

June 2018

**Northside Multiple Myeloma Support Group Meeting
June 2, 2018**

Business

Thank you to **Nancy B.** who led the meeting.

-Please note our new meeting location beginning with the July 7th meeting: Shallowford Presbyterian Church, 2375 Shallowford Rd, Atlanta, GA 30345. The meeting will be held in the church's library and there will be signs and greeters in the parking lot to help you find the room.

-There will be an offsite luncheon scheduled on August 4th instead of the regular meeting. The luncheon will be at the 57th Fighter Group Restaurant, 3829 Clairmont Rd, Atlanta, GA 30341. More details will be provided at a later time.

-Please note that the group's PO Box was closed last year. You may send donations to Nancy B's home address (see bottom of newsletter for details).

-When you order from Amazon, please remember to use the Smile Amazon link: which supports the **Atlanta Area Multiple Myeloma Support Group** and please <https://smile.amazon.com/>, share this link with family and friends.

The month of August marks 20 years since **Nancy and Mike B.** joined the group. Nancy is planning a fundraiser in late August to help support the group and to sponsor a research grant. Details will follow as the event draws near.

Thank you to **Jeannie** who plans our programs.

In October, a speaker will join the group to discuss Medicare.

New Members

The group welcomed two new members. **Vicki** was diagnosed with multiple myeloma (MM) in October 2017 and is preparing for a stem cell transplant (SCT). **Rhea** was diagnosed with MM in September 2017. She is not a candidate for SCT and is deciding on other alternative treatments. She currently suffers from severe neuropathy.

Guest Speaker

Thank you to **Dr. Jennifer Rooke**, Internal Medicine Physician, and Preventative Medicine Specialist. Dr. Rooke joined the group to discuss nutrition and began by asking those at the meeting to voice their concerns on this topic. Concerns included chemicals in food, processed food, immune boosting foods, benefits of nutritional supplements and vitamins, boredom with food, eating too much, eating too little, sugar and junk food cravings, lack of appetite, unplanned weight gain and weight loss, eating to prevent or control disease, controlling stress eating, eating what appeals to you when not feeling well or managing side effects even if you know that the food is not nutritional, and a general lack of understanding of what "eating well" means when you have a chronic disease.

Dr. Rooke has seen amazing results when people with chronic illnesses change their lifestyle. For example, by adopting a plant-based diet she has seen patients reverse diabetes and high blood pressure in 6-12 months, and some results are apparent within just weeks. Diabetes is

a metabolic disorder. Fat and protein make diabetes worse, and limiting both helps control diabetes. Other chronic illnesses can also be controlled with a healthy diet. Cancer is a disease in which cells grow abnormally and don't die as they should. There are three basic stages of cancer development: 1) initiation (DNA damage), 2) promotion (cells multiply into masses or tumors), and 3) progression. There are many causes of DNA damage. The immune system contains natural killer cells. Phytonutrients in fruits and vegetables can also kill cancer cells. In the promotion stage your immune system tries to kill cancer cells. The reason people get cancer is because their system does not kill the rogue cells. When there are too many damaged cells that overwhelm a weakened immune system then cancer occurs. In the promotion stage, cancer is reversible. A whole food, plant-based diet supports this effort. There are over 500 genes that are affected by lifestyle changes. Cancer suppressors can be turned on or off in the promotion stage by diet. Dr. Rooke provided a lot of information and answered many questions for us, as follows.

Q: What is your recommendation for healthy eating? **A:** Following a whole food, plant-based diet is the recommendation. You should consume at least five servings of fruit and vegetables a day, but more is highly beneficial and recommended.

Q: What can I do to manage my sweet tooth? **A:** Honor your sweet tooth. Mother Nature gave us a sweet tooth and vision for bright colors so that we would eat fruit, which is packed with nutrients, not for eating candy and baked goods. Eat whole, unprocessed fresh fruit. All fruits and vegetables suppress and kill cancer cells.

Q: What about dark chocolate? **A:** Dark chocolate is a bean, and is good for us. Sugar and processing is not good for us. Consuming dark chocolate from a clean source is fine in moderation.

Q: How can I control diarrhea with diet? **A:** A BRAT diet – bananas, rice, applesauce, and toast can be an effective way to control diarrhea.

Q: Can you recommend how not to stress eat? **A:** Find healthy ways to manage stress to avoid emotional eating. When you snack, opt to eat healthy, nutritional calories only, and avoid processed foods that can lead to unnatural cravings.

