

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group April 3, 2021

Thank you to **Nancy B.** who hosted the meeting, with approximately 30 people attending. The meeting began with a very informative presentation about estate planning. After that we had an open forum discussion where members provided status updates and shared information. At the next meeting in May, Dr. Harvey from Emory will join the group to talk about clinical trials.

Guest Speaker

Thank you to **Shannon Pawley, J.D., LL. M, and Managing Partner from The Estate & Asset Protection Law Firm**, who joined the meeting to educate us on estate planning. Shannon began her presentation by disclosing that everything discussed in the meeting is for educational purposes only, and that she urges everyone to seek the advice of an experienced estate planning and wealth protection attorney regarding your particular circumstances.

The Estate & Asset Protection Law Firm's mission is to ensure that people live and die with the highest quality of life possible. This is achieved by listening, educating and then preparing solid estate plans designed around your self-directed choices to preserve independence and assets. An educated consumer is the best type of consumer. The presentation covered the following:

- The three foundational documents that everyone over the age of 18 should have on their estate planning journey
- The positive effects of having each of these documents, and negative effects of not having them
- How you can be even more secure on your estate planning journey beyond the three foundational documents

Note that all family members should have these important documents, not only patients.

Document 1: Financial Power of Attorney

A Financial Power of Attorney (POA) is a legal document that allows a person(s) that you designate to perform financial actions and make financial decisions on your behalf if you are incapable of doing so. Some examples of actions that can be performed on your behalf through a Financial POA include legal access to your financial accounts, ability to pay your bills, authority to enter into or terminate contracts, and ability to actively participate in asset preservation strategies for long term care. The time to prepare a

Financial POA is before you are incapacitated, as it is too late to sign a Financial POA once you become incapacitated.

If a person becomes incapacitated without a Financial POA, loved ones could possess no legal authority to stop the financial hemorrhage of existing contracts (i.e. bills), or of managing your personal financial assets (i.e. investment accounts). Additionally, loved ones may become liable when signing documents to get you the care that you require and they will not be able to strategize with an attorney for asset protection to cover your long-term care needs. Then, in order for your loved ones to be able to take care of your financial affairs, they will have to go down a litigious route with a conservator with the Probate court, which is a costly and emotional process.

Document 2: Healthcare Power of Attorney with Medical Directive

A Healthcare Power of Attorney (POA) with Medical Directive is a legal document that allows a person(s) that you designate to have access to healthcare records, participate in consultations with your doctors, and to make healthcare decisions on your behalf if you are incapable of doing so. The Medical Directive portion of this document is where you are able to explicitly detail your end-of-life treatment plan.

Examples of actions that can be performed through a Healthcare POA include legal access to your medical records, legal authority to discuss medical treatment plans with your doctors, legal authority to make health care decisions on your behalf, and ability to act as your health care advocate to ensure that your medical wishes are understood and followed by your attending medical staff. A Healthcare Power of Attorney (POA) with Medical Directive is one of the kindest gifts that you can give a loved one.

If a person becomes incapacitated without a Healthcare POA, risks could include loved ones being shut out of all medical discussions and decisions, loved ones being unable to obtain health care updates due to medical privacy laws, and loved ones being unable to ensure that your end-of-life wishes are being met by the medical staff. Loved ones will have to go through the court system to get guardianship in order to gain these rights because the person lacks the capacity to grant it to them.

Document 3: Will

A Will is a legal document that details your instructions for the distribution of your assets after your death. If you die without a Will, you're deemed to have died "intestate" or without a testamentary instrument. When this occurs, the court system takes the responsibility of dividing your assets between your descendants through the Probate courts, utilizing what's called the laws of intestacy, which focuses on your assets being distributed to your closest recognized relatives.

The Pros of having a Will include: You leave property to those you chose, you choose your executor, you can plan for personal matters, you can create testamentary trusts, you can have one prepared quickly, you can amend it, and you can revoke it.

The Cons of a having a Will include: It only takes effect at your death, it may need to go through Probate, lack of privacy (the will becomes public record once filed with Probate Court), it can be challenged, it may require an ancillary Probate process to be filed in other state(s) if you have property in multiple states, and it may not address estate and income tax concerns.

