ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes
Northside October Virtual SG Meeting
October 3, 2020

Introduction & News

Thank you to **Nancy B.** and **Jim M**. who co-hosted the meeting, with approximately 45 attendees. Thank you to **Jeannie**, who reported that she is working with the board and some hospitals so that we will be able to continue to provide gifts to children with cancer during the December holiday season.

Guest Speaker

Thank you to **Dr. Harvey**, PharmD, BCOP, FCCP, FHOPA, and Director of Winship Cancer Institute's Phase I Clinical Trials, who joined the group to discuss some new and promising therapies. Dr. Harvey started the discussion with a summary of some of new therapies that have been recently approved, and then continued with some others that are in various stages of clinical trials (CT) and look very promising. Then, he answered many questions for us. Dr. Harvey mentioned that his team at Emory has been continually fortunate to be involved with so many trials of therapies that have been approved or are on their way to approval. Dr. Lonial and the entire group has been instrumental in a lot of these trials and helping to answer some important questions, particularly in the relapsed refractory MM (RRMM) space.

FDA-approved **Selinexor/Xpovio** is a first-in-class, oral, selective inhibitor of nuclear export compound exportin 1 (XP01). XP01 is overexpressed in myeloma cells. This drug inhibits XP01, which leads to the accumulation of tumor suppressor proteins, cell cycle arrest, and apoptosis (cell death). It is approved for use with Dexamethasone (Dex) following treatment with 4 prior therapies. The CT in which the drug was approved was the **STORM Phase 2b CT**, which was an accelerated approval, as Phase 3 CTs are the standard path for FDA approval. In the STORM Phase 2b CT, Selinexor 80 mg. was combined with Dex 20 mg. twice weekly. The most common side effects were anemia, thrombocytopenia, fatigue, nausea, and decreased appetite. Selinexor is hard to tolerate, so many doctors are prescribing 80 mg. once weekly, and this dosage reduction even occurred during the trial. A lot of patients needed to have a dose reduction due to tolerability, yet even with the dose reduction, the drug proved to be effective. The **BOSTON Phase 3 CT**, studied once weekly Selinexor 100 mg. in combination with Velcade and Dex 40 mg in patients with 1 to 3 prior therapies. Common side effects were thrombocytopenia, fatigue, and nausea. In this CT, rather than 160 mg. of the total weekly dose (as in the STORM Phase 2b CT) it became clear that getting a higher dose on one day leads to much better tolerability. Fatigue was still present in 11% of patients but it was much better than with the

previous regimen of 80 mg. twice a week, and nausea was much better as well, but still present. Overall, it was a better regimen in tolerability and efficacy with the 3 combined drugs. The **STOMP Phase 1b CT** is ongoing, and studies Selinexor in combination with Carfilozmib (Kyprolis), Lenalidomide (Revlimid) or Pomalidomide (Pomalyst). In conclusion, the activity of Selinexor/Xpovio is promising and looks even better when combined with other drugs.

FDA-approved **Isatuximab/Sarclisa** is an anti-CD38 monoclonal antibody drug, like Daratumumab (Dara), and is approved for use in combination with Pomalidomide and Dex. It is administered as an intravenous infusion every week for 4 weeks, then every 2 weeks, and does not get phased out to less than every 2 weeks. Premeds that are always included are Dex, acetaminophen, H2 antagonist, and diphenhydramine. It has infusion reactions like Dara, but also like Dara, the infusion reaction gets better over time. The infusion rate depends on the patient's tolerability and can take as little as approximately 1.25 hours up to 3.5 hours.

