ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

April 4, 2020

Introduction
Thank you to **Nancy B.** who led our first virtual meeting! We are glad to be able to continue with our support meetings during these challenging times.

Guest Speaker
Thank you to **Aigars Brants**, from the **Binding Site**, who joined the meeting to explain light chains and testing. The Binding Site has been in business for over 25 years and specializes in developing diagnostic tests that specifically target blood cancers and other immune system disorders. They have partnered with the International Myeloma Foundation (IMF) for the Black Swan and Iceland projects; not only focused on testing, but also on finding a cure. Multiple myeloma (MM) is a malignancy of plasma cells and a very complicated disease. Plasma cells produce immunoglobulins that contain two types of chains: 1) heavy chains, of which there are five types (IgG, IgM, IgA, IgE, and IgD), and 2) light chains (kappa and lambda). Different types of MM secrete different products. There are many tests used to diagnose and monitor MM. There are tests to measure the **CRAB** (hyper **C**alcemia, **R**enal insufficiency, **A**nemia, **B**one lesions) criteria and also tests to measure malignancy biomarkers. Freelite, developed by Binding Site is one of the tests used in diagnosis that measures malignancy biomarkers by calculating the amount and ratio of free light chains in the patient's blood serum. The very sensitive Freelite test, when used in conjunction with the Serum Protein Electrophoresis (SPE) test, can result in 99% accuracy. **Mr. Brants's** presentation answered the questions: 1) What is Freelite? 2) How does Freelite work? 3) How is Freelite useful to patients? and 4) Why do my Freelite values change so suddenly?

Plasma cells normally produce some excess *light chains* that ultimately enter the bloodstream. *Free light chains* (*or* serum *free light chains)* refer to those that are not part of whole (*intact*) immunoglobulins *and* are present in the blood, that can indicate a problem. Healthy individuals have many intact antibody molecules circulating in their blood, but there are fewer free light chains circulating in the blood of healthy individuals. The normal range of free kappa light chains is 3.3–19.4 mg/L. The normal range of free lambda light chains is 5.7–26.3 mg/L of. The normal ratio of kappa/lambda is 0.26 - 1.65. It is the kappa/lambda ratio that is most important and tells the full story. A ratio outside of that range indicates there is monoclonal free light chain protein circulating in the blood. When a patient has a higher than normal ratio they are Kappa secretors, and when a patient has a lower than normal ratio they are Lambda secretors.

In addition to diagnostic testing, Freelite is highly beneficial in treatment monitoring because it provides a means for rapid assessment of the effectiveness of treatment and real-time response changes. Freelite allows the medical team to know quickly whether a treatment is working or not.

It is not uncommon to see Freelite values change suddenly. Seeing large fluctuations in Freelite results can be confusing to patients. There is a natural 20-30% day-to-day variation. There are some things for patients to consider when they see their values suddenly change unexpectedly, such as:

1. Were your tests sent to a different lab?
2. Did you lab change methods?

Both changes in lab and in lab methods can result in unexpected Freelite test result changes.

Some suggestions for monitoring Freelite results include:

1. Compare new results with previous results and graph the trend over time
2. Ask: Does the trend make sense with your symptoms?
3. Ask your medical team for help with anything that you don't understand

Websites with more information on this topic:
www.us.bindingsite.com
www.wikilite.com

