

March 2018

Northside Multiple Myeloma Support Group Meeting March 3, 2018

Our meeting featured guest speaker Kimberly Curseen, MD, Director of Supportive and Palliative Care Outpatient Services at Winship. Dr. Curseen spoke to the group about the services that her group provides and encouraged patients and caregivers to seek the support they need. Previously, the oncologist did it all, but as treatment has become more complex, it is more difficult for the oncology team to be everything to all patients within the short visit. The oncology team can focus on myeloma and the supportive team can address the patient's well-being.

What is supportive care and who is eligible? Supportive care, also known as palliative care, provides a layer of support to the myeloma treatment team to help patients and caregivers reach treatment goals. Although palliative care is sometimes equated with hospice or end-of-life care, this is not necessarily true; palliative care actually provides support across the whole treatment spectrum. They can help with symptom management, pain control, and coordinating care.

Who is on the team? The supportive care team includes Dr. Curseen as well as nurses, a social worker, and a chaplain. There is also a point of contact person for scheduling.

When might someone seek the services of supportive care? If a patient has symptoms that they cannot seem to control—if they get to be too much to handle, despite working with the main oncology treatment team to resolve it. Or if a patient is interested in alternative therapies, in particular if they have uncontrolled pain and are interested in learning more about medical marijuana. Dr. Curseen discussed potential benefits of marijuana, but the laws are prohibiting research to define these benefits. Some research is being done in Europe. For the updated status of medical marijuana, there is information available here: <https://www.georgiacannabis.org/obtain-medical-marijuana/>. Supportive care can also help with navigating support services such as disability.

Should I talk to my oncologist about seeking supportive care? Yes; there should be open communication between the supportive care team and the oncologist. The oncologist understands the patient's situation best and it works well when treatment recommendations and approaches are openly discussed between teams. The doctors read each other's notes across practices. The supportive care team is trying to change oncology practice to have them involve supportive care sooner in the treatment cycle.

Different doctors have issues with disability forms and insurance issues. Can supportive care help with that? There are many reasons for the issues with disability forms. The forms require

a lot of information and the doctors do not want to mess up the disability request with a notation that would get it dismissed. The criteria for disability is to understand what the patient did before and the reason that they cannot do that job now: fatigue, pain, peripheral neuropathy, stamina, etc. Be sure to collect all online records for disability application, including PT and OT records. Get an Occupational Therapy (OT) evaluation.

What does the supportive care team do? They look at how the patient was feeling and functioning before and compare it to how they are feeling now and what symptoms are occurring. There is a difference between when the doctor says that the myeloma is doing better but the patient does not feel better. Dr. Curseen made some points about adjusting to life after a diagnosis like myeloma:

- It may take time to adjust to a 'new normal' following the diagnosis and intense treatments, especially a transplant
- It is important to give this 'new person' a chance. Embrace the greatness of this new person, but it is hard to let go of that old person.
- Stress can have a negative impact on quality-of-life; do what you can to manage it. Stress can also distract the immune system from doing its job to fight infection and cancer.

What else should patients do to ensure their needs are being met? Talk with your healthcare team about your preferences and goals. Be empowered to ask for what you need. Bring a notebook to write down questions and incoming information. Check your online portal to see test results.

Where can I find a supportive care clinic? Most major hospitals have a palliative care or supportive care team. Talk to your oncologist if you would like a referral.

Southside Multiple Myeloma Support Group Meeting March 24, 2018

Guest speaker on April 28 will be Natalyn Hawk, MD, PhD. Emory Winship Cancer Center and Veteran's Administration Hospital. Department of Hematology and Medical Oncology at Emory University School of Medicine. Dr. Hawk is board certified in hematology and medical oncology and treats patients with gastrointestinal as well as connective tissue malignancies. Her primary focus will be on colorectal cancer prevention, risks, and treatment.

There were 25 people present for this meeting of Myeloma Awareness Month (MAM). No new members were present.

We applauded everyone for their participation so far in helping to raise awareness about Multiple Myeloma (MM) among frontline healthcare providers in Georgia. In joining the IMF-initiated effort, we connected our Primary Care Providers and non-research oncologists/Hematologists with IMF to receive a reminder letter of the MM-related lab values, signs, and symptoms of MM.