FDA-approved **Belantamab mafodotin/Blenrep** is an antibody drug conjugate type therapy. It is composed of an antibody that is linked to a very toxic drug. This type of therapy is also used in other cancers such as leukemia, lymphoma, and breast cancer, but it is the first time that this type of drug has been used for MM successfully. The antibody in Blenrep specifically targets B cell maturation antigen (BCMA), a protein found on the surface of MM cells. The antibody attaches to F (MMAF), a toxic agent that inhibits MM cell division. Side effects that cause dose delays in treatment of this drug include keratopathy, blurred vision, and pneumonia. Side effects that cause dose reduction in treatment include keratopathy, thrombocytopenia, and blurred vision. It's important to note that the eye issues caused by this drug are not permanent, but they must be addressed early so that they do not cause long term problems. Corneal supportive care is necessary when using this drug. Baseline and subsequent eye exams are required prior to every dose, preservative-free artificial tears are used to mitigate corneal issues, and dose delays and/or reductions are sometimes necessary until keratopathy improves. Side effect management strategies include pre-meds with acetaminophen, diphenhydramine, and corticosteroids for infusion-related reactions; and red blood cell and platelet transfusions as needed for support. In the **DREAMM Phase 2 CT**, patients that had progressed on 3 or 4 prior therapies, many of whom had prior stem cell transplants (SCT) participated. Most of the patients had also taken both Bortezomib and Carfilzomib, and some had taken Dara previously. The drug was given every three weeks as an IV infusion, and the results were very promising early on. There are ocular side effects that led to the FDA having a very specific safety program in combination with the approval. Some of the side effects are noticeable and some are not. In the CT every patient was seen at least every month by an ophthalmologist. Patients may notice blurred vision as the first side effect, yet many patients didn't have any changes in their vision. As part of the use of the drug now post approval it's mandated that all patients have an eye exam before they start the drug, and then have eye exams while they're on the drug to make sure that anything that's happening is monitored and to decide if we need to hold off on the drug. Patients also have to agree to take eye drops daily, 4 times a day, while on the drug to help prevent some of the ocular side effects. The drug can also cause thrombocytopenia and nausea. Overall, the side effects are well managed. In conclusion, the drug used as a single agent showed anti MM activity with a manageable safety profile, and was FDA-approved for relapsed refractory MM patients who have received 4 prior therapies including a PI, IMiD, and CD38 MoAB.

There are some drugs currently in CTs that are very interesting and hopefully will be approved. One of these drugs is called **Idecabtagene vicleucel**, which is under FDA priority review. This drug is a CAR-T Cell therapy directed against BCMA. Another drug called **Teclistamab** is in Phase 2 CTs. This drug is a BCMA-CD3 bispecific monoclonal antibody, which means that it has two heads. One is targeted to BCMA and the other is targeted to bring a T cell population, specifically CD3 positive T cells, together to kill MM cells. It's believed that BCMA will be one of those targets where there will be different drugs and we will be able to use them all. So, if a patient is resistant to one BCMA targeted drug we don't currently think that means that all the others are not options. Another drug called **Melflufen** is in Phase 3 CTs and is a new formulation of Melphalan that directly targets MM cells. Finally, **Iberdomide** is a new IMID in Phase 1 CTs and being tested in combination with other IMIDs, such as Lenalidomide and Pomalidomide. This drug is potent and it's showing very promising activity. It's one of the more promising therapies we've seen so far in early phase combination trials.

We now have a lot of ways to combine drugs and the planning is getting very complicated. MM treatment has started to look more and more like Acute Lymphoblastic Leukemia (ALL) treatment. The approach that was taken in ALL treatment was to combine drugs to try to get deep responses, early, soon after diagnosis. This methodical approach led to cures in many kids with ALL. MM is another B cell related cancer that we're continuing to try to get deeper responses with the first treatment.

Dr. Harvey answered many questions for us as follows:

Q: I know that the shingles vaccine is recommended. I was told my copay is almost $200 and I wondered if others have encountered that cost. **A:** Dr. Harvey stated the importance of staying on antiviral therapy while in treatment for preventative reasons, and some alternatives, such as acyclovir, may be less expensive than the vaccine.

Q: Are hot flashes a side effect of Dara? **A:** Yes, early on, but not after the first 2-4 weeks.

Q: When on Dara alone and doing well, does it shorten the timeline of continuing to do well if not combining Dara with other drugs? **A:** No

Q: If you are refractory to Dara, will Isatuximab be ruled out for your treatment? **A:** Isatuximab alone would not be an option, but Isatuximab combined with other drugs could be an option in this case.

Q: Discuss how such a small deletion from the Thalidomide molecule can make such substantial changes in impact and effectiveness of treatment. **A:** Small changes in the structure of drugs can affect how the drug gets into bone marrow, how the drug is metabolized, and how it kills MM cells.

