Meeting Minutes

Northside MM Support Group

October 5, 2024

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Business and News: The November and December meetings will be virtual only as we get into flu and Covid season, even though Covid got a head start. The November meeting will be separate sessions for patients and caregivers to discuss their journeys, which are from different perspectives. Patients and caregivers have alternate difficulties within the stages of the journey.

Guest Speaker Presentation

Northside welcomed our guest speaker, Danielle Doheny, Advocacy Director for the IMF. Prior to joining the IMF, she was a staffer for two Congresspeople where she focused on healthcare and issues regarding energy, the environment, science, and technology. Her father has multiple myeloma, so she is passionate about advocating for the myeloma community at the executive and legislative levels on Capitol Hill. Danielle's agenda included two topics:

- IMF advocacy role for myeloma patients
- Changes in Medicare for 2025

Danielle started her presentation by outlining the three main principles of advocacy for multiple myeloma.

1. Making sure patients have equitable access to myeloma medications available.
2. Combating the financial and insurance barriers to medication access.

3. Assuring funding is available for myeloma research and patient grants.

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Healthcare advocacy involves a lot of education and negotiation. The ***Step therapy protocol*** is one that impedes the physician from delivering needed medications to patients in a timely fashion. Insurance providers may require a “fail first” medication by prescribing alternative medications and/or generics that are less expensive before allowing patients access to more successful treatment options. **The *Pharmacy Benefit Manager Transparency Act of 2023*** (PBM) regulates incentive programs between insurance providers and drug companies in setting prescription costs and drug approval timelines. *Telehealth* is also a hot topic that allows patients to gain access to physicians virtually, particularly if specialists are not locally available. The ***Cancer Parity Act of 2023*** strives at more availability to oral prescription drugs that are affordable to the patient. Several changes in **Medicare 2025** will have a positive impact for recipients, particularly in Part D drug costs. Equitable access and diversity to treatment and clinical trials are also critical issues being addressed.

Danielle’s primary role for the IMF is to represent the myeloma community in Washington, D.C. The **Grassroots Advocacy Program** invites patients to Capitol Hill to share their experiences with myeloma to lawmakers. This program is vital in influencing healthcare policy decisions. One goal is to have a MM Hill Day during Myeloma Action Month for everyone to attend. The Grassroots initiative also includes leadership development, legislative education, campaign planning, health policy forums, resource development and personal interests. You can be involved at any level as an opportunity to have your voice heard. Many legislative proposals are prioritized based on how many calls and letters are received on a topic or issue. Highlights of recent advocacy events in 2024 are shown in the file attached. Note that the IMF is the only myeloma organization advocating on Capitol Hill.

Danielle continued her discussion on Medicare changes for 2025. Open enrollment is October 15 to December 7 for the 2025 Medicare plan election. The Inflation Reduction Act of 2022 (IRA) has phased- in several changes over the past three years (see attached slide). Major changes to Medicare starting on January 1. 2025, will include - out-of-pocket maximum spending cap of $2000 for all prescriptions billed under Medicare Part D. This includes all drugs listed on the Formulary list for Medicare and Advantage plans. No matter how many drugs you are taking monthly or throughout the year, the total maximum cost in 2025 will be $2000 for Medicare Part D. This will be a significant benefit for patients taking medications for myeloma. Important to note that any drugs given at the office or medical facility is considered under Medicare Part B for billing. according to your health insurance policy. Current Medicare plans include no copays for vaccines given under Part D, Insulin copays limited to $35/ mo. and expanded eligibility for federal extra help with insurance premiums, deductibles, copays, etc. for low-income recipients. Along with the $2000 cap on prescription drugs next year, there is a monthly payment program available to spread the out-of-pocket costs over the course of the year through the Medicare Prescription Payment Plan. You will need to "opt-in" to take advantage of this program. This program was the direct result of groups like IMF and other chronic diseases advocating for relief from the excessive cost for specialty drugs. Remember: Talk to your insurance provider to "opt-in" to the program. Danielle cited a Wall Street Journal article from January 2024 showing the cost savings on the priciest drugs prescribed; Pomalyst and Revlimid were numbers 1 & 2 on the list.

It is especially important to go over all the details on any insurance plans you may be considering. Call the provider to double-check what prescriptions are covered on their Formulary list as well as how office visits, treatments, co-pays, and deductibles are billed. Remember that open enrollment runs through December 7, 2024. Review the following resources for further details and call them early to help with any questions you may have.

- **Medicare.gov**

- Medicare and You 2025 -decision guidebook
- Georgia SHIP – Medicare Assistance / counseling
- Triage Cancer – Health Insurance articles.
- IMF Infoline - 800-452 CURE (2873)
- Medicare Prescription Payment Plan – monthly payments for Medicare Part D
- Pan Foundation – Medicare reform and clinical trial options
- Kaiser Family Foundation – Medicare Part D 2025 drug benefit

Q & A

Q. How is working with other organizations beneficial since there is only so much money to be given out? A. Research funding is spread across overall needs. The blood cancers collectively receive the greatest portion from the Department of Defense (DoD) based on the quality of the research.

Q. Who is picking up the tremendous remaining cost for prescriptions now that Medicare has capped yearly out of pocket max to $2000? A. Some costs will be absorbed by Medicare along with pushing back costs on the Pharma industry. Drug price negotiations will continue to balance overall cost through the PBM program. It is amazing that Revlimid has the second highest Medicare drug cost.

Q. To clarify, those on Medicare will not have to pay more than $2000 for drugs in 2025, correct? A. Yes. Part D (oral medications) will have a maximum OOP cap at $2000. Q. So why are drugs so less expensive in other countries? Why the discrepancy? A. There has been talk on drug importation and tying US costs to pricing in other countries, but nothing is moving forward right now.

