

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group January 14, 2023

Business & News

Thank you to **Nancy B.** who hosted the ASH review meeting. Northside's next meeting will be on **Saturday, February 4, 2023, at 11:00 AM.** This will be an open discussion about the Winship ASH meeting and what it means to change in treatments.

ASH 2023 Recap session with Emory Winship Physicians

Thank you to **Charise Gleason** for her organization to set up and present the 2023 ASH recap session with the Emory Winship hematology team. Over 50 people attended online to hear about and gain a greater understanding on current myeloma updates. There were 1041 abstracts about myeloma research at the December ASH conference which is amazing and significant to patients. The Winship team presented several multiple myeloma abstracts at the “hematology nerd-fest” as Dr. Hofmeister called it. Dr. Kaufman noted that this was our 11th year having these annual ASH recap sessions.

Dr. Craig Hofmeister started the session with a key take-home message: *reduce patient harm.*

- CAR T-cells can cause prolonged low blood counts and low-circulating normal antibody levels.
- While DEX can boost treatment responses, it has little anti-myeloma impact itself. For many patients the long-term side effects may outweigh the benefits of Dex.
- Bispecific antibodies can be more effective if they are given with step-up dosing. Emory is currently treating two patients per week on Bispecifics now that it is approved by FDA at lower dosages to reduce side effects.

An overview of MM was presented, including the impact on kidneys and bones along with anemia which leads to infections. The pre-cancerous states leading to myeloma are **MGUS** (monoclonal gammopathy of undetermined significance) or **SMM** (smoldering multiple myeloma).

The initial diagnosis for active myeloma was [CRAB criteria](#):

- **Calcium** (high levels in the blood)
- **Renal** issues (kidney failure)
- **Anemia** (low red blood cells)
- **Bone** lesions (holes or fractures)

Now doctors use [SLiM CRAB](#) which includes additional criteria:

- **Sixty +** percent plasma cells in bone
- **Light chain ratio** ≥ 100
- **MRI abnormalities** (>5 mm) in 2+ sites to identify MM earlier to determine treatment is needed.

These patients do not have significant CRAB symptoms, so treatment timeline for these patients may vary.

The [IMWG criteria](#) to diagnose MM:

- Active myeloma status determines the need for earlier treatment.
- bone marrow plasma cells $\geq 10\%$
- ≥ 1 plasmacytoma with 1+ SLiM-CRAB criteria.

Dr. Hofmeister explained [CAR-T](#) Therapy where the patient's T-cells are harvested and sent to a lab to re-engineer the T-Cells ability to target myeloma cells. 64% of CAR-T patients have prolonged anemia and low [ANC](#) that requires patients to stay close to the CAR-T center beyond 21 days. This can have a significant impact on the patient and caregiver. He also talked about a clinical trial [IFM 2017-03](#) where frail patients aged ≥ 65 years with newly diagnosed MM are given either DARA+Rev or Rev+dex. The DARA+Rev regimen had a higher overall response (96% vs 85%) and fewer discontinuations (32% vs 45%). Winship is treating two patients per week with **Tecvayli** ([Teclistamab](#)) which is a bispecific immunotherapy drug. Patients are treated in the hospital to get three escalating doses and are discharged in one week if no symptoms occur. The primary symptoms are **CRS** ([cytokine release syndrome](#)) and neurological issues. Both side effects are treatable and generally controlled.

Next **Dr. Nina Joseph** discussed [MGUS and SMM](#) testing criteria and how to determine the risk of progressing to active MM. The myeloma risk for progression in two years is 5% for low risk, 17% intermediate risk, and 66% for high risk. The challenge of treating SMM is the toxicity of therapies and the testing for MM advancing. Diagnostic testing is better with improved imaging through PET/CT or MRI. Newer treatments have improved efficacy and tolerability. There are several on-going clinical trials that are improving outcomes that prevent/delay progression or may someday cure the SMM disease. Emory is participating in preventative trials vs curing SMM which involves more intense treatment. Dr. Lonial is the Principal Investigator for [E3A06 Trial](#) that divides SMM patients into Rev (25 mg) vs monitor without treatment. After three years, the **PFS** (progression free survival) for Rev patients was 91% vs 66% for monitored patients. Dr. Joseph detailed the [GEM-CESAR Trial](#) where high-risk SMM patients were treated with KRd (Kyprolis/Rev/dex), followed by ASCT (transplant), KRd consolidation, and Rev maintenance. 94% of patients had not relapsed to active MM at 70 months (5.8 years). More clinical trials for MGUS and SMM at Emory are forthcoming, including [NUTRIVENTION-3](#) plant-based nutritional study. Additional trials include: [DETER-SMM](#) (Dara+Rev+dex vs Rev+dex) and Winship 5157-20 with Iberdomide. Watch for data on these trials at the next ASH.

