

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes

Northside Virtual MM Support Group

March 4, 2023

Business & News:

The Northside meeting on Saturday, April 1 at 11 AM will be a review of myeloma tests and what they mean. This is important to understand for new patients that are overwhelmed by the terminology. Myeloma patients can always learn a few new points in a very complex process that takes place regularly.

Guest Speaker Presentation:

Thank you, **Nancy**, for hosting the meeting. 40+ members were in attendance. The group welcomed Emory Physicians, **Dr. Ashish Khanna**, *Director of Emory Physical Medicine and Rehabilitation* along with **Dr. Anna Bausum**, *Doctor of Naturopathic Medicine and Integrative Oncology Acupuncture Clinic*.

Dr. Bausum opened the program with an overview of a new initiative called **Winship Integrated Oncology & Survivorship at Emory (WISE)**. At Emory and cancer centers across the country, they are recognizing that pharmaceutical drugs and cancer treatment alone does not bridge the gap between patients' medical condition and underlining symptoms/side effects while engaging a whole person center-based approach to their quality of life. Winship is moving in the direction of *Integrative Oncology and Survivorship* where the health care team is comprised of medical specialists in oncology, primary care, cardiology, naturopathic medicine, physical and occupational therapy, acupuncture, palliative care, dietary nutrition, and specific symptom support sharing the patient needs collectively to coordinate and streamline total health care more effectively. Dr. Bausum heads the *Integrative Oncology Acupuncture Clinic* for symptom support. Acupuncture treatment can help for a variety of symptoms. She explained the difference between acupuncture and dry needling. Dry needling is done at the point of pain, while acupuncture is not at the pain point and can take more sessions to relieve pain. These therapies are made available to complement and support the oncology treatments received at Emory.

Dr. Ashish Khanna continued the presentation explaining his role as *Director of Physical Medicine and Rehabilitation* along with colleague **Dr. Sonal Oza** at Emory. He works closely with physical and occupational therapists in the *Integrative Oncology Department*. Dr. Khanna sees patients with all types of cancer with persistent side effect issues aside from the cancer. He understands that a *major concern of myeloma patients is the symptoms and side effects of neuropathy*. He started his talk by explaining symptoms and issues of neuropathy. Few people realize there are **two types of neuropathies: positive and negative**. The positive symptoms are when you experience and feel unusual sensations due to nerves being damaged. Positive neuropathy causes the nerves to send funny *sensation signals of pain, tingling, burning, shooting, stabbing, itching and tightness*). In negative neuropathy, *there is an absence of sensation nerve signals*. Instead, the nerves are not working at all, calling them "dead nerves." Negative

neuropathy symptoms present as a *numbness sensation or absence of feeling, and coldness or absence of heat* being the two main side effects. This is important to understand because there are treatments available for positive neuropathy, but not for negative. When you discuss the side effects of neuropathy your doctor will ask what symptoms you are experiencing. Do you have any itching? Do you have tingling, stabbing or tightness? If so, these are positive neuropathy symptoms. There are many effective treatments available. *Gabapentin* is a nerve stabilizer that can calm down the sensation signals if sensation nerves are irritated and misbehaving. Note the nerve stabilizers main side effect is drowsiness, although medications for positive neuropathy work to calm the nerve signals to the brain but are ineffective with negative neuropathy since the nerves are so damaged that they no longer send any signals. So, nerve stabilizers would not be prescribed for patients with numbness. There are no drugs available to “wake up” unresponsive nerves from negative neuropathy at this time.

The [nervous system](#) includes several types of nerves. The hub for sensory nerves is located in the spine which makes the nerves to the fingers and toes the longest single cells in the body. The sensory nerves signal to feel pressure, temperature, pain, and pinprick to nerves found in the hands and feet. They are the first ones to be damaged from neuropathy. As the neuropathy symptoms progress, damage to the muscles and then general weakness occurs. For patients newly diagnosed or changing to a new drug regimen, it would be helpful to “rehabilitate” any physical impairments prior to treatment with strength training for body balance and generally improve fitness and well-being. Acupuncture is a technique that can reduce fatigue, headaches, digestion issues, stress, sleep apnea and other side effects of cancer and/or treatment medications. Acupuncture initial treatment runs 6-8 weeks to become really effective in reducing side effects and improving quality of life. Dr Khanna and Dr Bausum also took some additional time to answer member questions regarding compression fractures, Kyphoplasty, scoliosis, foot drop syndrome, and functional reserve. The presentation was very informative, and Dr. Khanna encouraged the group to reach out to his department with any questions or specific needs. He noted that they will be moving into the new Winship Tower in Midtown, next to Emory Midtown Hospital.