Q: Please comment on supplements in our diet. **A:** In general, the recommendation is to avoid supplements. The only recommended supplement to incorporate into your diet is Vitamin B12 because there is no natural source. When you eat whole foods and avoid processed foods you should be able to obtain your nutrients from your diet alone. It is best to obtain all nutrients from food, not supplements. Some supplements increase the risk of cancer. For example, beta carotene in pill form increases the risk of cancer but beta carotene in food helps prevent cancer. Fish oil promotes aggressive prostate cancer. Dr. Rooke cautioned against supplements including beta carotene, folate, fish oil, folic acid, and other isolated supplements.

Q: What are some immune suppression causes? **A:** Alcohol, psychological stress (cortisol), and animal protein.

Q: Do any plants contain cortisol? **A:** No. Some plants have small amounts of cholesterol only. Cortisol is produced from cholesterol and when cholesterol is cooked, its structure changes. For more information, conduct an internet search on “oxidized cholesterol and immune system” to learn how this can lead to chronic inflammation.

Q: What promotes cancer growth? **A:** Weakened immune system, stress, and high protein diets.

Q: Can cancer be prevented through diet? **A:** Yes. Some foods, such as processed foods and animal protein, can increase the risk of developing cancer. Other foods such as fruits and vegetables can reduce the risk of cancer. How you eat can determine if you will get cancer.

Plant-based diets can stop the growth of cancer cells. Animal sourced food leads to developing cancer. A diet containing more than 10-12% of animal protein increases the risk of cancer. To learn more about this, Dr. Rooke recommends researching “The China Study”, which examined the relationship between a diet of animal products and the development of chronic illnesses. People who follow a whole food, plant-based diet are less likely to develop numerous diseases.

Q: How can I regain my appetite? **A:** Flavor can help enhance appetite, such as the use of herbs and spices in recipes.

Q: How do I know if my diet is balanced? **A:** A good indicator is how you feel.

Q: Is there a connection between eating meat and developing MM? **A:** Meat consumers are at high risk of developing blood cancers. Consuming two boneless chicken breasts is the equivalent of smoking ten cigarettes a day. Developing lymphoma is linked with the consumption of red meat, processed meat, poultry, and eggs. This may be due to viruses in poultry. Also, the pesticides in meat are within the meat and on the inside. Pesticides in fruits and vegetables are external and can be removed by washing.

Q: What is recommended when purchasing fruits and vegetables to avoid pesticides? **A:** Buy organic to avoid any injected chemicals. If the fruits and vegetables have skin, some of the pesticides can be washed away.

Q: How can we get protein from plants? **A:** Beans, nuts, and seeds are good sources of plant-based protein. Also vegetables such as broccoli and kale contain protein. 100 calories of broccoli has more protein than 100 calories of red meat.

Q: What about mushrooms?

A: Mushrooms are a good substitute for meat. It is recommended to eat cooked mushrooms only, as raw mushrooms may contain a compound that may promote cancer cell growth.

Q: What about tofu as an alternative to meat? **A:** Tofu is a processed food, so you should avoid making it a staple in your diet. Eating soybeans is OK but avoid isolated soy protein because it promotes inflammation and may be a carcinogen.

Q: Why not eat fish? **A:** Eating fish increases the risk of developing diabetes because it blocks insulin.

Q: Why avoid dairy? **A:** There is a protein in dairy products called casein, which may promote cancer cell growth. There are many plant-based options for milk that are readily available and recommended, such as almond milk.

Q: Why avoid eggs? **A:** Eggs are animal protein and there is a substance in egg whites that promotes cancer cell growth.

Q: What about egg substitute? **A:** This is a processed food, so it is not recommended.

Q: Is oatmeal a good food to consume? **A:** Yes.

Q: Is pasta a good food to consume? **A:** Yes, whole grain pasta (not egg pasta).

Q: Is juicing good? **A:** Juicing became popular in the 1920s. It is not recommended today because it removes all of the fiber that helps increase good bacteria. Blending whole fruits and vegetables with their skin is a good option, and eat with a spoon, do not drink or gulp.

Q: Do you recommend colonics? **A:** No.

