

# ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

## Meeting Minutes

### Northside Virtual MM Support Group

October 10, 2022

#### Business & News

Thank you to **Dirk B.** who hosted the meeting with approximately 35 attendees. In this meeting representatives from Georgia State Health Insurance Program (SHIP) presented the 2023 Medicare program and answered our questions followed by an open group discussion.

#### Guest Speakers Presentation

Thank you to SHIP guest speakers, **Paul Lee** and **Shirley**, professional counselors from the **GA Division of Aging Services** who joined the group to discuss the Medicare program/ updates for 2023 and answer questions. Formally *GeorgiaCares* is now [State Health Insurance Assistance Program](#) (SHIP) that provides free and equitable information assisting beneficiaries and their caregivers on Medicare, Medicaid, and other health related insurance. SHIP assists seniors to understand Medicare benefits to make better informed decisions about their healthcare options. Medicare trains counselors to deliver information about what is and is not covered, along with what is available in your area, to help you make the best choices available. SHIP department offers timely education on health care benefits, wellness and preventative services, financial assistance programs, Medicare parts A, B, C and D, Medicare Advantage Plans, Medicare supplement insurance (a.k.a. Medigap), and free, one-on-one counseling.

For further assistance, contact Paul *Lee cell: 470-552-5362 / ofc: 877 -220- 0127.*

The discussion began with a brief, comprehensive overview of [Medicare](#). What is known as “**Original Medicare**” includes only **Part A and Part B**. The following outlines the “**Basics**” of Medicare coverage with some highlights for each part.

#### [Part A \(Hospital Insurance\)](#)

- Covers hospital stay, blood work, diagnostic tests, labs, skilled nursing, hospice care
- No cost to eligible participants, no monthly premium
- 2023 deductible is increasing to \$1600 (from \$1,556 in 2022)

#### [Part B \(Medical Insurance\)](#)

- Covers medically necessary and preventive services to diagnose and treat medical conditions
- Includes home health care, durable medical equipment (DME), ambulance transport and [clinical research](#) services
- Not free, deductibles and 20% Medicare Approved amount may apply
- Reduced average premium in 2023 to \$164.90 (from \$170 in 2022)

- After paying the Part B deductible, Medicare pays 80% of medically approved services cost and you are responsible for 20%.

#### Part D (Prescription Drug Coverage)

- Medicare Part D covers prescription drugs

Part D drug plans cover the costs of prescription medications, some of which are 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 initially enroll when eligible in a prescription drug plan your costs could be considerably higher the longer you wait to enroll. Medicare adds a penalty fee to coverage for every year you are not enrolled in Part D. You will continue to pay the additional coverage fee premium for life. Look for Part D plans with zero cost premium even if you do not take prescription drugs to avoid penalties.

#### Medicare Supplement Insurance (a.k.a. “Medigap”)

- Available through private insurance companies
- Plan changes can be made during any month
- Covers insurance gaps in Original Medicare for deductibles, coinsurance, and copayments for additional covered services
- Provides additional coverage to Original Medicare
- Has a monthly premium
- May not be necessary if you receive supplemental insurance elsewhere (i.e., employer)

#### Part C (Advantage Plan)

- Includes “bundled” coverage plan for Medicare Part A, Part B and usually Part D
  - Changes to you plan need to be made during Open Enrollment for the following year
  - Offers additional services (plans vary) such as dental, vision, hearing, gym membership, over the counter (OTC) drugs, chiropractors, and acupuncture
- Review all plans for specific benefits and eligibility requirements
- All Advantage plans are different. In Georgia there are over 465 plans

#### Medicare coverage choices include:

- **Original Medicare** (Parts A & B), optional Part D prescription plan and/or additional **Supplemental** (Medigap) **Coverage** to cover cost gaps in Medicare insurance
- **Medicare Advantage** (a.k.a. Part C), which includes Parts A, B, most times Part D along with extra plan benefits. Medicare Advantage may also lower premiums, deductible costs, and out of pocket expenses.

When selecting between **Original Medicare and Medicare Advantage** plans it is important to analyze the many differences between each plan 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. A SHIP counselor can help set

up your Medicare.gov account. You can make an appointment to meet for free, unbiased, and professional assistance. There is a lot of help and resources available when preparing to enroll in Medicare initially, and when making changes to existing Medicare selections. It is not something that you need to do 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 plans that cover you when you travel
- When you make plan selections, be sure that your doctors are in the network and find 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

If you already have plans that you like and are still available to you, be wary of anyone trying to talk you out of them and into different plans and beware of Medicare frauds. If you have questions about the validity of certain plans, feel free to call GeorgiaCares for assistance.