Discussion
We discussed the need to stay physically distanced but still socially connected during these active COVID-19 times. Social connections are very important for all humans. There was some discussion about the benefit for MM patients to stay on Acyclovir during active COVID-19 times. Currently there are very few US MM patients with coronavirus. The IMF website, www.myeloma.org has fast-changing and pertinent information about MM and COVID-19. Refer to "Dr. Brian G.M. Durie: Myeloma Patients' Top 10 Questions About COVID-19", "Myeloma Patient Safety and the Coronavirus" and more. **Jim M.** mentioned (per doctor recommendations) that it is extremely important that MM patients protect themselves by always wearing a mask in public places at this time. The paper type that is available in clinics is good. **Gail** commented on the importance of staying updated with the rapidly changing information that is available, for example the "Top 10 Questions About COVID-19" on the IMF website changes frequently and patients need to stay aware. Other advice and recommendations for staying healthy that were communicated in the meeting include: if something seems questionable to you, then avoid it, assume that everyone has coronavirus and always be cautious, stay mentally positive and physically heathy (good nutrition, sleep, exercise, limit alcohol, no smoking, breathe deeply, practice meditation, etc.). Stay socially connected with friends, family, and community. Stem cell transplants (SCT) are not recommended at this time. There are always exceptions, but if your doctor is recommended that you move forward with a SCT ask why and find out if there is a temporary alternative. **Dave O.** recommended a good website: www.smartpatients.com and **Nancy** mentioned that the IMF monitors the site for accuracy. We also discussed the desire to be treated at home versus going onsite to medical facilities for treatments. **Ian** asked if anyone in the meeting was getting home infusions - no one was. **Belinda** requested in-home treatment for drug, Dara, from her doctor at Emory/Johns Creek but it was denied due to the risk of potential complications. She is going to continue to try

for in-home treatment. Someone mentioned that Medicare is approving doctors to use telemedicine instead of in-office visits for some types of appointments, and someone mentioned that they had a good experience with telemedicine at Wellstar Kennesaw/Marietta. **Jim M.** knows of a medical facility in NJ that was allowing Velcade and some other types of drugs to be administered by a private nurse in patient homes. Gail suggested that if someone is getting in-office transfusions and would rather be treated at home to reduce their risk of exposure to coronavirus, ask if there is an oral substitute for the drug, or if they could be treated with a different drug (orally at home). Another member mentioned that at their on-site appointments, the facilities were keeping people in their cars until a room was ready for them. Others mentioned that using doctor portals for getting answers to your questions are very useful.

Everyone stay strong, safe, and at home!

Submitted by Wendy R.

Southside Myeloma Support Group

This was our second virtual meeting using the "GotoMeeting" platform provided by IMF. There were 27 participants in attendance. We were joined by Support Group leaders from Birmingham and from Charlotte. **Diedre J.** (Birmingham) has abnormal cytogenetics and is on Venetoclax. **Marva** (Charlotte) is a 21-year survivor, is a proponent of natural healing, and is currently on Daratumumab and Pomalyst. We also had two new members: **Stephanie** diagnosed in December 2018. She is being treated at Emory Winship and **Amy**, a 5-year survivor is also being treated at Emory Winship and is currently in remission.
We were honored to have two speakers – the first was Vermell Sanford, Nurse Practitioner (NP), retired from the Veterans Administration Hospital (Atlanta). The second speaker was **Kendelle Miller**, LCSW, ACM, Emory Winship Cancer Institute.
After a few technical difficulties with the connection from the host, **Nancy** conducted roll call. **Doris** welcomed everyone and led a moment of silence to express gratitude, remember those who are in discomfort (physical, mental, or emotional), and to center our focus for the meeting. Vermell's topic was **The Role of Imaging in Myeloma Diagnosis and Treatment.** Vermell defined each type of Imaging and important factors of their purpose in myeloma. The types of imaging are: X-rays, MRI, CT or CAT scans, PET or PET/CT scans assess the status of bones or bone marrow at diagnosis or relapse.

Imaging is used to determine the level of bone disease in myeloma. Bone disease is a common symptom of Multiple Myeloma (MM). As a reminder, in the CRAB criteria of myeloma symptoms, the initials are for excess **Calcium** in the blood or urine, **Renal** (Kidney) **Failure**, Anemia, and **Bone** loss. Scans are generally used to assess the status of bones or bone marrow at the time of diagnosis or relapse.
X-rays are the oldest and least sensitive to detect myeloma that has caused bone damage. X-rays are simple and quick procedures and insurance covers most x-rays. Full skeletal survey x-ray can show loss or thinning of bone (osteoporosis/osteopenia), holes in bone (lytic lesions)

and/or fractures.
Other imaging studies are more precise. X-rays detect bone damage only after 30% of hard outer bone has been destroyed. It is important to know X-rays cannot distinguish between old bone damage where myeloma is no longer active and sites of active disease