Q: Are the secondary cancer risks for the newer formulated IMIDs reduced?

A: We don't know yet because they are so new – we do not have the historical data. For example, we didn't know about the secondary cancer risk associated with Revlimid until it was on the market for about two or three years.

Q: I hear about Zinc, Vitamin D and other supplements for COVID. Can these interfere with MM drugs? **A:** There are some known issues with Velcade and supplements, such as Vitamin C. Most supplements in general will not interfere with MM drugs but always bring a list of all of your drugs, including prescribed and over the counter drugs, and supplements that you take to review

with your care team. Your physicians, nurses, and pharmacists all want to know what you're taking.

Q: I have been on Revlimid for many years, and I have known all along that Revlimid use increases your chances of getting other tumors. In the paperwork, it says that when using Revlimid there is a 1.7 or 2.2% chance of increased tumors, what does that really mean over a period of 10 years? **A:** Those are annual rates of risk of developing a second cancer with Revlimid use. There is risk with developing second cancers with Revlimid use, and the longer you're on it, the more that risk, because the same amount of risk occurs each year. If there are questions about the risks of taking Revlimid talk with your care team and your oncologist that treats you to help you weigh those things that are of concern. Also, it's very important that you continue to get all recommended screening tests for other cancers based on your potential risk. We all need to be diligent about preventative cancer screenings, as we want to make sure that we catch any problems that might happen sooner.

Q: Are there cognitive issues that develop from very long-term use of Revlimid? If so, are they reversible? **A:** We have seen cognitive changes with many Emory patients that take Revlimid. A lot of patients develop a Revlimid fog and it's real. We have not seen or really studied long term cognitive changes while taking Revlimid long term. If you're having cognitive changes on Revlimid, discuss it with your doctor, to determine what you might be able to do, such as lowering dosages, or taking a break from Revlimid to see if that helps.

Q: I'm on Revlimid and Velcade and developed a rash. What might be causing this? **A:** That would likely be due to the Revlimid. A rash that is developed when on Revlimid is managed in various ways. One way is to use a steroid topical cream and see if that can help to mitigate it.

Q: How is CAR-T evolving to reduce side effects and extend effectiveness? **A:** Early on, particularly in lymphoma, CAR-T treatment caused a lot of major side effects and patients had to be hospitalized so that we could monitor very carefully, something called CRS or cytokine release syndrome, which causes a lot of high fevers. Very effective treatments in killing a lot of the cancer cells can also wipe out the normal cells that produce antibodies that help us prevent and keep away infection. Now, some smaller changes in how the CAR-T cells are engineered are trying to maintain the effectiveness of the drug while reducing some of the side effects. We've had to go back to the drawing board for manufacturing reasons. These are products that are being produced on a patient by patient basis, and so they must be very careful in how they're made, which introduces some challenges to reproduce these cells in a consistent way. That's something that the FDA is very interested in, in making sure that companies can do well. The other big issue is that these CAR-T cell therapies may work for a while and then stop working, which is another big challenge. Researchers are looking at adding something called interleukin 15 to help boost the creation of a longer life of these cells for longer periods.

Q: A report by Reuters on Sept. 21 noted that COVID-19 may damage immune cells in the bone marrow. Can you speak on this finding and what we need to guard against? **A:** First, do what everyone should already be doing - wash your hands often, limit your contacts, and wear a mask. Reducing your interaction with lots of people in large groups is very important for patients undergoing MM treatment. Second, if you have signs of COVID get tested quickly. If you do get COVID we want to be sure to effectively manage things early. Since MM itself can reduce your ability to fight infection, having COVID can add to that, and so we have to be more vigilant than usual in treating MM patients who have COVID. In general, the recommendation for a

hematologic cancer patient who develops COVID is that the therapy for that cancer is paused until we understand how COVID might affect that patient overall. We don't want to add fuel to the fire if COVID is a significant risk for them.

Dr. Harvey ended the discussion by saying that he enjoys engaging with patients to learn about what's going on, how patients are being treated and their experiences in a bigger group. He mentioned that we now have over 26 drugs or interventions for the treatment of MM, yet it's still not enough. His team recognizes that we need more and better therapies, and we need changes to the paradigm to make sure that we continue to fight this fight, with patients, and their families and caregivers to eradicate MM.

