

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Hybrid MM Support Group

June 1, 2024

Next Meeting

Danielle Doheny from the IMF Advocacy team. She will describe the coalition of organizations in making a difference for patients. She will talk about monitoring legislative actions and protecting the interests of myeloma patients.

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Business and News

Nancy has been selected to join a small group going to Iceland to meet with the researchers for the iStopMM project. The project has collected data from 85,000 adults in Iceland who agreed to be tested for myeloma. They found about 4,000 people with MGUS, SMM, or MM and are evaluating treatment vs. monitoring for SMM and MGUS. These options are called *The Cure trials* to see if myeloma can be cured and what are the earliest stages MM is detected. Nancy will be taking notes to bring the information back to the groups.

Thank you, Nancy, for hosting the June 1 meeting. There were over 40 members in attendance: 28 in person at St. Joseph's Conference center and 19 participating virtually online. Aside from pesky audio issues, things ran pretty smoothly for our first attempt to host a guest speaker live.

Be sure to send your comments and suggestions so we can continue to improve the meeting format.

Guest Speaker Presentation

Welcome Dr. Sonal Oza. Dr. Oza is an Oncology Rehabilitation Physician at Emory Winship. She has worked at Kettering Center and Huntsman Cancer Institute prior to joining the Emory staff. Her presentation is Optimizing Function: The role of physical exercise in multiple myeloma.

Dr. Oza began her presentation with the question ***What is PM&R (Physiatry)?***

- By definition: “*medicine emphasizing the prevention, diagnosis, treatment and rehabilitation of temporary or permanent functional impairment.*”
- Individuals with cancer, particularly MM may develop several symptoms. Neuropathy, weakness, deep bone pain, muscle spasms, changes in balance, posture, and chemo brain) which may occur from the cancer, treatment, and/or side effects.
- These issues interfere with daily activities; walking, going up and down stairs.

The PROMIS -Physical Function study has shown that lung cancer, multiple myeloma, leukemia, and lymphoma patients had the lowest T-scores for physical function. Dr. Oza’s study included around 700 patients with data from questionnaires, clinical observations, T scores, physical activities, and daily routines. The *30 second Sit to Stand Test* is performed to assess functional lower extremity strength and endurance in older adults. It is a good predictor of one’s muscle strength, endurance, balance, and treatment complications associated with overall survival. Normal rep count is between 12-15 for patients over 60. A count of 12 or less reps in 30 seconds is considered below normal range of functional mobility. This indicates general weakness in the lower extremities, especially the hip muscles which cause increasing difficulty in daily functions like

getting in and out of chairs, cars, etc. This is called *generalized weakness or frailty* due to prolonged periods of reduced activity.

Cancer can cause the breaking down of muscle to occur faster than building it back up. Chemotherapy from PIs like Velcade and targeted therapies can cause neuropathy primarily in the hands and feet. Symptoms include numbness, tingling, and pain. Patients describe the sensations as pins and needles, walking on sandpaper and being uncomfortable and irritated. Severe cases can develop an involuntary foot drop from shuffling, dragging their toes, feet, and tripping when walking with muscle weakness. Round toe shoes and orthotic insoles can be prescribed to aid heel to toe motion when walking. An orthopedic brace may be necessary for foot drop to support balance and muscle assistance. These aids provide stability and reduce feeling wobbly and looking at the ground.

Rehab interventions after transplant, treatment and recovery may include physical therapy (PT) exercises and using assistive devices. Patients are deconditioned for weeks or months from weakness, low blood counts and fatigue. Thick car seat cushion pads and Easy-up Lifting Seats help with sit to stand motions. For strength in the hip and quad muscles along with knees buckling, leg braces aid in stability. Walkers and rollators provide greater support walking when becoming really fatigued, difficulty standing, hard to walk, dizziness and shortness of breath. This allows the body to recover, rebuild muscles and increase functional mobility. Pain management is also discussed during the evaluation since it is oftentimes a determining factor for the visit. This discussion may be with a pain management physician or palliative care specialist. Topical meds like lidocaine and Valsartan may be enough for nerve pain on the hands and feet. More severe pain medications include *Gabapentin*, *Pregabalin (Lyrica)*, *Duloxetine (Cymbalta)*, *Nortriptyline* and *Amitriptyline*. Acupuncture service is available for patients during treatment to

help with neuropathy as well as nausea, general fatigue, and speech issues. Emory currently has a grant that provides acupuncture free for 12 weeks. contact information for Acupuncture is 404-778-0600. Patients can get a referral from their oncology team. It may help get connected faster with the program.