### Patient Updates

**Jim M.** recently received a *stem cell transplant (SCT) as part of a Phase 1 Clinical Trial* with reduced dosage of Melphalan given on two separate days, versus the standard high dose one-day treatment. He said that it was a much more tolerable experience for him compared to his first SCT in July 2010. The reduced toxicity from the lower drug regimen helped Jim recover faster and easier. Jim walked nearly every day during his two-week hospitalization. His energy level is improved and experienced far less side effects this time than during his first SCT. **Sandy B.** continues to prepare for dental surgery. She copes with her challenges by practicing gratitude and appreciates sharing her experiences to help others. **Molly L.** asked if anyone continues to experience side effects from treatment drugs, even after being off them for years. Several people confirmed that they do. In particular chronic gastrointestinal (GI) issues such as diarrhea, constipation, and lactose intolerance continue long after MM drugs are discontinued. One member is considering a fecal transplant at the Mayo Clinic to help with some of the lingering GI side effects caused by drugs. Suggestions for controlling the GI side effects include OTC drugs, prescribed medications and diet changes including eliminating dairy and red meat and introducing oatmeal. It was noted that oatmeal can lower cholesterol and was able to reduce the cholesterol count by 150 points in just one month eating oatmeal for breakfast daily. **Molly** offered a tip she learned cooking steel cut oats in a rice cooker which can speed up the process. She is attending the [Optimal Healthy Lifestyle Nutrition Workshop](#). Several group members attending commented on the benefits of the free weekly workshops offered by **Dr. Rooke** from Morehouse College. They are a wealth of good information on nutrition and other health-related topics. There was group discussion regarding vaccinations and how they affect everyone differently and sometimes unexpectedly based

upon their prior reactions to the same type of vaccination. **Jeff W.** mentioned that he got his COVID booster and flu shot together on the weekend and then ended up with a fever Monday and Tuesday (days later), which surprised him, as he has not had such severe reactions with other boosters/vaccinations of the same type. **Marilyn M.** mentioned that her and her husband also both received their COVID booster and flu shot together and experienced extreme arm soreness and fatigue for 5+ days. She said that although they were not sick and did not have fevers, they did not feel their best. Other members commented that they have received both their COVID booster/ Flu shot vaccines and did not experience any severe reactions. **Sandy B.** commented that she has opted to get COVID booster and flu vaccinations separately, so if she does have a reaction, she will be able to determine which vaccination caused it. There was some discussion about getting the SHINGRIX vaccination or continuing to take Acyclovir or Valacyclovir long-term to prevent shingles. **Alicia B.** commented that Acyclovir causes a lot of overall dryness for her, i.e., her skin becomes very dry despite staying very well-hydrated. Someone mentioned that her PA told her that the pills that are used to prevent shingles are more effective than the vaccination. **Sandy W.** recommended a website, <https://costplusdrugs.com>, where she has been obtaining maintenance drugs that her doctor prescribes at a significantly reduced cost. **Glenn** mentioned that he recently read an AARP article that mentioned Revlimid as one of the top five most expensive Medicare drugs.

We discussed the likelihood of future in-person meetings. At this time, the board is looking for a new place to meet, as the church where we attended meetings in person pre-COVID is no longer available. There is currently no estimated timeframe as to when we will meet in person again, and much also still depends on safety, so we will continue meeting virtually for now.

Submitted by Wendy R.

## Meeting Minutes

### Southside Virtual MM Support Group

### October 22, 2022

#### Business and News

**Next Meeting:** Saturday, November 26, 2022. **Program:** Understanding Lab Values for Myeloma Patients and Caregivers. **Speaker:** Charise Gleason, NP – Emory Winship. Please study your lab reports and have specific questions or concerns for Charise. She has more than 20 years treating myeloma patients and is a member of the IMF Nurse Leadership Board.

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#### Group Discussion

**Doris M.** opened the meeting with a moment of silence. She shared with the group her experience at the *LLS Blood Cancer Conference* in September. There were 150+ participants along with seven AAMMSG members who attended the in-person conference. Doris and **Carolyn H.** volunteered at the LLS registration desk. Doris reported that Dr. N. Joseph (Emory Winship) gave a very informative presentation on Smoldering MM and relapse as part of the MM journey. **Sandy W.** joined the meeting from her road trip near Cordele. She also attended the conference. The keynote speaker from the CDC Infectious Disease Center stressed the importance of continuing to observe CDC guidelines and get vaccinated with the newest bivalent COVID booster (which

includes protection from the original COVID and new variants). There was also emphasis on children getting vaccinations to reduce the incidence of upper respiratory problems (**RSV**). **Ted** and **Anderson** extended an invitation for all men with myeloma to join them every 4<sup>th</sup> Tuesday evening at 6:00 PM during the **“For Men Only”** group. It is an opportunity for the fellas to spend an hour together to engage in active, lively discussions on myeloma-related issues as they impact the men – married, single, younger, older, black, or white. Wide-ranging topics have included communication, relationships, nutrition, lab values, and more. Please join us. **Light the Night** celebration was rescheduled for Thursday, November 10. The new location was the Home Depot Backyard at the Mercedes-Benz Stadium.

