

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

### Northside Virtual MM Support Group

October 7, 2023

#### Business & News

**Next Meeting:** November 4, 2023, at 11 a.m.

We will remain meeting virtually with the increased levels of COVID cases and flu season around the corner.

Thank you to **Jim M.** who hosted the meeting with approximately 30 attendees. In this meeting guest speaker from Georgia State Health Insurance Program (SHIP) presented the 2024 Medicare program and answered our questions followed by an open group discussion.

#### Guest Speaker Presentation

Thank you to SHIP guest speaker, **Janet Payne**, Certified SHIP counselor from the **GA Division of Aging Services** who presented the 2024 Medicare program and updates along with Q&A. State Health Insurance Assistance Program (SHIP) provides timely information on Medicare, Medicaid, and other health related insurance to assist seniors in understanding healthcare benefit options to make better informed decisions. SHIP department provides health care wellness and preventative services, financial assistance, educational programs on Medicare parts A, B, C and D, Medicare Advantage Plans, Medicare supplement insurance (a.k.a. Medigap), and one-on-one counseling. Georgia SHIP services include:

Georgia SHIP offers free counseling services, unbiased opinions and is not affiliated with any insurance company or sell/solicit any type of insurance.

Certified SHIP counselors will help with Medicare benefit questions:

Understand your health plan choices; enroll in a Medicare plan that meets your needs; Review Medicare summary notice(s); review explanation of benefits (EOB).

SHIP assists with sorting medical bills and filing Medicare claims and appeals. They will also help you apply for financial assistance programs to reduce Medicare out-of-pocket expenses.

**Georgia SHIP Contact:** Speak to a Georgia SHIP counselor for Medicare assistance anytime Monday through Friday, between 8 a.m. and 5 p.m. **Call 1-866-552-4464 and select Option 4.**

Janet began the presentation with a brief overview of Original Medicare. Also known as *Original Medicare “Basics”* coverage includes only Part A and Part B.

**Part A (Hospital Insurance)** covers hospital, blood work, labs, hospice care, and more. There is no premium to eligible participants with incomes under \$97,000.

**Part B (Medical Insurance)** covers doctor appointments, labs, testing, provider administered medications (i.e., Infusions) durable medical equipment (DME), short term rehabilitation and more. There is a premium deducted from monthly social security (SS) and employer retirement pension. Premiums for 2024 will be \$174.50. After paying the Part B deductible, Medicare pays 80% of the cost of medically approved services and the remaining costs are 20% is your responsibility.

Remember: There is no out-of-pocket maximum under the Original Medicare program.

**Part D (Prescription Drug Coverage)** covers prescription drugs. Prices are grouped by Tiers 1,2,3,4 and may require pre-authorization, quantity limits and generic alternatives.

Prescription drug plans cover the costs of prescription medications which can be extremely expensive. Even if you do not currently take Rx drugs it is advised that you enroll in a prescription drug plan. If you do not and later need coverage, your costs will be considerably higher since Medicare adds a penalty for every year you do not enroll in Part D which becomes an additional lifetime premium. There are Part D plans with a zero-cost premium if you do not take prescription drugs to avoid these penalties.

**Medicare Supplement Insurance (a.k.a. “Medigap”)** are sold by private insurance companies.

These plans cover insurance gaps in Original Medicare for deductibles, coinsurance, and copayments on additional covered services. Medigap / Supplemental Medicare insurance only works with Original Medicare, has a monthly premium, and may not be needed if supplemental insurance is available from an employer or secondary insurance.

Part C Medicare Advantage Plan (MAPD) includes coverage under Medicare Parts A, Part B and Part D. MAPD may offer additional services such as dental, vision, hearing, Silver Sneakers, over the counter (OTC) drugs, chiropractors, acupuncture and more. Review all plan specific benefits and eligibility requirements. Confirm that your providers accept the MAPD before enrolling. All Medicare Advantage plans are different. In Georgia there are over 600 plans.

