

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

October 2, 2021

Business & News

Thank you to **Nancy B.** who hosted the meeting where we had three guest speakers, then a short group discussion with approximately 35 attendees. Topics for upcoming meetings include **November:** will be separate Patient and Caregiver share sessions. **December:** will begin as an end of year holiday celebration and group discussion; and then will continue with separate, smaller groups to simulate a digital dinner table. **January:** will be an informative meeting with Emory doctors reporting American Society of Hematology (ASH) conference results.

Guest Speakers and Presentation

Thank you to our three guest speakers Starr Slade, Janet Payne, and Paul Lee, certified professionals from *GeorgiaCares* who joined the group to discuss Medicare and answer our questions. GeorgiaCares is a State Health Insurance Assistance Program (SHIP) that provides free and unbiased information to help beneficiaries and their caregivers on Medicare, Medicaid, and other related health insurance. GeorgiaCares helps people with Medicare understand their benefits and make informed decisions about health care options. SHIP does not sell anything, and is the only agency funded and endorsed by Centers for Medicare and Medicaid Services (CMS). Starr explained that they provide education to help individuals understand their 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 impartial and personalized group and one-on-one counseling. A lot of information presented in the meeting in a short amount of time and a brief synopsis follows

For further assistance, feel free to contact any of the GeorgiaCares presenters:

- Starr Slade, GeorgiaCares SHIP Coordinator, Email: sslade@glsp.org
- Janet Payne, GeorgiaCares SHIP Counselor, Email: jpayne@glsp.org
- Paul Lee, GeorgiaCares SHIP Counselor, Email: plee@glsp.org

Medicare is health insurance for people who are: **a)** age 65 and older, **b)** under age 65 with certain disabilities, or **c)** any age with End-Stage Renal disease. To receive Medicare, you must be a US citizen or lawfully present in the US for 5 continuous years. The agencies that

handle Medicare are Social Security, which enrolls most people in Medicare, the Railroad Retirement Board which enrolls railroad retirees in Medicare, and the Office of Personnel Management where Federal retirees' premiums are handled.

The Centers for Medicare & Medicaid Services (CMD) administers the Medicare Program.

The parts of Original Medicare include:

- Part A (Hospital Insurance)
- Part B (Medical Insurance)
- Part D (Prescription Drug Coverage)

Medicare options (you select one) include:

- Original Medicare (Parts A & B), with an **optional** Part D and an **optional** Supplemental Coverage that includes supplemental insurance to cover gaps in coverage such as Medigap, or coverage from a former employer or union, or Medicaid. Medicare supplemental insurance (Medigap) only works with original Medicare plans, not with Medicare Advantage plans.
- Medicare Advantage (a.k.a. Part C), which includes Parts A, B, D, extra benefits, and some plans that also include lower out of pocket costs.

When selecting between Original Medicare and Medicare Advantage plans it is very important to remember that there are many differences between the plans and so it is to your advantage to shop around and find someone to assist you in selecting the plan that best fits your individual needs. Medicare enrollment in Parts A and B is automatic for people at age 65 who have Social Security or Railroad benefits, and you will receive a welcome package with a Medicare card from Medicare three months before your 65th birthday, or on the 25th month of your disability benefits. It is recommended that you always carry your Medicare card with you. Replacement cards are available when you sign into your Medicare account at MyMedicare.gov or by calling Medicare at 1-800-MEDICARE (1-800-633-4227). If you're not automatically enrolled in Medicare Part A and Part B, you may need to enroll with Social Security. Either call Medicare at 1-800-MEDICARE (1-800-633-4227) or go online at [socialsecurity.gov](https://www.socialsecurity.gov). GeorgiaCares counselors are available to help with the enrollment process. Be aware that there are different Medicare enrollment periods depending on your circumstances. If you don't already have Medicare you can enroll during **a**) the initial enrollment period, **b**) the special enrollment period (in certain circumstances) or **c**) during the general enrollment period. If you already are enrolled in Medicare, you can make changes during **a**) the open enrollment period, **b**) the special enrollment period (in certain circumstances), **c**) at other times depending on your circumstances and the plans that you have selected.

