

October 2018

**Northside Multiple Myeloma Support Group Meeting
October 6, 2018**

News & Updates

Thank you to **Jim M.** who led the meeting; approximately 40 people attended. Jim recommended an IMF educational teleconference recording that addresses side effect management that can be found at <https://www.myeloma.org>. He said that it takes about an hour and is one of the best presentations on the topic that he has heard. The IMF website is an excellent place for obtaining information from myeloma experts, including a toll-free number to call to talk with highly qualified medical experts.

December - Please note that we will celebrate the holiday season at the ***December meeting which will take place on December 8th, which is the second Saturday of the month.*** More details will be provided at a later time.

January - An American Society of Hematology (ASH) review is planned at Emory on Saturday, January 5th.

New Members

The group welcomed **Vicky** and her husband, **Robert**. Vicky had a stem cell transplant at Emory at the end of June.

Guest Speaker

Thank you to **Bonnie Dobbs, Senior Health Benefits Consultant and Medicare Educator**, who joined the group to discuss Medicare. She began by mentioning that the federal government is discontinuing the use of Social Security Numbers (SSNs) as Medicare ID numbers. Medicare Services is mailing new cards with new Medicare numbers to all participants, which affects about 60 million individuals. Instead of your SSN, your new Medicare card will include a new, unique 11-character identifier. This will help to protect you against identity theft and protect Medicare from fraud. Medicare will

automatically mail new cards to Medicare participants to the address you have on file with Social Security. As long as your address is up to date, there's nothing you need to do. Mailing 60 million Medicare cards takes some time, so you might get your card at a different time than others in your area. This effort began in April 2018 and will continue through December 2019. While it is good that Medicaid and Medicare will no longer use SSNs as their identifiers, there are scams associated with the change. The scams are generally trying to steal identities or funds from individuals. It is important to understand that no one from Medicare, Medicaid, Social Security, or the IRS will ever call you. They will only contact you via mail or sometimes email if you have provided them with your email address. If you ever receive a phone call from someone identifying themselves as affiliated with any of these agencies, even if they seem legitimate, they are not, and so hang up immediately. Never speak to them or provide them with any information and report the call to the appropriate authorities. Examples of scams include phone calls with someone asking to confirm receipt of letters, or receipt of your Medicare card, or wanting to verify your address and other personal information in order to send the card to you. Do not respond to any phone calls, these are scams because no one would ever legitimately call you on this topic. Often times the caller will already have information about you and they may sound legitimate but don't be fooled. There are also scams requesting that you send \$20 or other monetary amounts in order to have your Medicare card sent to you. Sometimes these calls appear to be legitimate and some will show as "US Government" on your caller id displays, and some scammers will send you a birthday card as you are nearing your 65th birthday, so beware that these are scams. There are other scams asking for your Medicare card number so that they will be able to "help you" in some way. Never, under any circumstances provide any personal information to these callers. Another thing to be aware of is that there are some Medicare consultants that are paid larger commissions for selecting certain types of plans, or from certain companies for their clients, rather than choosing the best

plan for their customers. Bonnie is not incented by any specific company or plan and works only to select the best plan for you, her customer. Generally, to be considered “Medicare-eligible” you have to have worked and paid FICA taxes for a minimum of 10 years and be age 65 or older, or (if under age 65), be disabled for 24 months and receiving social security disability benefits. There are multiple parts of Medicare Insurance that cover different things. Parts A and B are original and automatically provided upon enrollment. Parts C and D can be added by the enrollee if desired. Part A – Hospital - covers inpatient hospital stays, nursing facility, and hospice care. Part B – Medical – covers doctors' services, outpatient care, and medical supplies. Parts A and B are known as original Medicare and together will pay for 80% of your medical costs. You will need additional coverage to pay for the rest of your costs. Part A is paid for by the government (i.e. you have paid into this plan). Part B is paid for by you i.e. either deducted from your social security benefits (if you have joined), or from your bank account on a monthly basis. Part D – adds prescription drug coverage to Parts A and B. There are also supplemental medical plans that will cover the 20% gap in medical costs that parts A and B do not cover. Supplemental plans provide coverage anywhere in the U.S. In summary, when you have Medicare Parts A and B, that pays 80% of your costs. Part A has a quarterly deductible and Part B also has an annual deductible. There's two ways to get your coverage to offset those costs. One is with a Medicare supplement plan because it will fill in the Parts A and B deductibles gap (i.e. the other 20%). That's the reason why a Medicare supplement plans are called Medigap plans. Medigap plans only cover the medical portion of your costs, so you also have to purchase a standalone drug plan. Additionally, Medicare Advantage (also known as Part C) is an “all in one” alternative to original Medicare. These “bundled” plans include Part A, Part B, and usually Part D. Advantage plans mimic traditional insurance plans and have deductibles, monthly premiums, and copays. Advantage plans do not provide coverage anywhere in the U.S. It is very