### **In Summary, Medicare selection options include:**

- ***Original Medicare*** (Parts A & B), with an optional Part D and an optional *Supplemental (Medigap) Coverage* that insures gaps in coverage. Enroll in Part D to avoid penalty.
- ***Medicare Advantage*** (a.k.a. Part C), which includes Parts A, B, D, extra benefits, and may also include lower out of pocket costs.

When selecting between ***Original Medicare and Medicare Advantage*** plans it is important to analyze the many differences between the plans to determine the best insurance options available. It is to your advantage to shop around and to find someone to assist you in selecting the plan that best fits your individual needs. Be sure to set up your Medicare.gov account to access general information, compare plans, doctors, and costs. It is an extremely useful tool, especially when so many plans change every year. You will need to review your plan yearly for coverage updates and changes on eligible providers. A SHIP counselor can help set up your [medicare.gov](https://www.medicare.gov) account. Make an appointment to meet with SHIP for free, unbiased, and professional help. Essential resources are available when preparing to enroll in Medicare initially, or when reviewing or making changes to existing Medicare selections. You do not need to do this alone.

### **Questions & Answers**

**Q:** If I set up a Medicare.gov account now, will it affect my current insurance in any way? **A:** No, not at all and in fact it is a good resource for your research. **Q:** I am still working at age 65. Do I need to sign up for Medicare? **A:** If you are still working at age 65 and are covered by your employer's medical insurance plan, you

should sign up for Medicare Part A now (it is free) even if you plan to continue with your employer's medical insurance plan. Check with your HR department to make sure they notify Medicare that you are covered under the employee plan to prevent being penalized. **Q:** With the upcoming open enrollment, if I do not want to change any of my insurance, do I need to do anything? **A:** No, your current coverage will automatically roll over for the next year.

### **Additional Reminders:**

- Open enrollment for Medicare begins in mid-October.
- Make sure that you select a plan that covers you when you travel.
- When deciding on a Medicare/MAP plan, be sure your doctors are in the network and select a drug plan that covers your prescriptions.
- Medicare generally does not cover dental and vision expenses, so be sure to find separate dental and vision coverage if you want those items to be covered.
- Even if you already have a plan that you like be sure to review it for changes in 2024.
- Be wary of anyone trying to talk you out of your current into different plans and frauds. You can check on the validity of all plans through the Georgia SHIP department.
- SHIP Request for Medical Assistance

Submitted by Sandy W.

## **Meeting Minutes**

### **Southside Hybrid MM Support Group**

**October 28, 2023**

**Next Meeting:** Saturday, November 25 at 10:00, VIRTUAL

Our meeting focus will be sharing beyond being a myeloma patient or care partner. Tell us your backstory.

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

You have set a precedence! The IMF has created a *Men's Only Group*, and you are invited. Stay tuned.

### Business & News

The 2023 **Light the Night** event was very successful. Thank you to everyone for your contributions and fund-raising efforts. Southside exceeded this year's goal of \$2,000, raising almost \$3,800. Several members including **Doris, Larry and Karen** represented Southside Group hoisting our AAMMSG banner high in event photos. Way to represent the Team! Recommendations to LLS for shuttles from designated parking lots would allow many others to attend next year's event. Ms. **Emma Stubbs'** two sisters, Mary, and Mildred made a donation to the Southside Group. Emma was a dedicated member who passed away from myeloma complications in August. We thank them for their thoughtfulness and generosity.

**Anderson** shared that *Men's Only Group* had a good meeting last Tuesday. Notices were sent out late due to some confusion of the 4<sup>th</sup> Tuesday fell *after* October's Saturday meeting. He invited the new men to join their group. The topic discussions are more than myeloma, it is whatever they choose. HealthTree is creating a Men's group (based on the Atlanta initiative), inviting men to attend from all over the country. Look for an invitation from that group.

### Guest Speaker Presentation

Our speaker was **Kendelle Miller**, an Oncology Social Worker, from Emory Winship. She has moved from the Clifton campus to Decatur and now works with patients and families of all cancer types. Her presentation was entitled "*Optimizing Your Relationship with Your Social Worker.*" Kendelle provided great insight, resources and support available from social services.

