April 2018

**Northside Multiple Myeloma Support Group Meeting**
**April 3, 2018**

## News and Business

Thank you to Lory M. and Ed S. who led the meeting. A new location is being sought for meetings beginning in July. The last meeting at the current location will be on June 2nd. We are exploring a new location near to the current location and should know something within the next few weeks. We have been fortunate to meet in such a great space for over 15 years!
We have some guest speakers who will visit the group in upcoming meetings. In May, Dr. Harvey, a pharmacologist from Emory will join the group to speak and answer questions. He is head of the Phase I clinical trials at Winship, so bring any questions about clinical trials. In June, a nutritionist will be the guest speaker. Carolyn H. spoke of the upcoming Multiple Myeloma Research Foundation (MMRF) – sponsored 5K Walk/Run scheduled for Saturday, May 12th. Per Joe H., if you would like to join a team to support this event, please consider "Team Joe's MMFs (Multiple Myeloma Fighters)". Search the internet to find additional information. With sadness we learned that Tom L., a long-time valuable contributor and supporter of our group recently lost his son. Please keep Tom in your thoughts and prayers. After discussing news and business the meeting commenced to meeting new members and hearing of others' status and progress.

## New Members

The group welcomed four new members this month. Each member introduced themselves and spoke of their multiple myeloma (MM) journey to date. Elaine M. was diagnosed in December 2017. She began treatment with Velcade, Revlimid, and Dex at Northside and is in the 4th cycle and considering a stem cell transplant (SCT). Nicole M. attended the meeting on behalf of her Mother, who lives in Columbus, GA, who was just diagnosed last week. Nicole attended the meeting to gather research and learn more. Patricia B. was diagnosed in September 2017. She began treatment with Velcade and Dex and is considering a SCT. Cynthia B. was diagnosed in January 2013. She had a SCT in 2013 and was in remission for 3 years. When she relapsed, she began treatment with Carfilzomib (a.k.a. Kyprolis) with great results and no side effects.

## Open Discussion

The majority of the meeting was used to get patient statuses and treatment updates. Many shared their stories and history. A show of hands indicated that there were many in the group who had had SCTs, including some who have had multiple SCTs. In general, the experiences of those who have had SCTs were quite varied from those who had a very good and easy experience to those who had more difficulties, especially in the weeks afterward when side effects such as fever and GI issues presented. Some individuals took longer than others to overcome the side effects of this treatment. It was noted that MM, itself, and the effects of the associated treatments are unique per individual. Steve S. was diagnosed in 2003 (at age 50) with smoldering MM before progression. He was treated with Kyprolis, Velcade and Revlimid. He stopped Velcade after getting pneumonia and had some complications with Revlimid. He had a SCT in October 2017 at Emory. He said that he had a great experience - he walked every day and stayed positive throughout his treatment. Recent tests indicate that no MM is present. He plans to begin maintenance with 10 mg. Revlimid in May. Steve also mentioned that he has had an IVIG (immunoglobulin booster) because his IGG level was low. Steve shared that he was hesitant to get a SCT because he had an aunt and several friends with MM and their experiences were not as good as his. Steve really likes Emory and the doctors there and is very positive about all the treatment options that are

