

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual AAMM Support Group December 4, 2021

Business & News

Northside January meeting will be on Saturday January 8 at 10:00 AM (*note time change*). This session is our annual update from the Winship MM team on research presented at ASH. This is always interesting to hear from our experts on what was reviewed at ASH and how it will impact future treatment in myeloma. So many new MM options will be available soon. Plan to attend to learn more about the advances. Links will be sent out prior to the meeting on other ASH discussions in preparation of the ASH session.

Patient Share Meeting

Our December Northside meeting was a Holiday Zoom session with small breakout rooms for people to get better acquainted. We started with a group meeting to welcome new patients and hear about their journey. **Laura** joined the group for the first time. She was diagnosed in 2019 with high protein. She delayed treatment and ended up with broken vertebrae. She was in bed for nine months and then was able to get on initial treatment which included Daralex. She had complete remission after three months. **Mary** was diagnosed in 2017 with no symptoms. She had a transplant in 2018 and is currently on Rev maintenance. She fell and broke two bones in her back and is having cataract surgery from all the steroids. Her husband recently filed for divorce after twenty-six years of marriage. Then we checked in with our members. **Jim M.** updated us that he had a lesion on his colon, but it turned out to be scar tissue from a prior surgery. He has a hip lesion that has become more painful. He had an MRI and biopsy of the hip and now is waiting on results. **Lori** zoomed in remotely while on the road from vacation in St. Augustine. Her MM numbers continue to progress but wants to stay on Dara/Rev for a while longer. She will have a PET/CT in January and is anemic. She has had MM for over ten years. **Jeff W.** is still on a clinical trial and on cycle thirty-seven of Venetoclax with Dara and Dex. This program is for high-risk with – t(11,14) genetics. **Bob** has been off Rev for over a year after taking it for ten years. His ratio is very good and continues getting better. He still has GI issues and believes that the Rev altered his gut biome.

The group discussed upcoming meetings in 2022. The annual ASH update meeting is in January. February's meeting will be an open discussion session followed by patient/caregiver breakout meetings in March. The Shallowford Presbyterian Church where we have been holding our meetings prior to the pandemic has an outdoor pavilion that we would like to use to schedule in April or May to meet in person. It will be great to finally get together unless Covid causes more problems. Stay tuned for that.

We are looking for additional ideas for meeting programs in the coming year. Please let us know if there were topics that you would like covered. We have access to the Winship team, and they our insight into what patients want to know. Those who work hard to keep the group thriving really appreciate your input.

Holiday Breakout Rooms

The group then moved into the smaller breakout rooms to virtually share Holiday stories, answer ice-breaker questions and hear specific information about each other's MM journey. **Nancy** was in a room with two new patients who got to hear both **Sandy B.** (31 years) and **Doris M.** (18 years) who are both doing well in their journeys, and they did not have transplants. Their stories are such an inspiration to newly diagnosed members.

Note that **Charise's mother** passed away recently since our meeting. We also learned of the passing of Joe Cassar over the summer. **Joe** and his wife Suzan were married almost 60 years and were long time members of the Northside group. We always enjoyed their positive outlook and gracious spirit. She is struggling to adjust to life without Joe and has her family helping her.

To see his interesting history, click here: [Joseph George Cassar Obituary \(tributearchive.com\)](https://www.tributearchive.com/obituary/joseph-george-cassar) (you may need to copy and paste)

submitted by Nancy B.

Meeting Minutes Southside AAMM Support Group December 18, 2021

Business & News:

Next Meeting: January 22, 2022, at 10AM.

Infection Risks and the Importance of Vaccinations. Tara S. Roy, MS, NP, AOCNP, Patient Advocacy Liaison (PAL) of Takeda Pharma will return once again to provide important responses to our special concerns as myeloma survivors and caregivers.

Please Note: Group members were unusually quiet during our last meeting. This meeting is for all of us. We hope to provide topics and speakers that are of interest to you.

Our speaker for February is **Wendy Baer, MD – Oncology Psychiatrist** at Emory Winship (we thought you might also like to hear about talk therapy in addition to maintaining mental health from Dr. McCoy). Our March meeting is on **Herbal Medicine** presented by Jewel L. Crawford, MD, family physician with an interest in nutrition and environmental health, from the Centers for Disease Control and Prevention.

General Business:

Thank you to **Gail M.** for hosting the meeting. Dr. McCoy opened our final meeting of 2021 with a non-denominational prayer of hope, gratitude, and healing. We honored the passing of our member and friend, Janice Stewart. We will miss her and her infectious happy spirit.

We welcomed two new members. **Faith** was referred to us by member and long-time supporter, Montine. She has been treated over the past four months and is being considered for an ASCT (Autologous Stem Cell Transplant). She is very nervous about all the unknowns and is being treated at Northside oncology. She has no relatives here and is concerned about the daily returns to the clinic after the transplant. Gail mentioned the Hope Lodge, which at one point provided a daily shuttle for appointments. Because of COVID, those shuttles are no longer available, according to **Susan**. Susan is planning for her second transplant after seven years in remission and is in a similar situation to Faith, with no family to support her during this procedure. She will have this transplant at Emory

Winship, after having the first at Northside. Faith should be sure to speak with her doctor and the Social Worker at Northside, and request an in-patient SCT, among her other needs.

