

August 2017

**Northside Multiple Myeloma Support Group Meeting  
August 5, 2017**

**Business**

Nancy B. led the meeting and approximately 50 people attended. The group has new business cards that are available at the meeting; feel free to take some to share with your new connections.

**Guest Speaker** (*Hardcopy prints of the presentation slides that contain details of the study are available in the group's library.*)

Thank you to **Dr. Elizabeth Brown**, from the **University of Alabama, Birmingham (UAB)**, who presented preliminary findings from the **Molecular and Genetic Epidemiology (iIMAGE) study** of multiple myeloma (MM), conducted to characterize molecular signatures of high-risk disease, understand the ethnic differences in disease prevalence, and determine the causes of myeloma. Many in the group participated in the information gathering part of this study years ago by giving blood and completing a questionnaire at Morehouse College. The trial is currently in the discovery phase in Birmingham, AL and remains open for enrollment in Birmingham. From May 2009 to present (ongoing) the iIMAGE team managed the study that included 2,001 unrelated participants comprised of 822 African American and European American patients; and 1,179 sex, age, and ancestry-matched controls (participants who do not have cancer and select comorbid conditions). Detailed clinical data included exposure, clinical, laboratory, radiology, genetics and survival from sources including patient and control group interviews, clinical bioinformatics, and national death index. Genetic, clinical, and environmental (macro and micro) markers were analyzed. UAB collaborates with the International Multiple Myeloma Consortium (IMMC). The IMMC collaborates worldwide and includes 22 studies and approximately 5,000 cases and 11,500 controls.

High level findings from the IMMC study that are also supported by the iIMAGE study follow:

- Smoking history and risk of MM: No significant relationship between smoking and MM risk.
- Alcohol consumption and risk of MM: Modest protective effect of drinking alcohol and MM risk, although likely not clinically significant.
- Reproductive factors and risk of MM: No significant relationship between parity, gravidity, oral contraceptive use, or hormone replacement therapy and MM risk among women.
- Body Mass Index (BMI) and risk and progression of MM: BMI is a modifiable risk factor that is associated with increased risk of MM and a recent study suggests the transition of MGUS to MM.
- Family history and risk of MM: First degree family members of MM patients are at increased risk for MM and this risk is stronger among African Americans
- Inherited genetic factors and risk of MM: a) Several inherited mutations are associated with increased risk of MM and survival, although integrative genomics and functional relevance studies are warranted, and b) Several inherited genetic factors also demonstrate abnormal gene function, which in time may become targets for drug development.

The findings from the ongoing studies suggest that genetic and epigenetic differences may advance biomarker discoveries. Improved diagnostics will assist with the ability to define patients who will progress from high-risk precursors (MGUS and smoldering multiple myeloma (SMM)) to MM. Researchers continue to look for biological patterns unique to high-risk MGUS patients in order to change screening practices and how these patients are managed. The ability to identify the markers of

events driving MM will improve the means for early detection, disease classification, and more effective therapies.

**Dr. Brown graciously answered many questions during the presentation:**

Q: How did you become interested in multiple myeloma?

A: In general, an interest in immune and inflammatory-related diseases.

Q: Was diet considered in the iMAGE study?

A: No.

Q: How do chromosome deletions occur?

A: They occur over time in monoclonal plasma cells due to exposures.

Q: How do toxins affect our bodies?

A: Toxins can cause changes in DNA and that affected DNA can become less or more active.

Q: Why don't doctors routinely check for MGUS?

A: Although we know that all patients that are diagnosed with myeloma have also had the high risk precursors to myeloma, i.e. MGUS and smoldering myeloma (SMM), MGUS in the population is rare and currently insurance does not support the testing as a routine test.

Q: In the future, how can patients with high risk factors for developing MM be identified by primary care physicians on routine visits?

A: First, there is a need to replicate the results of the study that indicate high risk factors with a larger population to re-confirm. Then, advocates will need to address with Capitol Hill, insurance companies, train medical staff, etc. Moving research findings to a clinical practice takes time.

Q: Is the UAB lab associated with Emory?

A: An association can be built by discussing with Emory doctors. Mention the iMAGE study performed at UAB when you meet with your medical staff.

Q: Can we tour the UAB lab?

A: Yes, contact UAB for a tour and mention the iMAGE study.

Q: How can I enroll in the iMAGE study?

A: To enroll in the study, contact UAB or Dr. Brown for instructions.

