

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group March 5, 2022

Business & News

Nancy B. opened the meeting with eighteen members in attendance. Nancy talked about the current virtual meeting format working well during the COVID 19 pandemic for the past two years. The current Omicron variant and upcoming BA-1 virus continues to dampen the possibility of meeting in person. Fingers crossed that our monthly meeting would return to a hybrid format to allow members to meet f2f or virtually.

March is Myeloma Action Month (MAM). Go to MAM.meloma.org to help increase myeloma awareness and to take action that positively impacts the myeloma community. Nancy thanked Doris M. for “taking action” with MAM information post on her community Facebook page which was highlighted on the IMF Get Inspired webpage .

Patient Session

Thank you to Jim M. for leading the patient’s session. This month’s topic “What are your travel plans this year?” The group discussion was lively on the possibility of travel. Destination points were near and far from Morgantown and San Diego to Jamaica and Japan. Reasons to travel included long weekend getaways, family reunions, beaches, outdoor activities, postponed trips, and perpetual pandemic lock down. Everyone seems eager to get out although there were many questions raised on the safety of travel.

Covid concerns were high on air flights due to masking expectations, vaccine and booster requirements and virus exposure in confined areas. It has been hard to navigate through the flight regulations and safety of travelling outside the United States. Driving seems to be the preferred mode of transportation over air travel. Similar worries were addressed on hotel stays and vacation hotspots. Travel preparation involves a vaccine booster two weeks prior to your trip for greatest protection and Covid testing. Try to pick off-peak travel times and lesser-known destination spots to visit. Consider outdoor activities and avoid Covid red zones. The CDC Travel Recommendation List posts regular information updates on Covid risk level locations internationally. Although many patients are making plans to venture out, several are sticking with their current routines at home. General apprehension on close social activities and crowds still remains the reality of the immune-compromised lifestyle myeloma patients face every day.

We also talked about selling our homes and being challenged on what to do with life-long possessions. Our children are not interested in heirlooms and many charity organizations are overrun with similar treasures already along with pandemic precautions. Group suggestions include checking the Salvation Army auction site downtown and posting valuables on Goodwill shop online. Some folks are travelling long distances to see family. Trips even include traveling by motorhome over a 26-day journey west to visit family they have not seen in the past two years. Travel safety increases by going to National Parks and tourist attractions during the off-season.

One member who had a stem cell transplant last year and is on maintenance is waiting for the second Covid booster before attending a high school reunion this year. Members report that they have started treatment on Elotuzumab, Pomalidomide, and Dexamethasone which has been more challenging

than expected. Clinical trials have started for Evusheld as a preventive Covid treatment for immunocompromised patients.

Caregivers Session

Thank you to **Molly L.** who hosted the caregiver session with three attendees. **Lynn** is new to caregiving and had questions for both **Ed** and Molly about their journey of 10+ years of caregiving. Her patient [**Tom**] is being treated at Emory. She believes Tom gets important information and insight attending our monthly support group meetings. Lynn does plentiful research, but it only "goes so far" so they rely heavily on their Emory team.

The group discussed "*removing ourselves from home*" from the daily routine and for a change of scenery. Booking a room for the two of you at a local hotel or taking a weekend trip to a nearby campground in your RV. Just planning a trip or activity together can be the relief...and joyful. Sometimes "*a me break*" may be as easy as pouring yourself a glass of wine and sitting in the car and listening to your favorite music or a guided meditation. The group shared integrative medicine options such as acupuncture, massage therapy and Laughter Yoga to help relieve the stress and anxiety of caregiving. The discussion was forty minutes of meaningful sharing.

Submitted by Jim M. & Molly L.

Meeting Minutes

Southside Virtual MM Support Group

March 26, 2022

Business and News

Next Meeting is **Saturday, April 23, at 10AM**. The agenda will feature a Patient and Caregiver Voices Roundtable session, how to access educational videos and sharing nutritional information. "*For Men Only*" meetings will resume next month. Watch for meeting details.

Doris talked about "**Light the Night**" annual Leukemia and Lymphoma Society (LLS) fundraiser. Look for more information and participation details. LLS is a very helpful organization to us individually and as a Support Group.