Dr. Jonathan Kaufman talked about three promising new myeloma drugs: **Venetoclax, Mezigdomide, and Markups**. Venetoclax + Dara/dex(VenDd) combination treats patients with t(11:14) high risk factor. Side effects are manageable and infections are low grade. [VenDd](#) Trial had an **ORR** (overall response rate) of 97%. This drug is now in Phase III clinical trials and may soon be presented to the FDA for approval. [Mezigdomide](#) (Mezi), a new drug class ([CELMod](#)), is combined with Dex in relapsed MM patients. ORR is 40% and patients with prior anti-BCMA therapy is 50%. A major side effect is low blood counts, but the rate of infections is low. There are Mezi ([CC-92480](#)) [clinical trials](#) combination with Vd and Kd showing promising results and is well tolerated in **RRMM** (relapsed refractory MM patients). Dr. Kaufman then talked about a clinical trial using [Modakafusp](#). In this trial, Modakafusp had an ORR of 43% in patients with a median of 7 lines of therapy (ranging from 3-16 lines). In patients with no prior anti-BCMA treatment, the ORR was

60%. This drug has a unique structure and mechanism of action. Watch for more news on this one at the next ASH.

Dr. Madhav Dhodapkar presented the emerging treatments on immune therapies that recognize and trigger [BCMA](#), [GPRC5D](#) and [FCRH5](#) receptors targeting the MM to gain more durable treatment responses. Several abstracts on these were presented at ASH. Studies are finding a high disparity within the immune system of patients. It has been exemplified by studying the variance in immune responses to Covid vaccines. Different regions within the same patient are keeping immune cells out. This is very important to understand for the future of immune treatments. Researchers have found the co-existence of T cell rich and poor samples in the same biopsy. Both Bispecifics and CAR-T work well, but patients still relapse. Researchers are working to better understand which tumors respond (or not) and what determines longer responses. Tumors may acquire resistance by changing or losing targets. What is the outcome of the myeloma that remains? Research will dig deeper into the properties of the T cells, both CAR-T and pre-existing T cells. Physicians are now using the Model T of Bispecifics and CAR-T. More to come with new combinations and sequences of treatment that could lead to complete eradication of MM = Cure!

Dr. Vikas Gupta provided an overview of normal T-cells and CAR-T cells to show how they can recognize a target antigen on the MM cell and kill the cell. Data on the two approved CAR-T treatment drugs were discussed; [Abecma](#) and [Carvykti](#). Abecma has an ORR of 84%, CR (complete response) of 42% and PFS of 8.5 months. Cavate has an ORR of 97%, CR of 82%, and PFS of 27 months for 55% of the patients. Further research is looking to improve on these outcomes:

- (1) use treatment drugs sooner since more lines of therapy may impact quality of patient's T-cells
- (2) change the manufacturing process to be faster and stimulate the cells differently to make them last longer
- (3) use different targets

Dr. Gupta reviewed clinical trials that supported these improvements. [KarMMa-2 Phase IIa](#) Trial treats high risk patients who relapsed within 18 months of starting therapy, including stem cell transplant. Patients who received CAR-T earlier in treatment, ORR was 83% and PFS was 11 months. Side effects were lower in this group vs patient population in initial KarMMa trial receiving Abecma later in their therapy. Investigators concluded that this data supports the benefit of using this in earlier lines of therapy to get better response and longer PFS. Changes in the manufacturing process are underway with the [NEX-T process](#) designed to shorten manufacturing and improve the effectiveness of the CAR-T product. BMS-986354 re-engineered with the NEX-T process has reduced manufacturing time to five days and maximized the CAR-T cell yield. In a Phase I trial, three dosing levels were compared; two had ORR 100% while side effects were low-grade and short in duration. This process is so proprietary that not much is still known about it. Watch for NEX-T to be applied to future CAR-T programs. A Phase I, first-in-human, multicenter, dose-finding clinical trial is underway using a new target GPRC5D, a receptor expressed on MM cells with limited expression in other tissues. Three dosing levels were tested with ORR \geq 80%. Side effects were low-grade and short-lived. Preliminary efficacy appeared promising, including patients who were MRD-negative at three months. This supports a new target for CAR-T as further testing advances.