Submitted by Wendy R.

Meeting Minutes
Southside Virtual MM Support Group
October 24, 2020

November Meeting:
Nina Logan, MD, Senior Manager for Patient and Community Outreach, Leukemia and Lymphoma Society; Member's Voices - What Ideas Do You Have About Letting Others Know About Our Support Group? *and* Question - from October presentation: What type of myeloma do you have?

Doris led the group in a moment of Silence. We welcomed two new members join us. Rachel is the Caregiver to her husband David. David was diagnosed with myeloma two years ago and had an autologous Stem Cell Transplant (ASCT) in 2018. Currently, he is on maintenance with Revlimid, 10 mg per day, on a 28- day cycle. They are at Emory with Dr. Hoffmeister. One area of concern is peripheral neuropathy and any options for treating it.

Doris congratulated and thanked the group on its successful fundraising campaign with Light the Night and LLS. The virtual event was held on October 1st. Though we could not get technology to work for us, we happily report that we exceeded our goal of $2,500. We raised about $3,000, including the annual donation from the Southside MM Support Group of $300.

Vermell walked us through the importance of learning about our lab reports in general and knowing which values are most important for our myeloma. First, the basics of multiple myeloma. Multiple myeloma (MM) cells are abnormal plasma cells (a type of white blood cell) that build up

in the bone marrow and can form tumors in bones of the body. Its effects can be at the spine, skull, pelvis, rib cage, shoulders, and hips. It can appear as tumors or areas of bone loss, called lytic lesions. A single tumor, called a plasmacytoma, can appear outside the bone marrow.

The early stages of myeloma are MGUS (Monoclonal Gammopathy of Undetermined Significance) and Smoldering Multiple Myeloma (SMM). MGUS is a benign condition (not cancer) where abnormal protein called monoclonal or M-protein is in your blood. The abnormal protein forms in your bone marrow. Usually, MGUS does not cause any problems. MGUS occurs at three times the rate in blacks as it does whites -About 1% of MGUS becomes myeloma each year – similar in blacks and whites.

SMM has no symptoms. It is a precursor stage of myeloma. There are no CRAB criteria present (Calcium, Renal, Anemia, & Bone disease). In the past, no treatment was recommended for SMM, because only 10% of SMM progresses to active myeloma in five years. Research has shown that there is a high risk SMM that shows benefit if treated early. Those with high-risk SMM are at risk of developing active myeloma in two years.

Updated criteria for diagnosing symptomatic myeloma recommends looking for biomarkers called SLiM. The diagnosis of myeloma now includes SLiM+CRAB. SLiM is Sixty (60%) percent or more clonal plasma cells in the bone marrow were more likely to progress. Light Chain disease - those patients with a kappa-to-lambda or lambda-to-kappa ratio of greater than 100 are more likely to progress to needing treatment. M is for MRI - patients with more than one focal lesion on MRI now have transitioned from smoldering myeloma to symptomatic disease warranting therapy. Can you define your myeloma? What are your numbers in the above criteria?
As myeloma cells grow, they crowd out and inhibit the growth of the healthy cells and antibodies. They produce an abnormal, nonfunctioning antibody called monoclonal protein M-spike, or paraprotein. This reduces the body's ability to fight infections.

Types of myeloma. Myeloma cells make one type of immunoglobulins, called monoclone (one clone). 65% patients have IgG myeloma with either Kappa or Lambda Light chain; the next most common type is IgA with either Kappa or Lambda Light Chain. IgD, IgE and IgM are rare. One third of patients produce free light chains (bound to heavy chains). Bence-Jones myeloma - 15 – 20% produce only light chain, no heavy chains. Is your myeloma IgG, IgA? Is it kappa or lambda? Define your myeloma.
Prognosis for myeloma. The more advanced the disease, the more complicated its treatment will be. There is ongoing research to reduce risk and improve approaches to treatment regimens. Each person is different. With the addition of the SLiM biomarkers, treatment for SMM may begin earlier than in the past. For those who have high-risk myeloma, the treatment regimen is more targeted.
Why is it important to know your type of myeloma?