Original Medicare - overview

Part A (Hospital Insurance) Coverage

- Inpatient care in a hospital
- Inpatient care in a skilled nursing facility
- Hospice care
- Home health care
- Inpatient care in a religious non-medical health care institution

Additional Information

- Most people do not pay a premium for Part A
- You can pay for it if it is not free to you
- You may have a penalty if you do not enroll when first eligible for Part A
- To avoid IRS tax penalties, stop contributions to your Health Savings Account (HSA) before Medicare starts

Part B (Medical Insurance) Coverage

- Doctor's services
- Outpatient medical and surgical services and supplies
- Clinical lab tests
- Durable medical equipment
- Diabetic testing equipment and supplies
- Preventative services
- Home health care
- Medically necessary outpatient physical and occupational therapy
- Outpatient mental health care services
- Acupuncture
- There is a 20% co-insurance cost for most services: \$0 for most preventative services

Additional Information

- Most people pay a monthly premium; amount depends on income
- Part B may be used to supplement an employer's insurance
- Sometimes Part B is required

Part A and Part B - What's Not Covered

- Most dental care
- Eye examination related to prescription glasses
- Dentures
- Cosmetic surgery
- Routine physical exams
- Hearing aids and exams for fittings

- Long term care
- Concierge care

When you must have Part A and Part B

- If you want to purchase a Medicare Supplement Insurance (Medigap) policy
- If you want to join a Medicare Advantage plan
- If you are employer coverage requires it
- If you are eligible for TRICARE for Life of Civilian Health and Medical Program of the Department of Veterans Affairs

Part D (Prescription Drug Coverage)

- Part D is an optional benefit available to all people with Medicare
- Part D is optional, but you may pay a lifetime penalty if you join late
- Usually included in Medicare Advantage plans
- Plans have formularies and tiers; be sure that the plan you select covers the prescriptions that you use. The cost of the same drug varies widely by different plans. It is very important to compare plans and find the right fit for your personal prescription needs; shopping around can save you thousands of dollars. Have an advisor help you with this and/or go to your MyMedicare.gov account where you can enter the drug name and compare the costs by plans.
- Out of pocket costs may be less if use preferred pharmacies
- Run by private companies that contract with Medicare
- Provided through a) Medicare prescription drug plans, b) Medicare Advantage prescription drug plans, and c) some other Medicare health plans
- Costs vary by plans. Most people pay monthly premium, yearly deductible, copayments or coinsurance, and a percentage of cost.
- There is extra help to pay for Part D costs if you have limited income
- Automatic catastrophic coverage begins once out of pocket maximum is reached

Medicare Advantage (MA) Plans - overview

- Also referred to as Medicare Part C
- These are the plans that you may receive phone calls about and see advertised on TV
- This is another way to get your Medicare coverage, Part C falls under the umbrella of Medicare
- Offered by Medicare-approved private companies that must comply with Medicare rules
- Your Medicare Part A and Part B coverage is through the MA plan not Original Medicare
- Generally, you need to use in-network providers, some plans offer out of network coverage

- Many MA plans offer prescription drug coverage and extra benefits like vision, dental, and fitness/wellness benefits
- There is an annual maximum limit on out-of-pocket costs
- Medicare pays a fixed amount for coverage each month to the companies offering MA plans
- Many plans have limited coverage when you travel outside of your residence state

Medicare Supplement Insurance (Medigap) - Coverage

- Plans are sold by private insurance companies
- Covers gaps in Original Medicare coverage i.e.) deductibles, coinsurance, and copayments for Medicare covered services
- All Medigap plans have letters associated with them for identification
- Supplement plan and Medigap plan terms are used synonymously
- Only works with Original Medicare coverage Good
- Has a monthly premium
- May not need if you receive supplemental insurance elsewhere (i.e., from and employer)

In summary, it is especially important for anyone eligible for Medicare to set up a MyMedicare.gov account. The website provides general information, compare plans, participating doctors, and costs. Also, feel free to contact any of the presenters for assistance including setting up your MyMedicare.gov account. You can make an appointment to meet via zoom, phone call, or in person for free, unbiased, and professional service. There is a lot of help and resources available in preparing to enroll in Medicare or make changes to existing Medicare selections. This not something that you need to do alone.