A will is a roadmap of where you want your assets to go, but it's not a ticket out of Probate.

What is Probate explained:

Probate is a legal process, controlled by the court and can occur whether or not there is a Will if the person has assets in their individual name at the time of their death. This includes all real property and assets that are individually owned (without a joint owner or payable on death beneficiary), even if you have a Will. You will have to go through Probate to get those titles transferred to the name of your designated individual or to your closest recognized legal heir.

During this process, all of the assets in the person's individual name at the time of their death are gathered for distribution. Creditors and debtors can make claims to get paid first. Then after the Probate fees (i.e. court, attorney, and legal fees) are paid, assets are distributed to heirs or beneficiaries under the terms of your Will. The Probate delay time frame is 6 - 48 months.

Trust Planning considerations:

You can avoid the time and expense of Probate court with Trust planning. A Trust is a fiduciary relationship which one party, the trust-maker (Grantor), gives another party, the trustee, the right to hold property for the benefit of a third party, the beneficiary.

This document allows the trust to own, sell, or transfer property, receive income, distribute income, make investments, gifts, and loans; and anything else with explicit instructions in the Trust.

In addition, Trust planning can also make things a lot easier from the financial management aspect because financial institutions work easier with the trustee than they do with a Financial POA.

Shannon graciously answered many questions for us as follows:

Q: How does a Financial POA work with a Trust? **A:** A Financial POA is no longer valid once a person passes. A trust can give similar powers, after the person passes.

Q: What is a living trust? **A:** A living trust is one that was created while you were alive, and there are several kinds of living trusts that serve different purposes such as Probate avoidance, asset protection, etc.

Q: When does a Healthcare POA take effect? **A:** Durable power of attorney becomes effective as soon as you sign the document, and it continues to be effective if you are incapacitated. A “Springing” POA takes effect when a pre-designated event occurs, i.e. it springs into action at that time.

Q: Regarding POA documents and Agents – can you/should you have more than one of each, depending on the multiple locations (states) where you live? **A:** Try to limit to one of each type of document, but make sure you reference all of the states where you reside and make sure that the rules apply to all states. Also try to limit to one Agent. Note the following:

- Financial POA – Agent does not need to be in close proximity to where you reside (electronic and telecommunication is an option). Important to know laws vary by state.
- Healthcare POA – Agent should be in close proximity to you. In the event of a medical emergency, the first 3 hours are very important.

Q: When is a trust not needed? **A:** If you have no assets, investments, or bank accounts, and do not own property.

Q: If you have a Will and leave your house to your spouse, what is the benefit of having a trust? **A:** The benefit of the Trust is to avoid Probate court.

Open Discussion

In the past month, two new multiple myeloma (MM) treatments were approved by the FDA after completing Phase 2 trials: 1) melphalan flufenamide, and 2) CAR T cell-therapy. Both treatments are very restricted at this time and are only approved for patients with relapsed or refractory MM who have received four or more prior lines of therapy, including an immunomodulatory agent, a proteasome inhibitor, and an anti-CD38 monoclonal antibody. This is very exciting and welcome news for patients whose options had started to become more limited! **Our group is very eager to hear from members who have been on either of these treatments or are considering them. Please contact Nancy B. if you would like to share your experiences with these newly approved therapies.**

Lory M. shared that she is continuing with Dara, 10 mg. every other week. She has been taking Dara for nearly 5 years, and while her paraprotein number increases, it is gradual, and the Dara is still working to control the MM. **Judy H.** explained that **Walt** has changed treatment. He was on Pomalyst, 2 mg. and Dara once a month, but his MM counts increased and blood counts decreased, and he was still in a lot of pain. After considering options, they decided to increase the Dara, reduce the Pomalyst and may possibly introduce Dex. Walt is now taking Dara twice a month, and Pomalyst 1 mg. Walt also just started using an implanted neuro-stimulator by Stimwave to help control pain. **Jim M.** mentioned that after he began taking Dex 20mg. per week it helped reduce pain tremendously and his counts are better. **Sandy B.** had a pain control device stimulator