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### **Guest Speaker Presentation**

Thank you to Mr. **Terrell Johnson** as our primary speaker who led the group in a discussion on CBD/Hemp. Terrell is the son-in-law of one of our members, **Ms. Anita J.** Anita is using CBD oil that provides relief from peripheral neuropathy and wanted to share her experience with others. Terrell is a fifth-generation farmer and graduated from Georgia Southern University with a degree in finance in 2010. He currently lives in Atlanta, GA working as a consultant. The family HK Farm (<https://www.hk.farm/>) is located in Cobbtown, GA near Statesboro, GA. His mother is one of 12 siblings, seven still reside on the farm. Terrell provided a brief family history of how they came to produce CBD oil products in South Georgia. In 1869, six years after the Emancipation Proclamation, his family, the Handy-Kennedy family purchased 175 acres of land. The acreage grew to 1900 acres. The family lost a great deal of this land during the Great Depression, then the farm grew to over 1000 acres in 1973. His uncle had read about some of the benefits of CBD oil, including relief from arthritis and prostate cancer, and saw an opportunity. They are working with the agriculture department of Fort Valley State University. In addition to medical marijuana, they grow fruits and vegetables and cattle. He extended an invitation to our group for a field trip to H.K. Farm.

### ***A quick vocabulary review – Hemp vs marijuana***

Hemp and marijuana are two plants in the same family. CBD may be derived from either plant. The difference is the amount of **THC** (*tetrahydrocannabinol*) present. THC is the ingredient that gets you high. Hemp has very little THC – less than 0.3% of THC. Most CBD is made from Hemp, which was made legal to grow by the 2018 Farm Act. This Act also made Hemp-derived CBD products legal.

**CBD** (*cannabidiol*) has no psychoactive effects. It does not get you high. CBD is legal in all 50 states. The family decided in 2000 that this is a product they would become part of their family legacy.

CBD, like most supplements, is not regulated by the FDA. While there is not extensive evidence-based, clinical trial research to support claims, there are ongoing reports of its effectiveness in the following health areas: reduces pain and inflammation, reduces anxiety and depression, improves sleep, and reduces anxiety and depression. Additionally, some claims for relief include reduced seizures in people with epilepsy, improved heart health, and improved symptoms of inflammatory bowel disease (IBD). There is also no oversight or FDA regulation on claims of potency of products from different brands. He shared a spectrum analysis of his product. Their products passed all lab tests for toxic chemicals. He believes most CBD brands are not pure, and we should look for and request a spectrum analysis on any CBD products that we purchase. There can be many unnecessary chemicals in CBD online, including products from China. H.K. Farm sells their CBD product line in several different formats. CBD comes in oil, tinctures, salves, roll-ons, and lotions. The form you order depends on your personal preferences and its intended use. The oils can work in combination with prescribed medication. The shelf-life of CBD products is about two years.

Anita provided testimonials for getting relief from neuropathy. She has used CBD for six months, after going to the pain management doctor at Emory. The pain doctor recommended alpha-lipoic acid, Vitamin D, and gabapentin, to no avail. She uses the lotion -- 4,000 spectrums, for neuropathy each evening. It does make her sleepy, so she is careful to use it in the evening. She tried the salve, but it was too thick for her liking. **Sandy B.** shared that a physician recommended 500 mg of CBD oil for pain relief. She has serious PN (peripheral neuropathy) and has had shots and prescription meds. Sandy currently gets it from a source in Lansing, MI but will now use HK Farm. She has used a salve that is 1,000 mg/2 ounces.

**What is the best dosage?** It depends. Definitely do your own research, but here are some considerations: your body weight, the condition you are being treated for, your individual body chemistry, the concentration of CBD in each pill, capsule, drop, or gummy. **Does it work with alopecia?** There is no known testimonial for this condition. **What about Alzheimer's or dementia?** Be sure to do your own research. While we know of no linkages, we do not claim to know all their benefits. **Can you safely travel with this product?** Yes. CBD oil is legal in all 50 states. For your own safety and peace of mind, do more research before traveling internationally with CBD products.

**How/where to purchase?** Terrell Johnson – 404.983.5290; tjohns93@gmail.com. Look for the flyer in your email. More formal purchase procedures will follow. Expect deliveries within one week. You can pay by Zelle, CashApp, or Credit card. The product comes in regular, peach, and mint flavors. The regular scent is a very nice scent. There is also a gift set for purchase. Website launch: <https://www.hk.farm/>. Follow them on Facebook and Instagram.

A **resource for Alzheimer's** is a free weekly online seminar from Emory University Alzheimer's research program. **Brain Talk Live.** Tuesdays at 2:00 PM. Contact Cornelya Dorbin, 404.712.1416. E-mail: [cdorbin@emory.edu](mailto:cdorbin@emory.edu). Emory Goizueta Alzheimer's Research Center. Paulette has been a faithful attendee for more than a year. Topics span exercise, nutrition, caregivers, and more.

Respectively submitted, Gail