Gloria was diagnosed in 2009, started a Clinical Trial in January 2021 and is doing well right now. She goes to Emory Winship once per month to receive her dosage of Dara/Darzalex. **“Kat”** joined us for the first time from the Northside Support Group. She was being treated with Venclexta®/venetoclax and Dara and is doing well. **Sarah** reported that she has restarted chemo. She is also a candidate for ASCT soon. She also has had a colorectal cancer diagnosis and had to focus on this treatment before now being able to focus on her myeloma. A heartfelt welcome to all who join us.

Guest Speaker:

With the many stresses and sometimes sadness that comes with the Holiday Season, we invited **Dr. James McCoy**, *psychiatrist, from Morehouse School of Medicine* to help us navigate these emotions. It can be a challenge to remain upbeat with the realities of a cancer diagnosis, remembering family and friends who are no longer with us, and the restrictions and uncertainties of the COVID-19 pandemic.

How is our health amid all these concerns?

Gail shared that Dr. McCoy’s initial training was as a cardiothoracic surgeon. Aside from that hugely impressive accomplishment, Dr. McCoy has a clear appreciation of the significance of our mental and physical health above and below the neck as well as the health of the heart, blood vessels, and nerve receptors. He is also a spiritual person, recognizing the important relationships among mind, body, and spirit.

Dr. McCoy started us with a lesson on the neurobiology of learning and the anatomy and function of the brain. The lesson: *Resilience is a learned behavior*. He says that prayer should be deliberate and intentional. Whether it is called **prayer or meditation**, one must create a **spiritual connection** with a defined time and place for when it will occur. That time can be two minutes or 32 minutes – it must be scheduled. You can ensure that you follow-through by being accountable to someone else. COVID has reinforced the message that support can be virtual or long distance.

Regular exercise – at least 20 minutes three times a week can help with stress reduction. The excuse that *“I have no one to exercise with...”* is no longer a valid excuse. You and your exercise partner do not have to be in the same place.

Proper Nutrition - A healthy brain and a healthy body are dependent upon a *prudent diet*. Consider moving towards a plant-based diet – more seeds, nuts, and berries – more raw rather than cooked vegetables and less sugar. After many years of continuing to add salmon and chicken to his diet, Dr. McCoy reports that he now follows a vegan diet. Dr. McCoy supplements his diet with Vitamin D3 and B-complex. *Ask your doctor to check your Vitamin D3 level on your next lab tests*. There is evidence between proper Vitamin D levels and improved myeloma.

Adequate sleep - is crucial for the brain and muscles to do their work. Watching TV, taking electronics to bed, sleep apnea, etc. can disrupt restful sleep. Recent studies have shown that adults need 7-9 hours of sleep per 24-hour period. We have four stages of sleep. The first two are light sleep. Stage three is “deep sleep,” when your brain waves slow down, and it is harder for you to wake up. During these periods, your body repairs tissues, works on growth and development, builds bone and muscle, and strengthens the immune system.

Building Relationships - Being socially distanced – separated from friends and family – and co-workers can have a negative impact on one’s psyche. **Kat** shared that she has convened her book club

in a park – everyone masked and distanced as they visit safely in the outdoor air. She also shared that there are several examples of safe exercises on YouTube – from chair exercises and yoga. She also suggested facetime as additional ways to connect.

All of our systems are brilliantly interconnected and respond to a similar foundation of **spirituality, exercise, good nutrition, and adequate sleep.**

*I would add to these four ingredients a **dose of daily laughter** – deep belly laugh is preferred. Gail*

Neurogenesis (the production of new brain cells) is:

Enhanced by	Reduced by
Exercise	Inactivity
Complex Environments	Depression
New Learning	Boredom
Prosocial Contact	Isolation and Low Social Status
Nutrition	Poor Nutrition
Low Stress	Distress

Meeting Related Resources:

IMF – <https://wellness.myeloma.org/>. A resource that includes meditation exercises; a nutritional approach to optimizing and protecting your immune system; an online seminar on how to build your resilience in challenging times.

YMCA – facilities are offered free of charge to cancer patients and care partners. Be sure to get a confirmed diagnosis from your doctor and double check with your local Y to be sure they participate. This program is under Lance Armstrong’s Foundation.

AIB (Atlanta Interfaith Broadcasting) Network - Dr. McCoy says they offer regular Tai Chi classes – a wonderful low impact exercise that can improve balance, coordination, concentration, and an improved immune system. <https://aibtv.com/taichi/>. Monday – Friday @ 7:30 AM. Check your local programming. (Comcast- Channel 295; AT&T – Channel 6)

Respectfully submitted, Gail