- It will help you understand and follow your test results over the course of treatment
- Free light assay and SPEP - used to monitor the level of monoclonal protein, assess response to treatment, the activity of the cancer and status during remission
- Advised to keep an ongoing record of your test results

- Newer medications may be more beneficial for your type of myeloma

Prognostic Factors:
Serum Beta 2 microglobulin – the higher the level the more advanced the disease
Serum Albumin – the lower the level the more advanced the disease
C-reactive protein – increased with active disease
Serum lactate dehydrogenase – increases with active disease. This is highly predictive of aggressive disease. Abnormal test results may indicate more active myeloma, and less likely to have a long response to treatment.

Genetic Indicators of Disease Risk. Genetics is an important part of the myeloma puzzle. Knowing the genetics can help direct the treatment regimen. Cytogenetics assessment of chromosomes in dividing myeloma cells. Fluorescence in situ hybridization (FISH) – is the most commonly used test for genetics in myeloma. It maps out the genetic material of a cell. It uses special fluorescent dyes that only attach to specific parts of chromosomes in a bone marrow sample. The test detects changes and whether myeloma cells are growing or not. High abnormalities include t(4;14), t(14;16), t(14;20), 17 p-, and 1q+ (read translocation of chromosomes 4-14; 17 p-deletion of chromosome 17p; gain in chromosome 1q). The presence of abnormal chromosomes generally suggests poor prognosis, and shorter duration of remission, but this is not a guaranteed outcome.

Baseline blood tests. Bone Marrow Biopsy- assesses prognosis (chromosomes, immune typing, amyloid); determines the presence & percentage of myeloma cells in bone marrow. Blood Testing. Complete Blood Count – assesses anemia, low white cell count, low platelet count; Chemistry panel – assesses kidney function (Creatinine, BUN), liver function, albumin, calcium level and LDH; Lipid Panel

Blood Tests.

Special protein testing - shows presence of monoclonal "spike" or M-spike.

- Serum protein electrophoresis (SPEP) – amount of abnormal myeloma heavy chain protein. Abnormal myeloma protein can also be identified through UPEP (Urine protein electrophoresis).
- Immunofixation electrophoresis (IFE) – shows heavy chain (G, A, D, E, M) and light chain Kappa or Lambda types of myeloma protein.
- Freelite® assay – used to measure the amount of free kappa or lambda light chains if no SPEP or UPEP abnormality discovered.
- Hevylite® assay – used to measure normal and abnormal levels of intact immunoglobulins.

Bone Testing. includes: X-Rays, MRI, CT scans, Nuclear Medicine Scans, FDG/PET Scan or PET/CT Scanning, & Bone Density Testing; Assesses the presence, severity, amount, location of any areas of bone damage.

Why is it important to know and monitor your lab results at all times? You can: Evaluate whether your results are within normal limits; Follow the effect of your current medications on your myeloma and on your entire system; Discuss concerns with your Oncology/medical team. *Do you have primarily kappa or lambda light chains?*

Note that your lab results will show different measurements in metric units – millimeters, deciliters, grams, etc. You do not have to know these but be aware that this is the case.

The most common lab test offered is the CBC or Complete Blood Count. Blood is made up of water, proteins, nutrients, and living cells. In the CBC, you will get values for your White Blood Count (WBC), Red Blood Count (RBC), and Platelets. By measuring the volume of blood cells, the CBC allows a doctor to evaluate an individual's overall health, as well as check for underlying conditions such as leukemia and anemia.

The White Blood Cells (WBC) is a major component of the body's immune system. A high white blood cell count can indicate the presence of infection. A differential WBC includes other measures which aid with health status monitoring: Neutrophils: 40 to 60 percent of the total; Lymphocytes: 20 to 40 percent; Monocytes: 2 to 8 percent; Eosinophiles: 1 to 4 percent; and Basophils: 0.5 to 1 percent.

Red Blood Cells (RBC) carry oxygen to tissues throughout the body, making them important to its healthy functioning. Hemoglobin is a protein in red blood cells, carries iron, and gives red blood cells their red color and hematocrit is a measurement of the amount of red blood cells as related to total blood cell count. Results that show that either test (hemoglobin or hematocrit) above or below normal levels can indicate various medical conditions, like anemia.

