ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes
Northside AAMM Support Group

July 10, 2021

Business News

Northside group welcomed Marilyn Pritchard, RN, MSN, OCN, Clinical Nurse Consultant for Bristol Myers Squibb, which acquired Celgene. 27 people attended the Zoom meeting.

Guest Speaker

Marilyn Pritchard has 35 years of experience as a Hem-Onc nurse and is passionate about MM patients. She has seen how far the treatments have advanced for MM and is excited about the new options. She remembers when Aredia was a 24-hour infusion drip! The topic discussion was "Learning About CAR T Cell Therapy."

CAR T cell therapy is one of the most exciting new treatments for MM. Marilyn recounted the history of CAR-T that included Emma Whitehead, a seven-year-old recipient of Car-T Therapy for ALL who was on Hospice in 2012. Her mother was exploring all options and found a clinical trial in Philadelphia. See Emma's story at: https://www.youtube.com/watch?v=pTQuZ2hWa-0

Marilyn started by explaining the difference between B cells and T cells. B cells create antibodies, which we are hearing a lot about around the COVID vaccine. T cells identify harmful cells and kill them. These are key to immunotherapy for myeloma that works with a patient's own immune system to find and fight cells, including cancer cells and healthy cells. The attack on normal cells causes side effects. CAR T cells are engineered and replicated, and then they are returned to the patient to find the specific target on cancerous cells and attack them.

CAR T may be an option for future treatment, as determined by your healthcare team. There are several versions of CAR T, some are still in clinical trials. The FDA has approved one version for MM patients who have relapsed on four prior lines of therapy. Another version has been submitted for fast-track approval and FDA response is expected by the end of the year. CAR T therapy can only be given to patients at select treatment centers. There are 140 centers in the US and both Emory and Northside perform this procedure. Your doctor's considerations for CAR T will include diagnosis, past treatments, overall health, and care support partner.

The steps in the CAR T procedure are:

1. *Apheresis* – harvesting T cells much like stem cells. Moving blood through a process that separates T cells and returns the rest to the body. This takes about 2-3 hours.
2. *Manufacturing* – adding the CAR (chimeric antigen receptor) to the T cells and then replicating hundreds of millions of these cells. This process takes 2-4 weeks at a specialized facility. Patients may receive additional MM therapy to keep disease under control during this time.
3. *Preparation* –receiving lymphodepleting therapy to destroy lymphocytes and T cells. This makes room for the new T cells to do their job.
4. *Infusion* – returning engineered T cells to the patient via IV in the infusion center or hospital.
5. *Monitor* – watching the patient closely for 30 days. The first seven days are critical with monitoring daily or more often. Severe side effects may occur and the patient is well prepared. Time in the hospital will vary and the patient will be at home when the doctor feels it is safe but may return to

hospital if side effects develop. The healthcare team is specially trained to monitor and treat the side effects. Each team goes through REMS (Risk Evaluation and Mitigation Strategy) training required by the FDA.

6. *Continued follow-up* – after 30 days, the patient is released back to their primary oncologist for follow-up every month or more, as needed.

The side effects of CAR T therapy will vary by patient and may be mild, moderate, or severe. The most serious are CRS (cytokine release syndrome) and NT (neurologic toxicity). CRS includes high fever, chills, irregular heartbeat, drop in blood pressure, shortness of breath, and other effects that will be covered by the team. There are medications available to suppress IL-6 that can reduce CRS symptoms. NT symptoms include confusion, disorientation, difficulty speaking, drowsiness, weakness, tremors, agitation, and other issues that must be monitored and reported by the caregiver. Other side effects from CAR T therapy could include low blood counts and GI problems, which are common in MM treatments.

The caregiving partner in CAR T therapy has an important role. It can be a spouse, adult child, family member, or friend. The treatment center social worker will help to analyze the situation for adequate assistance. Care partners provide essential support with daily activities: household chores, transportation to medical appointments (patient cannot drive for 8 weeks), monitoring status and making notes, and report side effects and changes to the HC (healthcare) team. Communication with your HC team is critical as you learn about CAR T and helps to set expectations for you and your care partner. You will also be enrolled in a CAR T registry and your progress is followed for 15 years. This information is very important to fully understand the scope of CAR T treatment. As you work with your HC team to consider CAR T, they will find the treatment site that will determine which treatment, define your disease state, work on insurance and approval process, and help with the final decision.