MAM efforts continued with local Atlanta/Fulton County libraries, where Doris and Vermell spent each Tuesday greeting library visitors with awareness information. Patients and caregivers distributed the Support Group brochures at Emory Winship in the lab, waiting rooms, and physician offices. Jameca and Portia got creative and hosted a new event called Teas and Jeans on March 31 for awareness and **fundraising**. Portia continued to include MM as one of the cancers for which her Fayetteville congregation provided a generous donation to support them along their cancer experience.

Our guest speaker this month, Jennifer Rooke, MD, MPH, FACOEM, FACPM, talked about the role of Plant-based Diets in Health Maintenance and Disease Prevention with a focus on Cancer. Dr. Rooke is the Medical Director of the Optimal Health and Wellness Clinic, Morehouse Healthcare and is a faculty member at Morehouse School of Medicine.

Dr. Rooke started with basic information and shared that with some research and effort, we can get all the nutrients we need from a diet of fruits, vegetables, nuts, and grains. We must be careful of processed foods. She said that we all have some level of cancer, and our bodies and our immune systems are constantly trying to rid ourselves of it. 40% of women and 45% of men will develop some type of cancer during their lifetime. Stress and alcohol can compromise our immune systems. African Americans are at least twice as likely to be diagnosed with myeloma as others – 20% or 1 in every 5 persons with Myeloma is African American.

Countries with the highest meat consumption also have the highest cancer rates. When you are poor, you tend to eat closer to nature. African Americans have the highest consumption of meats and the lowest self-reported consumption of fruits and vegetables compared other groups.

Dr. Rooke shared several studies with us to demonstrate her points throughout the presentation. She urged each of us to continue to do our own research. A couple of sources that she trusts and are consumer-friendly include: 1) one good resource to check fact versus fiction is **nutritionfacts.org**. There you can find reviews of the literature in videos about what is good and what is not, and 2) **YouTube: Natural Killer Cells**. T. Colin Campbell – Cornell University Professor Emeritus conducted international nutrition studies over several decades. One study compared people in the Philippines and in China with diets of 5% protein compared to 20% protein. Those with higher animal protein consumption had more cancers.

There were lots of questions from the very start – such that it was difficult for Dr. Rooke to get through her prepared comments. Below are some highlights from her presentation.

The three stages of cancer development are: **initiation, promotion, and progression**. **Initiation**, cigarette smoke, radiation, air pollution and viruses can damage the DNA. This is where that

uncontrolled growth of cells (cancer) begins. Millions of cells are damaged every day – our immune system has natural killer cells. All fruits and vegetables have something good for you. **Cancer promotion.** Too many damaged cells and a weakened immune system – few fruits and veggies. Cortisol hormone is released when we are under stress. Cancers take years to develop in this stage, but the situation is still reversible.

Disease Progression is metastasis – when the cancer spreads to surrounding tissues.

Organic is a better choice, but organic does not mean ‘no pesticides.’ Read the labels.

Sugar. Try to avoid it, including sugar substitutes. Concentrated carbohydrates or white sugar has no nutrient value. Use more maple sugar. Honey can be okay but look for 100% honey. Some of it can include corn syrup. Agave is highly processed. Molasses has more nutrients (like potassium), but the taste might be too strong for some uses. Be sure your calories come with some nutrients. Diet sodas have no nutrients. Do honor your sweet tooth.

Coffee. If you are a big coffee drinker, and plan to stop, come off gradually. Channel 2 showed a study where Pet scans showed a decrease in blood flow to the brain by 40%. Come off gradually. De-caffeinated coffee means it is processed. Caffeine constricts the blood vessels, and so can aggravate high blood pressure. Add more herbal teas to your diet, like peppermint, chamomile, etc.

Average breakfast of bacon and eggs. Even turkey or chicken bacon or sausage is highly processed. An international study that included 800 papers over a 20-year span linked processed diets to Group 1 (causes cancer in humans) carcinogens. Eggs have methionine and choline -- also associated with animal products and cancer. Oatmeal is a good breakfast. Use almond milk (Careful – read the label!). Some of has very few almonds.