Platelets are small cells that help the blood to clot. This test measures the amount of platelets present in the blood. If testing highlights a high count, this can indicate anemia, cancer or infection, while a low count can prevent wounds from healing and result in severe bleeding. This lab result is monitored closely with many myeloma medications.

A Comprehensive Metabolic Panel or Chemistry Panel includes a: long list of important tests.

Creatinine test - Creatinine is a chemical waste molecule that is important for creating muscle energy. Increased levels of creatinine can be a sign of kidney dysfunction.

Fasting blood sugar test - Blood sugar levels are easily affected by recent food or drink intake. The fasting blood sugar test is therefore done after a minimum of six hours of fasting. Abnormal results can indicate diabetes, among other medical conditions.

Phosphorus test - The lab tests the amount of phosphorus in the blood. Elevated levels can indicate problems with the kidneys and parathyroid glands, and they may be a sign of malnutrition or alcohol abuse.

Potassium test – an electrolyte that aids the communication between nerves and muscles, regulates the heart and maintains muscle function. Diuretics (a substance or medication used to increase urination) can cause potassium levels to fall.

Sodium test – an electrolyte that is a mineral that aids nerve impulses and muscle contractions, as well as balancing water levels. Irregularities are a possible indication of dehydration, adrenal gland disorders, corticosteroids, and kidney or liver disorders.

Bilirubin test - The lab tests for kidney and liver dysfunction which is useful in diagnosing conditions such as neonatal jaundice, anemia and liver diseases.

Blood urea nitrogen (BUN) test - This test measures the volume of nitrogen in the blood. High levels can be caused by kidney damage or disease, while low levels may be a sign of malnutrition or severe liver damage.

Calcium test - This test measures the levels of calcium in the blood. If testing indicates low levels, this can indicate cancer, hyperparathyroidism, tuberculosis and other conditions, while high levels can indicate conditions including malnutrition, rickets and hypoparathyroidism.

Chloride test - This test measures the body's chloride levels. An increased level of chloride can indicate dehydration as well as kidney disorders and adrenal gland dysfunction.

Alanine aminotransferase (ALT) test - Alanine aminotransferase (ALT) is an enzyme mostly produced by liver cells. High levels can be an indication of liver damage.

Albumin test - Albumin is a protein produced by the liver. Its volume within the organ can be measured via this test. Abnormal levels can be caused by liver or kidney problems.

Total protein test - The lab tests the ratio of two types of proteins: albumin and globulin. Low protein levels can indicate various conditions, including liver and kidney disorders and malnutrition, while high levels can be a sign of inflammation, infection or bone marrow disorder.

Alkaline phosphatase test - Alkaline phosphatase is an enzyme typically produced in liver and bone cells. Results outside of the normal levels can signal liver damage and bone problems such as rickets or bone tumors.

Aspartate aminotransferase test - Aspartate aminotransferase is an enzyme usually found in RBCs and muscle tissue, as well as the heart, pancreas, liver and kidneys. This test measures the levels of this enzyme in the body, with results above the healthy range indicating a variety of conditions, including some types of cancer, as well as liver, heart or kidney damage.

Q & A. Discussion

Q: Talk about elevated calcium levels. Gail shared that one of her early disease indicators was a dangerously high calcium level.

A: High calcium levels can kill. Heart rate increases, arrhythmias, coma, and confusion are signs. In myeloma, the breakdown of bones -- lesions release calcium into the bloodstream. If calcium levels are elevated, check for MM. Gail lost 3 inches of height, so the bone breakdown was in her blood.

Some in the group have Light Chain disease. The approach to therapy will differ from other myeloma. *Can you define your myeloma?*

Glenda shared that she just completed her last weekly chemotherapy. She had lab draws each time on the same day prior to treatment (to determine if she was eligible for treatment that day). She will move to biweekly treatment. Others in the group get labs drawn several days before their doctor's appointment, so the complete lab tests results can be discussed at that time.

What about the long-term use of neupogen? It takes about 2 days for the body to produce white blood cells (with neupogen). You must allow for time to build up.