Dr. Ajay Nooka reviewed the bispecific [MajesTEC-1 Trial](#) which had 15 Emory patients enrolled prior to Teclistamab being approved by the FDA on October 25, 2022.. [Teclistamab](#) has two target arms on the drug, one attaches to the BCMA receptor on the MM cell and the other attaches to CD3 antigen on the T-cell. It brings these cells together for the T-cell to destroy the MM cell. The MajesTEC-1 trial had an ORR of 63% for patients who had failed on three classes of drugs. Bispecifics are an off the shelf treatment that does not require the long processing of CAR-T therapy. [Alnuctamab](#) is another bispecific in Phase I trial examining a different

process of binding links. When given via IV there were more severe side effects which were reduced when given sub-Q. [Elranatamab](#) is also a bispecific in clinical trials with step-up of pre-medication mitigating the rate and severity of side effects. Further trials will evaluate this treatment alone and in combination. Dr. Nooka thinks that Elranatamab may be the next bispecific approved by the FDA. **Talquetamab** is bispecific that uses the new target on the MM cell – GPRC5D. This treatment had an ORR of greater than 70% in phase I [MonumenTAL-1](#) clinical trial with heavily pre-treated patients. In those patients receiving T-cell therapy, ORR was 63%. Dr. Nooka noted how many new options are available for patients.

Dr. Sagar Lonial closed the session recognizing the teamwork that allows Winship to present their work to the MM community around Emory. He noted that in 2001-2002, Dr. Heffner had 75 MM patients. This year, Emory will see over 3000 MM patients. This provides a huge opportunity to move myeloma research forward. Emory patient involvement impacts research around the world. At the [International Myeloma Society](#) (IMS) Dr. Nooka and Dr. Joseph presented their data to the FDA. Many thanks to the patients who make such a difference. Myeloma treatment is progressing to talk about a Cure! Do not give up; continue active discussion about data and treatment decisions. Emory is one of the largest myeloma centers in the world which is a great resource for patients. Thanks to all patients and caregivers from the Winship team.

Patient questions for the Winship Physicians

Dr. Dhodapkar: **Q**- Thanks for all your work. How do you find the cure for MM? **A** - High response rate is the first step to cure MM, but it is complex. Similar to Covid that evolves, cancer evolves and creates variants. **Q** – Is Evusheld important for the immune system defense against Covid? **A** – Evusheld was for a previous version of Covid. It does not work against the current variant and is not of use at this time.

Dr. Gupta: **Q** – Is Emory building a CAR-T factory? **A** – We are working on it and it remains one of our goals. **Q** – Will CAR-T be used in front line treatment in place of SCT? **A** – There is a new trial with patients randomized for CAR-T vs SCT. More info is forthcoming. **Q** – Do you have to give all T-cells back to the patient or can some of them be kept frozen? **A** – Currently patients can get longer remission from front line therapy including transplant. CAR-T is used after several relapses and the T-cells are not as strong at that time. We would consider harvesting T-cells before all that treatment and transplant, but that may be up to ten years in storage with the cost as an issue. The better answer is to do CAR-T therapy sooner in the journey now that the treatments are approved.

Dr. Nooka: **Q** – There are so many options with bispecific and CAR-T treatment. How do the patient and doctor decide? **A** – If treatment is urgent, go for what is readily available and quick, like off-the-shelf Bispecifics. If there is time, do CAR-T now and Bispecifics later. How urgent is treatment and what are options? The patient's personal situation and quality of life should be considered. That is why patient involvement in the decisions is important.