important to be aware that although Medicare is a federal government plan, not all plans are available in all locations and plans can vary by location at state, county, and even within zip codes. Also, your plan may not cover you when you travel. Some plans will cover you for emergencies only when you are away from home. Be very careful about selecting plans that cover you when you leave your main residence location. Be sure to consider this when you are selecting plans for the year if you are planning to travel or move during the year. When you decide on a plan and enroll, be sure to make sure that your caregiver understands the coverage and terms of your plan. Bonnie is available to help with transitioning into Medicare Insurance for the first time and/or finding a new plan that fits your needs at open enrollment time. She also consults with caregivers and there is never a fee for her services. Remember that plans change annually and that she is a broker with access to plans from all of the major carriers and is available to shop and find the right plan for everyone. Bonnie can be contacted by phone at (866) 901-9162 and Email at bonniedobbs@gmail.com. Bonnie participates in panel discussions for the Atlanta Journal Constitution where there is a lot of good information from experts. The events are located at many locations around Atlanta – go to <https://ajc.com/agingevents> to find events at locations that are right for you. Also, if you are interested in a particular topic but there is not an event on the subject, you can contact Bonnie and she will bring it to the panel for consideration.

Bonnie responded to many questions:

Q: How should I initiate a consultation with you?

A: I always like to start working with everybody three months before they retire, three months before they turn 65, or three months before they're going to become Medicare eligible. It's very important that the first time you become Medicare eligible that you consult with a professional because we're going to make decisions that can affect you for the rest of your life.

Q: What is the difference between Medicare and Medicaid?

A: Medicare is a federal program that provides health coverage if you are 65 and older or have a severe disability, no matter your income. Medicaid is a state and federal program that provides health coverage if you have a low income.

Q: Is Medicare the same thing as Social Security?

A: No. Medicare is insurance and Social Security is money.

Q: Does Medicare pay for assisted living costs?

A: No, that is long term care insurance

Q: Are supplemental plans the same thing as an Advantage Plan?

A: No.

Q: Are Advantage Plans more expensive?

A: No, not necessarily.

Q: As a first-time Medicare-eligible enrollee, should I get a supplemental plan?

A: Yes, it is recommended because it is the time when you will be eligible to enroll without a medical underwriting exam. You may not qualify later if you have been diagnosed with any specific medical conditions. The only time you will not have to have a medical underwriting exam to qualify for a supplemental plan is when you become newly Medicare-eligible. **Important:** It is highly recommended that you consult with a professional a few months before you become Medicare-eligible, as the rules and plans change frequently.

Q: What are supplemental Plans?

A: Supplemental plans are used to cover the medical costs that are not covered by Medicare Parts A and B (i.e. the 20% gap). Supplemental plans have annual deductibles and only cover medical expenses.

Q: Are there Part D plans that are known to be especially helpful for coverage on drugs specific to Multiple Myeloma?

A: Plans are very individual and change a lot. When you are planning for your coverage it is good to research all drugs that you expect to take in the next year. Consulting with a professional for assistance is important, as they have research avenues that you might not have. Note that there are no costs for

these services and no consultation fees. **Additional tip:** If you are on an expensive drug, you can ask your pharmacist for the “cash price”. Often, if you pay cash, the price will be less. It is also recommended that you go to an in-network pharmacy to keep costs down and obtain all of your drugs from the same pharmacy for safety reasons.

Q: What if I had expectations of using a specific drug long-term that is covered under my Plan D, but then I switch to another drug unexpectedly that is not covered, or not covered as well under my Plan D?

A: In this circumstance, request a “Formulary Exception” or “Tier Reduction” from your doctor.

Q: What are characteristics of an HMO plan?

A: With HMOs you can only go to doctors in your service area in that network and you must get a referral to see a specialist.

Q: Are the only options for Medicare plans HMOs? I prefer PPO plans so that I can select my own doctors especially for second opinions without having to get a referral or stay in-network for coverage to apply.

A: There are PPO Medicare plans. PPO plans do not require a referral to see a specialist and out of network costs are less expensive than in HMO plans.

Q: Can you recommend a good online tool where you can enter information about your individual needs to be able to find an optimal Medicare plan?

A: Medicare.gov is available but it is not considered a good tool by professionals. I highly recommend talking with a professional, which is a much better option.

Q: I have already found a plan that appears to be ideal for me. Can I also consult with you to see if you can find a better plan?

A: Yes – this is encouraged.

Q: If you are under 65 and Medicare-eligible, can you get supplemental insurance?

A: Yes.

Q: I am under 65 and have been on social security disability for two years so I

am now Medicare-eligible. Can I continue with my spouse's medical insurance that is provided through her employment?