The GeorgiaCares team answered a lot of questions for us as follows:

Q: When I enrolled for Part D prescription drug coverage, I was not aware of an expensive drug that I would need in the future. Is there any way to reduce costs of this new drug? **A:** Your attending physician can advocate on your behalf with the drug company to possibly change that tier level and give it another tier classification. They can request a tier exception. A tier exception can also be requested by your physician on your behalf proactively when you are shopping for plans prior to enrolling in a specific plan.

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 can sign up for Medicare Part A now (it is free) even if you plan to continue with your employer's medical insurance plan? You should work with your HR department, and make sure they let Medicare know that you are covered under the employee plan, and therefore you will not be penalized.

Q: Is the drug Revlimid covered under Medicare Part D, and if so, what is the cost? **A:** Revlimid is covered by Medicare Part D plans. But it is a Tier 5 Specialty medication, and it is very expensive even with Part D coverage. It is estimated at \$5-6k a month on the Medicare.gov site. There are assistance programs and additional information about medications and costs at these websites: <https://www.needymeds.org/brand-drug/name/Revlimid> & <https://www.goodrx.com/revlimid/medicare-coverage>

Q: Does Medicare Parts A & B have age-related or other limitation on stem cell transplant procedures or any other procedures such as CAR T-Cell therapy? **A:** The CMS Coverage Database is available to research procedures and the limits: <https://www.cms.gov/medicare-coverage-database/search.aspx>

Q: FDA frequently approves new drugs that are used immediately. Are there Medicare-related limitations here? **A:** There may be limitations. CMS contracts with Medicare Part D drug plans to provide guidance.

Additional information answered by Starr after the meeting.

Q. Why are drug costs so expensive under Medicare. The drug Revlimid is one of many used, and costs \$20,000 a month. (Part D.) **A:** I looked up the medication and is it covered by Medicare Part D plans. But it is a Tier 5 Specialty medication, and it is very expensive even with Part D coverage. It is estimated at \$5-6k a month on the Medicare.gov site. **Action:** I searched Needymeds.org/ and there are assistance programs. You should read about each program and download the applications to share with your support group. i.e. Revlimid **Action:** GoodRx also has information about the medication and the costs. Our patients include several long-time survivors who have undergone stem cell transplants and may be suitable for an additional one in the future. Does Medicare have an age or other limitation on this procedure or any other? (Parts A & B.) **Action:** You can look on the CMS Coverage Database. It is available to research procedures and the limits. Click here for a tutorial.

Q: Car T-cell Therapy (cell-based gene therapy) is now available. Are there any limitations for this treatment? (Hospitalization Parts A & B.) **Action:** You can look at the CMS Coverage Database. It is available to research procedures and the limits. <https://www.cms.gov/medicare-coverage-database/search.aspx>

Q: Please discuss the donut hole. **A:** Informative articles on “A Closer Look at the Medicare Part D Donut Hole – Coverage Gap” and the “2021 Part D Cost Sharing Chart” were provided by GeorgiaCares.

Helpful Links

Centers for Medicare and Medicaid Services: <https://www.cms.gov/>

Medicare: <https://www.cms.gov/Medicare/Medicare>

Goodrx <https://www.goodrx.com/revlimid/medicare-coverage>

Needymeds <https://www.needymeds.org/brand-drug/name/Revlimid>

CMS <https://www.cms.gov/medicare-coverage-database/search-results.aspx?keyword=myeloma&keywordType=starts&areald=all&docType=NCA,CAL,NCD,MEDCAC,TA,MCD,6,3,5,1,F,P&contractOption=all>

*<https://www.cms.gov/medicare-coverage-database/search-results.aspx?keyword=t-cell%20therapy&keywordType=starts&areald=all&docType=NCA,CAL,NCD,MEDCAC,TA,MCD,6,3,5,1,F,P&contractOption=all&sortBy=relevance>

Group Collaboration

After the presentation, there was a short group discussion with collaboration on myeloma treatments, Covid, and Q&A. **Sandy B.** mentioned that although one of her numbers is rising, it is not a trend and she plans to continue with the same treatment for now, and all her other numbers are excellent, so no change is necessary. Bone density test showed osteopenia (not enough calcium) attributable to breaks and fractures. **Nancy B.** suggested Xgeva as an option for treating osteoporosis, and something to check with her doctor about as a treatment option.