Dr. Lonial: **Q** – You noted that clinical trials are down due to staffing. Are they up now? **A** – There are 25 trials now open. We took a hit six months ago but are up again with another research nurse on staff. There are now four research nurses which makes a big difference. They will be fully trained in a couple of months. All positions are filled now with more to come. **Q** – Is there any new data on the causes of MM? **A** – The DNA profile is very fragile and we think we should be seeing more MM. There is no new information available as to the cause. Looking at bacteria in the gut or lipids could influence disease research. More studies are needed. We do not understand the source of cell damage from exposure to certain products. MM events are sporadic and more studies are needed. **Q** – I was diagnosed with high-risk MM in 2020 and now in remission from a clinical trial. How do you determine to continue treatment once a patient is in remission? **A** – Continuation of treatment may be required in the trial. It has been shown the high-risk patients relapse sooner than with standard risk. Continuous treatment will hold MM at bay. Deeper testing for quality of remission is needed.

Submitted by Nancy B.

Meeting Minutes
Southside Virtual MM Support Group
January 28, 2023

Business and News

Next Meeting: **Saturday, February 25, 2023**, at 10 AM. Presentation topic: **Patient Portal - Provider Communications:** *Getting the most out of your visit and Emory's New My Epic system patient portal.* Speaker: **Rose Ann Pruitt, PA, Emory Winship.**

"For Men Only" AAMM Support Group meets every month on the 4th Tuesday at 6PM. Join the Men's group to share your experiences and concerns with others on the same journey. Hear about resources and ways to navigate the myeloma care maze.

Because of privacy laws, we were not able to record our session. Our primary reason for recording is to facilitate accurate meeting notes. We also want to protect the privacy of patients/care partners, so we do not distribute any recordings to the larger group.

Guest Speaker Presentation

Thank you to Gail M. who hosted this month's zoom session with 25+ attendees. The meeting opened with a moment of silence by Doris. We were happy to welcome back guest speaker, Tara Roy, MS, NP, Takeda Pharmaceuticals – Patient Advocacy Liaison (PAL). She is a favorite presenter for the Atlanta Northside and Southside Atlanta Support Group. Her topic was **"Managing Side Effects of Multiple Myeloma Treatment."** The goal of the presentation is to *encourage informed discussions with your healthcare providers (HCP) about disease side effects and complications* from the myeloma itself. The objectives of the presentation included empowering patients/care partners to ask questions of their healthcare team. **Have you ever wanted to ask your healthcare professional a question related to your treatment or side effects and not asked for some reason?** Both myeloma and the treatment of the disease can cause common symptoms: *bone damage and pain, kidney damage, frequent infections and fever, fatigue and weakness, thirst, and frequent urination, bleeding and bruising easily.* If you take note of something abnormal with your body; do not accept that your side effects not being addressed during your oncology visits are not important. *Problems with eyes, teeth, and more* have frequently been reported by patients and yet taken longer than necessary to address. Trust your instincts and due diligence to report all your side effects and symptoms during each appointment. The HCP may not know immediately what to do about it but you may be that important link to make HCPs and researchers pay attention. Review the table for symptoms you may be experiencing.

Note: This table is incomplete and does not include all MM classes or known side effects.

Common Symptoms and Side Effects	Immunomodulatory (IMiDs) (Revlimid, Pomalyst, Thalidomide)	Proteasome Inhibitor (Velcade, Ninlaro, Kyprolis)	Monoclonal Antibodies (Elotuzumab/Empliciti, Daratumumab/Darzalex, Isatuximab/Sarclisa)	Monoclonal Antibody Drug Conjugates (Belantamab mafodotin)
Neuropathy	Peripheral Neuropathy	Peripheral Neuropathy	Peripheral Neuropathy	
Blood and blood vessels	Anemia Thrombosis Edema	Anemia Thrombocytopenia Edema	Anemia Thrombocytopenia Edema Hypertension	Thrombocytopenia Thrombosis
Gastrointestinal System	Diarrhea Constipation Nausea Abdominal pain	Diarrhea Constipation Nausea Vomiting	Diarrhea Constipation, Nausea Decreased appetite	Constipation Nausea
Heart and Lungs	Shortness of breath		Shortness of breath	
Immune System	Prone to infection	Prone to infection	Prone to infection	Prone to infection
Fatigue/Weakness	Fatigue and weakness	Fatigue/weakness	Fatigue/Weakness	Fatigue
Infusion Reaction			Infusion reaction	Infusion reaction
Other	Back or muscle pain Rash or dry skin Tremor Fever / Cough Kidney damage	Rash Headache Fever Cough Nerve pain	Fever Cough Hyperglycemia Back pain Insomnia	Keratopathy Decrease visual acuity. Blurred vision

Comprehensive side effects table included on the Managing Side Effects file attached.