available for MM. Steve is using XGEVA (rather than Zometa) that is administered as an injection in the arm. Dirk B. had a SCT at Northside in November 2017 and had a good experience. He shared that he had a fever after receiving the Melphalan and was hospitalized for 6 days as a precaution, but generally felt OK throughout, even during the hospitalization period. Dirk has started maintenance with 10 mg. Revlimid and has not had any side effects. Lory M. was diagnosed with smoldering MM in 2011 at a routine physical exam. After a year the disease progressed, and she began treatment with Revlimid, Velcade and Dex. She had a SCT in 2013 and has relapsed several times since. She experienced separate relapses with Revlimid maintenance, Velcade, and Ninlaro. She is currently taking Daratumumab, Revlimid, and Prednisone which has been working well for two years. She has side effects from the Revlimid but is able to manage them. Carolyn H. was diagnosed with smoldering MM in 2007 after visiting four different doctors before visiting Emory. After six months the disease progressed, and Dr. L. took her goal to be cured seriously. She enrolled in a Phase 1 clinical trial (CT) with Elotuzumab (now approved). She enjoyed a very good partial response (VGPR) for 5-1/2 years. She then continued with another CT using Daratumumab (now approved) and is still on this drug with good results. Thank you to those who participate in CTs – they are helping the entire MM community with their participation! Dana D. was diagnosed in 2000 (at age 40). He consulted with Dr. Durie, Chairman of the International Myeloma Foundation (IMF), and had his first SCT in 2001 on his 41st birthday. He enjoyed being drug-free (no maintenance) for four years and then took MM drugs before his second STC in 2009. Dana described himself as "the worst patient" especially in the beginning of his journey. He did not want to get a SCT or be a part of a support group. His wife, Susan, encouraged him to think differently. Dana mentioned that he now appreciates a lot of support and was very complimentary of the group's non-judgmental attitude, encouragement and knowledge sharing. Dana reminded everyone to harvest stem cells early and ideally before much treatment, as the drugs used to treat MM will ultimately diminish the capability to collect stem cells. Hector (a retired doctor) was diagnosed seven years ago when a newly diagnosed MM patient was given a 4-5 year survival rate. Now a newly diagnosed patient is given a 9-11 year survival rate. Hector has had a SCT and is a big proponent of CTs and research. He also reminded new patients to collect stem cells early and explained that SCT is considered a "salvage" therapy, with the purpose being to allow recovery from the high-dose Melphalan that is administered just prior to the transplant. Jim M. also had a SCT and was very sick for about 3 weeks. He has maintained remission for about eight years using Revlimid. He began with 15 mg., then reduced to 10 mg., then reduced again to 5 mg. to control GI side effects. Jim mentioned that the reason for relapse is because the MM DNA changes when it resurfaces. He also mentioned that there are different kinds and levels of MM but they all have some common characteristics and, thus, can be treated by some of the same and specific drugs. This is also why multiple agents in combination are used and can best treat MM. With so many options available to us for treatment we can balance the side effects and dosages of drugs with our quality of life requirements to help make our individual treatment decisions. Jim mentioned that he has also consulted with Dr. Durie from the IMF to help with and confirm his decisions. Barbara H. was diagnosed 12 years ago. She has had two SCTs with no maintenance afterward until relapse occurred. Upon relapse she is able to control the disease with drugs and she has used most of the available drugs. She has no additional stem cells available for another SCT. She mentioned that she found the SCTs to be a fairly easy experience. Her current type of MM has presented as extramedullary (outside of the bone). Judy's husband, Walt was diagnosed in 2014. Walt has experienced lots of broken bones and has had kyphoplasty surgery as treatment. He has been treated with Pomalyst (a.k.a. Pomalidomide) and is not a candidate for SCT. Molly's husband, Bob was diagnosed in 2011 and has elected to treat the disease with drugs rather than having a SCT. Someone mentioned that those who are eligible for SCT but elect not to have a SCT early on should consider harvesting stem cells early anyway, as it is the best and easiest time for collection. You may change your mind later and it could become difficult or impossible to harvest stem cells after drug therapy. Brenda was diagnosed in 2009 and was treated with Revlimid and Velcade. She participated in a CT to produce SCT and has collected enough for three SCTs. She relapsed in January 2018 and is now considering a SCT. Libba has relapsed three times and most recently experienced a high-risk type of extramedullary MM, which was found on a PET scan and successfully

