

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside MM Support Group & Southside MM Support Group June 24, 2023

This month there was a combined meeting, the IMF Regional Community Workshop, at the *National Center of Civil and Human Rights* Museum in Atlanta

Business and News

Next Meeting: **Southside group will meet this Saturday, July 22 at 10 a.m.** The meeting will be virtual this month. The meeting will include the voices of patients and care partners, and discussion on the IMF Regional Community Workshop in June. Provide your feedback and if you were able to register and attend the workshop. Reminder that “Men’s Only” meets on the fourth Tuesday each month from 6 to 7 p.m.

Sad news. [Emma Stubbs](#) passed away on July 12, 2023. Her notice is attached below.

IMF Regional Community Workshop Recap

AAMMSG Southside and Northside groups attended the **IMF Atlanta Regional Community Workshop on June 24** held at the *National Center of Civil and Human Rights*. Over ninety participants attended the conference. Each session focused on aspects of myeloma and what testing, treatments, side effects and upcoming drug regimen are being investigated. The speakers were Emory Winship physicians and staff along with a panel discussion of local patients and care partners telling their myeloma journey. The workshop allowed ample time to network with each other and talk with pharma sponsors. Light breakfast and lunch were provided.

The morning session started with *Myeloma 101* primer presented by Dr. **Hofmeister**. He used the analogy of myeloma cells destroying the bone marrow to termites eating away the shell of a house. Chemo is the drug that kills the majority of myeloma cells but rarely gets to the “queen” myeloma stem cells. The differences of blood cancers leukemia, lymphoma and myeloma were explained along with the CRAB and SLiM-CRAB criteria revised by [IMWG](#) in initial diagnosis of myeloma. Understanding your risk and staging of the disease is essential in determining what treatments plans are best for you.

Dr. Nooka continued the morning session with *Frontline Therapy*. He explained the importance of “Depth of Response” during the first line treatment plan and how [MRD testing](#) helps to guide future

lines of therapy. Dr Nooka reviewed several treatment plans and clinical trials available to newly diagnosed patients. His talk concluded with a positive outlook to treatment through the evolution of myeloma therapy.

Charise presented *How to Manage Myeloma Symptoms and Side Effects*. Myeloma treatment and management, healthy living, and coordinating your care were key points. Charise discussed the side effects of steroids (DEX), cytokine release syndrome (CRS), neurotoxicity, infection, GI issues, neuropathy, and pain management along with physical, psychological, and financial burdens.

The afternoon session began with a *Local Patient-Care Partner Panel* discussion. **Guest presenters were Bob Cain & Molly Lay, and Ted & Mattie Price.** Each couple outlined their myeloma journey and provided personal and insightful tips on how to manage their life and daily activities with myeloma.

Dr. Nooka returned to present *Maintenance Therapy* and consolidation. He explained the benefits of lenalidomide (Revlimid) maintenance after treatment providing longer progression free survival (PFS) and overall survival (OS) for patients. Maintenance combinations with DEX, Daratumumab, and clinical trials were also discussed.

Dr. Hofmeister's session was *Relapsed Therapies and Clinical Trials*. He explained the course of treatment after the first relapse (Second line treatment), second relapse (third line treatment) and so on. As patients develop recurring [relapse](#) to myeloma or become [refractory](#) (resistant) to certain drugs the clonal plasma cells will mutate further or become more aggressive causing the disease to be much harder to control. The drug options at third line therapy and beyond are far less accessible. Dr Hofmeister discussed the common drug interactions and side effects that occur from IMDS, PIs and miscellaneous drugs as well as neuropathy and infusions. T-Cell therapy and Bi-specific treatment are available at some cancer centers. Dr. Hoffmeister outlined the history of clinical trials regarding patient disparities and availability to treatment. This was well received and greatly appreciated by the attendees.

Respectively submitted by Gail M & Sandy W