Q: What are your recommendations for starting a whole food, plant-based lifestyle? **A:** First continue to follow your doctor/oncologist’s advice for medication and therapies and notify them when you are beginning any new health-related regimen. Then, begin slowly. For example, start by making small changes such as substituting fruit for processed sweets (i.e. try frozen fruit instead of ice cream). Begin by trying a whole foods plant-based approach one day a

week. Once these changes become habits, make additional changes, and continue. If you research and plan it will become easier to adopt this lifestyle as you continue to make small changes frequently. Most people will feel better quickly and will want to continue moving toward with this lifestyle. Planning is important so that you have the necessary foods available when you need them. You must educate yourself and do this. It is your responsibility and it is unlikely that your doctors will teach you to do this. Some good places to start: <https://nutritionfacts.org/>, “Eat to Live Diet”, “Forks over Knives”, “Plantation”.

Some videos from Dr. Rooke:

Meat & Multiple Myeloma

<https://nutritionfacts.org/video/meat-multiple-myeloma>

- Meat consumption – high risk of blood cancers.
- 2 boneless chicken breasts = smoking 10 cigarettes/day
- Meat eaters had 75% higher risk than “vegetarians”

EPIC Findings on Lymphoma

<https://nutritionfacts.org/video/epic-findings-on-lymphoma/>

- Study - half million people. Which was most associated developing lymphoma? Red meat, processed meat, poultry, offal, eggs, or milk? Poultry/Chicken

For an appointment with Dr. Rooke at the Morehouse Clinic or to get the newsletter from The Optimal Health and Wellness Clinic, please call 404-756-1400.

Submitted by Wendy R.

Southside Multiple Myeloma Support Group Meeting June 23, 2018

The meeting opened with a moment of silence. Our agenda for this session was to discuss patient and caregiver experiences, issues, and concerns.

We had one new member at today’s meeting. Bill received a brochure from someone while on the waiting room of his oncologist’s office with his daughter, and decided to come in. As it turns out, it was Gail, making good on her renewed commitment to reach more people each month with the myeloma message. Brochures were also left at Emory Winship with permission on literature stands in the laboratory area and with the staff in Dr. Heffner’s office at Emory Winship. The staff promised to include brochures in each chart to pass on to patients. Bill was initially diagnosed with MM in 2006 – then his disease was ‘dormant for 2-3 years. He is in the midst of finding a new therapy, after determining he has an allergy to Revlimid. He is now on Daratumumab and Pomalyst. Carole and Bill’s daughter exercise together at the Atlanta Human Performance Center...small world.

This July 4, Carole will run her 30th Peachtree Road Race. Congratulations Carole, and to your unwavering commitment to a fit and healthy lifestyle. Carole was quick to remind us that she does not try to overly stress herself. She was committed to fitness and running before her MM diagnosis and tries to find ways to continue within the bounds of her new normal. If she feels the

need to walk, she will walk – or modify other exercises as needed. Carole says that exercise improves her quality of life and reduces fatigue. She says she does not want to be a burden to anyone and feels that maintaining a regular exercise regimen will help her remain independent throughout her life. At a very fit 68 years young, she is doing her part to ensure that she remains healthy. Members of Silver Sneakers (receive Medicare), can use the facilities and attend exercise classes free of charge at many facilities, including LA Fitness, Planet Fitness, etc. Doris, Montine, Vermell and others in the group attend free classes at the Ben Hill (Willie Walker) Recreation Center. As mentioned in previous meetings, Emory Winship and the YWCA have a partnership that will allow cancer patients and their caregivers to exercise free of charge. Please check details for the facility most convenient to you. Carole's mentor is Don Wright, a 15-year myeloma survivor who was given 5 years to live when he was diagnosed in 2003. He set as his personal goal running a marathon in each of the 50 states, while continuing his therapy, including clinical trials. He recently achieved that goal in November 2016 and has set new ones in track and field events for seniors at age 76. He always works with a trainer to help adapt workouts to his needs. Lesson: It is important to remain physically active – set fitness goals and stick to them. Exercise can be good for reducing stress and fatigue, preventing injury, and maintaining independence.

An additional reminder of resources for fitness and nutrition includes the Piedmont Wellness Center in various locations around the metropolitan area, including Newnan. The Wellness Centers invite and encourage cancer survivors and caregivers to increase their overall health through participation in classes in nutrition, food purchasing and preparation, stress control, and physical activity. You do not have to attend Piedmont Hospital for your care – and a survivor is anyone who has ever been diagnosed with cancer. Lesson: There are many resources for exercise and nutrition available for cancer survivors. Please do not hesitate to ask if you are not sure about what might be available for you.