Summary:

- CAR T cell therapy is an immunotherapy that modifies your T cells to find and attack targeted cells.
- The initial process takes 2-3 months and each step is important.
- After CAR T cell therapy, you and your care partner and healthcare team will continue to monitor for side effects and address them.
- Only you and your HC team can determine whether CAR T cell therapy is right for you.

Marilyn then took questions from the members:

Q – Does a patient continue treatment during the 2-4 weeks for manufacturing? **A** – Some patients do not need treatment or others continue on regular treatment to keep their myeloma under control.

Q – What is the funding for this process? **A** – This treatment is financially toxic, especially if the patient needs to leave home for a month. Many companies offer help with funding and expenses. Insurance approval is obtained before the process begins. So many of the current treatments are costly. If this treatment results in a year or more without any of the other treatments, the cost may seem more in line with overall expense.

Q – To avoid CRS, can the infusion be dispensed over a period of time? **A** – No, not at this time.

Q – How long does the neurological toxicity last? **A** – They can be resolved in two days up to two weeks.

Q – Is insurance dependent on the production site or treatment site? **A** – The production site is up to the doctor, not the insurance company. The patient may work with the insurance company to identify an alternate site that is covered.

Q – Is there an age limit for CAR T therapy? **A** – A patient's performance status is more important than chronological age. If they are healthy and in good shape, that is more important. The patient will be checked thoroughly before moving forward with this process.

Q – BMS has obtained approval for Abecma. Do you have any experience with that? **A** – Mostly through patient stories in support groups.

Q – How often do blood counts fall and a patient needs transfusion? **A** – Due to CRS, some patients need IVIG, platelets, or whole blood. For some patients, their counts do not recover.

Marilyn recommended watching a YouTube video of Emma Whitehead, the first child who had CAR T-cell therapy in 2012 for ALL. Watch here.

Check out these videos on two other discussions on CAR T therapy.

Dr. Thomas Martin --Patient & Family Webinar: The Future is Looking Bright for Myeloma Patients! - YouTube

Patricia Mangan RN at Univ. PA (first CAR T facility) - Patient & Family Webinar: The Future is Looking Bright for Myeloma Patients! - YouTube

Open Discussion

The group then had updates from some of the members:

Jeff said that he is in a study of antibody levels from the COVID vaccine. The vaccines are not as effective if a patient is in active treatment, especially with immunotherapy. **Jim** said that he is now diabetic from the dex which he now takes to keep the Pomalyst working, along with Darzalex. He had been off dex since 2010 and took Revlimid alone for 9.5 years. He said that the Pomalyst is not as bad as the Revlimid was and the GI problems have reduced. He is now lactose intolerant and has mental cloudiness. He is getting an MRI at the end of the month. Jeff said that he has bare bone exposed in his jaw and can feel bone spurs along his jawline. Others told him that it is ONJ from bone strengtheners. He is going to a dental specialist. **Lory** is still getting Darzalex every two weeks, but her numbers are creeping up. She was glad to have taken it for five years but may need to change treatment. She is getting a PET scan mid-July.

Submitted by Nancy B.

Meeting Minutes

Southside Virtual MM Support Group

July 24, 2021

Business News - **Next Meeting: Saturday, August 28, 2021.** Speaker will be Tara Roy, MS, NP, AOCNP of Takeda Pharmaceutical Company Limited. The topic this Saturday will be *Cancer Survivorship: Optimizing Your Wellness.* Tara was very well-received with her presentation on Understanding Lab Values. Georgia is home to 447,000 cancer survivors. Survivors are defined as anyone who has received a cancer diagnosis through the rest of his or her life (Georgia CORE)

General Business - **Vaccine News:** Many of us received text messages from Emory on Friday, August 20, recommending that we get the third dose of the vaccine from a local pharmacy or from special vaccine clinics at Emory. #Ask Dr. Durie says myeloma patients should get the third dose after consulting with their doctors. On Monday, August 23, the FDA gave full approval to the Pfizer vaccine, removing the EUA (Emergency Use Authorization) status. For many, this is criteria for getting the vaccine.

Guest Speaker - **Tara Roy, MS, NP, AOCNP** of Takeda Pharmaceutical Company Limited was the guest speaker for our August meeting. Her presentation was on *Understanding Lab Values.*

Doris opened our meeting with a moment of silence. **Tara** started the presentation by walking us through the basics of myeloma and connecting lab tests to the definition. Criteria for myeloma is abbreviated by the CRAB acronym. **C**alcium (in the blood or urine), **R**enal (kidneys), **A**nemia (unexplained low blood count), and **B**ones (unexplained bone pain). Your treatment will also affect your lab values. Everyone should be proactive about monitoring their myeloma lab reports, comparing current and past lab reports, and prepare questions to ask providers.

