ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Virtual MM Support Group

September 11, 2021

Business News

Thank you to **Nancy B**. who hosted the meeting with a guest speaker and then a short group discussion. Topics scheduled for upcoming meetings include **October**: a guest speaker to discuss Medicare; November: open discussion with separate Patient and Caregiver sessions.

We welcomed **Gavin**, who joined the group for the first time. Gavin was newly diagnosed in July 2020 at age 48. He is treated at Emory and received a stem cell transplant (SCT) in January 2021. Gavin has a 21-month-old baby. Nancy mentioned that there is another IMF support group for patients with young children that younger patients are welcome to join. To find more information about IMF support groups, go to the IMF web page https://www.myeloma.org/ click the "Resources & Support" tab, then scroll and click the "Find a Support Group" link.

Guest Speaker

Thank you to our guest speaker, Charise Gleason, MSN, NP-BC, AOCNP from Emory Winship. Charise updated us on new multiple myeloma (MM) treatments available at Emory Winship and then answered many questions from the group. Charise began her talk by giving us a background on her role with Emory's MM program. She explained that her administrative role is Chief Advanced Practice Provider and Nurse Practitioner at Emory Winship, where she leads the Physician Assistants and Nurse Practitioners across Emory Healthcare. Her clinical role and favorite part of the job is taking care of MM patients. Charise has worked with Dr. Lonial for over 18 years and has met a lot of patients and has seen some big changes in the growth of the MM Program and Clinical Trials (CT) and in the treatments and outcomes for MM patients. Emory Winship has available all of the FDA-approved drugs over the years, and many of their patients have participated in CTs prior to the drug approvals. Winship sees over 2000 patients a year. We're very fortunate that even though MM is considered a rare disease we have so many approved drugs and new drugs in CT to treat it. Charise provided insightful information on induction regimen, relapse treatment, emerging novel therapies, COVID status, and answered many questions for us. A summary of the discussion follows>

INDUCTION

When a newly diagnosed patient comes to Emory for treatment, the first thing that is considered is whether or not they are SCT-eligible. The type of MM and risk level is also considered. When deciding on induction treatments, standard risk patients are likely to start with a four-drug vs. the previous three-drug standard regimen of Revlimid, Velcade, Dex, and a 4th drug. New CT data shows that when a fourth drug is added for standard risk patients, there is an improved outcome. Emory uses a risk stratification method, based

on the biology of the individual's type of MM to tailor the type of treatment that is best for them.

A review of bone marrow biopsy can determine if patients have hypodiploid, meaning that they are missing chromosomes. A MM patient who is missing chromosomes is considered high risk. It is not uncommon to have more chromosomes than needed which is okay. When a patient is missing chromosomes that puts the patient into the high-risk category. There are different types of high-risk types such as *translocation* t(14;16), *translocation* t(4;14), and 17p deletion. A 17p deletion can be present at diagnosis or it can be acquired later. The goal with MM treatment is always to suppress the MM cells activity to as low as possible. New high risk MM patients are likely to start with treatments like Carfilzomib and Revlimid based upon CT outcomes.

Ongoing rumors that SCTs may be going away, but the current research continues to validate that when patients undergo a SCT early improves overall progression-free survival long term. Emory continues to recommend receiving induction therapy, followed by a SCT, and then proceed on continuous maintenance in standard treatment plan. Maintenance drugs are determined by risk factors and are tailored to each individual patient. Maintenance drug types, combinations, dosages, and frequencies can vary widely between patients

Q: *Why use so many different treatment drugs upfront for a patient vs. saving some of the drugs for later use at relapse?* **A:** CT data shows that patients get a better response to therapy when more drugs are used upfront. This approach is still new and not all patients will receive a four-drug regimen to start. It still depends on the patient's performance score, overall health, side effects, insurance coverage, and other factors. If a patient has started with a three-drug regimen that is OK, it is still a good regimen?

Q: *When after successful treatment we no longer see the MM cells in the bone marrow that we saw pre-treatment – does that mean that the disease is gone?* **A:** When the disease is under control, it is not able to be seen under a microscope. It doesn't mean that it's not there; it means that there is not enough of the active disease to see it. It's when there is a higher burden of disease that you are able to see the abnormalities.

