

June 2016 Northside Meeting

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Business and Announcements

Nancy B. led the meeting and approximately 30 people attended.

Teresa Wilson was our guest. She is a Medicare Specialist who works for the Centers for Medicare & Medicare Services (CMS) in Atlanta. She has worked for CMS for more than 30 years in both Medicaid and Medicare program areas. She managed the Medicare Coverage and Payment Policy Branch and the Medicare Beneficiary Services Branch. Her mother had lymphoma and died after seven years, her father has multiple medical issues and her niece has liver cancer at the age of 31. She said that she will try to answer questions as if she were talking to a family member.

She brought documentation and handouts that will be kept in the group library and available at future meetings. One of the handouts had the following information that is specific to MM and came from some of the member questions before the meeting.

MEDICARE WEBSITES

www.medicare.gov – Consumer website

www.cms.hhs.gov – Agency website

INSURANCE COUNSELORS

The State Health Insurance Assistance Program, or SHIP, is a national program that offers one-on-one counseling and assistance to people with Medicare and their families. Through grants directed to states, SHIPs provide free counseling and assistance via telephone and face-to-face interactive sessions, public education presentations and programs.. GeorgiaCares is the Georgia SHIP. You may reach a counselor at 1-866-552-4464, option 4.

In the “Medicare and You” book, there are supplemental plans A – N. There are lots of choices, so study and pick well. In some cases, the rates will go higher if you change. The Federal government gives money to the states for those with minimum income. State will pay you're a/B premiums based on assets and income. Apply online or call DFCS in your county. They will look at all cash accounts and resources. They also help with Medicare Part D. SHIP has trained counselors to review your paperwork and answer questions.

After going over the documentation, Teresa answered questions from the audience.

Q – Once there is a new drug approved by the FDA, how long does it take for Medicare to pay?

A – Medicare will pay as soon as the doctor prescribes it. The Hepatitis-C drug took longer because it was so expensive.

Q – Will Medicare pay for multi-drug combinations?

A – Medicare will generally pay. When you get a denial, always appeal and do not pay the bill. Keep appealing, even going to an Administrative judge where 68% of denials are overturned. Write a good letter. The judge is looking for a way to get it paid.

Q – Darzalex is approved as a single agent. Will Medicare pay in a combination therapy?

A – If the doctor prescribes it that way, then Medicare will pay, even if it is “off label”.

Q – What is “off label”?

A – During clinical trials, the drug is tested for a specific indication and the FDA will approve for that indication. Any other disease, dose, or combination is “off label”.

Q – Is the process of denial based on pharmaceutical prices?

A – CMS has no authority to get involved in pharmaceutical prices. Medicare is not in those discussions. In all the years that Teresa has worked with CMS, there has never been a decision based on life expectancy.

Q – For income levels to qualify for Medicare premium assistance, does Social Security considered in the income allowances?

A – Yes, it counts.

Q – There is a state Drug Parity law in Georgia. One person had high co-pays and talked to the manufacturer, but they didn't care about the state law. Does this apply to Medicare?

A – Medicare pays on an established fee schedule and does not work under state laws. The drug parity laws apply to commercial insurance co-payments, and not Medicare.

Q – Medicare pays for an annual “wellness check-up”, but it is not called a “physical”. What is the difference?

A – There is a lot of difference. The wellness check-up has a list of items to be evaluated, including: lifestyle risks from smoking or drinking; immunizations shots; Body Mass Index (BMI); mammograms; PSA tests; etc.

Q – Based on one person's statement from Medicare, Revlimid is \$125,000 per year. Is that a limit on what Medicare will pay?

A – Part C will limit out of pocket expenses. Look at your plan to know the limits. Part D has the “donut hole” where drugs are not paid, but congress is working to close that hole. Medicare Advantage plans have no donut hole, but pick a Medicare Advantage plan that is rated at four or five stars to get the best coverage.

Q – Whether I have Medicare or military Tri-Care, do I need supplemental insurance?

A – Tri-Care is a supplemental insurance.

Q – What is the difference between Medicare Advantage vs. supplemental insurance?

A – For Medicare A/B, Medicare pays 80% and you pay 20%. The supplemental insurance covers your 20%, which can be significant. Under Advantage Plans, you would have a limited co-pay amount instead of the 20%, but you would be limited to the doctors within their network. Most Advantage Plans include Medicare Part D.

Q – Does Advantage Plan cover you when you are traveling?

A – Medicare must cover when you are in an emergency room, but will not cover when you are out of the country. If you have an emergency, you will be covered by the local plan.

Q – Are hearing aids covered by supplemental insurance?

A – They are not covered. Tri-Care covers them. Try the low cost amplifiers to see if that helps. Glasses are covered by Medicare only after cataract surgery. You can get good glasses for less online. Some Advantage Plans cover dental, but only one cleaning per year. Medicare does not cover Dental.

Q – What is difference between long-term and short-term disability?