A second type of imaging is the **MRI** (Magnetic Resonance Imaging). This is a non-invasive way to produce a detailed two-or three – dimensional image of structures in the body. Positive aspects of the MRI include that they:

1- Detect images and damage of the spine, pelvis, back, hips and chest,

2 - Detect focal lesions (early abnormal lesions in the bone) in patients with smoldering myeloma,

3 - Obtain images of plasmacytoma as well as spinal cord compression, and

4 - Rapidly detect new disease.

Negative aspects of MRI are that there is a 9 -month lag before scans look normal after successful treatment of an area effected by myeloma (and no active disease) and that patients with metal implants may not be able to have MRIs.
Whole Body MRIs may provide more precise results for patients with MGUS, Soldering Multiple Myeloma (SMM), and Myeloma. Availability, cost, and standardization of technique continue to be areas of concern. The MRI requires a contrast agent called **Gadolinium**. Patients should discuss the use of gadolinium before scheduling an MRI. The FDA (Food and Drug Administration) required “new class warning” and safety measures for all gadolinium-based contrast agents (GBCAs)**. Reasons for the new safety measures include:** Gadolinium remains in the patient’s body, including the brain for months to years after receiving drug. There is **a** problem for myeloma patients with kidney involvement. It is possible to conduct an MRI without gadolinium to assess myeloma bone disease.

CT or CAT scan (Computerized Axial Tomography)- Whole-body low-dose computed tomography (WBLDCT) is the new standard for evaluating myeloma bone disease. It uses X-ray technology to create a three-dimensional digital image of the body that is more precise than standard X-ray. CAT-scans provide clear detailed images of bone lesions.

With **PET Scans (**Positron emission tomography), there is an injection with fluoro-deoxyglucose (FDG), a sugar-fluorine compound that is taken up by the body's actively multiplying cells. Areas with the highest concentrations of fluorine glow can indicate actively growing cancer cells. PET scans are valuable when standard blood and urine tests do not provide enough information about potential disease activity. This test is especially useful for patients with non-secretory myeloma (myeloma cells that secrete no monoclonal protein), and so following the protein numbers to indicate myeloma activity is not useful.
PET scans cover the whole body. They are sensitive in detecting potential tumor activity and detect early changes in the bone marrow before there is destruction of bone. PET scans allow assessment of disease status without the need for a bone marrow biopsy. They are the only imaging study that detect *extramedullary* disease, which is myeloma that grows outside the bone marrow. PET scans are the only "real-time" imaging study.

PET/CT Scans combine PET and CT scans and allows the radiologist to perform CT scan of areas that light up on PET.
Positive aspects of PET/CT Scans are that doctors can monitor a patient's changes over time because these scans provide information about past damage and current cancer activity. They are highly accurate for diagnosis, therapy or treatment assessment, and prognosis of myeloma.
The negative aspects of PET/CT Scans is that they may be expensive and time-consuming. The IMWG's consensus statement on assessment of response to treatment includes PET scanning. The IMWG states that PET scans are required, along with either Next-Generation Flow (NGF) or Next-Generation DNA Sequencing (NGS)—both of which analyze tissue from the bone marrow—to assess minimal residual disease (MRD). Only PET scans are able to detect areas where myeloma is growing both outside and inside the bone marrow.

The presentation of imaging tests led to a discussion about the importance of patient and caregiver engagement in their treatment process. Patients should ask their providers when and why are imaging tests offered. Why are they offered one test, not another? What about the Gadolinium and its risks? If this agent remains in your body (and brain), should you get more information about risks before being asked to sign a consent form?