- **Complete Blood Count (or CBC**). This includes the Red Blood Count, White Blood Count, platelets, hemoglobin, and more. Myeloma patients should discuss the expectations for these values. Low platelet could mean increased risk of bleeding, low hemoglobin indicates anemia.

- **Comprehensive Metabolic Panel** includes calcium, creatinine (kidney function), albumin, and protein levels in blood found in urine. *It is vital that each person be able to define their own myeloma.*

- **Beta-2 macroglobulin and C-reactive protein.** The levels of these proteins help show how multiple myeloma has spread. The level of C-reactive protein (CRP) increases when there's inflammation in your body. Since it is not myeloma specific, it is not conducted at each visit. Still, ask your providers about this value.

- **Serum protein electrophoresis (**SPEP). Check the levels of protein in the blood. This test can detect M protein. M protein is another name for a large number of abnormal monoclonal antibodies.

- **Urine protein electrophoresis (UPEP).** Levels of protein are checked in the urine.

- **Immunofixation electrophoresis (IFE**). This test also looks at proteins that come from abnormal antibodies.

Additional tests include:

- **Imaging tests.** X-rays can be used to check for bone damage. Other tests such as MRI, CT, or PET may be used to look at bones for damage and also to see the number and size of myeloma tumors.

- **Bone marrow (BM) biopsy**. A small amount of bone marrow is taken with a needle. The bone marrow cells are checked in a lab for signs of multiple myeloma. *Chromosome abnormalities* can be detected through the biopsy. **Cytogenetics** can be determined – whether there is a chromosome deletion, translocation, or trisome (added chromosome) can be determined from tests conducted at this time. You should discuss with your doctor how frequently you should receive a bone marrow biopsy. BM biopsy can help to determine whether you have an aggressive form of MM, your treatment path, and your prognosis. Myeloma patients routinely get the **FISH** test from a BM sample to help with the myeloma diagnosis. **MRD** (Minimal Residual Disease) testing is conducted after treatment to determine if there are any remaining myeloma cells. This is an expensive test and is not a part of standard care. Academic centers may conduct the test.

- **eGFR.** *is a test that shows up with a different value for African Americans.* The purpose is that the kidney function of African Americans is different from other race/ethnic groups, so a lower value may indicate a need for intervention. *There is some controversy about this value. Some nephrologists are working to remove this racial differential.*

Tara asked the group **Can you define your myeloma? Is it IgG or IgA, kappa or lambda?** You learned the myeloma vocabulary and the structure and function important to myeloma. *What is your total protein? What is your kappa or lambda level? What is the ratio of kappa and lambda?* Tara shared a visual of the heavy and light chains and the roles they play in your myeloma.

Multiple myeloma is a blood cancer of white blood cells called **plasma cells.** Plasma cells come from the bone marrow, and they produce **antibodies** (also called **immunoglobulins**) that fight a wide variety of infections. In myeloma, one of these antibodies grows out of control in the bone marrow, crowding out the other antibodies. This one kind of antibody is called a **monoclonal protein** (also called **M-protein or M-spike**).

Antibodies are made up of two parts: ***heavy chains*** (green/longer) and ***light chains*** (blue/shorter stems outside). When myeloma progresses, the myeloma cells start to produce more light chains than heavy chains. **Heavy chains** are immunoglobulins and there are five types: IgG, IgA, IgM, IgD, and IgE. IgG represents 60-70% of heavy chains, and about 20% are IgA. **Light chains** are kappa and lambda. **How do you define your myeloma?** If you have kappa light chain, your doctors will follow kappa levels on your lab report and likewise with lambda levels. In general, *the higher the light chain, the more aggressive the disease is.* Sometimes it is more helpful to follow a balance or ratio of kappa to lambda. Ask your provider what is better for you. Tara has provided *Understanding Your Labs booklet* from Takeda available electronically or print a hard copy. the pdf attachment is attached below.

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Patient Updates

Sarah was diagnosed with colon cancer and had surgery on July 8. She is taking chemotherapy and monitoring her MM monthly. We send extra prayers for Sarah's recovery along her journey.

Rosalyn just wished to say an extra Thank You for today's information.

Sandy B. underscored the loss of height that can occur with MM – she lost 5 inches -- from 5'6" to 5'1". Sandy also changed her Revlimid dosing from 21 days on/7 days off to 14 on/14 off. She seems to have more energy – this pattern allows her body more time to recover.

Respectively submitted, Gail