There was good news from Geraldine. In our May meeting, Geraldine explained that after being diagnosed in 2016, and being told by Northside Oncology that she needed to have a Stem Cell Transplant (SCT), she would not be scheduled for one until she could find a Caregiver/Supporter to accompany her to daily appointments during the process, which is their protocol. Geraldine's medical provider is Dr. Solomon at Northside Hospital and insurer is Kaiser Permanente *. She was not eligible to stay at the Hope House because she missed the eligibility by about two miles. Geraldine is a single mother of two school-age boys – most of her relatives live in Jamaica. Over the past several years, she has shared her personal status with Social Workers at both Kaiser and Northside. Geraldine reported that somehow things changed when she told them she would have to explore the option of having this potential life-saving procedure at Emory Winship, where the protocol is to remain in the hospital during the SCT procedure. She also has a new Health Care Provider (HCP), a Nurse Practitioner as part of her team who came to Kaiser from Emory, Mr. Paul Johnson. He asked her if she belonged to a Support Group (SG). They told her they would schedule the procedure as soon as her numbers came into a safe range. After more than two years of being told she must have this procedure to control her myeloma, she is excited to finally be able to make future plans for her life and her family. She is currently going to Northside three times a week for her treatment, including radiation. Geraldine has faithfully attended many educational sessions on ASH updates, and other research seminars where she learned about the importance of the SCT as a life-saving

procedure in myeloma treatment. *The SCT is also known as the more appropriately titled High Dose Therapy (HDT) with stem cell rescue (versus transplant)*. Congratulations Geraldine!*

Lessons learned: Any medical treatment should be patient-centered – to improve the quality of life of the patient; Learn all you can about ongoing best practices of myeloma in an effort to be the best partner in your treatment process; and practice finding your voice to ask questions and make requests of your healthcare providers – they are there to serve you. Learning these lessons might just save your life.

We talked about the possible benefits of Palliative Care under these circumstances. Palliative care is specialized medical care for people with serious illness. It focuses on providing you with relief from the symptoms, pain and stress of a serious illness like multiple myeloma. The goal is to improve quality of life for both you and your family. Carole, who also is a Kaiser patient, had her SCT at Northside a few years ago. Carole is in similar situation, single without a built-in support system. She was able to successfully navigate the standard Northside protocol -- going home and returning to the facility each of the 14 days following the transplant. Carole was assigned a Palliative Care provider several years ago through Kaiser. Her palliative care team consisted of physicians, nurses, and social workers. They coordinated her care and appointments. She had six visits with the social worker scheduled and monthly check-in phone calls. She also had access to a chaplain through palliative care. She has been able to have much of the stressors identified by Geraldine drastically reduced or avoided through palliative care. We do not know why Geraldine was not offered palliative care services. At any rate, Carole shared a Kaiser brochure on palliative care with Geraldine. We all hope that no other patients will fall through the cracks as Geraldine's circumstances did – especially when resources are already in place to assist the patient.

Another set of issues in moving forward with the best treatment options is financing cancer care – whether for SCT or expensive medications, co-pays for doctor's visits, or transportation to and from doctor's visits, including parking fees. These are sensitive issues that many patients are not comfortable discussing with their Health Care Providers (HCP) or in Support Group Meetings. The Social Worker at Emory, Kindale, has shared with us a comprehensive list of agencies that are there to assist patients. The handout is lime green in color. Again, patients must speak up and let the oncology staff know that they need help. Geraldine shared that the social worker and the finance department at Kaiser helped to clear her debt.

Karen stressed how important it is to check in regularly with LLS for assistance. She knows she must also check in with LLS and other sources regularly. Doris will check with Kindale and try to get her scheduled to speak with the SG as soon as possible. Larry shared that he is doing well. He and Karen listen regularly to the webinars made available. He continues to do well with the Daratumumab and Pomalyst combination.

Montine was a Caregiver to her brother who was diagnosed with myeloma in 2005. Her brother was diagnosed after he was in a car accident and broke several bones. Her brother lived about 60 miles from Atlanta – Montine used much of the information she gained from the Support Group to assist and make informed decisions in her brother's treatment. Her brother's doctor complimented her many times on her knowledge of myeloma and the therapy options. Though

her brother died in 2013, she continues to attend meetings and contribute to discussions with very thought-provoking questions. She expressed how important it is that we make a conscious effort to spread the word. She learned about a neighbor's suffering from leukemia only after the neighbor passed away. She feels she may have been able to pass on some of the information she gets from these meetings. Carole agreed – and shared that she makes sure she tries to raise awareness whenever possible.