Guest Speaker Presentation

Thank you to **Gail M.** for hosting the meeting with 28 members in attendance. **Doris** opened the meeting with a moment of silence. Our speaker was **Jewel Crawford, MD**, a physician-herbalist, who has studied natural herbal remedies and integrative medicine for more than 20 years. Dr. Crawford works in the Environmental Health section of CDC and is an adjunct faculty member at Morehouse School of Medicine. Our topic was **Natural Healing and Herbal Remedies**. Dr. Crawford started the meeting with a list of things to do to stay healthy. Her list mirrors many strategies from previous speakers regardless of their discipline: general oncology, psychiatry, nutrition, myeloma, etc. Dr Crawford focused on fresh air (plants inside and out), sunlight, exercise (especially outside), drinking filtered water and good nutrition (eat the colors of the rainbow). Important safeguards are avoiding processed foods, not drinking water from plastic bottles, managing your stress, and taking vitamin supplements, including Vitamin D (3). In addition, listening to music, dancing, strengthening, connecting with our spiritual side, and self-talk therapy are all non-pharmaceutical strategies for disease prevention and healing. Most physicians are not trained in holistic health and nutrition. They are trained in surgery and pharmacology, as supportive specialty areas.

Nutrition is not normally a primary consideration to combat the negative effects of illnesses since doctors have little training in this area. Fast food meals and junk foods are easily accessible alternatives particularly in low-income communities. Many of these communities are located in “food deserts” without viable access to fresh fruits and vegetables. Obesity, diabetes, hypertension, and metabolic syndrome are a few of the common health issues that result from this lack of access.

Roles of Vitamins and Supplements

Dr. Crawford continued her presentation with the importance of open communication with your health care providers. She urged us to continue to do our own research and discuss any desires or plans to change our treatment regimens with our doctors. There may be adverse interactions with your myeloma treatment and supplements. Some examples are [Green Tea and Velcade](#) and grapefruit drug interactions. Effectiveness of your myeloma treatment may be reduced when certain supplements are introduced. Ginseng is a very popular herb but has the side effect of increasing one’s blood pressure.

Vitamin D. Everyone including myeloma patients should know their Vitamin D levels. Vitamin D deficiency may increase susceptibility to respiratory infections along with an increased risk factor of worsen outcomes for COVID-19. Any vitamin deficiency should be diagnosed and treated in COVID and myeloma patients. Vitamin D and immunomodulation factors in about 20% of Vitamin D from diet and 80% from sunlight. Most of the immune cells including B-cells and T-cells (lymphocytes) have Vitamin D receptors. Dr. Crawford stressed the need to focus on Vitamin D and referenced a resource to help make the case for Vitamin D (Vitamin D: Nutrient, Hormone, and Immunomodulator, 2018. Nutrition. Sassa, et al.).

Vitamin C. Also known as ascorbic acid helps with the *stimulation of endothelial cells*. Endothelial cells form a thin membrane that lines the inside of the heart and blood vessels. These cells release substances that control vascular relaxation and contraction as well as enzymes that control blood clotting, immune function, and platelet (a colorless substance in the blood) adhesion. COVID patients with comorbidities including diabetes, cardiovascular disease, metabolic syndrome, and asthma have worsen COVID outcomes. The benefit from supplementing with a high dose of Vitamin C is to reduce severe infections. [Vitamin C and your immune system](#) protects the leukocytes' antioxidant functions. The phagocytic leucocytes produce and release cytokines and antiviral interferons. Vitamin C can help to mitigate cytokine release storms (CRS) that occur during CAR-T cell therapy and COVID infections. Neutrophil chemotaxis can also occur when neutrophils without enough Vitamin C are impaired and cannot migrate quickly to repair damaged tissues. The neutrophil killing of microbes and phagocytosis cycle depletes levels of Vitamin C causing neutrophils impairment with the killing microbes process.

Micronutrients. Active antiviral properties of zinc were identified in 1974 (Nature). Zinc is a stimulator in over 2000 enzymes. Zinc deficiency is still common. The upper limit of a zinc dosage is 40 mg/day.

