September 2018

Northside Multiple Myeloma Support Group Meeting
September 1, 2018

Charise Gleason, Nurse Practitioner from Winship, was our speaker. She has been at Emory for 20 years with 15 years in myeloma. Charise began her program on Multiple Myeloma Testing with a brief overview. Myeloma is a cancer of plasma cells. Healthy plasma cells produce immunoglobulins in response to foreign body invasion, such as an infection. Myeloma cells produce abnormal immunoglobulins that do not work correctly within the immune system to protect the body. This is why myeloma patients have more infections. Charise reviewed some of the more common labs that are used to monitor myeloma. Serum protein electrophoresis (SPEP) is a way of analyzing specific proteins (antibodies) in a blood sample. Proteins carry a positive or negative electrical charge. They move in a fluid when place in an electric field and separates the proteins into five groups: Albumin, Alpha-1 globulin, Alpha-2 globulin, Beta globulin, Gamma globulin. They are all part of reporting to track myeloma levels and impact. The abnormal protein is called the monoclonal immunoglobulin, monoclonal protein (M protein), or paraprotein. Urine paraprotein electrophoresis (UPEP) is the assessment of the urine paraprotein, which is known as Bence Jones Protein and is part of the light chain antibody. This test is performed on a 24-hour urine study. Immunofixation is testing for a type of myeloma protein: heavy or light chain, polyclonal or monoclonal. Free light chain assay (FLC) measures the number of light chains. FLC are bound to the ends of heavy chains. Plasma cells produce more light chains and that excess circulates in the blood. FLC calculates the light chain ratio. Normally, the free light chains and heavy light chains are present in equal amounts, but in myeloma, the ratio will be different. The FLC test will classify the type of myeloma:

- Heavy chain MM: IgG, IgA, IgD, IgM, IgE
- 77% of myeloma cases are heavy chain
- IgG and IgA are the most common
- Light chain MM: Kappa or Lambda
- 20% of myeloma cases are light chain
- There are no detectable immunoglobulin in non-secretory myeloma
- Only 1-2% of myeloma cases are non-secretory

The abnormal immunoglobulin produced by myeloma cells is call M-protein. M-protein from serum or urine produces and abnormal spike. Patients need to know what to track that is specific to your type of myeloma. Tests can alert to disease changes even with small changes in test results. Do not change treatment too soon. You want to get the most out of this round of treatment. Extended treatment can lead to extended survival. If tests change, get a PET test to check for disease activity. Check all proteins to trach disease changes. Myeloma can change so your healthcare team must look at the whole picture and evaluate quality of life and symptoms. Myeloma can change to non-secretory, so pay attention to any new pain.
Genetic test results from a bone marrow biopsy take longer because so many tests are performed.

· Immunohistochemistry – Part of the biopsy sample is treated with special proteins that cause color changes and help identify myeloma cells
· Flow Cytometry – sample is treated with special proteins that stick only to certain cells and helps determine if those are abnormal cells.
· Cytogenetics (karyotype) – Evaluates chromosomes. Determines if there are too many or too few chromosomes, or rearrangements (translocations and deletions). Takes 2-3 weeks to get results since they are growing cells to count abnormalities. Deletion of 1q and 17p can be acquired.
· Fluorescence in situ hybridization (FISH) – Visualize and map genetic material. Results are available in a couple of days. Deletions are considered higher risk myeloma.

Your healthcare team knows that bone marrow biopsies are unpleasant, but they give so much information about <u>your</u> myeloma. Biopsies are usually performed at diagnosis and at relapsed to see if the myeloma has genetically changed.

Cytogenetics in myeloma:

· These are the genes of the plasma cells, not the patient's cells
· Test may reveal more about the biology of the disease
· Most genetic abnormalities can be found at diagnosis, but others may be "acquired" later
· Could well be the most "prognostic" tool in myeloma as it may separate "high risk" myeloma from standard risk.
· Long-term survivors did not have genetic testing in the early days, so we are still learning about the impact of chromosomal differences.
· Learning how high-risk myeloma (HRMM) responds to monoclonal antibodies and other treatment.

Gene Expression Profiling (GEP)

· Looks at disease biology in a broad sense
· Separates out CD138 selected cells from bone marrow aspirate
· Advantage is that it can provide a global snapshot of disease such as a dominant clone
· Disadvantage is that we select CD138 cells and do not get information on other clones
· The majority of plasma cells have CD138, but this may evolve in the future.

There are so many tools and the doctors are still learning how to use them. The patient response to treatment is so important and can be tracked if watching different markers.

What does all this testing mean to you? What type is your myeloma? If IgG, track it, but get other tests since the disease can change. If you have protein in the urine, get regular testing to monitor those levels. If all tests look good, but you feel different – Speak UP. Get a PET scan to avoid more fractures or kidney damage. Keep your disease under control. We are not treating just one disease.