implanted in 2017. It was not as successful as she had hoped, as she still has neuropathy and tremors in her hands. Sandy changed her Revlimid dose recently (14 days on/14 days off), hoping this will help her reduce pain; results are pending. **Jeff W.** mentioned that Emory is doing a study, taking blood draws and tracking MM patients, to count antibodies post COVID vaccination. They are trying to determine how long their antibodies stay elevated after COVID vaccinations, and how long they remain covered. They are trying to answer questions such as: What antibody level brings you protection? Do MM patients have enough antibodies to stay protected? Do MM patients have fewer antibodies after COVID vaccinations than the general population, and will MM patients require COVID vaccine boosters sooner or more frequently than the general population, etc.

Nancy provided a demo on myeloma.org, showing us how to navigate through the IMF website on a variety of topics, some that we reviewed included:

1. **Ask Dr. Durie** - What should myeloma patients know about the COVID-19 variants.
2. The **Myeloma Treatment Discussion Tool** (a.k.a. Tip Card), a very helpful questionnaire to help patients when making treatment decisions (To navigate go to Publications & Videos, and under IMF Publications section list see “Tip Cards” near the bottom with a red block to view a video which explains the Treatment Discussion Tool.
3. **“M-Power Charlotte” Workshop. Sandy B. and Nancy B.** both recommend this workshop. Of great interest is that more African Americans are participating in clinical trials. This rollout has started in Charlotte and will continue in other cities. We know when MM awareness is raised in all communities, everyone benefits! (To navigate: **Click IMF Videos** at top of page, then page down to click to the next page).

Submitted by Wendy R.

Meeting Minutes

Southside Virtual MM Support Group

April 24, 2021

Business News

Next Meeting: May 22, 2021 – **Jennifer Rooke, MD, MPH, FACOEM, FACPM, Physician-Nutritionist. Optimal Health Lifestyle Medical Clinic and Plant-based Diets. Morehouse School of Medicine.**

There are many of Dr. Rooke's patients who report having reduced or eliminated chronic disease medications through following her lead. What questions do you have?

We opened our April meeting with a moment of silence, led by Doris and a welcome to all, especially new members. We welcomed one new member, **Rosalyn**, who was diagnosed with Multiple Myeloma (MM) in March 2019. Rosalyn went to her primary care physician, knowing there was "something wrong". She was referred to Dr. Nooka and was told she had Stage 2 MM. Since her Bone Marrow transplant in October 2019, Rosalyn has relapsed, and was taking *Ninlaro*. She is currently on a regimen of *Pomalyst-Dara(tumumab)-Dex*, going every 2 weeks for the Dara. She seems to always be cold and has pain in her hips. She's has been searching online to see if these symptoms are 'normal'. Rosalyn is not one to usually ask for help. **Petula** shared that she has a lesion under her ribs and has chronic pain.; **Vena** shared that it is not unusual to have pain as MM is a blood cancer that sets up in the bones. It attacks the biggest bones in the body, like the back, ribs, and hips.

Information on MM, bone pain, and vocabulary terms (various sources: Sloan Kettering, WebMD, etc.)

- *Multiple myeloma can weaken your bones and increase your risk of fractures and bone pain. Myeloma cells form tumors within the bone marrow and spread from the marrow to damage bone tissue. Myeloma cells can cause bone marrow cells to remove calcium from the bone, which causes soft spots called osteolytic lesions.*
- *When plasma cells grow out of control, they become diseased cells. These cells are found in the **marrow**, the spongy tissue inside some of your bigger bones, mostly in your **back, rib cage, and hips**. Sometimes these abnormal plasma cells, known as myeloma cells, form a single tumor called a solitary plasmacytoma. One or more tumors is called multiple myeloma.*
- *If you have bone fractures, surgeons can use metal rods and plates to provide support for weight-bearing bones. Doctors may also suggest wearing a back brace or a neck brace to support your bones and relieve pain.*
- *Back pain is often the first symptom of multiple myeloma. Because back problems are common, they might not initially be associated with the disease. However, a backache that lasts for months can be a signal that multiple myeloma is affecting the bones in the spine or ribs.*
- *Sudden, severe back pain can be a sign of a fracture or of the collapse of a vertebra in the spine. Rapid escalation of pain or pain associated with muscle weakness may indicate a fracture causing spinal cord compression. Shooting pain in the arms or legs can mean that a tumor in the spinal column is pressing on nerves in that area.*
- *You should notify your doctor immediately if you have these symptoms.*