Q: What is the importance of C-Reactive Protein?

A: A high level of CRP in the blood is a marker of inflammation. It can be caused by a wide variety of conditions, from infection to cancer. High CRP levels can also indicate that there's inflammation in the arteries of the heart, which can mean a higher risk of heart attack.
Q: What factors can affect my lab results?
A: There are many factors that can affect the accuracy of your test results. These include: Certain foods and drinks, Medicines, Stress, Vigorous exercise, Variations in lab procedures, Having an illness. We should be sure to drink more water for 24 hours before the visit.
Please find more information and resources on monitoring and tracking your lab tests results at:

IMF–Understanding your test results - **https://www.myeloma.org/resource-library/understanding-your-test-results**
LLS –Understanding your Lab results **https://www.lls.org/sites/default/files/file_assets/PS41_Understanding_Lab_Imaging_0120FINAL.pdf**
Myeloma Central - https://www.myelomacentral.com/multiple-myeloma-treatment-monitoring/understanding-multiple-myeloma-lab-test-results/

Deborah had us take a few minutes to acknowledge Breast Cancer Awareness Month. She cited the seriousness of regular screenings and reminded us that early detection saves lives. Only lung cancer claims more cancer lives than breast cancer in women. Black and white women get breast cancer at the same rate, however black women still have a much higher rate of death from breast cancer than do whites. Black women are more likely to get breast cancer even with no family history. They have dense breasts more often, so that regular screenings can also be difficult. Please pay attention to your body and act if you notice something different.

For the neuropathy that David mentioned earlier. There is no cure, but the Mayo Clinic has suggestions on its website. Newer medications and delivery style (e.g., oral, injection, subcutaneous) attempt to reduce the incidence of neuropathy. Please be sure to go to reliable websites if you google for relief from neuropathy. Vitamin B6 and B-complex are recommended. Gabapentin/Neurontin and Pregabalin/Lyrica are the often-prescribed oral medications. Topical lidocaine is also recommended. David has used heat and cold. Careful not to overheat. Others have found benefit in walking – getting more circulation in the feet. Do wear very comfortable shoes, cushioned with socks. Wear socks to bed if needed. Do not scratch.

Please read for side effects of any medication. Hear the side effects from the doctor, but also independently ask the pharmacist, and read for yourself, then ask again. Doctors generally talk to over 20 patients daily and may not remember to tell you everything – another reason for being sure to prepare for your visit with any concerns you have.

This month's question. *What do you know now that you wish you had known earlier? What are your lessons learned on this journey so far?*

Caregivers – *be sure to take time for yourself. You are human and cannot do everything. Find what others can do to help you, when offered. Ask for help, when needed.* Sheryl

Ted *Surprised at the expense of going through cancer. Thank God for the co-pay assistance service.*
I wish I had known about this Support Group. I have learned so much. Carolyn W.

Some patient Updates. Ted has been experiencing a lack of sleep. We are told not to substitute activity for sleep; Vena will meet with Vermell to talk about her lab reports –they are watching her myeloma. Her lung cancer is also stable; Concerns about secondary cancers from long-term maintenance therapy.

Announcement/Resources/Upcoming Events

- Gail and Marcia joined the flu vaccine trial mentioned by Dr. Nooka in September. Would myeloma patients benefit from a higher dosage of the flu vaccine?
- Check your Emails for Survey Opportunities. Some offer as more than $100.
- IMF. Patient and Family Seminars. Archived from August, September, and October.
- The Power of Vitamin D. for Myeloma – for COVID-19. Get your Vitamin D levels checked. Bones, joints, heart health, immune system
- MMRF. themmrf.org. Patient Education Series. Latest Updates on Precision Medicine in MM. October 28, 1 – 2:00 PM; Updates on New Drug Approvals and the Expanding Therapeutic Landscape in MM – November 17, 1-2 PM; Patient Summit – Saturday, November 7, 10-2 PM
- Patient Empowerment Network (PEN). 5 min Educational sessions. Why Myeloma Patients should Speak Up; How a Second Opinion Saved a Patient's Life; Myeloma targeted therapy- Why Identifying Chromosomal Abnormalities is Key.

Respectfully submitted, Gail

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