

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

March 2, 2019

The meeting began with open discussion and new patients. Aletha was diagnosed in 2008 and did not have a transplant. She was caregiver for her mother. After her mother died, her myeloma relapsed and she had collapsed vertebrae. She is on Pom and has terrible cramps along with pain in feet and hands. Jeff was diagnosed less than a year ago and has not had a transplant. He has a chromosome marker for high risk, t(11,14), and is on Venetoclax with Dara and dex. Lory is on Dara and it is slowing her myeloma. Both Bob and Jim have been on Rev maintenance for eight years and dealing with the side effects. Sandy W. is going to Mayo for an evaluation of back pain. Her mother passed away in February from amyloidosis and lymphoma, both diseases of the immune system. Sandy B. is dealing with pain from multiple fractures. Since the meeting, she has fallen and has increased pain from the fall. X-ray did not show a fracture, but further evaluation revealed blood clots in her legs. Reminder to get answers about new pain, even if it requires multiple doctors (as much as patients hate more doctors!).

Caregiver session -

Thanks to Ed for leading the caregiver session. The participants gave a brief introduction and talked about quality of life issues. One caregiver is dealing with aging parents as well as the MM patient. The monitoring of parents keeps them from going out of town when they want to get away. Caregivers talked about concerns about the patients. One issue was sleep problems with dex. They are working to adjust to a "new normal", but for some, it keeps changing. They also discussed how to take a break and do something for themselves. Stress can be toxic for both patients and caregivers. Try meditation, deep breaths, and long walks. Be grateful for small events in your lives.

Patient session –

Thanks to Lory for leading the patient session. Took a survey in the room on disease/treatment status. Four had no transplant; four were on maintenance; and eight were on treatment. Lots of discussion on side effects of treatment. As many side effects as people in the room. Two people had ringing in their ears.

Several have had trouble walking. One person is taking anti-depressant to reduce pain and anxiety. Someone is using a compound from pharmacist to rub on feet and pain areas. High blood pressure is a common effect from some medications. Patients were reminded of the importance of keeping a diary of symptoms and daily vital signs. Suggestions were given for relief of leg cramps: Tonic water (too much sugar); coconut water (high in potassium); heat applied to the area; periodic stretching; and more magnesium. The patients gave each other many ideas on nutrition benefits. There was a discussion on CBD oil and how it is being used in many diseases and conditions.

Nancy and Sandy W.

Southside Myeloma Support Group

March 23, 2019

Our speaker for April 27, 2019 will be K. Elizabeth Carter, RN, BSN, OCN, Clinical Nurse Educator from Takeda Oncology. Her topic will be Cancer Survivorship: Optimizing your wellness. In 2006, the Institute of Medicine issued a report that every cancer patient should be issued a cancer plan from their provider, but we must often be responsible for creating those plans ourselves (American Cancer Society, National Cancer Institute). Lunch will be provided.

Our March speaker was Dr. Tyra Wingo, Executive Vice President of Tool Cribbs International, to help us sort out the ins and outs of **CBD oil**. Dr. Wingo is an independent ambassador for Kannaway, a distributor of CBD oil products. CBD is marketed as anti-inflammatory that can help to relieve chronic pain, anxiety, and insomnia. It is derived from the hemp plant. So, what is the real deal on medical marijuana, hemp, CBD products, etc.? Tyra provided for us a history of hemp in American history – the 13 colonies, and in the War of 1812, which made it illegal. For many of us, this was our first in depth conversation about CBD – and we needed to start at the very beginning – to figure out cannabis, hemp, marijuana, what is legal (in Georgia) or not, and where we can find the product. Following is a simplified primer on CBD products. Since many of us have chronic pain, and there are so many issues, including addiction, even with opioids and that are needed and prescribed, we are all looking for the best alternatives. Jameca shared that her oncologist has suggested CBD to her, since she has so much and so many sources of pain. She has tried many avenues, including the prescribed opioids and radiotherapy. CBD does not require a prescription. Jameca thankfully extended the invitation to Dr. Wingo to help educate us on CBD oil. The minutes below are integrated with background research to help us all learn the facts surrounding CBD. First, we provide a summary of CBD products, and for those who are interested, a much more detailed coverage of CBD.

Summary of CBD Products. Hemp and Marijuana are two different plants in the cannabis family. CBD comes from the hemp product that has several uses. When you observe the plants, marijuana grows as a short fat bush – hemp grows taller and skinnier and looks like bamboo. THC, the psychoactive agent, which causes you to get “high” comes from marijuana. CBD has less than 0.3% of THC, and is more widely accepted than marijuana, including medical marijuana. Since the passage of the 2018 Farm Bill, hemp has been removed from the 1970

controlled substances Act list and is now legal. Even after 45 years, the government still seems to have some [confusion](#) in distinguishing the two plants. CBD is still subject to FDA regulations. CBD, though not approved by FDA, is growing into a billion-dollar industry and is widely said to help with chronic pain, anxiety, and insomnia. Within days of each other, Walgreens and CVS reported they will sell topical CBD products in 2,300 stores across the country (Forbes, April 2019).

