ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

July 8, 2023

Business & News

Next Meeting: **Saturday, August 5 at 11 a.m.** This will be a hybrid meeting in-person at Emory St. Joseph Hospital of Atlanta and virtually via Zoom to provide flexible accessibility to all our members. We will have an open discussion and review of new treatments. Watch your email for more information and meeting details.

Thank you, Nancy, for hosting the July meeting. There were 28 participants in attendance. Nancy introduced *Jill Pauli, PhD., Director of Scientific Affairs for Binding Site Inc*., Birmingham UK. Binding Site specializes in diagnostic tools and precision tests for blood cancers and immune disorders, in detecting proteins previously unquantified. The topic of the presentation is *Understanding free light chain testing.*

Guest Presentation

Bone marrow is where the blood cells are produced; red cells and white cells are the two main types. Red blood cells carry oxygen throughout the body. White blood cells are broken down further by types to fight infection and disease. White cell lymphocytes (T and B cells) are an essential part of the immune system. This presentation will focus on B cells. B cells have antibody receptors on their surface that recognize and attach to cell invaders like bacteria or viruses. This binding process activates the B cell to replicate itself which produces millions of plasma cells, the same kind of immunoglobulin antibody that releases into the circulation system to attack and destroy the foreign invaders infecting your body. Once the infection is cleared, the plasma cells return to normal levels with a small number of memory B cells in reserve for future attacks. In myeloma the clonal cell process goes haywire and millions of single clonal type plasma cells continue multiplying out of control crowding out the other types of B cells in your bone marrow. This excessive amount of abnormal plasma cells is called monoclonal protein, paraprotein, or M-spike.

It is important to understand the basic antibody structure. All antibodies have a common Y shape that consists of two identical heavy chains of the same classification (IgG, IgA, IgM, IgD, or IgE). The second part of the antibody is the light chain portion (kappa or lambda). There are three types of myeloma light chains: intact

immunoglobulin, light chain only, and no secretory. Initial diagnosis of the monoclonal protein helps to determine what type of myeloma you may have.

Clinical diagnosis for myeloma uses CRAB criteria to recognize myeloma signs and symptoms. Additional *SLiM criteria have been added to identify pre-cancerous myeloma symptoms sooner*. A bone marrow biopsy is the gold standard to identify how many clonal plasma cells are in bone marrow along with the amount of impact the monoclonal cells are having on the other plasma cell types. This procedure provides specific results on what is happening in the bone marrow and what type of B cells are being released. Bone marrow biopsies are unpleasant and expensive.

Current technologies are being improved to gather this data through blood testing using the B cell markers and free light chains that circulate throughout the bloodstream. Serum protein electrophoresis blood test (SPE) profiles your polyclonal protein distribution and identifies any M spikes present in the gamma region. Immunofixation (IFE) stains the heavy and light chain regions of the antibody to understand what type of antibody is being produced to monitor over time.

The results are much better in monoclonal intact immunoglobulins than the free light chains only type. Using SPE testing, the sensitivity of detecting myeloma at diagnosis is about 97% of intact immunoglobulins and 61% light chain only (average 88% overall). This leaves 1 in 8 patients with light chain only myeloma undiagnosed. Serum free light chain testing (sFLC) detects the *free light chains only* antibody that are not bound to heavy chains. Since only the free light chains are being tested in sFLC assay the results can be addressed in all myeloma by type; kappa, lambda, and ratio of the two providing a very sensitive marker of plasma cell activity. *By adding the sFLC testing to standard SPE results the sensitivity of myeloma diagnosis and monitoring goes up to over 99%.* Free light chain only myeloma patients can be properly diagnosed using sFLC testing.

Diagnostic Criteria for myeloma has changed with the addition of SLiM criteria.. Patients presenting with 10+% clonal bone marrow plasma cells and at least one CRAB or SLiM criteria feature are considered to have myeloma. This will increase the chance of catching the disease before organ damage occurs. An important point is that intact immunoglobulins have a much longer half-life than free light chains. Since free light chains pass through the kidneys in 2 to 6 hours the response to treatment can be monitored much closer to real time, rather than waiting weeks or months. This makes sFLC testing a valuable diagnostic tool with SPE as a baseline at initial diagnosis, monitor response to treatment, during remission and relapse and if you attain a complete response (sCR) from treatment in compliance with the IMWG depth of response guidelines. Advances in testing and treatment have led to deeper responses to therapy for patients with better outcomes over the last 10 years.