A: Yes, but there will be a penalty to continue with your current plan because you are Medicare-eligible. It is recommended that you compare the new cost for your coverage with Medicare plan costs and coverage. Also, consult with a professional to get the best plan for your needs. And be aware, that if you do not accept Medicare once you are Medicare-eligible you will incur penalties and may not be able to enroll in some plans later.

Q: Does it make sense to continue with other health care plans if you are 65 and Medicare-eligible?

A: Once you are Medicare-eligible you are penalized when you opt for non-Medicare health coverage, unless you notify Medicare of your choice. .

Q: I work full time and my company offers Medicare-equivalent health care coverage. I will turn 65 soon and plan to continue to work. Should I continue with my company's health care plan or select Medicare coverage?

A: It is recommended that you consult with a Medicare professional a few months before you turn 65 to determine the correct plan for you. Also, you can check with your corporate Human Resources department.

Q: How do you determine if a Supplement Plan or Advantage Plan is right for an individual?

A: There are certain people where an Advantage Plan is the very best thing I can suggest, and there are others that the best thing I can recommend is a Supplement Plan. I will ask you over 100 questions to understand who you are and what you need. From there I can determine the best plan for you.

Submitted by Wendy R.

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Southside Myeloma Support Group
Saturday, October 27, 2018

There were 21 people attended the meeting.

We had two representatives from Walgreen's Specialty Pharmacy at Piedmont.

The speakers were Khsna Patel and Jason Vo – who graciously replaced our originally scheduled speaker/pharmacists, Drs. Katina Richmond and Binoy Shah. They provided a handout for reference, Medicare Part D Prescription Savings Guide, an 11-page Walgreens document.

The speakers reviewed the upcoming 2019 changes for Medicare and walked us through the booklet and ways to save. This booklet can be picked up at any Walgreen Pharmacy. You can call a Medicare plan Advisor – it's easy and it's free. Phone: 844.263.5972 or visit ehealthmedicare.com/Walgreens. Get the best possible information on your personal plan before you get into catastrophic phase. You can get all this information without sharing your birthdate. You just provide your list of medications. Page 7 of the publication guides you on some questions you should ask. Example: "Does my plan have a preferred pharmacy network? Is my pharmacy preferred? ... and "Do I qualify for financial assistance such as Extra Help or low-income subsidies?

Walgreens specialty pharmacies distribute Revlimid, Pomalyst, and Thalidomide

Some ways to save on medications: Use a preferred pharmacy. Some plans have a preferred pharmacy network; Use Generics versus brand names; Use lower cost brands; and Plan an evaluation with a Medicare Plan Advisor (Page 6).

The "Donut hole" will change this year. You will get into the donut hole quicker. See Page 5 of handout.

How much you pay for each phase depends on annual expenses. Look at medication list and cost for each month to estimate expenses for the year. Different insurers or premiums have different deductibles. Call your plan or go online to get appropriate numbers.

100% deductible – Coverage – Copay Different for brand names versus generics

Q: Difference between brand and generics. The active ingredient is the same, but binders in generics may be different. Generics are a copy formula and they work similar. There are sometimes allergic reactions to capsule/binding.

Generics do not have full clinical trials conducted on their formula. Generics are called biosimilar as injections and bioequivalents in pill form. Several in the group have documented allergies or negative reactions to generic forms of drugs, both biosimilar and bioequivalent. Alma has documented allergic reactions to three medications – including Amoxicillin, acyclovir, and Revlimid – she needs brand, not generics.

One pharmacy gave Alma coupons to use, in recognition of the trouble she had with her prescriptions. Tell pharmacist and doctor – document must be in a clinical note for approval. Both the physician and the pharmacist can initiate notes in the medical record for the insurer to note as a negative reaction to a drug.

In the past, pharmacists were not allowed to discuss price. A different price for different plans is allowed. In October, a bipartisan group supported legislation to strike down the “gag clause.” Pharmacists are now free to help patients find ways to decrease their medication costs. In the past, pharmacists, who provide great care were prohibited by contractual agreement from sharing information with patients on ways to navigate their prescription costs.

Caution: If you use a coupon – insurance will not “see” that you got that savings. This does not count against your annual deductions. Also, coupon information goes to Big Data – they sometimes sell your information.

The issues in paying for your medication while on Medicare continues to be complex and often confusing. Some areas discussed include the following.

Please take time to review

A specialty tier drug is defined as a category of prescription drugs within a tier in a drug formulary for which a beneficiary's cost-sharing is greater than tiers

for generic drugs, preferred brand drugs, or non-preferred drugs in the prescription drug plan's formulary. Specialty drugs like Revlimid and Pomalyst are in Tier 5. The percentage you will pay for these drugs varies depending on the Tier and whether it is brand or generic.