Larry reminded us to register for the LLS Blood Conference Georgia 2018. The date is Saturday, July 21 from 9:00 – 3:00 PM at the Westin Buckhead Atlanta, 3391 Peachtree road, Atlanta, GA 30326. Registration is required. Call: 404.720.7838. Online: www.etches.com/GABCC19. For questions, contact: Tricia Hernandez, Senior Manager-404.720.7838. tricia.hernandez@lls.org. Thanks Karen, for going back to your car for the flyers! This year's Light the Night celebration is on Saturday, October 6, from 5:30 PM – 9:00 PM. In Piedmont Park. Doris offered that we can raise funds as a group, and she would set up the web page. You are also welcome to raise funds on your own. Light the Night is sponsored by the Leukemia and Lymphoma Society (LLS), which has proven to be a vital resource for many of us.

There is a new shingles (Varicella zoster) vaccine called Shingrix that is touted to be more effective and longer lasting than the old vaccine, Zostavax. It is delivered in two dosages. Since it is not a live vaccine, it may be safe for patients with compromised immune systems, like myeloma patients. The CDC recommends: 1) that those 50 and over receive the Shingrix vaccine; 2) even if you received the old Zostavax vaccine, you should get the newer vaccine; 3) if you have had shingles before, because it occasionally recurs, you should get the new vaccine. Please check with your provider and pharmacists -- and share the information with all your family and friends who are over the age of 50. FDA approval for this GSK produced drug came in October 2017. Can we possibly be on the way to doing away with a lifetime with Acyclovir? Announcements/Resources/Upcoming Meetings/Webinars

- TGI Fridays – Thank you to TGI Fridays (Camp Creek) for sponsoring our August meeting. It is a breakfast meeting - August 25 from 8:00 AM – 10:30 AM. – You must sign up with Paulette – a headcount is essential. Contact Paulette: ppmneely@gmail.com or 470.428.2988
- Calling Posts: Thank you again Robin Carnell, for the very energetic, thoughtful and professional calling posts you send each month for our Support Group. Your enthusiasm is contagious – and we know you are part of the reason people place the meeting high on their agendas. Thank you.
- Free rides for cancer patients. 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.
- IMF - *archived* "Bone Health and Myeloma Treatment" (June 20)
- IMF - "Making Sense of Treatment" *archived* from June 13. IMWG and European

Hematology Groups

- 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)
- IMF – Proteasome Inhibitors – Webinar Sections 1-6. Ask Dr. Durie - Doctor's Edition. Patients are encouraged to listen for an understanding of proteasome inhibitors.
- LLS. Emerging Therapies for Multiple Myeloma. Archived.
- LLS. Patients and Caregivers may get one FREE Nutrition Consult or (800) 955-4572 and provide your contact information.
- MMRF - Immunotherapy Webinar Series: 1 - Antibody Therapy for Multiple Myeloma - June 20; 2- CART-T cell Therapy - July 17 at 1 PM; 3- Myeloma Vaccines - August 2018

- MMRF - Precision Medicine Webinar - June 26 at 1 PM and 7 PM; June 27 at 10 AM
- Searching for Clinical Trials? Myeloma Matrix 2.0 Smart Search makes it much easier. - myeloma.org/matrix

The question of the day was What is precision medicine? *Karen got the correct response and re-gifted her prize.*

According to the Precision Medicine Initiative, precision medicine is "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person." This approach will allow doctors and researchers to predict more accurately, which treatment and prevention strategies for a particular disease will work in which groups of people. It is in contrast to a one-size-fits-all approach, in which disease treatment and prevention strategies are developed for the average person, with less consideration for the differences between individuals.

Although the term "precision medicine" is relatively new, the concept has been a part of healthcare for many years. For example, a person who needs a blood transfusion is not given blood from a randomly selected donor; instead, the donor's blood type is matched to the recipient to reduce the risk of complications. Although examples can be found in several areas of medicine, the role of precision medicine in day-to-day healthcare is relatively limited. Researchers hope that this approach will expand to many areas of health and healthcare in coming years.

Source: <https://ghr.nlm.nih.gov/primer/precisionmedicine/definition>

*Stem Cell Transplant. *This term is being changed in favor of High Dose Therapy (HDT) with stem cell rescue.* (See IMF publication – Understanding High Dose Therapy with stem cell rescue).

Respectfully submitted, Gail

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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.