treated with Revlimid. There is no sign of the disease now. Libba explained that the same drugs work for treating both types of MM – extramedullary and non-extramedullary. Milton B. was diagnosed in 2007. He had a SCT in 2010, which did not help him, and participated in a CT which did not work for him. He is now on a single agent therapy of Daratumumab, a monoclonal antibody, which has helped him achieve remission for over a year. Milton has not experienced side effects from taking Daratumumab. Todd B. was diagnosed in January 2015. He had a SCT in June 2015, followed by Velcade for maintenance, which resulted in neuropathy. He has been on Ninlaro for about two years with fatigue as the only side effect. Todd explained that he has high risk MM, identified with the FISH test which does chromosome mapping. He has been MRD (minimal residual disease) tested via a bone marrow biopsy as part of a trial in which he participated. Todd is interested in the Bluebird Bio CAR-T cell immunotherapy trial at the University of PA, which genetically modifies CAR-T cells to make them kill cancer cells. Marilyn was diagnosed with smoldering MM ten years ago. She has adopted a very healthy lifestyle and has not been treated with any MM drugs. She is monitored regularly, and her MM numbers are increasing, but she has no bone pain, good kidney function, and all CRAB criteria are good. Scott was diagnosed in June 2014 (at age 44). He experienced 4 broken ribs, a broken clavicle, and broken arm and leg. He had a SCT in October 2014 and has been in remission since then. He is using 10 mg. Revlimid for maintenance. He has side effects from the Revlimid but is able to manage them. Sandy B. has been a member of the group since 1998. Sandy was diagnosed in 1986 (at age 46) with smoldering MM. The disease progressed after five years and she eventually began traditional chemotherapy, which caused her to be sick often and requiring frequent transfusions. She began taking Thalidomide in 1999. It took ten years (1994-2004) for her to achieve remission, and from 1999-2009 she was on maintenance therapy. She has not had a SCT and from 2009-2016 she did not take any MM drugs. In 2016 she relapsed due to stress. Sandy suffers from severe neuropathy and damaged nerves from many years of drug therapy. In 2017 she had a spinal cord stimulator implanted to help manage pain, which is working but not providing the response that she had hoped for. Sandy rises to her challenges and enjoys helping others. She is an inspiration to us and regularly checks in with group members who are unable to attend meetings; she reported on several members that she has recently spoken with: Vanessa F. has taken Revlimid for a long time and is experiencing GI issues, which she is managing with Welchol and Viversa. She hopes to join the group again soon. Virgil P. has been on Revlimid for 11 years with stable MM but other challenges. He has had skin cancer, which is much better and has been in a wheelchair for three years. He also hopes to join the group again soon. Throughout the discussion various members talked of the importance of maintaining general health by getting regular exercise, having a healthy diet, getting good sleep, and managing stress. It was clear from the discussion that controlling MM is a very individual decision that requires ongoing, never-ending research. With so many options, combinations, and dosages we are able to change our treatments according to our needs with the help of our own research and knowledge and our medical team's assistance.

Submitted by Wendy R.

**Southside Multiple Myeloma Support Group Meeting**
**April 28, 2018**

Our May Meeting will be a focus on patient/caregiver discussions. There will not be a guest speaker.

We were excited to have Dr. Natalyn Hawk, MD, PhD present at our April meeting. Dr. Hawk is a hematologist/oncologist and is a clinician/researcher at the Veteran's Hospital and Emory Winship. Her presentation was on **Colorectal cancer: Screening, Diagnosis, and Treatment.**

**Presentation:** A strong immune system is the first round of defense from infection – and from cancers. Some of the current research and therapies are immunotherapies. Immunotherapy offers the possibility of retraining a patients' own immune system to recognize and attack cancer within their own body. There are already several immunotherapy drugs being tested in clinical trials in myeloma. Elotuzumab and Daratumumab are monoclonal antibodies that are a part of immunotherapy.

The signs and symptoms of colorectal cancer can be vague. Sometimes there is abdominal pain, but 80% of more advanced colon cancer cases have abdominal pain.
**For Stage 1 cancers** -there are usually no symptoms. Constipation can be a symptom. Sometimes, it's a matter of putting nonspecific signs and symptoms together over time. Colorectal cancer is a disease in which abnormal cells in the colon or rectum divide uncontrollably, ultimately forming a malignant tumor. (The colon and rectum are parts of the body's digestive system, which takes up nutrients from food and water and stores solid waste until it passes out of the body.) Colorectal cancer is the third most common cancer in both men and women, after lung and breast cancers in women – after lung and prostate cancers in men. Risk factors for **cancer** of the **colon** and rectum (**colorectal cancer**) include **colon** polyps, long-standing ulcerative colitis, and genetic family history. Most **colorectal cancers** develop from polyps.