Minimal Residual Disease (MRD) allows a deeper look to find the hidden myeloma. The myeloma healthcare community does not know what to do with this information. Research centers are collecting data and tracking patients to learn what the markers mean. They are still looking and learning. So much new information in the last 10-12 years.

Q – When tracking the ratio of kappa to lambda, what does it mean when the lambda is low? What is this ratio showing? **A –** When the lambda is suppressed, it may be from the myeloma or from another disease or an infection. Know what to track that is specific to your myeloma. Watch for small changes and track them**.**
Q – What about Staging? **A –** Staging does not change from stage given at first diagnosis. Staging changes from MGUS to SMM (smoldering myeloma) to active myeloma. Stage of myeloma is not as important as the type of myeloma and genetic testing.
Q – When should a patient harvest stem cells? **A –** No stem cell harvest for MGUS. Harvesting only in high risk SMM in clinical trials. Long exposure to Revlimid makes it harder to harvest stem cells. At diagnosis, transplant eligibility is one of the first questions to determine course of treatment. Best to harvest after four cycles of RVd, when the disease is under control. Treatment and radiation impacts harvesting. Data shows that an up-front transplant gives longer survival.
Q – What is success rate of transplants? **A –** Transplant is not a cure. At this time, a transplant can give 2-3 years remission without maintenance and 4 years with maintenance. This is average, and we know that everyone is different. Now maintenance has been shown to extend life and talk to your doctor about quality of life issues with maintenance.
Q – How long can stem cells be stored? **A –** It used to be ten years, but now there are viable after 12 – 13 years. Check with the location storing cells. Sometimes after extended treatment, the marrow is in trouble. A small dose of melphalan and injected stem cells can rebuild the marrow.
Q – Can a patient harvest a second time? **A –** It is difficult to collect stem cells after the myeloma is exposed to melphalan and Cytoxin. The marrow changes so that cells cannot be collected. At Emory, patients are tested at day 100 and offered a second transplant if full remission is not achieved. They do not automatically do the second transplant since the data does not show benefit from tandem transplants. After relapse, an additional transplant generally may achieve a remission for half the length of time as the first transplant.
Q – What is the significance of plasma cells in the blood? **A –** If it is right after a transplant, that may be from growth factor injections. If in relapse with more myeloma in the marrow, the plasma cells spill into the bloodstream.

After the program, we welcomed four new members to the group:
David was diagnosed about nine years ago and had remission from a transplant. His numbers are increasing, and he came to the group to learn of new treatment options.
Evan was diagnosed earlier this year and had RVd. He is being treated at Emory.
Alicia was diagnosed a few months ago and is still learning about the disease. She was glad to hear about all the new treatments from the group.
Bianca was diagnosed with MGUS last year and is researching this disease and chances of progression. She found our web site and appreciated the posting of the monthly news.

Submitted by Nancy B.

Southside Multiple Myeloma Support Group Meeting
September 22, 2018

The meeting was opened by Doris with a moment of silence. There were 21 members present.

There was a miscommunication about dates for the scheduled speakers, Kendelle Miller -Social Worker from Emory Winship and Tricia Hernandez from Leukemia and Lymphoma Society. They will be rescheduled as soon as possible. This unexpected 'found time' gave the group an added opportunity to share issues of concern to them.

It was great to see **Sheryl B**. after almost a year. Sheryl was a very engaged caregiver to her very dear husband, who has since passed away. Her life has been very busy, but she urges the group to make memories. It's the small things you think about when your loved one is gone. The things that made you laugh… the things that made you cry.

We had one new member, **Shirley M.** She was diagnosed in 2011 and she had no symptoms. She is being treated at Emory Winship. Shirley had a roundabout journey to her myeloma diagnosis. In 2011, she was sent to Milwaukee for medical tests. Her doctors thought it was "Something with her muscles..." and she should see a neurologist. She was told by the Physician's Assistant, not the doctor/neurologist, that she likely had myeloma and then had her first visit with a hematologist. Her myeloma is under control – she did not have a stem cell transplant. She is a person of faith. Along the way, she had two brain tumors – one in 2014. She has had problems with her back.

Question: Is there a higher risk among family members having myeloma? **Gail** shared that from information she has read and heard, there is not a genetic or biological link for myeloma in families. However, since exposure to environmental toxins is a noted risk factor, it may be that families who live together, might share the same risks. Several members in the group know

family members, including sisters who have myeloma. **Selina**'s father had myeloma. In his August 30, 2018 blog, Dr. Durie mentioned the Monsanto, manufacturer of Roundup, settlement of $289 million for use of its cancer-causing agent, glyphosate. The article further speaks about toxins we encounter in our daily lives, like the food preservative, sodium benzoate. Benzoate/benzene can cause changes to DNA/Chromosome functions. In his April 5 blog (Toxins Unleashed), Dr. Durie shares a long list of cancer-causing toxins (https://www.myeloma.org/blog/dr-duries/toxic-exposures-unleashed). This is a list he shares as one way to prevent myeloma. The list includes Agent Orange, many forms of benzene, and glyphosates. **Carole O**. shared with the group a news link that popped up prophetically on her phone during our discussion about these toxins.