Additional categories include:

Alkylating agents (melphalan, melflufen);	Steroids (dexamethasone, prednisone);
Car-T cell therapy (cilta cartagene autoleucl) (Carvykti) idcabtagene, vicleucl (Abecma)	Selective Inhibitors of Nuclear Export (SINE) (XPOVIO/Selinexor)

Targeted protein BCL2 (Venetoclax)	Chemotherapy (doxorubicin, cytarabine).
Be sure to frequently review several potential side effects and take them seriously.	

Infusion reactions: Ask the nursing staff about the potential for allergic reactions while taking the drug.

GI system side effects: Note any changes in your bowel habits. There is a difference between liquid stools and soft stools in describing diarrhea. Be sure to stay hydrated. *How much fluid do I need each day?* For most adults, it is at least 64 oz/day. It will be less if you have heart disease or kidney disease. Check with your HCP about over the counter (OTC) medications. The instructions may be different from what is in the print instructions. For your meals, try grazing – eating several small meals a little bit at a time.

Side Effects (SE) information and vocabulary:

Thrombosis – one SE of immunomodulatory agents is venous thrombosis. This is when a blood clot forms in a vein located deep in your body or when a clot travels to the lungs. Venous Thromboembolisms can occur with no symptoms, but be watchful for *swelling, pain, redness, or warmth in your lower extremities. Shortness of breath or sudden onset of chest pain* may also be signs. *Reduce your risk.* Avoid sitting still (unless bedrest has been prescribed), maintain a *healthy weight, and stay away from smoking or secondhand smoke.*

Hypertension. High blood pressure (HBP) can be a side effect of *monoclonal antibodies* and *proteasome inhibitors*. The more blood your heart pumps and the narrower your blood vessels, the higher your blood pressure and uncontrolled HBP can put one at a higher risk of heart attacks and strokes. *HBP often happens with no symptoms, so routine proper pressure measurements by your HC team are essential.* A healthy diet low in salt (already prepared and packaged foods) and higher in potassium (fresh fruit and vegetables) is helpful in controlling HBP.

Eat from the farm, not the factory! Additionally, do not smoke cigarettes, limit alcohol intake, and get at least 150 minutes of exercise in a week – 30 minutes each day. Start out with 10 minutes each day and expand your routine from there.

Peripheral Neuropathy (PN). Peripheral nerves are the nerves aside from those in your brain or spine. Symptoms of PN include *pain, tingling, numbness, or weakness in the hands or feet* and can be a SE of immunomodulatory drugs (Rev, Pomalyst, thalidomide) or proteasome inhibitors (Velcade, Ninlaro, Kyprolis). *To avoid permanent damage, report these symptoms as soon as you feel anything* to your HCP. There are many available treatments for PN including anti-seizure and antidepressant medications, physical therapy, surgery or IV immune globulin. Some people benefit from capsaicin creams and other pain relief creams or patches, nonsteroidal anti-inflammatory drugs (if you do not have kidney issues), transcutaneous electrical nerve stimulation (TENS), acupuncture, meditation, Vitamin B12, and more.

Immune System. Monoclonal antibody treatments and drug conjugates, proteasome inhibitors, immunomodulatory drugs, chemotherapy, and steroids can increase your risk of infection. Infections from Shingles (reactivated chicken pox virus and Hepatitis B can become reactivated due to some myeloma treatments.

People with multiple myeloma are:

- 7 times more likely to get a bacterial infection.
- 10 times more likely to get a viral infection.

Diarrhea is defined as loose or watery stools three or more times in a single day. Cut back on caffeine and drink plenty of water, juices, or sports drinks to be sure to stay hydrated. Consider a probiotic or an over-the-counter ant-diarrheal medication. Consult with your healthcare team (HCT) team when you experience any side effect or want to add anything to your regimen.