Dr. Oza is interested in spinal compression fractures that are common among individuals with multiple myeloma. Lesions and metastases to the bone and compression fractures account for up to 45% of newly diagnosed patients. Myeloma is a cancer that starts mostly in the bone, particularly to the spine. Normal images show spine bones as a series of boxes. As the myeloma invades the bone and it becomes brittle, the bone collapses into a compression fracture. The fracture may bulge towards the spinal cord which can lead to emergency surgery and potential radiation. Multiple compressions may occur over time weakening spinal extensor muscles along the spine from our neck to our pelvis called **Kyphotic-Lordotic** posture. The patient's *posture notably changes with the head flexed forward, chin pointing down and patient's walking scrunched over rather than standing upright.* These are high endurance muscles that work non-stop to keep you upright and moving all day long. Strengthening these muscles is essential to reducing pain and loss of physical function that can impact treatment options. Focus on strengthening the little back muscles along the spine so the core can support the total weight of our spine. A spinal brace can also improve posture and reduce pain from multiple fractures. There are different types of braces to consider depending on the severity. The stable brace is more flexible and provides ample support while your own muscles are still doing the work. Medicare only pays for one every few years so be sure to have your provider help with the approval process. Out-of-pocket costs can run up to \$500.

Dr. Oza continued the presentation discussing exercise for *generalized strengthening* for MM patients without skeletal bone lesions or fractures. The Emory rehab clinic uses the **Medbridge** PT program.

- Focuses on the hips, buttocks and lower extremities with bridges and sit-stand reps.
- Shoulder external rotations, low/seated band rows and lateral pull downs are good for upper back muscle weakness.
- Back and core exercises include thoracic extensions, scapula retractors, bicycles, marches, and hamstring stretches while on your back.
- Avoid any exercise that repeatedly bends forward. That includes *no sit-ups -- no crunches ever!* Focus on moving the spine the opposite way with *extension-based exercises*.
- Patients with spine fractures, pelvis, hip and femur issues or bone replacements should also *avoid high impact activities*: jumping, hopping, running, and oscillating motion (ATV, Horseback riding).
- If there is a history of shoulder injuries or humerus fractures *avoid weight bearing arm exercises*: push-ups, planks, bench/chest presses, triceps bench dips.
- Muscles are like shock absorbers protecting your bones against fractures and injury.

Resistance exercise can help maintain bone health.

There are 3 categories for bone density. Normal bone t-score is greater than minus 1, *osteopenia* T-score range is -1 to -2.5, and *osteoporosis* T-score is anything less than negative 2.5. Osteopenia is porous, but not brittle bones. Doing resistance exercise can maintain bone density at its current state. Studies have shown that routine exercise and aerobic activity helps maintains

bone health and physical function regardless of the time or stage of diagnosis. *Patients are counseled to start or continue a regimen of cardio, weight-bearing, and resistance training.* Patients should start a cardio routine with brisk 3-4 mph walking 90 minutes a week done in 10 to 15 increments to improve cancer related fatigue, physical function, mental health, bone health and overall quality of life (QOL). Add resistance exercise 2-3 times a week. Rehabilitation therapy can help you work through the symptoms of pain, fatigue, neuropathy, bone fractures even if it is unrelated to the myeloma or treatment.

Appointments can be scheduled with Dr. Oza or Dr. Khanna for Oncology Rehabilitation Medicine at Emory Winship – 404-778-1900.

Submitted by Sandy W.

Meeting Minutes
Southside Hybrid MM Support Group
June 22, 2024

Next Meeting: Saturday, July 27, 2024. The meeting will be hybrid in-person at the Atlanta-Fulton County library on Cascade Road along with virtually via Zoom.

Business & News

“For Men Only” Support Group hosted the quarterly meeting with men with myeloma from across the country. The guest speaker was Dr. Joe Mikhael, Medical Director of the IMF/Professor, Lead of M-Power to eliminate health disparities and increase health

equity. His discussion included hot topics in myeloma, minimizing concerns, and updates on myeloma advances going forward.

Group Discussion

Thank you, Gail, for hosting the meeting. The meeting opened with a moment of silence and centering with deep breaths led by Gail.

Welcome to **new member, Karen C.** She was diagnosed in November 2023, after being watched by her oncologist at Piedmont Hospital for 7 years. Karen is scheduled for a Stem Cell Transplant (SCT) on June 26 with Dr. Hofmeister, and welcomes hearing from others in the group about their experiences. Karen also has compromised vertebra in her lower back that causes pain in her legs. There is not yet a plan to deal with that.

Dirk, Jeff, Gail, and others shared some pearls of wisdom. Understand that SCT is just another treatment not a cure. Be careful of pets and grandchildren at home that might spread infections. You will be encouraged to get up and walk around the floor frequently after transplant. There will be plenty of downtime so take easy reading, your laptop, and other activities/hobbies to stay entertained. **Gloria** also reminded us that we lose our hair, but it does grow back.

