ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes
Northside Virtual MM Support Group
April 1, 2023

Business & News

Nancy B. and **Sandy W.** are researching locations to meet in person. The goal is to begin having hybrid (simultaneous in-person and virtual) meetings starting in May. A formal invitation to the May in-person meeting location along with directions will be sent in a separate email announcement.

Jim M. highly recommended a video presentation on the myeloma.org website by Dr. Joseph Mikhael, Chief Medical Officer of the IMF. The presentation includes a great description of multiple myeloma (MM) drugs and how they work in understandable terms. View the video here - Living Well with Myeloma Webinar - New Drugs in Myeloma – What, How and When? What Patients and Care Partners Need to Know

Guest Speaker

Thank you to **Jim M.** who hosted the meeting with 30+ attendees at the meeting. Jim introduced our guest speaker **Tara S. Roy, MS, NP, AOCNP**, Patient Advocacy Liaison from Takeda Pharmaceutical. She educated us on the topic, "*Understanding Lab Values*." Tara is a nurse practitioner with a 30+ year career taking care of people living with blood cancers. The material discussed in the presentation is for educational purposes and should not be considered personal medical advice. It is intended to provide information to help formulate questions that can be brought to your healthcare team for further discussion. Tara mentioned that treating myeloma has come a long way over the past 20 years. There have been approximately 18 new FDA-approved drugs for treating myeloma (MM) along with great strides in not only diagnosing the disease earlier, but having a really good understanding about identifying a patient's type of MM.

Tara began the presentation by providing an overview of the immune system and MM in general. Myeloma is blood cancer. Blood is made up of three types of cells: red blood cells (**RBC**), white blood cells (**WBC**), and **platelets**. Platelets are the clotting factor of the blood. RBCs (a.k.a. *hemoglobin*) help carry oxygen throughout the body to keep vital organs and tissues healthy. WBCs *(neutrophils and lymphocytes*) fight infection contracted from bacteria, viruses, and fungi. Red and white blood cells are made in the bone marrow. *MM occurs in the bone marrow in a subgroup of WBCs called* **plasma cells**. Normally, plasma cells are produced in small numbers of different types of antibodies. Each type of antibody has a role in the immune response against different infections. When MM occurs, a specific plasma cell type increases significantly producing a single antibody protein known as **monoclonal M protein, paraprotein or M-spike** *which means "one type of protein."* The healthy plasma cells become crowded out, causing reduced production of the remaining normal white blood cells. The results include less effective antibodies, leading to low blood counts, and putting a patient at higher risk for infection.

An **antibody**, (a.k.a. *immunoglobulin*) is a molecule with two identical **light chain types** *(Kappa and Lambda)* and two identical **heavy chain types** (IgA, IgD, IgE, IgG, and IgM). Everyone has antibodies with different combinations of heavy and light chains. Immunoglobulin is characterized by light and heavy chains. This is the structure that helps identify what type of MM a patient has. All myeloma types are patient specific based on abnormal antibody markers. The majority of MM patients

have *Secretory MM*, where MM cells secrete an abnormal antibody type within the monoclonal protein, or M-spike. If your healthcare team performs blood and urine tests and detects proteins circulating in your body, then you have Secretory MM. Approximately 3-5% of MM patients do not secrete M protein into the blood or urine, which is called "*Non-Secretory" MM*. Additional blood and urine tests cannot detect M protein in a measurable number for those patients. Additional diagnostic tests are performed for these patients such as PET, MRI, and bone marrow biopsy.
An important question to ***ask your healthcare team is what type of MM you have***. The labs and diagnostic testing performed varies from person to person. It is important to understand why these tests are being performed. This will help you understand why your healthcare team is ordering specific tests for diagnosis and monitoring your MM.
Until about seven years ago, a person who was diagnosed with MM had to have at least 10% plasma cells in their bone marrow, a measurable amount of protein in their blood or urine, and at least one of the **CRAB criteria** (*Calcium/ Renal/Anemia/Bone*). Now MM is being diagnosed sooner, when less damage has occurred, using the **SLiM criteria**. If a patient meets the SLiM criteria, then a MM diagnosis is made, and the patient moves on to treatment. You do not have to wait for the CRAB criteria to occur, although sometimes they do occur together.