She started the presentation by explaining ways "**How can a Social Worker help?**"

- emotional support – a safe place to discuss fears about cancer diagnosis and treatment.
- practical support including transportation, local lodging, such as HOPE lodge and financial assistance.

- financial support - **Social Workers** can help to identify funds through grants and foundations.
- navigate the healthcare system to connect patients and families to community resources.
- healthcare education and advocacy on treatment options (i.e., stem cell transplants), information on rehabilitation, disability, respite, and palliative care
- care coordination – Does your treatment create a burden in daily activities? household tasks, grooming, etc.
- quality of life support including advance care planning, pain management, grief counseling, hospice care, bereavement support

### **What are the strategies for gaining support from your Social Worker?**

Use clear communication with your healthcare team that you would like to meet with a Social Worker. Do not hesitate to share your concerns (i.e., *emotional, physical, financial*). Social services help you navigate and figure out your needs. Just call and introduce yourself. Openly and honestly communicate your needs.

Develop a comprehensive plan with your Social Worker for your specific needs.

Care coordination – Does treatment plan create a burden in daily activities? Personal care, housekeeping, etc.

Be engaged– ask questions. Everyone has different challenges.

Some myeloma is asymptomatic. Disease progression includes symptoms like back pain, anemia, renal issues, and elevated calcium. Blood and urine tests provide strong indications. A bone marrow biopsy can confirm a myeloma diagnosis. Be vigilant and spread the word about myeloma and possible symptoms, while urging physicians to listen to their patients and look for warning signs. Clear communication is essential no matter the decision for treatment.

Finding transportation resources can be tricky. MARTA mobility (scheduled pick up and return to your home) can be a resource. Contact your health insurance provider regarding transportation benefits that may be available. Insurance companies do not readily provide that information. Insurers sometimes may have a case manager who should help navigate and can be assigned to help with resources. Some Medicare Advantage Plans offer these benefits, with a limited

number of trips for medical care. [Mercy Medical Angels](#) is another resource that offers air, ground, and gas cards for transportation. Consider your close support system – family, friends, sorority, fraternity members, congregation members, etc.

Whether in mid-career – or retired due to your myeloma inquiry on disability, short-term / social security.

As patients, we generally have no foundation for navigating these resources. You may live alone with no care partner – or with a partner who does not drive. Discuss your special concerns with a social worker trained to listen and help with resources that meet your needs. It may be helpful to write down your concerns – the things that disturb you about your journey (much as you do with your doctor) and discuss them with a social worker.

### **Additional Resources:**

Kendelle directs a support group for patients and care partners regarding blood cancers via Zoom on the 2<sup>nd</sup> Tuesday of each month at 2:00 PM through Emory. [Email](#). A flyer will be sent out with more details.

There are also caregiver resources at [Emory Winship Cancer \(Caregiver\) Support Groups](#) at Emory Winship. You do not have to be an Emory patient to attend.

[Association of Oncology Social Workers](#) resources. [IMF](#). [National Cancer Institute](#) (NIH)

[American Cancer Society](#) (800.227.2345) – financial, transportation, wigs, nutrition demonstrations

[Bone Marrow and Cancer Foundation](#) – “cancer buddy.”

[Cancer Care](#) – publications addressing practical, emotional and medical concerns.

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**Gwendolyn** attended our meeting. **Doris** exercises with Gwendolyn and has talked about myeloma for many years. Gwendolyn’s mother had recently passed away from myeloma after many years of weekly injections for anemia and pain. The doctors never disclosed that her mom had cancer. Gwendolyn questioned whether one had to have a bone marrow biopsy to know if they have myeloma.

Her mom was 95 years old. Many recommendations for treatment may be made based on age. Some treatments can be very hard on one's mind and body. **Sandy W.** assured Gwendolyn that she was doing her family a great service by following up on myeloma. Several blood diseases have been diagnosed in Sandy's family, including *amyloidosis*. Family members now look more closely at any blood work labs and diagnoses and have more informed questions for the doctor.

**Barbara W.** primary care doctor missed her myeloma although she had elevated calcium. She was referred to a sports medicine doctor due to chronic hip pain. "Holes" in her bones were identified from scans and she was eventually referred to an oncologist. Her myeloma was diagnosed as high risk.