A – If you apply for SSI, it is based on whether the person can work. If no longer able to work, after two years on SSI, you will get Medicare. The exception where Medicare is immediate is ALS and renal failure.

Q – What are the criteria for Advantage Plans?

A -- The plans are rated by stars: one through five stars. If you chose Advantage, select only four or five stars for superior care. Remember that they have specific doctors in their network and your current doctor may not be listed. Emory is not there. Determine your relationship with your current doctor to decide if you are willing to work with a new doctor. The Advantage Plan protects you financially. Do not select a lower star rating because you will have coverage holes. Doctors are now rated, so care is rated. Go to Medicare.gov and put in your drugs to determine your out-of-pocket costs for every plan in your zip code. Take the time to put in all your drugs so you can get the most accurate information.

Medicare.gov also has rating of every hospital, skilled nursing facility, and dialysis clinics. Doctor ratings are not ready.

Q – Can I switch to a Medicare Advantage plan?

A – Yes, any time for a four or five star plan. They do not have an open enrollment period like the regular Medicare plans.

Q – Do you need Medicare if you continue to work after retirement age?

A – It is not required, but work with your HR department to notify Medicare that you are covered by your employer's insurance. If you don't sign up for Medicare when you are first eligible, then you will pay an increased rate for the remainder of your time with Medicare, when you do sign up. Notification will cancel this penalty. When you are getting ready to retire, you have a seven month window to notify Medicare: three months before, the month you retire, or three months after. If you do not notify, your rates will be higher.

Southside Multiple Myeloma Support Group June 2016

Instead of our regular fourth Saturday monthly meeting, the Southside MM Support Group celebrated its 10th anniversary on June 18th at Pascal's restaurant. There were 45 present.

The July 23rd meeting will feature Shannon Reilly, MS, ACNP, Clinical Nurse, Consultant, Atlanta District, Celgene Corporation. Celgene is the maker of Thalidomide, Revlimid and Pomalyst. Her talk will feature reviewing lab reports; so, bring your last 3 or 4 reports and your questions.

The Tenth Anniversary of the Southside Atlanta Support Group: If you were not there, you missed a wonderful gathering. We had a glorious celebration!! The event was held at Pascal's Restaurant and was sponsored by John Schwarz, pharmaceutical representative for Takada makers of NINLARO® (ixazomib), and VELCADE (bortezomib). Thank you, John.

In 2006, after her diagnosis of MM, Doris Morgan with the assistance of Andy Lebkuecher (former IMF Southeastern Regional Director) and his wife (Cathy, a MM patient) developed a proposal to establish the SSAMMSG as an affiliate of the Atlanta Area Multiple Myeloma Support Group. Doris's vision was to have a support group closer to home since there were probably MM patients on the Southside of the city that may have difficulty traveling to Briarcliff Road; therefore, she began work to do just that. They submitted a proposal to the IMF to add SSAMMSG to the Atlanta Area MM Support Groups "and the rest is history". In case you missed it, with an IMF banner used as the back drop,

Bridgette, Doris' daughter served as mistress of ceremony. On display was a photograph album prepared by **Pat and Doris** featuring pictures of members from various events over the years. Doris presented John a gift denoting our appreciation for his continued support. Those present provided moving comments expressing their appreciation to Doris, members and what the support group has meant to them and their families—very moving tributes.

Candles were lit for members who have transitioned over the 10-year existence of the support group. Those recognized were **Darlene Glove Parks, Folami Abiade, James Lester, Shirley Jones, Terriel Covington, Milton Scott, Nina Murray, Ruby Elaine Daniel, Rev. W Arthur Lewis, Yolanda Michelle Kitchen, Janice Hampton, Rev. Gerald Richardson, Lonnie Ward, Leo Smith, and Loretta Robbins**. Many were represented by family members who expressed gratitude to the group and Doris for her support to their family member and them over the years. **Joe** led the group in grace and at the end of the luncheon participants enjoyed a delicious carrot cake wonderfully decorated with the **Myeloma** ribbon provided by IMF.

The group presented **Doris** a beautiful glass sculpture with a silver ribbon paying tribute to the 10th anniversary of the dedicated and committed service **Doris** has provided to the Myeloma patients, families and friends on the Southside of Atlanta.

Business

Shop for a Cause: Friday, August 26, 2016 through Sunday, August 28, 2016, Macy's will host its 11th annual "**Shop For a Cause**" benefiting charities nationwide. This is our opportunity to raise funds for our support group by selling the \$5 "Shop for a Cause" savings passes. If we sell 100 passes, that's \$500 for our support group. This is our only fund raiser; please plan to participate by selling at least 4-5 saving passes. It gives a shopping pass discount of 25% throughout the store on an assortment of regular, sale and clearance merchandise and 10% on electrics/electronics, watches, furniture, mattresses and rugs/floor coverings. However, they are not valid on macys.com. Plus, at each Macy's store, customers who bring in their savings pass will be eligible to win a \$500 gift card, no purchase necessary. We are hoping each member will be responsible for at least 4 tickets. This can be your way to communicate with 3 other people about myeloma. Contact **Paulette (470-428-2988 or email ppmneely@gmail.com) or Doris 404-346-1372 to get your tickets.**

Pat is Moving: We are saying goodbye to a longtime, faithful member who is moving to California to be closer to her son and family. **Pat** rarely missed a meeting and was usually the first to on the fourth Saturday morning. She will be missed.