Laboratory testing needs increased sensitivity to address minimal (or measurable) residual disease (MRD). Diagnostic tools include SPE, sFLC, next generation flow and sequencing (NGF & NGS) which require a bone marrow specimen. An exciting new research tool is Mass Spectrometry that monitors the presence of protein over time through a blood test. Mass spec measures the protein the cells produce rather than the cells themselves. The MALDI-TOF spectrometer can identify monoclonal proteins by their unique molecular mass. This is obtained from the plasma cell clone's unique immunoglobulins, and heavy and light chains to determine clone intensity and mass clonality. Binding Site has also been working on the iStopMM trial being conducted in Iceland.

Patient Updates

There was a lengthy discussion on the concerns and lack of timely communication that has been occurring at Emory Winship. **Jim M.** outlined the issues he has experienced since receiving his stem cell transplant last August. He had a second transplant with his original stem cells that did not work. Jim could tell right away that myeloma was acting differently this time and the light chains were continuing to go up. The light chain level is how Jim has monitored his myeloma since 2008. The first stem cell transplant held the myeloma in remission for nine years before going into relapse. He has gone through two more relapses with other treatments, most recently *Carfilzomib* and *Dex* that worked to control the myeloma over a year before his second transplant but stopped working afterwards. Jim and his healthcare team all expected a successful outcome, but the transplant failed. It is nobody's fault. As Jim calls it "The beast has changed." The recent infusion has relieved much of his pain.

The main issue Jim's facing right now is what is his next line of treatment which has also caused concern with the level of communication with Dr Kaufman and his healthcare team at Emory. There were several occasions where phone calls and portal messages were not answered. Treatment plans were developed without his input. Recurring symptoms were not addressed. This was not the case in the past. A CAR-T opening came available three weeks ago to schedule without any consultation. When that treatment was not doable for his family, the next consideration was Bi-specific Teclistamab. Things were moving too fast, and Jim was not getting his questions answered concerning such big decisions. This has added increased stress to Jim and his family on life critical issues. Several members confirmed similar issues and encouraged Jim to advocate for himself and become more vocal on his questions and concerns.

Sandy W. just changed treatment plans in June. She was on a Phase I Clinical Trial CC-92480 (Mezigdomide) with Darzalex and Dex. The investigational drug was pill

form, but it did require a monthly infusion of Dara-SubQ along with time consuming blood tests. The Phase I infusion center was very responsive to her questions and needs, but there were a number of nurse temps along the way. Sandy's portal had to be rebuilt on the first day of the new system. She realized at 3 a.m. that the Darzalex was omitted and had to return the next day. It is important to know your drug regimen. The treatment was not very effective, and the results were minimal PR trending to relapse after a year.

Dr. Hofmeister messaged to schedule a teleconference for a treatment update. He noted his concerns on the progression of the trial going back into relapse. Fewer lines of treatment were readily available. He recommended SOC Kyprolis, Pomalyst, and Dex, but indicated that this combination may not work since similar combinations stopped working before. A second option would be another clinical trial -LAVA starting up at Emory. The investigational drug was brand new and never used before for any type of cancer. There were too many unknowns and potential side effects involved. Sandy chose the KPd standard of care since the drugs were new to her and may open future opportunities for new lines of therapy. The new treatment started working on day 1. The new drug combination was starting to show signs of remission right away and Dr. Hofmeister even stated that in the visit notes, being unexpectedly surprised at the results after the first month of treatment. Sandy's take away is to really know your own body. She monitors high protein levels through bubbles in the urine and curling hair (yes, odd symptoms) which began to disappear right away. Do not be afraid to go back to older drugs that worked before. You are the only one that knows the whole story. You may not understand it all, but you must keep advocating for yourself.

Submitted by Sandy W.

Meeting Minutes
Southside Virtual MM Support Group
July 22, 2023

Business and News:

Southside Next Meeting: Saturday, August 26, 2023 @ 10:00 AM. This will be a **hybrid meeting**. For those **in-person**, the location is the Fulton County Library off Cascade Road (near 285). We will send the **Zoom link** as usual. We hope to have a representative from LLS join us to provide information on Light the Night.

For Men Only. **Next Meeting:** Tuesday, August 23, 2023, at 6:00 PM Our July meeting was completely virtual, as we continued to work out tech issues for holding

hybrid meetings. Thank you, Doris, Nancy, and Sandy W., for continuing to work on this.

Southside Group discussion:

Doris led us into a moment of silence and a special remembrance of our member, Emma Stubbs, who attended all the meetings she could even through the last couple of months. Her sisters, Mary, and Lois, who attended meetings with her and were her care partners, expressed their gratitude for the outpouring of condolences from the group. **Gloria** grew up with the sisters in South Georgia. She remembered them all as very smart. We learned at her Celebration of Life that Emma was valedictorian of her class and that she was selected as Teacher of the Year at her Elementary School multiple times.