Constipation is generally defined as having three or fewer bowel movements each week. It can be a side effect of your treatment, like immunomodulatory agents. *Solutions:* take your time when you go to the bathroom. Consider increasing your fiber intake with fruits, vegetables, and whole grains. Discuss with your HC team using a laxative, such as a fiber supplement, suppository, or mineral oil. If the problem persists, there are prescription medications you can discuss with your HC team.

Nausea/Vomiting. It is critical to tell your HC team right away if you experience nausea or vomiting. There are many medical options to reduce or eliminate these issues. There are relaxation techniques that may help as well, including breathing exercises, hypnosis, music therapy, guided imagery, acupuncture and acupressure, and music therapy.

Mouth ulcers. Also called *oral mucositis*, involve swelling, pain, bleeding, and sores in the mouth. It can be a side effect of chemotherapy and radiation. Avoid eating foods and drinks that are high in sugar. Sip water, chew ice chips, and eat sugar free candies to keep your mouth moist. Use lip balm to keep your lips from chapping, practice good oral hygiene, brush your teeth 2-3 times a day, and floss gently once a day. Use a soft toothbrush.

The Brain. In addition to the fog or “chemo brain”, many people experience persistent distress. You are not alone. Share your feelings and fears. Talk with your HC team about counseling or a support group. Take time to relax regularly. Consider meditation, prayer, or other types of emotional support. Try also walking, yoga, or calming types of exercise. Boost your mind activity with games, crossword puzzles, etc. Talk with your HCP about effective medications.

Cancer-related Fatigue. Is persistent and out of proportion to your activity level. It gets in the way of your everyday life. *The American Cancer Society estimates that between 80-100% of people with cancer experience cancer-related fatigue.* There are medical and non-medical treatments for cancer-related fatigue. Ask your doctor whether medical intervention may be helpful with your fatigue. Consider exercise, cognitive behavioral interventions, sleep interventions, aromatherapy, mindfulness-based stress reduction, and yoga. *Make sure to have a conversation with your doctor about your fatigue.*

Enhance your overall wellness.

- Prioritize a **healthy diet, regular exercise** (if cleared by your doctor). **Consider chair exercises, and sleep** (7-8 hours each day).
- **Stick with your treatment.** If you are considering stopping your treatment, make an appointment and talk with your doctor about it. Ask your provider if a dose reduction may be possible. Maintain scheduled visits with all your healthcare team members – **not just your oncologist.**

Questions to ask yourself about complications and side effects.

- Do not worry about knowing the proper medical terms. Describe it in your own words, as you might to a family member.

- How would you describe the side effect issue? Was the issue specific to a particular part of your body?
- What time did the issue occur? Did the side effects come and go? How many minutes or hours did it happen?
- Did the issue interfere with daily activities? If so, how?
- What happened right before you experienced the issue?
- What, if anything, helped alleviate the symptoms or made them worse?

Ways to keep track of your complications and side effects.

- Always keep notes on issues as they happen.
- Use a journal or your phone to take notes if possible.

There are apps and websites you can use to track side effects, including

All4cure.com	Cancer.net Mobile
Care Clinic	Flaredown for Chronic Illness
Healthtree.org	LLS health Manager
Simple Symptom tracker	

Additional Online Resources

- American Cancer Society – www.cancer.org – 800.227.2345
- CancerCare – www.cancercare.org – 800.813.HOPE (4673)
- International Myeloma Foundation – www.myeloma.org – 818.487.7455
- HealthTree for Myeloma Crowd – www.healthtree.org; 800.709.1113
- The Leukemia and Lymphoma Society – www.lls.org – 800.955.4572
- Multiple Myeloma research Foundation – www.mmrf.org – 203.229.0464
- The National Comprehensive Cancer Network - Nccn.org/patients. – 215.690.0300

Tara is requesting feedback on her presentation. Please complete [Managing Side effects](#) Evaluation Form.