"Making Miracles": The Spring/Summer issue of IMF "Making Miracles" featured an article titled "Celebrating 75th with Style". It was a summary of the celebration of Doris' 75th birthday event with contributions donated to the IMF. Bridgette and Elliott, her children and her two grandchildren hosted the celebration. Bridgette's planning started with convincing her mother to have a party. She was used to her mother's standard decline in other years, always with an explanation of "not needing gifts." So this time Bridgette was armed with the idea of the fundraiser – donations to the IMF in lieu of gifts –honoring the organization that has helped Ms. Morgan and her family since her myeloma diagnosis. This time Doris said "YES". So, on November 28, 2015, more than 125 friends and family gathered at the Ben Hill Recreation Center in Atlanta, GA. The evening included dinner, dancing, toasts to Ms. Morgan, and information about myeloma. The room was beautifully decorated with flowers, banners, and IMF-colored tablecloths and chair covers. Leading up to the celebration, those decorations being "just right" was the most important part for Ms. Morgan. But, once her guests arrived, it was all about the people. "She was so happy to see everyone that she could not sit still. It was a beautiful event and my mother looked so pretty and was so happy. Celebrating her 75th birthday with a fundraiser to find a cure for this disease was well worth it." Bridgette says.

The current total for the IMF donation from Doris Morgan's 75th birthday celebration is \$4,655!!

MM Advisory Board: In early June **Gail and Paulette** traveled to Cambridge to serve on the Multiple Myeloma Advisory Board providing input on packaging and content literature regarding Ninlaro. This patient education awareness activity/program was organized by the Snow companies.

Announcements/Resources/Upcoming Meetings

- REGISTER FOR THE GEORGIA BLOOD CANCER CONFERENCE. Visit lls.org/georgia to register for this complimentary conference on **Saturday, July 23, 2016 at the Cobb Galleria Centre**. The keynote speaker is Craig Sager, America's Sideline Reporter for Turner Sports. Craig will be receiving the Jimmy V Award for Perseverance at this year's ESPYS and was featured on the cover of the May issue of Sports Illustrated. He was diagnosed with Acute Myeloid Leukemia in 2014 and has undergone two bone marrow transplants.
- Registration is required for this FREE education event.
- Register at www.eiseverywhere.com/ehome/gabcc/409485/.
- If you have questions or need assistance registering, contact Tricia Hernandez, Patient Access Manager, at Tricia.Hernandez@lls.org call 404-720-7838

- LLS. Oral Therapies in Myeloma. Medication Adherence.. . <http://www.lls.org/patient-education-videos/oral-therapies-in-myeloma-medication-adherence>
- Telephone Support Groups. CancerCare's telephone and online support groups are free and professionally facilitated for people living with cancer and their loved ones. To join a telephone support group, contact us at 1-800-813-HOPE (4673). To join an online support group, please register through our website at www.cancercare.org
- Stay alert. Institute for Clinical and Economic Review (ICER) published an article challenging the cost-effectiveness of treating relapsed or refractory MM. http://icer-review.org/wp-content/uploads/2016/04/MWCEPAC_MM_Draft_Evidence_Report_040716.pdf
- Myeloma Canada is reaching out to US myeloma patients and caregivers to take a few minutes to complete a brief online survey by clicking either the patient survey or the caregiver survey link.
Patient survey -- <https://www.surveymonkey.com/r/MCNinlaroPatientSurveyMay2016>
Caregiver survey - <https://www.surveymonkey.com/r/MCNinlaroCaregiverNinlaroSurveyMay2016>
- Surveys for Money. On the Wall. We are looking for people who would like to share their stories and be paid up to \$75. www.on-thewall.com/12YLZ
- IMF - Smart Patients is an online peer-to-peer program – get daily emails from patients and caregivers regarding their MM treatment journey. They share experiences from preparation for SCT to hints on increasing energy to discussions on new medications, side effects, and more. <http://www.smartpatients.com/imf>

Multiple Myeloma Classes of Drugs and/or Therapies:

1. Proteasome Inhibitors - Bortezomib/Velcade; Carfilzomib/Kyprolis; Ninlaro/Ixazomib
2. Immunomodulating - Thalidomide, Lenalidomide/Revlimid; Pomalidomide/Pomalyst
3. Monoclonal Antibodies - Daratumumab/Darzalex; Elotuzumab/Empliciti
4. Histone Deacetylase - Panobinostat/Farydak

*New agents in 2015 - Farydak, Darzalex, Ninlaro, and Empliciti

Submitted by Paulette Neely