Clinical Features for Evaluating MM

Laboratory test results help to diagnose disease**,** determine the stage and prognosis**,** plan treatment**,** monitor disease progression, and monitor the toxicity of treatment therapy. Factors that affect lab test results include medical history and general health, gender, race, and age, techniques used by laboratories, medications, diet and/or specific foods. It is important to understand that you cannot always compare test results. Specialized equipment processes and machine calibrations to determine specific normal ranges cause varying results between lab testing facilities. Make sure when comparing the test results, their normal values range are the same. If not, do not compare the results, even if it is the same test. When a patient is first diagnosed with MM, a battery of lab tests is performed. Each lab test is like a piece of a puzzle that your healthcare team uses to understand your myeloma. Once your healthcare team has put the pieces of the puzzle together to understand your MM, some tests may be removed if they do not pertain to your prognosis. LABS fall into three categories: 1) General laboratory tests, 2) MM specific laboratory tests, and 3) Other important tests.

1. General Laboratory Tests: not MM specific, but help put pieces of the puzzles together to understand patient MM

- **Complete blood count (CBC)**
  - *RBC*: low counts could indicate anemia.
  - *WBC*: low counts could signify a weak immune system and a higher risk of infection.
  - *Platelets*: low counts may lead to increased risk of bleeding.
  - *Hemoglobin* (Hgb): low counts signify anemia, which results in decreased oxygen in the blood.
- **Comprehensive Metabolic Panel (CMP)** – Provides an analysis of blood chemistry and metabolism.
  - *Calcium*: high count may indicate bone destruction or kidney disease.
  - *Creatinine*: high count may indicate loss of kidney function.
  - *Albumin:* low levels may indicate severe disease or kidney failure.

- *Total protein in blood helps* measure tumor burden for light chain only MM.

- **Urine Test**
  - Measures the total amount and type of protein in the urine.
  - In a total protein urine test, urine is collected over a 24-hour period.
  - Helps measure tumor burden for light chain only MM.
- **Beta-2 macroglobulin**
  - This protein is made of many types of cells, including MM cells.
  - The amount of this protein often determines how far the MM has progressed.
- **Serum albumin level**
- **Serum viscosity**
  - Measures the thickness of blood.
  - Large amounts of M proteins can cause blood to become very thick. Note: when this level is elevated, the symptoms may be similar to a stroke causing confusion, dizziness, numbness, and tingling.
- **Lactate dehydrogenase (LDH)**
  - This protein is made of many types of cells, including MM cells.
  - High levels of LDH suggest advanced MM. Note: the more plasma cells that are circulating in your body, the higher the LDH a person may have. This was not known until about eight to 10 years ago. Patients diagnosed before that time may not have an LDH baseline.

2. <u>MM Specific Laboratory Tests:</u> performed during diagnosis and monitoring of patient MM

- **Protein electrophoresis**
  - Sort/ measures all proteins in blood or urine (antibodies/related proteins) by size and electrical charge.
  - For patients with MM, the test results are an M-shaped graph indicating monoclonal protein.
- **Immunofixation electrophoresis**
  - Identifies specific type of antibody produced by MM cells (the antibody's light and heavy chains)
  - Performed as a follow-up test when an M spike is present in protein electrophoresis results.
- **Quantitative immunoglobulins**
  - Measures levels of each type of antibody – IgA, IgD, IgE, IgG, and IgM
  - Shows whether the level of any of these types of antibodies is too high or too low.
  - Monitors MM and its treatment including: the level of the MM antibody, and the level of normal antibodies that can be decreased (impairing immunity)
- **Serum free light chains (SFLC) analysis** (a.k.a. serum assay free light chain ratio)
  - Measures the count of free light chains (kappa and lambda) in the blood and kappa-lambda ratio.
  - Used to diagnose, monitor, and evaluate the prognosis of MM.