In 2019 insurance will pay 45%. You pay 55%. For brand name drugs, the Plan will pay 20-30 %. This is a drop from 45-55%

Our speakers walked us through important points included in the Walgreen Booklet.

Page 4 of the document provides important definitions of Costs associated with Medicare Part D, including Premium, Deductible, Copay, and Penalty. For example, you may owe a late enrollment penalty if you go without prescription drug coverage for 63 days or more after your Initial Enrollment Period. Page 5 – reviews four Phases – Deductible phase, Initial coverage, Coverage phase, and finally the Catastrophic phases. Once you and your plan spend a certain amount determined by Medicare you reach a Coverage gap phase or the “Donut Hole.” The donut hole might be different for brand versus generic.

During this phase, you will be responsible for higher out-of-pocket expenses.

The donut hole is changing this year, and you will get into the catastrophic phase quicker. In the catastrophic phase, the insurance plan pays 95%.

The booklet has very helpful information, however, it requires some study of terms and what is allowed with your plan. You should know how much (and what percentage) your own health plan will pay for your medications – brand versus generic.

Celgene products require prior authorization – three months to one year. Enroll in their reduced cost program. Call your pharmacist. The doctor can intervene – doctor submits information for reduced cost with prior authorization. The pharmacist can submit requests for prior authorization. The doctor's review can take 24-72 hours.

There are six Specialty Walgreens: Dekalb General – now Emory (sees more children), AFLAC and CHOA – Dekalb General is now Emory, Albany Center;

Atlanta Medical, and Eastside Medical is a free-standing pharmacy. – will follow-up with patients to see if they have the medications they need. Use grants, funds from Foundations.

We also distributed handouts of interest from LLS on the following topics: Cancer and your Finances; Palliative Care – Fast Facts; Sexuality and Intimacy; Pain Management Facts; Personalized Support Palm Card; Co-Pay Assistance Program; and Personalized Nutrition Consultations. Many of these may be copied from the website at www.lls.org.

Jameca collected responses to questions about why more African Americans do not attend our Support Group meetings. She posed two questions for member feedback. 1) Why do you think African American's within the community do not attend our support group meetings, and/or Myeloma awareness & education community sponsored events. 2) What motivated you to attend our support group meeting, and how has the support group helped you along your Myeloma journey? Please feel free to respond to those questions directly to Jameca at jamecabmail@gmail.com.

Announcements

- Light the Night. LLS. Thank you so much for attending this year's Light The Night and for helping us bring light to the darkness of cancer! Thanks to you and Southside Multi Myeloma Support Group. Atlanta Southside raised \$1,773.00 as of October 8 (from Paulette). We had an original goal of \$400. Congrats to all and THANK YOU!

- IMF - Teleconference. Impact of Nutrition on Side Effect Management Did you know that what you eat can sometimes impact side effects experienced with myeloma and/or the various treatment regimens? (Living Well with Myeloma Series). Replay available at www.myeloma.org, click on Education & Publications at the top, then select IMFTV and click on Living Well with Myeloma.

- MMRF - Fall Webinar Series: 1. Evaluating treatment options for relapsed/refractory patients. September 5 @ 1:00 ET.;2-Caregivers: An

essential part of the myeloma care team – October 24 @ 1 PM; 3 - Multiple Myeloma in African Americans: Staying informed about risks and care – November 2018. Register online or call 866.872.5840.

- IMF - Stand up to Cancer (SU2C). New project to model population study in Iceland. For Myeloma patients over age 45 and African-Americans -- with first degree relatives (Mother, Father, Sister, Brother) who have MM.
- IMF. New – Diversity Communications Group. All are urged to be involved.
- Fundraiser – Jameca Barrett – Second fundraiser with Dexter Myers Cookies. The fundraiser serves two purposes: 1) Promotion for our support group & Myeloma Awareness and 2) Promotion & Fundraising for IMF (a percentage of all sales will be donated directly to IMF). Jameca asks that you spread the word through your social networks.

<https://www.cookieckstar.com/imf.htm>

- Health Fair. Sunday, November 4. Our Lady of Lourdes. Need volunteers.
- We celebrated six birthdays for October and November.

Respectfully submitted by Gail

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Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com web site: ssatlanta.support.myeloma.org

Southside Meetings; 12/22/2018

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Northside Meetings: 12/8/2018; 1/5/2019 at Emory Meets 11:00 AM on the 1st Saturday of each month
Shallowford Presbyterian Church
2375 Shallowford Rd.
Atlanta, GA 30345

mmsg.org, email: aammsg-2@comcast.net

For additional information, contact:

Nancy Bruno 404-374-9020;

Sandy Brown 470-514-5330

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.