Report from “For Men Only.” Ted shared they had a productive and enlightening meeting. There were about 9 who attended. They announced that Dr. Joseph Mikhael from IMF will be the guest speaker and men from all Support Groups across the country will be invited to attend. Dirk complimented Anderson on being such an accomplished facilitator.

Reflections on the exercise presentation by Dr. Oza from Emory Winship Oncology Rehabilitation department. A detailed summary is in the **July 2024 Newsletter** with helpful recommendations for myeloma patients. Be careful of bones and

compression fractures that are especially affected by myeloma. It is encouraged to exercise a minimum of 150 minutes/week, 30 minutes 5 days a week.

Appointments can be scheduled with Dr. Oza or Dr. Khanna for Oncology Rehabilitation Medicine at Emory Winship – 404-778-1900. All Emory patients are eligible along with MM patients during myeloma treatment.

Wanda shared that Kaiser has opportunities for exercise with vetted instructors, there are classes offered in chair yoga, Pilates, and more. AARP and Silver Sneakers also have classes, including virtual classes. Dirk shared that strength training should be a part of our daily regimen. Many in the group are exercising regularly, most are walking, climbing stairs, and physical activity included in household chores.

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Recommended Videos to Review

[Dietary Guidelines for Blood Cancers after Treatment](#). Healthtree Foundation. June 2024. – 1 Hour

LLS. videos share information about nutrition and wellness, tips, recipes and more.

Making Good Food Choices: The Grocery Store (February 2023)

Making Good Food Choices, Recipes for Health (February 2023)

Childhood Nutrition: Making Good Food Choices and Nutrition Tips & Tricks (Jun 2022)

ASCO Update. Dr. Brandon Blue. MM.ASCO Updates_ PEN-B Blue. June 2024. 6 min

ASCO 2024: “Caregivers Are Our Unsung Heroes”, Jun 17, 2024. Sunita Puri, MD. – 2 min

MM.ASCO_Caregivers. 2 min- 2024.

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Additional discussion points.

Gail shared that she asked again about getting a **second opinion** when the world of myeloma specialists concentrated to the same city or state. Dr. Blue encourages everyone who feels they need it to pursue a second opinion. It is true that myeloma oncologists in the same facility (Winship, Northside, etc.) will have very similar advice since they hold weekly meetings to discuss their patients' treatment plan. There are myeloma specialist centers throughout the country; in Boston- Dana Farber, FL/MN/AZ- Mayo Clinics, Arkansas, TX- MD Anderson to name a few. While insurance companies encourage second opinions, please check to see if they will cover the cost.

MM – Risk Factors, Prevention, Causes

1. **Age** – primary risk factor. Most people diagnosed with multiple myeloma are over 65 years old, and the average age at diagnosis is 70. This means that people over 65 have an increased chance of developing the disease compared to younger people.
2. African American
3. **Obesity** - *Advances in Hematology* noted that obesity, along with type 2 diabetes, is associated with a higher risk of developing multiple myeloma.

The exact reason for the link between obesity and multiple myeloma is not known. However, it is suggested that MGUS – a condition involving excessive paraproteins in the blood – may be higher among obese individuals.

4. **Radiation, chemicals** - Journal of Radiological Protection showed that people with a history of radiation exposure were more likely to develop multiple myeloma than those without a history of radiation exposure. Interestingly, the risk was more significant in industrial workers and those who were last exposed less than five years before the study began.

5. **Gender** - Dr. Braunstein, males are more likely than females to develop multiple myeloma. “Statistically, males are about 1.5 times more likely than females to be diagnosed with myeloma.”

The American Cancer Society estimates around 19,860 new cases of multiple myeloma will be diagnosed in men in 2023, compared to 15,870 new cases in women.

6. **Race** - Multiple myeloma is more common in certain racial groups than others. According to research published in Blood Advances, African Americans are more likely to develop multiple myeloma than white people. The exact cause of this disparity is not known.

7. **Genetics/hereditary** – Dr. Braunstein - several genome-wide association studies and pedigree analyses of certain families have suggested a 2 to 3 times higher risk of MGUS among first-degree relatives.”

Evidence shows that genetics does play a role in MM. Myeloma cells typically show acquired abnormalities like deletion, translocation, and chromosome duplication. For instance, the typical human cell has 46 chromosomes. But some findings show that **parts of the number 17 chromosome are missing in MM cells**. According to a 2018 study published in the International Journal of Laboratory Hematology, **chromosomal translocation** – a chromosomal rearrangement whereby fragmented pieces of a chromosome re-attach to different chromosomes – was found in about 50%-70% of MM cases. More than 90% of the translocations happened on chromosome 14 at the IGH locus.

Respectfully submitted, Gail.