<u>3. Other Important Tests</u>: Specific to MM diagnosis and monitoring disease

- **Bone marrow aspirate and biopsy**

- Used to diagnose, monitor, and evaluate prognosis of MM by sampling cell types found in bone marrow.
- Cytogenetic Analysis
  - Testing chromosomal abnormalities to predict treatment response.
  - identify standard risk versus high-risk MM.
  - Not all MM patients have chromosomal abnormalities at diagnosis.
- *Fluorescence in situ hybridization (FISH):*
  - Single abnormal DNA strand (probe) is identified and labeled with fluorescent dye.
  - Bone marrow sample is taken, and probe is added to sample.
  - Patterns of binding can reveal abnormalities in the chromosomes.
- *Karyotyping*
  - marrow sample is taken and stained with special dyes.
  - Chromosomes are identified and organized based on unique patterns of light and dark areas.
  - The chromosomes are evaluated for numbers and structural changes.

- **Minimum Residual Disease (MRD) Testing:** MRD testing goes deep into a DNA genetic level to help identify if there are any microscopic cancers or MM cells left in your body.
  - MRD tests are done to see if any cancer remains after treatment.
  - If a small number of MM cells are detected in the body, the patient is considered *MRD-positive.*
  - If no cancer cells are detected, the patient is considered *MRD-negative.*
- Tests for MRD include:
  - Bone marrow aspirates and biopsies
  - Multi parametric flow cytometry
  - Next-generation sequencing
  - Polymerase chain reaction
  - Mass Spectrometry
- **Mass Spectrometry**
  - A technique that determines the chemicals in a sample
  - Works by classifying ions in a sample by their mass and charge.
  - In MM, mass spectrometry can be used to take a very detailed look at what is in the blood sample.
  - Mass spectrometry can determine when an M spike is due to MM or therapeutic monoclonal antibodies.
  - Research suggests mass spectrometry might be as sensitive as bone marrow biopsies for testing MRD.

Normal values for these tests can vary from person to person. Test values are typically shown in a range. Treatment decisions should be based on a patient's lab portfolio (multiple types of tests), test values over time, and assessments and discussions with your doctors. Tara closed the presentation by encouraging everyone to understand their MM type and the testing that is performed for by their medical team and why those tests are performed.

Group Q&A:

Q: What tests are used to determine renal problems? **A:** Creatinine and BUN tests are used for determining kidney function. **Q:** What levels of albumin indicate kidney issues? **A:** That is the level is determined by your albumin baseline. **Q:** Does insurance pay for MRD testing? **A:** Ask your healthcare provider if MRD testing is covered by your insurance. Every insurance company is different, coverage varies from person to person when it comes to MRD testing. **Q:** Why is it important if we do not have a plan of action that test results are MRD-negative? **A:** A Plan for MRD is different for everyone. Your healthcare team can guide you in the process, but you make the final decision. **Q:** Does taking blood thinner medication affect platelet counts? **A:** Yes, along with many other factors besides medication. **Q:** Can you have both a kappa and lambda light chain MM? **A:** Yes, but it is very rare; usually one strand is more elevated than the other.

Submitted by Wendy R.

Meeting Minutes

Business and News

Next Meeting: Saturday, May 27, 2023, at 10 AM. **The in-person location is *Fulton County - Evelyn G Lowery Library, 3665 Cascade Rd SW, Atlanta GA*. Reminder: "For Men Only" Group meets on the fourth Tuesday of each month from 6:00-7:00 PM.**

IMF is hosting the Regional Community Workshop on Saturday, June 24, from 9AM to 3PM in Atlanta. The IMF event is located at the National Center for Civil & Human Rights – The Glenn, 100 Ivan Allen Junior Blvd. NW. Atlanta, GA. The Southside group will attend the RCW workshop on June 24 along with the Northside group to learn and network together. The guest speakers include Dr. Nooka, Dr. Hofmeister and RN Charise Gleason from Emory Winship along with patient/ care partner perspective on the myeloma journey from Bob Cain and Molly Lay.

Please Note:

Due to technology/ computer issues the Southside notes for the April 22 meeting are unavailable. Sorry for any inconvenience.