What exactly is CBD? It is a product that comes from hemp in the cannabis family. Industrial Hemp naturally produces higher levels of **Cannabidiols (CBD)** and low levels of **tetrahydrocannabinol (THC)**. CBD is one of more than 100 chemicals in cannabis and is emerging as a wellness ingredient. It is found in lotions, beverages, gummy/candy products, and dog treats. CBD is a different product from THC – or the active ingredient in marijuana. Hemp is a variety of the cannabis plant with a negligible amount of the THC found in marijuana. There are still plenty of unknowns when it comes to CBD. The FDA has approved GW Pharmaceutical's drug Epidiolex for the use of CBD oil only in specific cases of epilepsy. **Hemp is used to** make a variety of commercial and industrial products including rope, textiles, clothing, shoes, food, paper, bioplastics, insulation, and biofuel. Hemp oil is very beneficial containing a lot of antioxidants and omega 3 and 6 fatty acids. Hemp oil is normally pressed from the seeds of the **hemp** plant, which means it does not contain the same amount of cannabinoids found in **CBD oil** or **Hemp Extract** which are extracted from the whole plant. **Industrial Hemp has been legalized** for cultivating in the USA according to the Farm Bill Act and is where most Hemp Oil and CBD Oil products come from. Marijuana plants are just the opposite, producing high levels of THC and lower levels of CBD. *Pure CBD oil is the consistency of cooking oil. Pill form is a different delivery. Topical cream is like Neosporin. Massage therapists mix the oil with other oils. Jameca has kidney issues and cannot take NSAIDS, like Ibuprofen. This is an alternative.*

What are the Side Effects? Very little research in humans means not much is known about side effects. In epilepsy research, CBD changed the way the body processed other drugs. That suggests **CBD could interact with medications** in ways we still don't know about. The most common side effects of the CBD drug Epidiolex include sleepiness, decreased appetite, diarrhea, increases in liver enzymes, exhaustion, rash and infections. FDA's Gottlieb noted the potential for liver injury and other risks can be handled with medical supervision but less is known about how that would be managed without oversight. And there are questions about overlap if multiple CBD products are used. (AJC, April 2019)

The business of CBD. The market for hemp-derived CBD sales has grown from \$174 million in 2016 to \$590 million this year. If Congress passes legislation this year that would fully legalize hemp, CBD sales could explode to \$22 billion by 2022, which would rival the national cannabis market. Consumers must be aware that claims are largely unproven and quality control standards don't exist. Sold in drops, salves, and creams online and in person from \$12 to \$150 per ounce. CBD is sold online, and locally in health food stores, spas, local representatives of companies. In the days after the meeting, first Walgreens, then CVS publicized they would begin to sell CBD products. Of the 1500 stores Walgreens said would sell the products, none was in Georgia.

CBD and Quality Control. What you buy may contain much less than the label states — or much more. It may include more THC than you want, and it may be contaminated with mold or pesticides. Ask to see testing reports. A 2017 study in the Journal of the American Medical

Association found 70% of CBD products were mislabeled. Researchers used an independent lab to test 84 products from 31 companies. "You're really flying by the seat of your pants when you buy this stuff," said author Marcel Bonn-Miller of University of Pennsylvania. A product labeled as containing 100 milligrams of CBD may only have 5 milligrams or it may have 200, said Bonn-Miller, now an adviser for a company that sells CBD and other cannabis products. He did not work in the industry when he did the research.

But, is it legal? CBD products are legal, following the 2018 Farm Bill. In the 2018 Farm Bill, Congress removed hemp from the drug schedules outlined in the Controlled Substances Act, legalizing it under federal law (Forbes, 2019). It does not have approval from FDA, and those who sell it make vague claims about its effectiveness to get around that approval. There are now thousands of CBD products on the shelves, and the market is growing. *Dr. Wingo says she would never be arrested for having all the products that she has for sale.* Police in Georgia say they're concerned about the vast growth of the CBD market without oversight to ensure it's safe for consumption. Without access to medical marijuana, business is booming in Georgia for cannabidiol — or CBD — to find relief for anxiety, arthritis and back pain. Lawmakers are considering whether to [expand](#) the state's official medical marijuana program so low THC oil could be [manufactured and distributed](#) here (AJC). The FDA announced it has sent warning letters to three companies marketing products with what outgoing Commissioner Scott Gottlieb called "egregious, over-the-line claims" for CBD's effects on cancer, Alzheimer's disease, fibromyalgia and drug addiction. Among the cited examples: "CBD successfully stopped cancer cells" in cervical cancer. Experts, including those with the World Health Organization, note that there's some potential for treatment beyond epilepsy, but research isn't as advanced (AJC).

Question: Can CBD or hemp cause you to fail a drug test? Be careful. There is very little THC, so some say CBD will not cause you to fail a drug test, however, it is documented that CBD has caused some people to fail a drug test. Err on the side of caution.