Or click Link: https://forms.office.com/Pages/ResponsePage.aspx?id=O_b9VyJ-o0WD3NNwAxY6rhPaXhmtwuFOuggV5yV5o1xUOFIWOUlyNTVVT1dOQk82QTBTWUdJSTgyQSQIQCN0PWcu

The “For Men’s Only” Group is progressing well, reports Anderson. They had a great meeting as they welcomed **Courtney** as a new member at their last meeting, The meeting found its purpose with the men able to openly share their thoughts and feelings from a male perspective. An open invitation to all the male myeloma patients to join them each **4th Tuesday evening for one hour. The meeting is from 6- 7:00 PM.** Look for your meeting reminder and Zoom link in your email. *For more information, contact Anderson – 404.219.7890.*

Patient and Caregiver Voices

Gail M. recently started [Venetoclax](#) and has had nausea and constipation. She has taken Zofran before meds to help. **Jeff** also takes Venetoclax and it has worked well in reducing his myeloma numbers. We encouraged Gail to speak with her healthcare providers before making any changes to her regimen.

Flora is sleep deprived. Tara suggests “sleep hygiene” habits of exercise and healthy eating can help . Also reduce electronic stimulation (TV, phone, etc.) and no caffeine late in the day. There are sleep clinics the HC team can recommend. Consider moving your medications to a different time of the day to help with sleep.

Sarah takes generic *Revlimid* and found no difference in side effects from it. With her insurer, Humana, she pays \$3.95 every six months. **Sandy** also takes generic Revlimid. Kaiser changed her script to generic (\$13,000/month) from brand Revlimid (\$19,000/month). Her co-pay fortunately is \$9 or \$18/month. Medicare must pay 50% of the cost.

The [Livestrong Foundation](#) has a program that allows all patients and caregivers to have free memberships at their local YMCA. Check with your local Y– you will need verification from your oncologist of your diagnosis.

IVIG treatment - Intravenous Immunoglobulin (IVIG) is a therapy treatment for patients with antibody deficiencies. It is prepared from a pool of immunoglobulins (antibodies) from the plasma of thousands of healthy donors. Immunoglobulins are made by the immune system of healthy people for the purpose of fighting infections. We shared an immune system video of less than 10 minutes. [IMF - Diet for Strong Immune System](#) with Dr. Durie.

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Heart and Lungs	Shortness of breath		Shortness of breath	
Immune System	Prone to infection	Prone to infection	Prone to infection	Prone to infection

Fatigue/Weakness	Fatigue and weakness	Fatigue/weakness	Fatigue/Weakness	Fatigue
Infusion Reaction			Infusion reaction	Infusion reaction
Other	Back or muscle pain Rash or dry skin Tremor Fever / Cough Kidney damage	Rash Headache Fever Cough Nerve pain	Fever Cough Hyperglycemia Back pain Insomnia	Keratopathy Decrease visual acuity. Blurred vision
<i>Comprehensive side effects table included on the Managing Side Effects file attached.</i>				
Additional categories include:				
Alkylating agents (melphalan, melflufen);		Steroids (dexamethasone, prednisone);		
Car-T cell therapy (cilta cartagene autoleucel) (Carvykti) idecabtagene, vicleucel (Abecma)		Selective Inhibitors of Nuclear Export (SINE) (XPOVIO/Selinexor)		
Targeted protein BCL2 (Venetoclax)		Chemotherapy (doxin, cytotoxin).		
Be sure to frequently review several potential side effects and take them seriously.				

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happens with no symptoms, so routine proper pressure measurements by your HC team are essential. A healthy diet low in salt (already prepared and packaged foods) and higher in potassium (fresh fruit and vegetables) is helpful in controlling HBP.

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Nausea/Vomiting. It is critical to tell your HC team right away if you experience nausea or vomiting. There are many medical options to reduce or eliminate these issues. There are relaxation techniques that may help as well, including breathing exercises, hypnosis, music therapy, guided imagery, acupuncture and acupressure, and music therapy.

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Care Clinic	Flaredown for Chronic Illness
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Simple Symptom tracker	

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Gail M. recently started [Venetoclax](#) and has had nausea and constipation. She has taken Zofran before meds to help. **Jeff** also takes Venetoclax and it has worked well in reducing his myeloma numbers. We encouraged Gail to speak with her healthcare providers before making any changes to her regimen.