RELAPSE

When a patient relapses, the second line treatment is determined after considering such things as a patient's induction treatment, rate of disease progression, data from CTs, and overall health - i.e. are there any other health problems that can be impacted from the treatment we choose? As a group practice, Emory typically chooses treatments for relapsed patients with a monoclonal antibody drug and another drug, or a suitable CT. Approved monoclonal antibody treatments for MM use includes Daratumumab, Elotuzumab, and Isatuximab. Antibody drug conjugate therapy is also used in relapsed patients, which means patients get the antibody drug and when it attaches to the MM cell it delivers a strong chemotherapy. Emory typically uses combinations of drugs to start. There are some patients that are on single agents and often after starting with drug combinations the treatment was stopped using certain drugs due to adverse side effects.

Q: *Are there any recent changes in treatment for patients who have not had a SCT?* **A:** Basically, the same drugs are available to these patients, and it is really just a matter of understanding why they did not have a SCT (i.e., not eligible, personal decision, etc.) and finding the right drugs for their circumstances using the same process as for all patients.

OTHER THERAPIES

CAR-T therapy involves taking a patient's T-cells, reengineering them, and then returning them to the patient. With this therapy, you do not have to continue with maintenance therapy afterward. CAR-T targets BCMA, which is a target for a lot of the newer therapies. The median time to progression is one year, some patients go longer while others who do not get a full year before disease progression.

Q: *How many CAR-T procedures have been performed at Emory this year vs. last year? Has the cost come down from the millions of dollars?* **A:** There have been many CTs involving CAR-T at Emory, and now it has also been FDA approved so the cost has come down. Charise didn't have the exact numbers. Emory has lots of experience with CAR-T. It is expensive and the demand is high. There are a lot of patients who want it and Emory wants to be able to provide it. While Emory has the capacity to provide CAR-T to patients, the company that manufactures the CAR-T cells does not necessarily have the capacity to keep up with the demand at this time.

Q: *Is Emory building a CAR-T lab?* **A:** Yes, but progress has been delayed with COVID. At some point Emory will manufacture their own CAR-T cells that will be good for our patients and make this therapy more available to our patients.

Venetoclax is another drug being used both on and off trials. It's not FDA approved for MM yet, but it targets the translocation 11;14 that is present in many MM patients. Emory has begun using it as a single agent and now using it in combination with other drugs. Caution with some of these combinations is needed because it can make our patients very immune compromised.

COVID & MM

We know that MM is a disease of the immune system, which protects us. So, when we have a disease that impacts our immune system and B cells, then vaccines aren't going to work as well for us as they do for someone without a disease that impacts the healthy immune system. Emory has seen many more cases of COVID in vaccinated patients due to the variants. Emory is advising patients to get the COVID vaccine and the booster, but to continue acting like you haven't been vaccinated. Patients are instructed to wear a mask around people that they do not know and where there is a risk that somebody in the crowd is not vaccinated.

Emory and other institutions are conducting studies on the effectiveness of the COVID vaccine on MM patients using blood samples. Some studies are looking at blood samples of patients prior to receiving the vaccine, but most of Emory's samples are post vaccine and then monitored over periods of time. Studies are reviewing antibody activity looking at the B cells, and also the T-cell mediated response. Early findings are that COVID vaccines are not working well for MM patients; and possibly up to 40% of patients are

getting no response to the vaccine or not enough of a response to protect them. Even though the third shots are recommended, it is still not known the efficacy for MM patients. Patients have had a lot of questions regarding whether or not it is necessary to get the same type of vaccine booster as the initial vaccine received previously – Pfizer or Moderna. There is not data to support mixing brands yet, and currently Emory is only prescribing the same brand for the third booster dose

Q: *Some patients have seen a spike in their protein levels in lab reports after receiving the COVID vaccination; would you please comment on this.* **A:** Emory has seen this reactive polyclonal response and some people develop a lymph node as well, typically on the same side as where the vaccine was administered. Never react to one number, changes in numbers due to the vaccination should be stabilized again in future lab reports.