Recent Georgia Law. On April 17, 2019, Georgia Governor Kemp signed into law to allow people with 16 specific conditions, including cancer, seizure disorders and Parkinson's disease, to possess cannabis oil with less than 5 percent THC, the chemical that gets users high. There are 8,400 patients registered for the use of medical marijuana. A 2015 law allowed the use of the drug, but it was still illegal to possess it. The law goes into effect July 1, 2019 (Associated Press).

More on pain control. Gail shared that after about 10 years on different forms of oxycodone, her oncologists are recommending a reduction in dosage over time with the help of an Emory pain control specialist. The specialist focused on peripheral neuropathy pain for the first visit. Natural supplements like turmeric with black pepper (500 mg twice a day) and Alpha lipoic acid (300 mg twice a day) were part of the discussion. These supplements should be taken with food – and can lower blood sugar. Exercise was recommended – tai chi and yoga to strengthen the core. It is important to avoid falls. I will also go to physical therapy. I was already taking gabapentin (Neurontin) and vitamin B-complex to help control the pain and discomfort. Some say Vitamin B-12 uses a different nerve pathway and may be useful on its own. Additionally, creams were prescribed – lidocaine and voltaren gel. Dr. Singh had a book in her office that she

highly recommends – “Managing Pain before it Manages You” by Margaret A. Caudell, MD, MPH.

References

- <https://www.ajc.com/news/health-med-fit-science/cbd-getting-buzz-but-does-work/Ps3SFItAe8uXhcqj0CHS5L/>
- <https://www.forbes.com/sites/bencurren/2019/04/01/cvs-and-walgreens-bet-on-cannabis-testing-the-market-and-responding-to-consumer-demand-for-cbd/#6717bc3c49f1>
- <https://ministryofhemp.com/hemp/not-marijuana/>

Member Updates

BELK – fundraiser – **Jameca**. We can sell tickets for \$5.00 which will entitle the holder to discounts on merchandise. The group can keep 100% of the profit. The event takes place in May. Jameca will get more details;

THANK YOU from **Andrew** Jackson’s family to the Support Group. His nieces, Linda and Carolyn, came to the meeting to express their appreciation in person about how much the family appreciated all the group did for him before his passing;

Luther J. had a Stem cell transplant two weeks ago and wanted to come to the meeting. He is doing well – “I just did what they told me to do”

Sandy J. – they go back for a checkup on Wednesday;

Bernard and Carole – will set up a Myeloma Awareness table at Zion Hill Baptist Church for their Men’s group. He found out that his neighbor had back surgery and has myeloma;

Barbara M. attended the meeting with her caregiver, **Catherlean W.** and her friend,

Margaret J. It took her a very long time to be diagnosed – and she had very good insurance. She was diagnosed in June 2015. She went for months – was in kidney failure, was not able to walk, was on crutches – without a diagnosis. She was told she had arthritis – went to the best facilities Emory and Northside. She was at a military facility and had to be flown to their medical facility before being properly diagnosed. This was the second visit for **Ted P.**, and he was glad to see other healthy-looking people walking like they are “normal.” He was diagnosed January 18, 2019, and it blew his mind. He was diagnosed after lab tests showed low white and red blood counts. Someone said this was normal for a black man. He is normally a very healthy person – and is maybe 3 months from a SCT. All the paperwork is scary – the nurses are excellent.

Announcements/Upcoming Events

- **IMF** - Teleconference - **Living Well with Myeloma, Dr. Brian Durie** April 25 at 7 PM
- **MMRF. Team Cures – 5K Walk/Run. May 11.** 7:30 – 9:30 AM. 665 North Avenue, ATL GA 30308. Historic Fourth Ward. \$30 Adults online. \$35 on site. <https://themmrf.org/>

- **LLS:** Tips for Managing Stress and Communicating with your Healthcare Team and Healthy Behaviors.
- **LLS. Myeloma Conference.** May 18-19. Holiday Inn Suites, Virginia Avenue.
- **MMRF.** MyDRUG (**M**yeloma – **D**eveloping **R**egimens **U**sing **G**enomics), the MMRF is leading the charge in this new research approach. The MyDRUG trial was developed based on key findings from the MMRF CoMMpass Study and the Multiple Myeloma Research Consortium (MMRC) Molecular Profiling Initiative, which revealed that myeloma is not one uniform disease but rather a variety of
 - different disease subtypes defined by different genetic mutations. In other words, an individual's genomic blueprint determines how myeloma behaves.
 - **IMF** – Amazon donates 0.5% of all purchases you make to the IMF when: You shop at smile.amazon.com, AND You designate the International Myeloma Foundation as your preferred charity. All donations are made at no added cost to you! It's that simple
 - **Free rides for cancer patients. Lyft partnering with American Cancer Society through its Road to Recovery Program.** Call 1.877.277.2345. Must call at least three days before appointment.

Respectfully submitted, Gail