**Family history** is extremely important in determining your risk. Family reunions are a good time to exchange health (cancer) information among family members and across generations. Genetic counselors can help you to create detailed family health history trees. Knowledge of your family history can help you to determine if you should get mammograms earlier and more frequently. You may need to request colonoscopies earlier and more frequently. Your lifetime risk of getting colorectal cancer increases 2-4 times if you have a first-degree relative (mother, father, sister, brother) as well as if you have second-degree relatives (grandparents, aunts, uncles, first cousins, etc.). Genetics play a definite role. There are some things you can change – genetics you cannot change.

Outcomes might be different. Consider these two cases: 1. A 65-year old female who gets routine care – she has had no new events. She had a colonoscopy at age 50. A recent GI exam found a mass; 2- A 65-year old male has had symptoms for one year. He has had weight loss, abdominal pain that comes and goes. A mass was found in his abdomen on a CT-scan. Which do you think might have a better outcome, and why?

Fortunately, Dr. Hawk reviewed cancer 101 with us, to provide us with a baseline for understanding colorectal cancer. All the cells in our body know what they are supposed to be when they grow up – whether skin or hair cells, or liver or heart cells, for example. These cells divide and continue to grow in a normal, regular pattern. When those cells are injured – whether from the environment, alcohol consumption, or too many fried foods – the body in its wisdom tries to repair itself. Our immune system will kill most foreign cells. It tries its best to repair and replace these foreign cells. If the cells are not repaired, they divide in an uncontrolled cell growth and become cancer cells, which may move about the body in an uncontrolled, unchecked way. As a mass of cancerous cells grows, it can develop into a tumor. Polyps are genetic modifications – they can be spontaneous or come from other exposures.

**Most colon cancer starts as a polyp. A** polyp may show as the two most common polyps: hyperplastic or adenoma in the pathology report. A polyp is a group of cells that grow bigger in size, not in number. **Adenomas** can be reluctantly benign but have the potential for being cancerous. They increase in both number and size. If benign polyps are not removed, they may become cancerous over a 10-year period.

Polyps can come back. They also may have been missed the first time. The polyp that was biopsied may have been benign. Adenomatous polyps are a common type. They are gland-like growths that develop on the mucous membrane that lines the large intestine. They are also called adenomas and are most often one of the following: Tubular polyp, which protrudes out in the lumen (open space) of the colon and Villous adenoma, which is sometimes flat and spreading, and is more likely to become a cancer. If you have adenomas, the polyps should be removed, and your next colonoscopy will be sooner than if adenomas were not present.

When you get results back for pathology report, there may be a mass, but "results not available." Insist on the pathology report. If there is dysplasia, it's free from cancer. There may be a potential of cancer in 2,3, or 5 years. Dr. Hawk thinks colonoscopies should be done more frequently that every 10 years. Dysplastic polyps need to have follow-ups to ensure it has not spread to lymph nodes. Sessile Polyps are those that tend to grow as slightly flattened, broad-based polyps. Serrated polyps have a saw-tooth like edges in appearance and need to be removed from your colon (Understanding your pathology report: colonoscopies – American Cancer Society -https://www.cancer.org/treatment/understanding-your-diagnosis/tests/understanding-your-pathology-report/colon-pathology/colon-polyps-sessile-or-traditional-serrated-adenomas.html).

There are a small number of people who have inherited disorders with polyps, Familial adenomatous polyposis (FAP) and Lynch syndrome – genetic conditions where there are hundreds of polyps in the colon. They may need to have annual colonoscopies to remove the polyps.
Dr. Hawk says her antennae go up if she finds 5 polyps on the right – and 3 polyps on the left transverse colon. There may be cancers that are left behind during the endoscopy.