Dr. Elizabeth E. Brown, PhD, MPH

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**Member Updates**

Someone reported that Anthony, who had a second stem cell transplant in July at Northside, is doing well. Dirk was scheduled for a stem cell transplant in July, but was not yet cleared on the heart function test. He was prescribed some standard heart medication and will retest. Libba reported that she has reduced her Revlimid dosage to 10 mg. every other day with 2 weeks on and 2 weeks off. The drug is still working well for her and the side effects are reduced. Carolyn H. reported that she had been getting

lots of infections and so she will begin IVIG (Intravenous Immunoglobulin) treatments once a month in the November – March timeframe. She mentioned that the treatments work well but can be hard to get approved. Others also mentioned having good results from the IVIG treatments. Libba also recommended getting a pneumonia vaccine. Sandy B. has been experiencing severe pain in her back and legs, which used to be controlled with epidurals every 4 months. Due to scar tissue that formed, the epidurals were no longer an option for her and so she has recently completed a trial for a spinal cord *neurostimulator* manufactured by Medtronic, which is used to treat chronic pain and is controlled with a hand-held device. During the 5 day trial period the device was used externally, and after one day Sandy was able to control the pain and remained nearly pain-free the entire time. Sandy will soon have the outpatient surgery to implant the system internally, which will entail a 4-6 week recovery period. Sandy mentioned that the representative from Medtronic, Rick Jernigan has been very attentive and helpful.

- Submitted by Wendy R.

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**Southside Multiple Myeloma Support Group  
August 26, 2017**

Doris opened the meeting with a moment of silence. There were 16 present, 3 were new members.

We welcomed three new members Everett (MM patient), his daughter April and son EJ. Everett was diagnosed in 2003 with smoldering MM he went through chemo 4 cycles - 2 shots per week – of Revlimid (Rev), Velcade (Vel), and Dexamethasone (Dex), . He is being treated at Northside and is preparing for a stem cell transplant (SCT) on September 11. Everett has severe peripheral neuropathy, which is debilitating and is seeking some relief. Others shared their experiences with Gabapentin/Neurontin, Vitamin B-complex, (Vitamin B-12, B-6, Folate, and Thiamine). *A reliable source of more information for PN and other info is the Mayo Clinic ([www.mayoclinic.org](http://www.mayoclinic.org)). Vitamin B is the nervous system vitamin.*

We welcomed back Carla who has been living in middle Georgia for the past 2 years. She was diagnosed in 2012; she went through Rev/Vel/Dex regimen, and has been in remission since 2013. She is on Revlimid (5 mg) for maintenance and acyclovir (400 mg once daily). Carla visits her oncology team once every six months, and continues to live a happy and fulfilling life.

Those present introduced themselves by way of their experiences along the Multiple Myeloma (MM) journey. Deidra and her mother Mattie were present; Deidra is enrolled in a clinical trial using Dex, Velcade, and Panobinostat/Farydak, one of the newer classes of MM drugs; she will start this treatment next week 2 times per week. She is seeking resources for health insurance plan as she is currently uninsured. It seems once her daughter turned 18 years old specifics of her insurance changed; Joyce offered to talk with them about possible resources.

Doris was diagnosed in 2004 and was given 3-5 years to live; she was treated with Thalidomide and Dex. Doris chose not to have a stem cell transplant because she went into remission after her initial treatment. She was in remission for several years, relapsed in 2016 started treatment with Rev (15mg), Dex, and Acyclovir, to reduce the chance of getting shingles. *Those who have gone through SCT should not have the shingles vaccine, as its component is a live virus.*

Ethel was diagnosed Feb 2015, went through treatment and had a-SCT in same the year in July. She is on maintenance with 10 mg of Rev, Klor-Con (a prescription potassium supplement). Philip is Ethel's caregiver and husband of - 50 years.

In 2014 Don had a triple coronary artery bypass. He got sick soon after the bypass, and was then diagnosed with MM. He was being treated at the Hillandale Hospital in Decatur, had physical therapy at Northside, where he was diagnosed with MM in 2015. He is in remission – taking Revlimid (25mg) for maintenance – 14 days on, 14 days off. Don did not have a SCT.