Q. Can you discuss the Medicare Formulary List? A. Medicare r the drug cost on the formulary list by a price or using the step therapy or changing the tier of prescriptions or require prior authorization. If this

occurs, file an appeal because most people win. The advantage plan formulary list is not always the same as

Medicare's list, so always check that your specific prescription is covered through Part D.

Q. Prior to being on Medicare there were patient subsidies available through the Pharma companies. Once you are enrolled through Medicare these benefits go away and it becomes a lot harder to get copay assistance for the same medication. What is the pharmacy's role in the Medicare Part D changes? A. It is considered an anti-kickback law that would entice patients to use certain drugs that were for Medicare to provide or increase participation in certain clinical trials.

Q. Who should I contact regarding Medicare plans for 2025? A. The Georgia SHIP program is a good place to start. It is a state insurance counseling center that guides you through the enrollment process. They can answer your questions and work with you to compare plan benefits and insurance. Be sure not to delay in looking at your options before everyone tries to call in.

Jim M. noted that he was a part of the IMF advocacy group and partnered with the LLS on the Parity Bill, contacting state legislators as one force. There is collaboration between the IMF, LLS, and others on common Bills. Danielle agreed that this has occurred on DoD bills and the Cancer Parity Bill.

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Patient Updates

Nancy introduced a new member to the group, Susan, and her husband Howard. She was diagnosed last month and just started induction therapy before receiving a stem cell transplant. Welcome Susan. Phyliss shared that Rolf is about to turn 90 and never had a transplant. He has been on his myeloma journey since 2009. That is fifteen years, so he is one of our heroes. Phyliss is going to connect with Susan on her journey. Treatment and transplant decisions are different compared to 10-15 years ago. Over the last 20 years there have been over seventeen new treatments available. The support group is here to help educate and share experiences with each other.

Submitted by Sandy W

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Southside Virtual MM Support Group

October 26, 2024

Next Meeting:

The Southside group will meet on Saturday, November 23 at 10 AM. This is a virtual meeting. Discussions will include Doris' retirement, Southside plans in 2025, and sharing your ideas for the upcoming holidays.

For Men Only: Next Meeting – Tuesday, November 26, 6:00 – 7:00 PM.

Join us for some enlightening man-to-man discussions.

Group Presentation

Nancy hosted the meeting for about thirty members. Gail recently started a new treatment on Friday and was unsure how she would be feeling. Thank you, Nancy, for leading the group this month on the latest updates from the IMF. The International Myeloma Foundation (IMF) started in 1990. Its mission statement:

"The IMF is dedicated to improving the quality of life of myeloma patients.

while working toward prevention and a cure."

The IMF celebrates its 35th anniversary next year and the word "cure" is being used now more than ever. *Quality of Life* is important to a patient's overall survival and well-being. Support group meetings boost your QOL by providing accurate myeloma information and empowering you to engage in conversations with your healthcare

team. IMF vision states: *"A world where every myeloma patient can live life to the fullest, unburdened by disease."* CEO, Yelak Biru, is a 28-year survivor and we have members in our own support groups who exceed 30 years. There are over 160 support groups throughout the country meeting regularly to inform members of the latest research and MM treatment options available. IMF Special Interest groups meet virtually to discuss topics specific to the myeloma community. The Southside "For Men Only" group is scheduling quarterly meetings nationwide. A virtual support group for Veterans is also in the works for next year.

Myeloma research from around the world is available on the IMF website providing publications on drugs/treatments, Understanding Myeloma series guides, and online seminar events. Look under the website drop down tabs for these topics. Over three hundred myeloma experts are directly involved with IMF working groups (IMWG) and writing standard of care (SOC) for doctors worldwide to know the best practices for myeloma treatment. IMF contributions on MM directly impacts the patients with treatment guidelines throughout their myeloma journey and funds the Black Swan Research Initiative keeping experts and patients alike informed on the most current myeloma research and clinical trials being addressed at the annual ASH, ASCO EHA and IMWG meetings. Their partnership with Sparkcures focuses on clinical trials specific to myeloma. Nancy pointed out several locations on the website to get pertinent information on myeloma. You can also contact the InfoLine for additional help at 800-452-CURE or InfoLine@myeloma.org

The newest feature on Myeloma.org is Myelo (look for the message box at the bottom right of the website to activate.) Myelo is an enhanced GenAI chatbot tool that can provide real-time comprehensive information regarding MM on the IMF website to assist patients, doctors, and researchers with user specific questions. Nancy demonstrated the function of Myelo, and the group spent several minutes asking questions that produced thoughtful, comprehensive answers that users know are reliable.

Patient Updates

Glen I. tested MRD negative on his most recent bone biopsy. He has been on Revlimid for four years and never had an ASCT. He does not present any protein or M spike and was not sure how it is monitored through light chain testing. Nancy noted that it is important to understand what lab tests the doctor is watching in your blood work so you can be proactive in your treatment plan. Wanda P. had five bone marrow biopsies last year which provided minimal diagnosis. She takes Darzalex with Dex along with Tylenol and Claritin to avoid a reaction during the infusion. Wanda experiences shooting pains in her head and her muscles sting which occur about 5-6 days after the infusion that last about 10 days. She receives Dara SubQ every 8 weeks. Wanda is hypersensitive to treatment but hopes the side effects will get better over time. Doctors continue to monitor her treatment monthly through blood labs. Dirk suggested having a discussion on *Bone marrow biopsy: A necessary evil or just evil* "at a future meeting. He also thanked Doris for the post call he received and noted that it was more personable than getting the email blast. It is nice to see the support group use multiple ways for communication.

Nancy reminded the group that it is Medicare enrollment until December 7 and that state employees must select a plan for next year.

Submitted by Sandy W.

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