Q: Is anyone taking both Dara and Dex simultaneously? **A:** **Dirk, Jeff B., and Dave O.** are taking both drugs

Q: Can you get the vaccine for shingles if you are in treatment? **A:** Yes, you can receive the latest 2-part SHINGRIX vaccine while in treatment. Check with your doctor.

Q: Is anyone getting IV vitamins to help combat fatigue? **A:** While fatigue is quite common to myeloma patients, no one in the group reported that they are getting IV vitamins. There was some discussion about managing fatigue by reducing drug dosages and/or timing when taking certain drugs. Some have tried a two week on/two week off schedule with Revlimid and felt like it helped them manage fatigue better and take advantage of counts rebounding before getting knocked down again. **Sandy W.** mentioned that Dex may lose its effectiveness after being on it for 2-3 years. **Nancy B.** knows a patient in another support group who has been on Dex only for 10 years at relatively high amounts doing well.

Q: Has anyone in the group had an antibody test to determine Covid vaccine efficacy? **A:** **Jeff B.** responded that he had one about a month ago. It was positive, but the test does not disclose at what level. Nancy mentioned that we do not know what level of antibodies is necessary to make the vaccine protection effective. **Jim M.** had antibody treatment 3 weeks ago when he was exposed to Covid. It was administered as 4 shots in his abdomen. His wife, who had contracted Covid also had the antibody treatment and felt better afterward. Now, if exposed to Covid, you can also get the antibody treatment. A reminder to everyone regarding

Covid exposure: With the aggressiveness of the new variant, if you are exposed you can get tested within two days. You no longer have to, or should, wait a week or longer before getting tested. Instead, it is now important to be tested within two days of your exposure.

Submitted by Wendy R

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Meeting Minutes
Southside Virtual MM Support Group
October 23, 2021

Business & News

Next Meeting: November 27, 2021. Meeting discussion: *Patient and Caregiver Voices, Let's Talk*

General Business

Thank you to **Gail M.** who hosted the meeting. **Doris** opened our meeting with the Serenity Prayer. Two new patients joined the group. **Jerry** is from Macon (Central Georgia) and is being treated at Cancer Care. He was diagnosed with smoldering myeloma in 2008. Jerry had a stem cell transplant in 2012 and is currently on maintenance therapy with Revlimid and a bone strengthener. He has a meeting every six months with Dr. Kaufman at Emory Winship. Since the pandemic, these meetings have been virtual, which is much easier on him and his wife. He was referred to the group by **Carol**, a member of the same walking group as one of his Atlanta-based high school classmates. The other new member was **Susan** from Talking Rock in North Georgia. **Deborah** joined the meeting as she was in mile three of her daily walk of four miles. Go, Deborah! Thanks for your fitness commitment and for calling in to the meeting.

Guest Speaker

Tara Roy was the guest speaker and is a Patient Advocate from Takeda Pharmaceuticals. **Living with Myeloma** was the topic presentation in October. This is her third visit with us, and she has been well-received for the previous topics of *Understanding Lab Results* and *Survivorship*. Tara started her presentation with a brief overview of multiple myeloma.

Myeloma is the second most common of all blood cancers after non-Hodgkin's lymphoma. Myeloma is the 14th most common cancer overall. Blood is made up of **platelets, red blood cells, and white blood cells** – each of which has its own functions. Myeloma starts in a subset of the white blood cells called **plasma cells** in the bone marrow, which makes antibodies to fight infection under normal conditions. When cancerous, these plasma cells

produce abnormal proteins that damage organs and prevent the production of normal blood cells. Myeloma plasma cells start producing just one type of antibodies/proteins. These are called **monoclonal** antibodies, which create a higher risk of infection.