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IVIG treatment - Intravenous Immunoglobulin (IVIG) is a therapy treatment for patients with antibody deficiencies. It is prepared from a pool of immunoglobulins (antibodies) from the plasma of thousands of healthy donors. Immunoglobulins are made by the immune system of healthy people for the purpose of fighting infections. We shared an immune system video of less than 10 minutes. [IMF - Diet for Strong Immune System](#) with Dr. Durie.

Meeting Minutes
Southside Virtual MM Support Group
January 28, 2023

Business and News

Next Meeting: **Saturday, February 25, 2023** at 10 AM. Presentation topic: **Patient Portal - Provider Communications: *Getting the most out of your visit and Emory's New My Epic system patient portal.*** Speaker: **Rose Ann Pruitt, PA, Emory Winship.**

"For Men Only" AAMM Support Group meets every month on the 4th Tuesday at 6PM . Join the Men's group to share your experiences and concerns with others on the same journey. Hear about resources and ways to navigate the myeloma care maze.

Because of privacy laws, we were not able to record our session. Our primary reason for recording is to facilitate accurate meeting notes. We also want to protect the privacy of patients/care partners, so we do not distribute any recordings to the larger group.

Guest Speaker Presentation

Thank you to Gail M. who hosted this month's zoom session with 25+ attendees. The meeting opened with a moment of silence by Doris. We were happy to welcome back guest speaker, Tara Roy, MS, NP, Takeda Pharmaceuticals – Patient Advocacy Liaison (PAL). She is a favorite presenter for the Atlanta Northside and Southside Atlanta Support Group. Her topic was **"Managing Side Effects of Multiple Myeloma Treatment."** The goal of the presentation is to *encourage informed discussions with your healthcare providers (HCP) about disease side effects and complications* from the myeloma itself. The objectives of the presentation included empowering patients/care partners to ask questions of their healthcare team. **Have you ever wanted to ask your healthcare professional a question related to your treatment or side effects and not asked for some reason?** Both myeloma and the treatment of the disease can cause common symptoms: *bone damage and pain, kidney damage, frequent infections and fever, fatigue and weakness, thirst, and frequent urination, bleeding and bruising easily.* If you take note of something abnormal with your body; do not accept that your side effects not being addressed during your oncology visits are not important. *Problems with eyes, teeth, and more* have frequently been reported by patients and yet taken longer than necessary to address. Trust your instincts and due diligence to report all your side effects and symptoms during each appointment. The HCP may not know immediately what to do about it but you may be that important link to make HCPs and researchers pay attention. Review the table for symptoms you may be experiencing.

<p>Note: This table is incomplete and does not include all MM classes or known side effects.</p>

Common Symptoms and Side Effects	Immunomodulatory (IMiDs) (Revlimid, Pomalyst, Thalidomide)	Proteasome Inhibitor (Velcade, Ninlaro, Kyprolis)	Monoclonal Antibodies (Elotuzumab/Empliciti, Daratumumab/Darzalex, Isatuximab/Sarclisa)	Monoclonal Antibody Drug Conjugates (Belantamab mafodotin)
Neuropathy	Peripheral Neuropathy	Peripheral Neuropathy	Peripheral Neuropathy	
Blood and blood vessels	Anemia Thrombosis Edema	Anemia Thrombocytopenia Edema	Anemia Thrombocytopenia Edema Hypertension	Thrombocytopenia Thrombosis
Gastrointestinal System	Diarrhea Constipation Nausea Abdominal pain	Diarrhea Constipation Nausea Vomiting	Diarrhea Constipation, Nausea Decreased appetite	Constipation Nausea
Heart and Lungs	Shortness of breath		Shortness of breath	
Immune System	Prone to infection	Prone to infection	Prone to infection	Prone to infection
Fatigue/Weakness	Fatigue and weakness	Fatigue/weakness	Fatigue/Weakness	Fatigue
Infusion Reaction			Infusion reaction	Infusion reaction
Other	Back or muscle pain Rash or dry skin Tremor Fever / Cough Kidney damage	Rash Headache Fever Cough Nerve pain	Fever Cough Hyperglycemia Back pain Insomnia	Keratopathy Decrease visual acuity. Blurred vision
<i>Comprehensive side effects table included on the Managing Side Effects file attached.</i>				
Additional categories include:				
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