Toxic Exposures. Dr. Crawford referred to the IMF website in her myeloma research and found information on potential toxic exposures causing myeloma. Take precautions to avoid toxic exposures. There are many chemicals known to cause cancers and brain damage in children. [Benzene](#) has been linked to myeloma since 1897. More recent studies reported in 2011 and 2015 confirmed the association of benzene exposure with the development of myeloma. Herbicide glyphosate has also been linked to myeloma in agriculture workers. This is a primary ingredient in Roundup weed killer which is used widely in GMO (genetically modified organism) products. Glyphosates are found in many of our everyday foods including cereals and hummus. Eating an organic diet as much as possible will reduce the risks from these chemicals. [Dioxin exposure](#) is also a major health concern.

Additional Precaution: Without FDA oversight many supplements on the market have heavy metals like lead and mercury. Discuss all supplements with your doctor and be sure to look for any toxicity to the liver and kidneys.

Dr. Crawford introduced us to the [Environmental Group \(EWG\)](#) website to help further our own research into toxic chemicals. EWG is a non-profit organization that specializes in research and advocacy in the areas of agricultural subsidies, toxic chemicals, drinking water pollutants, and corporate accountability. Be mindful that there is no FDA regulation on vitamins and supplements or any regulation on products from China and other countries. Herbal medicine has many proven health benefits. Continue to research and learn through peer-reviewed articles and respected websites. We have to vet companies on our own and be vigilant.

Related Research articles

The [National Center for Complementary Medicine and Integrative Health](#) (NIH)

Emory Winship Integrative Medicine Department

[Natural products extract from Parthenolide and andrographolide](#) (Leukemia and Lymphoma, 2011. Gunn E. et al.)

[Ganoderma lucidum \(mushrooms\) causes apoptosis in leukemia, lymphoma, and multiple myeloma cells](#) (Leukemia Research, 2006)

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For Men Only Meetings

Anderson and Ted reported on the two meetings, “For Men Only.” The initial purpose of the group is to allow a safe space for the men in the group to express and discuss their unique challenges and stressors with a myeloma diagnosis and treatment. The group will set their own goals for the meeting. The meeting will be held the Tuesday before the 4th Saturday Support Group meeting from 6-7 PM. For the time being,

Group Discussion and Member Updates

There was a lively discussion on integrative medicine, herbal remedies, and botanicals with support group members. **Vinnie** updated us on his journey with turmeric. He has smoldering myeloma (SMM) and followed the regimen for a clinical trial using turmeric. He gets regular checks for his MM progression levels and has increased his dosage when protein levels started to rise. He has been stable for 10 years. Vinnie uses the brand “Doctors Best” for pepperine (black pepper) and takes the turmeric on an empty stomach with fish oil. *Frontier Herbs* is an American company that Dr. Crawford uses. **Robert** shared that he has seen Oscar Sierra, LAC in Marietta. Oscar is a follower of [Donnie Yance](#), a master naturalist in Colorado. Mr. Sierra created a regimen for Robert over the past 11 years which has been helpful. **Sarah H.** shared that Stephen Tate, ND (404.435.9336), is an herbalist she has known about for some time. We will invite Dr. Tate to speak with the group. **Sandy B.** shared with the group that as a 32-year myeloma survivor and has gone through many challenges most recently with dental challenges. Sudden loosening of her teeth has resulted in three teeth being removed. She has not taken bone strengtheners for several years and they are researching the potential causes. Sandy is seeing an oral surgeon, Dr. Bankston, whose brother has myeloma. **Vena** had a recent bone marrow biopsy. She is living with myeloma and also being treated for lung cancer. She shared that the lung cancer had spread to the left side of her brain that caused partial paralysis. She had emergency surgery to remove the tumor and is now on radiation and chemotherapy. Vena needs your special prayers. **Robert C.** had fractures from arthritis and received kyphoplasty surgery. He is currently receiving interventional radiology and his doctor suggests medial lateral radiofrequency ablation (RFA). Robert’s arthritis is not cured but the procedure will prevent the nerves from sending painful signals to the brain. **Carole O.** went to the Emergency Room with severe pain in her left leg and

chest pain. Her D-Diamond test (DDI) results came back within the normal range. There was a protein fragment detected and the pain may have come from a dissolving blood clot.

Respectfully submitted,

Gail