Gail suggested that we get to know each other beyond our myeloma –whatever we wish to share. What were you like in High School? Do you play an instrument? Do you sing? What would you like to share about your spouse and your children? How do you spend your spare time? We will have a **"Getting to know you"** session at our **September meeting**. Please bring your pictures.

We spent some time reflecting on the IMF Regional Meeting that was held June 24 at the Center for Civil and Human Rights. The meeting went very well with over 90 participants attending. The attendees were impressed by the simplicity of explanations of what myeloma is, why certain therapies are selected and why there are different therapies for different people.

One of the patients in the audience was impressed by Dr. Hofmeister's explanation of the myeloma journey. She had an unpleasant experience with another oncologist who made her feel as if she should not ask questions and just follow the doctor's orders. Her husband had a similar experience with the same doctor. This patient expressed that because of Dr. Hofmeister's explanation of myeloma and his philosophy of patient-doctor relationships that she was going to reconsider getting treatment for her myeloma.

A second person in the audience spoke up and thanked Dr. Hofmeister for his courage in recognizing the hesitancy of many African Americans trust in the medical care system and that doctors have the patient's best interest at heart. This includes prior participation in clinical trials. Based on the history of medical experimentation on Blacks, particularly the U.S. Tuskegee Syphilis Study that recruited over 600 Black men and told them that they needed to be treated for "bad blood" would be free of charge. The Study started in 1932 and continued for decades until Peter Buxton, a social worker/epidemiologist became a whistleblower when he reported it to CDC first in 1966 and again in 1968. It was only stopped in 1972 when the story was leaked to the press. Penicillin was discovered in 1943. By the rationale for the study, it should have been terminated then. It did not, because they said they wanted to find out what

happened if syphilis went untreated over time. The experiment affected not only the men involved, but their wives and families. There were about only eight men still alive when President Clinton issued an apology on behalf of the U.S. on May 16, 1997.
An audience participant commended Dr. Hofmeister for voluntarily speaking about the experiment as a possible reason for distrust. She had come to the meeting with her 16- year-old son because her grandfather died from myeloma many years before. She watched him go from doctor to doctor in New Orleans without a diagnosis while he deteriorated from a very physically and mentally strong, capable man to one constantly doubled over in pain until his death. Since then, she made it her journey to find out more about this disease. Because of Dr. Hofmeister's delivery, she felt she found her answers and felt she understood the disease more and felt doctors have come a long way since her grandfathers' experience. She felt informed for her family and liberated from the need to attend so many myeloma meetings.
LLS is sponsoring its annual Light the Night fundraising event. We are asking all members to please consider donating. We will have a team, or you are welcome to create your own team. We will have more information about the date and the process during the month and at our next meeting.
Jeff shared that the Men's Only group continues to be a place for men to gather virtually for an hour on the 4th Tuesday evening at 6:00 PM. They share myeloma experiences, but also life experiences. They encourage any other men with myeloma to join them.

Patient/Caregiver Updates

Sandy B. shared that she continues to work on her dental problems. She will have a second surgery to remove more bone. The dentures they made for her are ill fitting. She has a Plan B to get dentures that fit. **Mike S.** has had myeloma for 23 years. He met his wife, a nurse practitioner, after his transplant. He has had radiation therapy and is doing well. His wife is an excellent advocate for him when working with the doctors. Others in the group have some suspicions of myeloma drug therapies (e.g., Pomalyst) having some effect on their dental health. **Tom H.** shared that he ran out of funding for his Venetoclax, which costs $1,700/month. With the help of his Emory team, he was able to get the Venetoclax Foundation to cover the costs. Everyone, please keep your applications current with LLS and others who financially support myeloma drugs. This is especially true if you are on Medicare because some additional considerations must be made by the pharmaceutical companies. Tom also shared that he had recent respiratory issues. He advised that while one never wants to go to the Emergency Room, that the one set up for oncology patients at Emory is excellent. His oncology team set up the appointment. The Emory Immediate Care Clinic is at Emory on Clifton Road. **Geraldine** shared that she has been having a difficult time. Her myeloma is in remission one year after her CAR-T cell therapy, followed by a tandem SCT at Northside, after which she never achieved remission.

Since CAR-T, she has unexplained 'body pain' and tooth extractions. Her husband, who was her caregiver, has been in the ICU in a coma since May following a stroke. **Cynthia B.** was recently released from the hospital from a bout with chest and nasal congestion. She is on Cytoxan and Pomalyst. She is scheduled for a biopsy soon. **Sandy W.** reported that she had a back molar extracted and grafted for bad bone damage in her mouth that was presented from a dental visit nine months prior. Please everyone, stay alert with your dental visits and possible relationships to myeloma or myeloma treatment/drugs.

Respectively submitted, Gail.