Juicing. Takes away more than half the nutrients We need the fiber in foods – carrots, apples, etc. Try to eat them in their whole version. Reduce the amount of juices you consume. This is consuming concentrated sugar into system quickly.

Alkaline water. Better to use a Brita or some other water filter. No need to purchase alkaline water, it’s neither helpful or harmful to drink alkaline.

Fruits and Veggies. It is crucial to eat mostly fruits and vegetables – 5 servings a day. It is also important to wash fruits and veggies, but most of the pesticides are grown inside the produce – inside the meats. Eat a wide range of fruits and veggies to get the protein you need. Fruits and veggies are composed of phytochemicals. Phyto = plant = nutrient

Supplements. Dr. Rooke is not a big fan of food supplements. In prevention, the only supplement needed on a plant-based diet is Vitamin B12. There is no natural source of B12. What about Vitamin D? We often test for the wrong Vitamin D. Vitamin D *25 hydroxy* Vitamin D – we do not store, so we might be deficient. We have plenty of the *25 Di-hydroxy* Vitamin D. We generally are tested for wrong one. D2 is from mushrooms, Vitamin D3 is from animal sources.

Gene expression Study. Over 500 genes are affected by lifestyle and lifestyle changes. Cancer suppressing genes can be turned on and turned off. Optimal health programs must include both prudent diets and physical activity. Those with more lifestyle changes had more inhibited prostate cell growth, lower PSA levels. For those who want to learn more about plant-based eating, Dr. Rooke and colleagues offer 12-week series of educational and cooking classes. You are welcome to take a single class. The information is below.

Announcements/Meetings

- **IMF.** IMF has launched initiative to raise awareness about myeloma advances among frontline providers, including physicians, community pharmacists, and nurses. There are brief educational videos in the “AskDrDurie” format on the website created primarily for providers. www.myeloma.org
 - **IMF.** See videos from Myeloma Warriors on website. Please add your own story.
 - **IMF.** Ask Dr. Durie. Sample Topics: What supplements should MM patients take?; What is the best treatment option after relapse – after Stem Cell Transplant?
 - **Cancer and Public Health Conference:** Strategies to Advance Health Equity. Morehouse School of Medicine. Wednesday, April 4, 8:00 – 5:00 PM.
 - **LLS.** Myeloma Link: Connecting African American Communities to Information, Expert Care, and Support. Do you know of a congregation or organization where we can share more myeloma information? Contact: Tricia Hernandez – tricia.hernandez@lls.org
 - **MMRF.** Archived talks about Myeloma Cures. <https://curetalks.com/?ref=myeloma>
 - **MMRF.** Myeloma Series Archived. Caregivers; Immunotherapy; Hot Topics in MM.
 - **New Medicare cards.** Look for your cards in April with randomized numbers versus Social Security numbers
 - **Research partnership for targeted treatment/precision medicine.** IMF and Abbvie. Largest comprehensive chart review study of myeloma patients **with the t(11;14)** translocation. 16-24% of MM patients have this mutation.
 - **IMF.** Smart patients. An online peer-to-peer programs. Get regular emails from patients and caregivers in the MM community regarding their journey. Discussions on side effects, medications, fatigue, and more. <http://www.smartpatients.com.imf>.
- Recent Journal Article Racial Disparities in Myeloma.** *Cancer Therapy Advisory, March 8, 2018.*
Bryant Furlow “Are African Americans and Hispanic patients receiving the best care?”
 Myeloma occurs at twice the rate in blacks versus whites. There is a difference in drug utilization and in the incidence of myeloma defining events (MDEs) between blacks and whites. Greater myeloma symptoms might indicate later diagnosis. In first year of treatment among Medicare patients, African Americans get more Velcade, Hispanics get more Imids (immunomodulatory) drugs. For better outcomes, these drugs should be combined in early treatment. In general, African Americans have better outcomes than other populations. Outcomes could be better if treatment were optimal.

Respectfully submitted by 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.