*An endoscopy is a procedure used in medicine to look inside the body. The endoscopy procedure uses a flexible scope to examine the interior of a hollow organ or cavity of the body. An upper endoscopy uses a flexible tube called the upper endoscope through which the **lining** of the esophagus, stomach, and duodenum. In a **Colonoscopy**, the endoscopy examines the lining of the large intestine, colon and rectum. They can be viewed by a flexible tube inserted through the rectum.*

**Screening Guidelines.** The guidelines do not recommend regular screening colonoscopies after age 75 (US Preventive Task Force). If you are symptomatic, then they may be indicated. For seniors who are active, colonoscopy may be recommended versus a senior who has Alzheimer's. Other co-morbid conditions might be considered. Do ask for a second opinion, if you have any concerns about what is recommended for you. Colonoscopies are necessary.
**Stool cards.** This is a test used to look for occult (hidden) blood in your stool – Fecal Occult Blood Tests (FOBT). Blood in the stool would indicate a colonoscopy is needed. Colvera – DNA in stool is more common than a stool card. Stool cards should be administered every year. Check with your primary care doctor, if this is not offered to you. The VA is consistent with offering regular screenings, where many primary care doctors do not.

Begin colonoscopies by age 50. For African Americans, where colon cancer is more prevalent, it's better to consider starting at age 40. Pay attention to any symptoms, including bleeding and hemorrhoids.
**Q:** Who gets more colon cancer? **A:** It's mostly equal in males and females. As we age, the risk is higher.
**Q**: Say more about the guidelines. **A**: If you have a completely clear colonoscopy, the recommendation is every 10 years, for anything else, every 5 years is probably better. Insurance coverage is dependent on how the procedure is coded – whether it's coded as a screening or diagnostic procedure. This is something your provider can work on. You should feel empowered to ask for more frequent colonoscopies, if you feel it's needed. Remember, a second opinion is your right in protecting your health.
**Q:** What is the largest polyp ever removed? **A:** Probably 8-9 cm or 4-5 inches. Sometimes, polyps are cancerous, sometimes they are benign.

**Prevention.** While we cannot change our family history, we can modify other risk behaviors. Physical activity seems to be an answer to many of our health issues. Exercise can help with the transit time (amount of time your food remains in your body) of food in your GI tract – and that includes any toxins that may be in your foods. Limit the amount of red meat, fatty foods, and fried foods you eat each week. Obesity is a risk factor for many cancers, including breast, colon, and myeloma. Cigarette smoking and excessive alcohol consumption (more than a 6-pack per week). Pay attention to what happens between screenings.

**More.** Folic acid in a multivitamin may help to decrease colorectal cancer risk. Aspirin may also decrease the risk. Please check with your healthcare provider to be sure you have no reasons in your medical history that would conflict with any supplements you take. A baby aspirin might be better for you. If you get dark stools, stop the aspirin and check with your doctor. Hormones can protect women from breast cancer and colorectal cancer. After menopause, the risk increases. Calcium supplements and selenium in multivitamins might decrease the risk of colorectal cancer.

**Post-presentation comments.** We had a discussion about the Golden State Murderer who was caught after more than 40 years. He was found through DNA that came from a genealogy program similar to *23 and me*. Can DNA be so easily accessed across private businesses and public safety and other agencies? Dr. Hawk agreed that we should all think critically about when and where we share our genetic information. With our clinical trials that are more often contributing to the science of precision medicine, we should read our Informed Consent Forms more carefully, and hold more discussions with the research team. We should invite an IRB member to talk about informed consent.
**Announcements/Upcoming Events**
· **MMRF. Webinar - CoMMpass Study: Insights for Patients and Caregivers. Wednesday, May 23 @ 1:00 PM.** This is a Myeloma Genetics Study. Register: https://beacon360.content.online/xbcs/S1531/catalog/product.xhtml?eid=6997 OR call 1.866.872.5840
· **IMF - Stand up to Cancer (SU2C).** New project to model population study in Iceland. For Myeloma patients over age 45 and African-Americans -- with first degree relatives Mother, Father, Sister, Brother) who have MM. (4/26/2018 released). Details to follow.
· **Morehouse School of Medicine** – Survey. For all Georgians – 5-10 minute survey to determine most health topics. Consensus of group was that we could send survey via email. Hard copies will be brought to May meeting. (Gail)

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

More information on Colorectal Cancer Screening:
Fact Sheet from the National Cancer Institute - www.cancer.gov/types/colorectal/screening-fact-sheet
Respectfully submitted, 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.