Problems created from myeloma can include too much **Calcium** in the blood or urine, **Renal** (kidney) dysfunction, **Anemia**, and **Bone damage/ pain**. These symptoms are referred to as the **CRAB** criteria.

Newer (**SLiM**) criteria can lead to earlier diagnoses and improved treatment. It provides guidance on precursors of active myeloma, MGUS (monoclonal gammopathy of undetermined significance) and Smoldering Myeloma. Blood serum with sixty percent or greater bone marrow cells are monoclonal antibodies. The **Light Chain ratio** (kappa to lambda) is one hundred or greater in the serum. Scans are needed to monitor whether there are changes in the bones – in the skeletal system, since myeloma develops in the bones. PET scans, MRIs, and CT scans are a part of the monitoring for myeloma patients. *Magnetic Resonance Imaging* shows more than one focal lesion in the **SLiM CRAB** criteria. It is important to know what kind of myeloma we have.

Your **lab reports** should be a major part of your conversation with your oncologist on your therapy and the different options available for your treatment. Lab tests include SPEP (serum) and UPEP (urine) protein electrophoresis. These tests detect whether there is abnormal protein and how much, but not the kind of protein. Your M-spike is the elevation of abnormal protein. M-protein is short for **monoclonal protein** – all the cells are being produced from the same type of cell.

Each plasma cell produces one of five types of antibodies. The antibody is a Y-shaped protein molecule used by the immune system to identify and neutralize foreign pathogens like bacteria and viruses. It is made up of heavy chains and light chains. The five immunoglobulin classes are – **IgA**, **IgD**, **IgE**, **IgG**, and **IgM**. The two types of light chains on the molecule are kappa and lambda. Your doctor may refer to your type of myeloma by the type of protein or immunoglobulin and the associated light chain produced, like IgG kappa, for example. The most common type of myeloma is IgG Kappa followed by IgA, then IgM. Less common types are IgD and IgE. Twenty percent of MM patients have only Light chain myeloma, no heavy chain. They will follow only kappa and lambda levels and ratios.

In the past two years, there have been *six new myeloma drugs approved by FDA*. There are different treatment classes that attack the myeloma in different ways. These classes include *immunomodulators, proteasome inhibitors, monoclonal antibodies, and antibody drug conjugates*. These classes of drugs may be combined with other drugs and in different dosages specific to the treatment plan and patient. It quickly becomes easy to understand why a specialist is needed to keep up with the most up-to-date treatment landscape. Treatment choice continues to become more *precise and dependent upon your type of myeloma*. You should always ask the question, “*What treatment is best for me?*” and “*Why is this one better than another one?*” These are treatment options along with Clinical Trials that

you might discuss with your doctor. Comorbid conditions like diabetes or heart disease will play a major role in deciding the better treatment course for you.

You and your family should be comfortable and confident with your healthcare team. You should meet with every member of your team – your Hematologist-Oncologist, Pharmacist, Nurse/Physician's Assistant, Social Worker, etc. PFS and Overall Survival with myeloma has increased steadily since 2003 when the 5-year survival rate was 35%. The most recent data shows a five-year survival rate is greater than 55% -- mostly due to the ongoing research, clinical trials, and new drug therapies. Several group members are currently 10, 15, 20, and 30-year myeloma survivors. Myeloma perception should be viewed as more of a chronic or long-term disease. Your discussions with your providers should always include your *treatment goals*.

Questions for discussion should include:

1. Genetic counseling
2. How long does remission last?
3. What is the difference between being treated by a local oncologist and a myeloma specialist? In Georgia, Emory Winship is the only myeloma research center. Myeloma Specialists can provide a second or even third opinion, and it is common practice for them to work alongside your local oncologist to provide expert input. They work with community oncologists across the state and country to reduce unnecessary burden on the patient and their family.
4. Can I still exercise and continue daily activities since myeloma can develop in the bone?
5. What Clinical Trials are available and when should I consider them?
6. Do I have any cytogenetic abnormalities?