Some myeloma is asymptomatic. Disease progression includes symptoms like back pain, anemia, kidney issues, and elevated calcium. Blood and urine tests provide strong indications. A bone marrow biopsy can confirm a myeloma diagnosis. Be vigilant and spread the word about myeloma and possible symptoms, while urging physicians to listen to their patients and look for warning signs. Clear communication is essential no matter the decision for treatment,

**Bernard** added that a Social Worker at the time a patient is diagnosed might be helpful for patients to include in their own decision-making about which treatment regimen to accept. Patients should also take all the time they need in order to try to understand better about the disease, treatment, and expectations – to be a better part of shared decision making.

**Flora** has a complaint about recurring back pain. While physical therapy seems to help some, the pain remains, especially while walking. She has been taking Ninlaro (Ixasomib) for over four years. The side effects of nausea and weakness seem to be getting worse. Sandy W. shared a new resource at Emory called [Physical Medicine and Rehabilitation](#). Drs. Khanna and Oza are the lead physicians. Sandy gives their work high praises. There are many things to check with your doctor. Be sure to report all the symptoms to your doctor. Please do not suffer in silence.

**Greg** is a new member who has high risk myeloma and has a history with PI drug Ninlaro. He shared that he found that taking this drug with food helped with the nausea. *Read the labels. Talk with your **pharmacists**. When they ask if you have any questions about your medications, contact them. They are underutilized members of our healthcare teams.* Gail added that side effects are a part of taking medications, but there are things we can do to minimize those side effects. Greg has had some challenging times on his myeloma journey. He was in the ICU in two different



hospitals and was in kidney failure. He has been in remission now for about seven years. He is being treated at Emory Winship by Dr. Kaufman. He is also a counselor at LLS.

**Cynthia B.** wanted to hear from others who may have experienced **Bispecifics**. This may be her next regimen. A [\*\*\*Bispecific monoclonal antibody\*\*\*](#) is an artificial protein that binds to sites on the myeloma cell and the T-cell simultaneously to destroy the myeloma cell. It harnesses the power of your own immune system through **immunotherapy**. Naturally occurring antibodies usually attack one site at a time. Talquetamab-tgvs (Talvey) is the most recently approved by the FDA in August 2023. Teclistamab and Elranatamab were approved earlier. Bispecifics are used after four previous therapies – in relapsed or refractory therapy. HealthTree video “[\*\*Know Your Myeloma Immunotherapy: Teclistamab and other Bispecifics\*\*](#)” and IMF has some videos explaining bispecifics - [Using the Immune System to Fight Multiple Myeloma | International Myeloma Foundation](#)

Gail shared that IMF is developing new **special interest myeloma Support Groups**: High-Risk myeloma, Smoldering myeloma, for those more comfortable speaking Spanish, for those who live alone, and for young adults with myeloma. We all can learn so much more about our own myeloma, and the IMF is working to help us do that.

Greg shared that too many myeloma patients have no idea that there is a Social Worker available to help respond to many of their concerns. He suggested that all new patients should be introduced to the Social Workers. Kendelle noted that each social worker is assigned to a healthcare team, and the number of new patients has grown tremendously over the past few years. Including a color-coded resource sheet in every new patient’s chart may provide information to initiate the visit with a social worker. An idea would be to have every new patient meet their healthcare team – the doctor, PA, nutritionist, pharmacist, social worker, etc. within the first few visits. This happens in the Phase I center. This approach puts the patient at the center of what they do.

Gail recommended a couple of educational videos for the group. One is the hour-long online seminar on **nutrition and myeloma** with Dr. Urvi Shah. Many of us want to know what to eat to help us reduce our risk from cancer or other health challenges. The second was a **six-minute video** for those who are **not eligible for transplant** and what it means for their treatment regimen. Dr. Joseph Mikhael is the speaker in this “Myeloma made simple” series.

**Alma** has been on Teclistamab since Labor Day – and so far, so good. There is an initial hospital stay for close monitoring, then once weekly visits to Emory’s infusion lab for a subcutaneous injection.

Respectively submitted, Gail.