In celebration of September as Blood Cancer Month and **The Diversity in Healthcare,** LLS featured **Pat C**. in a full-page article in a USA Today (September 25) insert. She tells her story about her Myeloma journey since her diagnosis in 2004. She talked about her tandem transplant, her 12 years in remission, and her recent relapse. Pat was also one of several patients interviewed for a ProPublica article, **Black Patients Miss Out on Promising Cancer Drugs (September 19).** She spoke about her desire to participate in clinical trials but being told she was not eligible. They want the healthiest of the sickest people – no high blood pressure, no diabetes, etc. This is one of several reasons blacks are under-represented in clinical trials. Sheryl shared her (and Ozzie's) story about her very positive clinical trial experience with the drug, Elotuzumab , made by Bristol Myers Squibb. Her husband was not interested in "being treated as a guinea pig" until one of the staff shared with him the advantages of participation. He did very well for a long time, and had energy for church, family, friends – and having some laughs! It is so important to share your stories.

Some in the group have been invited and consented to an observational myeloma study at Emory Winship. They feel more comfortable after our discussions of trials in these meetings. They also know they can change their minds at any time. This is a multicenter study and the information will be available to all scientists to advance a cure for MM. The study is funded by each Center – Emory Winship in our case.

Alma shared her recent experiences with the drug Kyprolis. She suffered severe shortness of breath and reported it at each visit. She had a baseline echocardiogram. She had always had a healthy heart. The last echo showed heart damage. It is hoped that this damage can be reversed. We all know that our medications have some major side effects. We expect that our regular doctor visits and good communication will control side effects to the extent possible. The biggest issue was that the problems persisted over six months, that she reported it, along with her sister/caregiver, and that she did not see the doctor during this period at all. She was given an inhaler. From **Deborah**: This can be a teachable moment. You can say, “as a patient, I will not take this (next) treatment until you find out why… I am having this problem.” This is a real red flag for the medical team, and you will usually get someone to stop and act on your concerns. Gail said she recognizes the value of Kyprolis in myeloma treatment. She wants to research the Kyprolis study that was halted due to excess deaths to see what changes were made to advance it to its current status. This is a reminder for us all about what it means to be active participants in our care – request to see the doctor if there are concerns that are not being met. However, know that PAs, nurse practitioners, etc. are very well-trained health professionals, and can provide great care for you.

Vermell reminded the group that she is available for phone calls. Vermell is a retired nurse practitioner. She worked for many years at the VA Hospital with myeloma patients. She volunteers with our group and helps to answer some of

the medical questions patients/caregivers might have. She is also a spiritual person – and will offer some mind, body, and spirit support.

Announcements

IMF. New – ***Diversity Communications*** Group. All are urged to be involved.

· **LLS. Funding Updates.** There are two travel assistant programs for patients. Susan Lang Pay-It-Forward Patient Travel Assistance Program for Myeloma and the General Fund. Neither is accepting applications at this time**. Check back to see if more funds have become available.**

· **LLS**. Patients and Caregivers may get one FREE Nutrition Consult. (800) 955-4572 or provide your name for email.

- **Need a ride to your cancer treatment appointments? Lyft partnering with American Cancer Society through its Road to Recovery Program.** Call 1.877.277.2345. You must call at least three days before appointment.

The meeting ended with a prayer led by Pat C. and an inspirational message from Alma – *"Let your love send so much positive energy that it shifts the vibrations in the room."*

Respectfully submitted by Gail

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Southside Multiple Myeloma Support Group – Southside group meets at 10:00 on the fourth Saturday of each month in second floor Meeting Room at the Macy's on Greenbriar Pkwy. Doris Morgan 404-346-1372; dorismorgana@aol.com , Gail McCray 770-996-4964; mccrayg@aol.com web

site: ssatlanta.support.myeloma.org

Southside Meetings: **10/27/2018; 11/24/2018**

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Northside Meetings: **11/3; 12/8/2018**

Meets 11:00 AM on the 1st Saturday of each month

New location starting in July ----

Shallowford Presbyterian Church

2375 Shallowford Rd.

Atlanta, GA 30345

mmsg.org, email: aammsg-2@comcast.net

For additional information, contact:

Nancy Bruno 404-374-9020;

Sandy Brown 470-514-5330

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.