Each person has twenty-three chromosome pairs. Cytogenetics determines abnormalities in your chromosomes. In myeloma, there may be deletions of a chromosome or a transfer of a chromosome. Lab results may look like 17p deletion (17th chromosome) or translocation (11;14) – chromosomes 11 and 14 have exchanged positions. These factors determine whether your myeloma is considered standard or high risk and what the preferred treatment regimen.

7. When should a *Bone Marrow Biopsy* be conducted?
8. How many cycles of treatment are needed before restaging my myeloma?

Myeloma Staging. Myeloma is a blood or liquid (versus solid) cancer. The Staging is different from solid tumors (Stage 1 breast cancer or Stage 4 lung cancer, for example). Specific blood work will tell you the status of your disease. Ask your doctor to explain myeloma staging to

help you understand your disease. Second opinions are common for choosing the best course of treatment. This is a common request for insurance companies. Even third and fourth opinions are encouraged.

You should learn as much as possible about your myeloma, so you are fully engaged throughout your journey. Be sure to prepare for each visit with questions, concerns, side effects discussions to attain knowledge and perspective of your specific needs. In summary, *Living Well with Myeloma* requires patient/caregiver engagement with their healthcare team and ensuring that you work to regain and maintain your health in all other aspects of your life.

- **Communication is key** – with providers and family
- **Good nutrition and exercise** are crucial throughout your journey. Exercise will be modified to match the stage of your myeloma journey. Start by walking for five minutes. Be sure to get up and move at least every hour. Myeloma medications may increase the risk of blood clots as a side effect. Exercise can be helpful in reducing stress in your body and take your mind off your disease for a short time.
- **Get plenty of rest** when you need it. Myeloma treatment can be physically, mentally, and emotionally exhausting.
- **Take your time and be patient.** You do not need to learn everything at once. It is easy to become overwhelmed with the diagnosis, impact on you and your family, financial concerns, and treatment options. It Depends on your team. Join Support Groups to learn from others who continue to walk this same path – both patients and caregivers. Attend educational sessions and webinars when you can. Understanding medical and myeloma terms are one of the big challenges.
- **Be an information seeker.** Keep a journal or a binder with all your lab and test results. Research information on financial resources as well as information about your diagnosis and treatment. Check out Leukemia and Lymphoma Society (LLS), American Cancer Society (ACS), Cancer Care, International Myeloma Foundation (IMF) websites for services or resources they might provide.
- **Stay up to date with other healthcare checkups and screenings.**

Patient updates and discussion

Susan feels as if she is on an emotional roller coaster and may need a referral to a psychologist or psychiatrist. Gail suggested that Susan reach her by email or follow-up. **Jerry** will be contacting Gail to discuss a possible Support Group in the Macon area. **Carol** is on maintenance therapy of Kyprolis and a steroid. **Alma** is recovering from COVID after returning from a family trip to a wedding. Her Clinical Trial with CC220 has been halted until she is in better health. Alma has a meeting with nurse practitioner Charise to

determine next steps. We wish Alma a full recovery from COVID and successful next steps. **Dr. Kaufman** conducted an antibody study that showed that myeloma reduces the efficacy of the vaccine. **Bernard** wants to know if there is an association between Parkinson's and myeloma. In addition to General Colin Powell, we have had at least three men in our group with a Parkinson's diagnosis. Gail will follow-up with the myeloma specialists for a response. **Dave** joined us from Northside. He is a 10-year myeloma survivor and is on Dara(tumumab), Revlimid, and Dex (steroid). He is seeking to reducing the dosage of Dex. **Workshop reminder: M-Power Atlanta** is an initiative by the IMF with an aim towards increasing awareness and health equity in myeloma diagnosis and treatment for African Americans. Following M-Power kickoff Community Workshops in Charlotte and in Baltimore, *the Atlanta Workshop will take place on November 13*. Replay is available at M-Power | An International Myeloma Foundation Initiative and click on Atlanta.

Respectively submitted, Gail