In 2012 Joyce was treated for a broken rib. She was diagnosed with a non-aggressive type of MM. She went through a tandem SCT at Northside Hospital, and has been in remission for two years. Her protein went from 12% to 4.9%. She does take Rev for maintenance. Joyce was diagnosed with ovarian cancer in 2016 and had a hysterectomy. She emphasized to everyone how important it is for *everyone to continue regular visits with their Primary Care doctors.*

Janice was diagnosed in 2012 with anemia. Tests determined she had MM. She was treated with Revlimid and dex. In September, 2012 she had a SCT and achieved a partial remission. In August 2016, Janice developed a rash; the dermatologist's biopsy determined a type of lymphoma. She is now being treated for lymphoma, specifically CTCL (Cutaneous T-cell Lymphoma. This is a secondary cancer developed from MM treatment. She was taken off Velcade because she developed toxicity. Janice was also treated with Pomalyst last year and she developed Atrial Fibrillation (Afib). She was hospitalized three times last year. Janice is not in treatment currently and her team is watching and waiting to determine the next step. Janice is treated at Emory and Atlanta Cancer Care and has quarterly appointments for her MM.

Geraldine had a broken rib and collar bone in 2013 – they found bone lesions; she had stem cells collected, but due to treatment for dental issues, her SCT has been held off, her numbers are climbing again. She has had pain and swelling with her radiation. Her regimen now includes Velcade, Dex and Daratumamab. She is being treated at Kaiser Permanente.

Paulette is Caregiver to Gail and is Communications Coordinator for the Group. Gail was diagnosed in 2008, went through four rounds of standard Rev/Vel, Dex, harvested her cells, and was in 'near complete remission' for almost 7 years. Protein numbers began to climb in 2015. She is now on an oral regimen of Ninlaro (same class as Velcade) and Pomalyst (same class as Revlimid). Dex was reduced over time and finally discontinued after about one year. Ninlaro and Pomalyst were started at maximum dosage of 4 mg, and at last appointment were reduced to 2.3 and 3 mg, respectively. They are following the lab values closely as medications and dosages are adjusted.

Kimberly was diagnosed after a gynecologic check-up in 2008; it took a month to determine she had MM. Her team has consisted of Kaiser, Georgia Cancer Specialists, and Northside to arrive at her current status. She had her Stem Cell Transplant at Northside. She has been in 'stringent complete remission' since October 2, 2009, and is on no medication. *There are about seven levels of remission in MM. Be sure to ask what kind of remission you have attained.*

Larry was diagnosed in October 2012 after a car accident. While being treated at Grady, X-rays and other tests conducted during a thorough evaluation revealed he had MM. He had a Stem Cell transplant at Emory in February 2013 and achieved stringent complete remission. Larry is back at Emory with Dr. Kaufman. He is on Revlimid (25mg), Dexamethasone (40 mg/week) and Daratumamab (3hr infusion). He is back on Zometa every 3 months, and takes aspirin and acyclovir. Early on, Larry struggled with the question of taking medications when there were no symptoms. We should always know why we are taking each of the medications we take, and pay attention to lab values at each visit. Kyle was diagnosed in 2005 with smoldering MM and enrolled in nursing school at Tuskegee University so he could learn as much as he could about the disease. In 2015, the MM became active, and he had a stem cell transplant. He just completed a six month, Phase 1 of a clinical trial with Ninlaro and Revlimid. His myeloma will be re-staged in the coming week.

Vena was diagnosed in 2007 by her Primary Care doctor. She had been a very active person, and was diagnosed with anemia. A bone marrow biopsy resulted in a definite MM diagnosis. She was told to expect to live about three years with this diagnosis. She was treated for 1 year. Vena says we should *find out as much information as we can – usually the pharmacist knows a lot – this is an underutilized resource*. The first part of this year, she was diagnosed with an even more vicious cancer -- Lung cancer that has spread. She now gets frequent blood transfusions and injections for her white blood cell count. She is enrolled in a Clinical Trial with Ovio, an Immune therapy drug. This therapy has provided her with much relief.

Yvonne is a breast cancer survivor and has been a faithful friend and supporter of our MM support group since 2006. Motine is also a great supporter of the group. Her brother had MM, lived near Athens, and passed away a few years ago. They both are very engaged in the group, and ask insightful questions. We are fortunate to have them. We are also grateful for Deborah one of our two nurse members, was able to assist with some of questions and concerns from members. Deborah has worked at the V.A. Hospital for 39 years. She encouraged any of the members who are Veteran's to strongly consider the VA for their care. *There are many benefits for MM patients who are also Veterans.*

*Thoughts and Prayers for our members who may be struggling physically, mentally, and emotionally are encouraged.*

- Submitted by Paulette and Gail

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.