The importance of keeping a Cancer Survivorship Plan was also re-visited. Copies and results of all imaging and lab tests should be kept. We forget when and why tests are administered as we continue our myeloma journey. The Southside MM SG will continue to work on a patient-friendly, patient-initiated Survivorship Plan. All of us should access the Patient Portal so that we can get this information ourselves – and communicate with our providers. The COVID-19 experience exposed many reasons for patients to be more engaged in their treatment and the importance of learning to use as much technology as possible. More telehealth visits were conducted during this period than anyone could ever have anticipated.

Kendelle opened her presentation by asking all to think of something positive – and monitor the body's reaction to the mind's commands. She said this is one of the ways we can respond to our feelings of stress and anxiety. Thoughts of hope and healing can help to get us through. She talked about several COVID-19 specific resources that have been created. There is a Georgia Emotional Support line – 866.399.8938. She spoke about the reality of many turning to drugs and alcohol during this time. Unemployment and other contributors to financial toxicity create lots of stress. There is help. There seem to be new resources that come up daily. Social Workers share these resources and patients should ask for the assistance of their Social Workers if they have not been offered. She offered to help guide some patients, if they are in need. Some resources mentioned: Leukemia and Lymphoma Society (LLS) – Co-pay Financial Assistance, $11,000; LLS - $250 COVID-19 grant for myeloma patients. For some financial support, you must provide tax returns – for others, there is no income requirement. If you are denied for some support or if agencies have run out of funds, do not give up. Apply for whatever funds you are eligible, keep your records, because usually you will have to apply each year, apply early, and engage a Social Worker when needed. That is their job. Some of the resources she mentioned are included in these minutes. (Contact information: Kendelle Miller – kendelle.miller@emoryhealthcare.org/404.778.5535)

Patient Update. Sandy (30-year survivor) reported that **Ulysses**, who had a Stem Cell Transplant (SCT) at Emory and during COVID-19 since our March meeting is now at home and is doing well. **Sheila** wanted us to know. This is another instance of the individualized decision-making that must occur with myeloma. The recommendations from both the American Society of Hematology (ASH) and the IMF are to delay SCTs until after the crisis has passed. It is important to be informed, ask questions, and come to a joint decision with your provider. Congratulations Sheila and Ulysses.

Resources

1. **www.myeloma.org –** COVID-19 and Myeloma. 10 tips. Dr. Durie and IMF
2. **Emergency**

- LLS - $250 - not income-related. Call 877-557-2672
- Cancer Care – Medication, food, transportation, etc. - Call 800-813-4673 to apply for the financial assistance available for people affected by COVID-19
- Cancer Support Community - $250

3. **Emotional/Mental Health**

- Georgia COVID-19 Emotional Health -24/7 – 866.399.8938
- Georgia Crisis/Access Line - 800.715.4225

4. **Exercise and Reduce Stress –**

- Do Something physical every day
  - Chair yoga with Adrianne - https://www.youtube.com/watch?v=-Ts01MC2mIo
  - Deep Breathing - https://www.youtube.com/watch?v=Wemm-i6XHr8

5. **Handwashing Videos**

- Six Steps to Prevent COVID-19 -1:54 seconds

https://www.youtube.com/watch?v=9Ay4u7OYOhA

- What Older Adults Need to Know?

https://www.youtube.com/watch?v=TjcoN9Aek24

6. **Official COVID-19 reliable websites**

- **Centers for Disease Control and Prevention (https://www.cdc.gov/coronavirus/2019-nCoV/index.html),**
- **Georgia Department of Health (https://dph.georgia.gov/)**

Announcements/Resources/Upcoming Meetings

- **IMF -** https://www.myeloma.org/covid19-myeloma-patients
- **IMF** - diversity.myeloma.org- Includes website and links to articles on current research for minority populations
- **IMF -** Replay Patient Safety and COVID-19 https://www.myeloma.org/videos/multiple-myeloma-patient-safety-coronavirus
- **Fulton County Library online**. Free eBooks, movies, music, virtual stories. Afpls.org