OTHER QUESTIONS & ANSWERS

Q: *What are the qualifications to be eligible for SCT? Is there a certain age that makes you ineligible?*

A: Patients are considered from a clinical performance standpoint so if you are mobile, have a healthy heart and lungs, and without other comorbidities Emory performs SCT to people up into their late 70s depending on physical condition.

Q: *What is the Medicare age limit for paying for a SCT?* **A:** Approximately late 70s – like 78 or 79.

Q: *Why do some patients do a second SCT?* **A:** Data does not support getting a tandem SCT unless the patient did not get at least a very good partial remission (VGPR) after the first SCT. There is the option to get a second SCT, but Emory rarely does this because the drugs available now are so good, and may provide a better response with the drugs, versus another SCT. Another reason to consider another SCT is that after years and years of therapies, your bone marrow can get beat up, and so a second SCT can help to restore bone marrow.

Q: *What does consolidation mean?* **A:** Consolidation refers to getting two more cycles of the drugs that you received at induction, generally after transplant.

Q: *What is the oldest age for you to be eligible to participate in CT? What might prevent you from being able to participate in a CT?* **A:** The patient's general health performance status is an important consideration. Other comorbidities, neuropathy, low blood counts, and weakness might prevent you from participating in a CT. It is important that you are able to tolerate side effects. Age in general will not eliminate your eligibility to participate in a CT.

Q: *Why does the subcutaneous delivery of Daratumumab (Dara) require a six-hour observation the first time? (I'm getting it via IV, and it only takes 90 minutes, so I'm not inclined to switch).* **A:** At Emory, the very first time you get subcutaneous Dara we monitor you for some time and treat you for any adverse side effects. Most of our patients have switched from IV to subcutaneous Dara and the data from CTs indicates that it works just as well. The majority of patients prefer it, as they are in and out much quicker (after the infusion).

Q: *For patients under treatment, how often should tests and/or scans be performed? Should they be performed every few years, regardless of the status of the treatment?* **A:** That's a great question and it is different from patient to patient. If patients are post SCT and doing well on maintenance, typically a complete restaging once a year, looking at bone marrow. If previous PET scans

have never shown anything, then PET scans are not repeated until it's indicated during regular monitoring. Typically, in a relapse setting bone marrow tests and restaging are more frequently, especially when seeing the MM numbers changing, called a biochemical relapse. If a bone marrow biopsy and PET scan are negative, sometimes we wait to repeat tests.
Q: *My diseased bone marrow was sent for MRD testing but was not viable. Can I ever get MRD results?*
A: MRD tests look for minimal residual disease. It helps better define and understand the depth of response to treatment, but currently treatment decisions are not based on MRD test results. There is still no consensus within the MM community on how to use the data. To track, an original sample at diagnosis of MM disease is needed that contains a monoclonal component for subsequent sample comparisons. For some patients, their first sample doesn't provide all that is needed, which is unfortunate.
Q: *Do you ever revisit or retry a drug that a patient was successful with at one time, but then progressed on?* **A:** Yes, sometimes a prior drug is on a different regimen with different combinations than it was used initially.

In closing, there is a lot of evolution with new therapies, targets, and combination possibilities. More drugs that are used for other cancers are also being used to treat MM based upon their targets. The future is in treatments that we don't even know about yet! We thank Charise for her informative discussion and taking the time to answer all our questions.

<u>Group Discussion</u>
There was discussion surrounding the third COVID booster shot. Several in the group have received a third shot through their doctor and others at places such as CVS. All reported that it has been easy to schedule and receive the booster. Immunocompromised MM patients are encouraged to get the booster now, rather than waiting. It is recommended to get the booster between treatments, as it can complicate or contribute to the side effects of treatments. Some members fully vaccinated along with spouses have gotten breakthrough COVID cases. **Chuck**'s wife only had mild cold symptoms for a couple of days. Nancy reported that **Jim M**.'s wife has also been diagnosed with COVID and is being treated with antibodies. **Nancy** described a home remedy (also prescribed by doctors) to help stop the COVID cough: 1 teaspoon of honey and 1 teaspoon of onion juice. It's nasty but it works!