Vertebroplasty and Kyphoplasty therapy:

- *In vertebroplasty the doctor injects a special kind of **bone cement** directly into a collapsed vertebra. In kyphoplasty, a small balloon called a tamp is inserted into the vertebra and inflated creating a space into which the bone cement is injected. These procedures are usually performed on an outpatient basis and can help improve mobility and quality of life. If kyphoplasty is not effective, an interventional radiology team will explore whether it helps to insert a stabilizing rod through the skin for spine support. This could avoid the need for surgery.*
- *...your “old” bone is constantly being dissolved by cells called **osteoclasts**. Meanwhile, cells known as **osteoblasts** are making new bone. These things normally happen together. Myeloma cells speed up the breakdown process, and the tumor cells take over the bone. The result: Your bones get weak and can fracture easily.*
- *Because your bone dissolves faster than normal, you may have a high level of calcium in your blood. You might also feel really thirsty and dehydrated.*
- *Your doctor might add **bisphosphonates** to your treatment plan if your multiple myeloma is causing a lot of bone problems. These drugs can slow bone disease, prevent fractures, and ease your bone pain. Two common drugs are pamidronate (Aredia) and zoledronic acid (Zometa). You get them in a shot that goes into a vein.*

Guest Speakers: We had two speakers for our April meeting.

The first presentation was a national research study called **All of Us** with **Cheryl Simpson**, from a National Institutes of Health (NIH) **Outreach Program Lead at the Southeastern regional Hub of the program/Morehouse School of Medicine**

All of Us is a 10-year research program seeking to enroll 1 million people from across the nation in an effort that will help us along the path to better precision medicine. Information collected from those who join will be a part of a national database that will help to answer about why disease is more prevalent in certain regions, certain communities across the United States, and among certain racial/ethnic groups. What keeps us healthy, and why is there more disease burden in certain populations? Is there something in our environment that contributes to greater disease in certain geographic areas. The surveys and genetic materials will also help to develop more targeted therapies for diseases like MM and hypertension that can require very different drug therapies for optimal health outcomes.

- Part 1 of enrollment in *All of Us* is online, where you complete two consent forms and four surveys.
- Part Two requires a one-time visit where you get measures of height and weight, blood and urine samples. As part of your participation, you will receive your DNA

profile within 90 days of your lab visit, similar to Ancestry.com or 23 and Me. You will also be compensated for your time and effort.

While All of Us is for everyone, there is particular interest in people of color. The usual participants in research Clinical Trials are 35-year-old white males. With good reason, people of color point to a history of unethical medical experimentation and disrespect that did not benefit them and a skepticism that information collected could be used to further support racist practices in our society. The current number of enrollees is approximately 400,000 of the 1 million targeted. This will create a biobank of information for researchers across the United States. It will provide an opportunity to make positive changes in our healthcare system and practices. You can join *All of Us* at allofus.nih.gov. There are YouTube videos on the *All of Us* Research program. **Pat C.** (2021) and **Petula** (2019) have already joined and recommended that we invite the staff so others might have the same opportunity. Please call 404.752.1120 for more information. Invite your family and friends to join this very worthwhile research program.

The next speaker was **Yun Ping Moore, OD – Emory University, Department of Ophthalmology.** on **Common Eye Diseases and Vision Changes Associated with Myeloma Clinical Trials** with the presentation, **It's About our Eyes.**

Doris was impressed with Dr. Ping Moore's clinical skills and knowledge during her own exam and invited her to our Support Group meeting. There is a new myeloma medication called *Blenrep* that has as a major risk factor or side effect of blurry vision. While you are on this medication, you will be required to see an ophthalmologist at each visit. Dr. Moore walked us through the structure, function, and anatomy of the eyes, and talked about common eye diseases, and normal aging of our eyes, like **cataracts, glaucoma, diabetic retinopathy, and macular degeneration.** Anyone can get **cataracts** and risk factors include exposure to UV rays over time, medications, diabetes, and heredity.

