients will receive, at a minimum, the best standard treatment.
- If the new treatment or intervention is proven to work, patients may be among the first to benefit.
- Patients have a chance to help others and improve cancer care.

*Possible risks of clinical trial participation:*

- New treatments or interventions under study are not always better than, or even as good as, standard care.
- Even if a new treatment has benefits, it may not work for every patient.
- Health insurance and managed care providers do not always cover clinical trials.

*Why do so few cancer patients participate in clinical trials?*

Patients may:

- Be unaware of clinical trials
- Lack access to trials.

- Fear, distrust, or be suspicious of research.
- Have practical or personal obstacles.
- Face insurance or cost problems
- Be unwilling to go against their physicians' wishes.
- Not have physicians who offer them trials.
- Have a disconnect with their healthcare team.

Dr. Kaufman also reviewed the [IMF M-Power project](#) within communities to improve access to treatments. There has been a lack of diverse representation in clinical trials in myeloma. In the U.S., approximately 20% of all myeloma patients are of African descent, but only 5%–8% of patients in myeloma clinical trials are of African descent. All patients of all races and ethnicities should be able to benefit from clinical trials. Diverse patient representation in clinical trials is required to ensure that the outcomes are applicable to all. Reasons for underrepresentation in clinical trials are complex and include systemic racism, accessibility of clinical trials, sensitivity to diversity by medical professionals, misconduct in medicine in the past, the lack of trust in the system, and more.

Submitted by  
Nancy B

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## Meeting Minutes

Southside Virtual MM Support Group

April 27, 2024

### Next Meeting:

**Saturday, May 25, 2024 @ 10:00** – Virtual only. Meeting room reserved for primary election.

**For Men Only:** Next Meeting – Tuesday, May 28 at 6:00 – 7:00 PM.

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### Open Group Discussion

The meeting opened with a moment of silence from Doris and a brief centering/deep breathing exercise led by Gail. We welcomed two new members. **Alf** was diagnosed with smoldering myeloma in 2020 which has progressed into active myeloma in 2023. He is being treated at Emory Winship and is taking Revlimid, dex, Daratumumab, and Talvey (A bispecific from Johnson and Johnson). Alf is experiencing loss of taste from Talvey. Kim, nurse rep from Johnson and Johnson spoke to us extensively in February about the loss of taste as a possible side effect from Talvey. Other side effects include skin and fingernails issues. **Gail** will share the minutes from Kim's February presentation with Alf and also check on info kits to assist with information and other potential issues. **Wynne** was

diagnosed in November 2023. Wynne is treated at the WellStar-Kennestone location. Dr. Dean Kinkle is his oncologist, in collaboration with Dr. Hofmeister at Emory Winship.

Highlights from our Regional Community Workshop (RCW) were discussed by those who were able to attend on April 14. Some participants reported that it would have been helpful to have known about complimentary parking in advance. Many parked far away and walked to avoid the parking fee. Gail had to wait more than 20 minutes to get out of the hotel parking lot after the workshop due to a malfunctioning exit arm. The workshop location was easily accessible by roads from all directions allowing many members to travel surface streets to avoid the interstates. The meeting was well-organized, the food was good, and it was enjoyable to have lunch in the atrium with the outside light coming in. We applauded Nancy for her first time facilitating an RCW following Kelley Cox retirement. **Nancy** shared that even with her many years with myeloma experiences and the IMF, she continues to learn something new almost every time. There were about 60 people in attendance.

Nancy shared that people are expressing challenges they are having with Emory Winship patient services causing frustration with lack of assistance and communication. Emory staff responded that they are aware and seemed to

receive the critiques well and are making plans to improve patient services. Problems with getting prescriptions on time and getting staff to return calls to patients have been real-time issues. Gail said a highpoint of the workshop for her was hearing the Patient / Care-partner stories from Sandy B. and her husband Joe, and from Jim M. and his wife Lisa. Both patients were so open about their myeloma journeys as a couple, their many challenges, and their gratitude for family, doctors, and science advances in myeloma.

Ted reported from the “For Men Only” Group. In Anderson's absence, Ted was lead facilitator for this meeting for the first time. The men had a good meeting with great participation. Two new members joined. As a group, it was decided to have the *national men only meeting* once each quarter. They want to maintain the local camaraderie and fellowship.

We featured three short videos of about 3 minutes each:  
1 – The Promise Study – this is a way to get free tests to determine if your first-degree relatives might be at risk for myeloma.

2 – The importance of self-advocacy by a myeloma expert.

3 – Is there a link between CAR-T therapy and T-cell malignancies?

Alf has participated in the Promise Study, starting in 2021-2022. He also mentioned Cure Cloud, an MMRF initiative

to look at the genetics of myeloma. Dr. Nooka (Emory) had planned to present information on this program, but said they are on hold for now.

### **Patient / Care-partner Voices**

**Dirk B.** was in the hospital last month with an infected colon. About six inches of his small intestine was removed and was fortunate to have avoided a colostomy bag. Dirk thinks sepsis may be myeloma related since myeloma patients are more prone to infections. **Cynthia B.** is not content with the “*watch and wait*” advice she was given by her providers. Gail, Doris, Alf, and others encouraged her to seek a second opinion and that it should be accepted in myeloma as normal standard practice. Cynthia shared the difficulty in knowing how to find a specialist who could provide a second opinion. Alf maintains his myeloma specialists at the Mayo Clinic in Jacksonville as well as Emory Winship. Cynthia was encouraged to ask other group members about their doctors and experiences as additional sources for a second opinion. **Mary F.**, who is a nurse, suggested asking the PAs and nurse practitioners. (Also note: Call the IMF myeloma support line for suggestions. Also check with your insurance company to determine the coverage for a second opinion.) **Veronica** wanted to know if there is a connection between the Korean War and myeloma. There

are a few veterans who are members and would like to be able to meet each other. There are special services for veterans, including disability coverage through the PACT Act and dental services that we want to share.

Respectfully submitted, Gail.

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