Even if we are vaccinated, we always need to continue being very cautious. **Jeff**, who is in a COVID CT at Emory has been cautioned by his doctor to basically "act like it is July 2020 and wear your mask".
Proceed as though you have not been vaccinated and adhere to all possible precautions at all times.

Submitted by Wendy R

Meeting Minutes

Southside Virtual MM Support Group

September 25, 2021

Business News

We will have our last session in the Myeloma series from Tara S. Roy, MS, NP, AOCNP, of Takeda Pharmaceuticals on **Saturday, October 23 at 10AM**. The topic presented will be simply **Living with Myeloma.** Tara has had excellent reviews from her two previous presentations on *Understanding Lab Results* and *Cancer Survivorship*. Also mark your calendar and plan to attend the **M-Power Atlanta area on Saturday, November 13**. M-Power Atlanta will feature information about the increased risk of myeloma in African Americans. Look for registration details in your email box.

Group Discussion

Our September meeting opened with a moment of silence led by Doris. September's meeting focus was to hear patient and caregiver voices on their journey successes and challenges. Gail demonstrated navigating the Internet for the resources on multiple myeloma (MM) offered by the IMF, LLS, Patient Power, and others. September is Blood Cancer Awareness Month.

IMF, Patient Power, and Patient Empowerment Network (PEN) organizations all have short educational videos for easier consumption. Gail used the IMF website myeloma.org to demonstrate on how to locate the videos. She also showed where "Ask Dr. Durie" blogs, Myeloma Minute videos, and educational print materials. We encourage all patients and caregivers to use the information hotline at IMF with any questions and concerns.

IMF Information Hotline - 800-452 CURE (2873) - 12 noon – 7 PM, M-F.

Patient Power has a short informational video on Xpovio on their website. Xpovio/Selinexor is an oral medication taken by patients who have gone through at least three previous treatment regimens. Selinexor is the only drug in its class called Selective Inhibitor of Nuclear Export (SINE). Serious side effects include low platelet counts, low white blood cell counts, serious infections, neurological side effects, nausea and vomiting, and diarrhea. Common side effects include weakness, low red blood cell count (anemia), constipation, shortness of breath, and increased blood sugar.

It was clearly time for patients and caregivers to share their concerns. Much of our meeting was focused on finding resources that would be helpful to Geraldine who has several issues that guided our discussion. Geraldine had a tandem transplant at Northside in 2020. The tandem transplant was not successful, and she is now on a different regimen that includes Xpovio/Selinexor and Dex. She requested a change from Kyprolis because of the side effects she experienced. The possibility of CAR-T was discussed, but without a strong support system, the CAR-T was not possible at this time. Geraldine has high-risk myeloma. Geraldine is a patient at Kaiser Permanente. At one time, Kaiser patients went to Northside only. They now have a relationship with Emory Winship, and she has had labs done at Emory. Gail and others advised her to get a second opinion from the myeloma specialists at Emory to inform her treatment plan.

Nutrition is another concern for Geraldine. She is anemic, has had radiation in her mouth along with treatment-induced diabetes. "*I have no appetite. What should I eat?"* We advised Geraldine to eat with plastic utensils, not metal, which might mix with the chemicals from treatment for a metallic taste in her mouth. We also suggested the BRAT diet for those times of nausea, diarrhea, or little appetite. **BRAT = Bananas, Rice, Applesauce,**

and Tea/Toast. Ask your myeloma team for assistance from the nutrition team member. Additional resources listed below. equifyhealth.com/joinstudy

- LLS offers Free Nutrition Consults to both patients and caregivers. LLS One-on-One Consultations Chat, Email, Phone: 1.800.955.4572.
- The IMF has an excellent 60-minute online seminar on myeloma and nutrition. **How to Optimize and Protect your Immune System: A Nutrition Approach.**
- Doris shared a flyer she saw at Emory. Emory Winship Study - Input from Black Patients to Improve Cancer Care equifyhealth.com/joinstudy 1 Hour Interview. $50 gift card on completion
- Paulette shared a great webinar **on How to talk with your Medical Team Effectively** from the African American Chapter of Myeloma Crowd. The video is about 30 min presentation and 30 min Q & A with patients. The speaker is Amy Pierre of IMF Nurse Leadership Group, IMF.

Respectively submitted, Gail

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