- Three types of **cataracts**: 1 - the lens becomes yellowed or cloudy; 2 – an apparent hammering or granular deposit on lens; and 3 – cortical spokes or swollen lens.
- **Glaucoma** is the damage of the optic nerve that disrupts communication between the brain and the eye. Risk factors for optic nerve damage is increased pressure in the eye from diabetes or high blood pressure or even increased pressure with no defined cause.
- Age related **macular degeneration** (ARMD) is the accumulation of fatty deposits called drusen at the macula, which controls our central vision. A healthy macula gives us the best correctable vision of 20/20. For each of these eye ailments, there is a surgical option and less invasive options that you should follow up with your doctor. There are over-the-counter vitamin **eye drops** that might help to slow the progression of macular degeneration. Look for **ARED-S2** ingredient on the eye drops label, brand is not important.

- **Diabetic retinopathy** is uncontrolled or fluctuating blood sugar causing leakage of the blood vessels in the eyes. There is a risk of blindness from diabetic retinopathy from vitreous hemorrhages, retinal detachments, or macula edema. Treatment options for diabetic retinopathy include blood sugar control and dietary changes, laser, and injections. She spoke of several other contributors to vision loss, including stroke, traumatic injury, and retinal disease. We must take care of our eyes.

Dr. Moore then pivoted to a discussion about the myeloma drug recently approved by FDA. It was in clinical trials (CT) in several DREAMM studies and is called **BLNREP or Bela (belantamab-mafodotin-blmf)**. She has worked with the CT and other patients who are on the Bela therapy. Blenrep is the first antibody-drug conjugate (ADC) approved by the FDA for the treatment of myeloma. Blenrep is the combination of a monoclonal antibody that binds to the B-cell maturation antigen (BCMA) on the surface of myeloma cells coupled with monomethyl auristatin F (MMAF), a drug that can kill myeloma cells. When the monoclonal antibody portion of Blenrep attaches to BCMA, Blenrep enters the cell and releases MMAF, which leads to cell death. The antibody part of the ADC attracts your body's own immune system to recognize myeloma cells and attack them. The medication is for those who have undergone at least four other therapies. It is delivered by infusion once every three weeks – about 30 minutes each time. Side effects of Blenrep include “severe vision loss”, corneal ulcer, dry eyes, and blurred vision. Each visit requires a consultation with an ophthalmologist. Throughout CTs and after approval, these eye problems have been temporary.

Gail asked a follow-up question of why patients would choose a drug with such daunting side effects. The answer was “risks versus benefits”. The therapy is currently open only to those who are relapsed/refractory to other therapies. They have gone through at least four prior therapies. Bela seems to have good success with the myeloma and the eye problems have been shown to be temporary.

Patient Updates

Candice asks for prayers as she continues to heal at her Mother's home in Illinois. She had a brain hemorrhage and is on the mend. We all collectively offer our heartfelt thoughts and prayers to Candice. **Emma** is making progress through her radiation treatment and with transportation issues so far. Most members report having either gotten the COVID-19 vaccine or knowing resources to have any questions or concerns about the vaccine answered.

The students from the Rollins School of Public Health/Emory University are concluding their Evaluation Project for increasing our reach for more myeloma patients, especially African Americans. We want to be sure that people are not suffering needlessly and alone from MM. Since we are virtual, our reach should be wider across the state. We are sensitive to the fact that many may not have computer access and we should emphasize the capacity to join us by phone. Stay tuned.

Group members stated that the IMF-sponsored May 6 Webinar on Nutrition and Your Immune System was excellent and highly recommended. Watch the [Living Well with Myeloma replay link](#) and build on that nutrition information for Dr. Rooke's presentation this Saturday, May 22.

Respectively submitted,

Gail