Q – Why do hands and feet get peripheral neuropathy (PN) first? **A** – The nerve that conducts the feeling from the foot to the spine is one cell. Once it is structurally damaged by treatment, then it is difficult to transmit nutrition from the spine to the foot with the infrastructure damaged. If there is any damage to nerves, the longest one hurts first. Short ones usually don’t have as much impact from treatment. **Q** – Patient is one month since diagnosis. Is there any way to prevent PN? **A** – Have an evaluation before starting treatment for fitness and get a “tune-up” to improve strength. Dr. Bausum said that they do not know who will benefit from acupuncture or acupressure until they try. She has group sessions with 20+ patients per day to reach more patients. **Q** – Patient had 15 vertebral fractures and lost 4” in height. What can help with the pain? **A** – Physical therapy can help but get a full work up before proceeding. Nerves from the spinal cord get crushed when the vertebrae fracture. Kyphoplasty can help raise the vertebrae and un-pinch the nerves. 90% of fractures are preceded by pain. If you are experiencing pain, back off and do not power through the pain! Those days are over for cancer patients. **Q** – Can scoliosis impact the process for Kyphoplasty? **A** – Scoliosis can develop over decades but can still treat fractures and pain. **Q** – Can my diaphragm collapse be from vertebrae fractures? **A** – Several different nerves control the diaphragm, but they do not go through the spine and will not be impacted by fractures. **Q** – What is the impact of diabetes on pain? **A** – Sugar destroys nerves. Organs have a functional reserve, but chemo takes it over the edge and destroys the reserve.

Group Discussion:

Jeff W. asked if anyone in the group had taken IVIG infusions and what were the side effects. **Bob C.** said IVIG was remarkable with no bad side effects. It helped him feel better in general and added how much it helped after induction therapy brought down his immune system with low energy. **Jim M.** was getting colds, pneumonia and lots of illness after his first stem cell transplant. He started IVIG in the spring and it wiped out everything. Jim's lab levels went back up with no side effects and felt great after the series of IVIG. The drug is expensive and normally needs insurance approval, but it is quite effective and contributes to the out-of-pocket total for the year. Jeff was glad to hear the good responses. He has been fighting sinus infections quarterly that last up to 4 weeks. Rosie, his nurse at Emory, suggested the IVIG infusion therapy last month which takes 3-4 hours. Jeff is quite happy that insurance has approved the procedure.

Nancy B. asked the group if anyone has received bispecific engager treatment. It is new and there is quite a buzz about it being the latest and greatest. Bispecifics are an "off the shelf" CAR-T alternative that bypasses the need to harvest one's own T cells to send off to re-modification process and return in a timely manner. CAR-T requests are limited to one or two slots a month for Emory or other hospitals equipped with CAR-T facilities. **Richard** explained that **Thyra** was preparing to have Bispecifics at Emory with Dr. Hofmeister. She has non-secretory MM and critical care. Thyra's most recent imaging tests showed positive results and she's doing so well on the Dara-Velcade regimen, Dr. Hoffmeister elected to hold off for now. Bispecifics require a hospital stay to ramp up the dosage for the drug.

Meeting Minutes Southside Virtual MM Support Group March 25, 2023

Business and News

Next Meeting: **Saturday, April 22, 2023, at 10 AM. Topic:** Group discussion on patient treatments and caregiver voices. **"For Men Only":** Tuesday, April 25, 2023, at 6:00 PM

General Discussion

Thank you to **Gail M.** who hosted the March zoom session with 20+ attendees. The meeting opened with a moment of silence by Doris. This month's meeting focused on three new members: Joseph C. from Savannah and John and Shaunte L. from Orangeburg, S.C.

Joe C. was diagnosed on March 8 and immediately started to search the Internet for resources where he found the IMF website and the Atlanta Area MM Support Groups. Joe is 47 years old and retired from the U.S. Army. His family is from Germany where he lived for 20 years and his sister who lives in Charlotte. His cousin was diagnosed with myeloma 10-12 years ago. In December, Joe started having back pain. He was seen at a Low Country Cancer Center in Pooler, GA and was diagnosed with Stage 1 myeloma. Joe has started his first round of therapy with RVd (Velcade, Revlimid, Dex(amethasone)) along with a bone strengthener (a bisphosphonate – e.g., Zometa, Aredia, Xgeva). A major problem currently is pain management. He has discussed it with his oncologist, but so far has not been able to get it under control. Gail advised him to insist on a resolution...that he should not be in chronic intense pain with myeloma. A second suggestion is that he should seek a myeloma specialist as soon as possible. Gail explained that second opinions are expected and considered a routine occurrence. This is especially true if your general oncologist is not a myeloma expert. His oncologist is willing to work with anyone Joe chooses, so he feels good about the possibilities.

Jeff W. suggested investing in a new bed with a good supportive mattress that could make a huge difference. Others recommended that Joe maintain a positive attitude and surround himself with

positive people. **Thyra** thanked him for his service and reminded him “you’re young and strong – do not give up!” Thyra explained that everyone is on a different journey and that her myeloma was diagnosed at a later stage. She was told she had bursitis for a long time. MRI imaging found her left hip had deteriorated from myeloma.

John L. was diagnosed in November 2022. He is completing Cycle 4 of the induction treatment in preparation for a SCT (Stem Cell Transplant). He and his wife, **Shaunte**, live in Orangeburg with their two young children. John’s myeloma specialist is in Charleston, where he will have the SCT at the Harlan Cancer Center. Post transplant arrangements have been made for John’s recovery, but there is concern about where the children will stay for the month when infection risk can be high. They do not want to be away from their children that long. Shaunte wants to talk this through with someone who can take into account the whole picture. Gail will put them in touch with Support Group leader, **Tiffany**, from Orangeburg who lives in Charleston. Thank you, **Portia**, for being a myeloma champion all the time.

Member Updates

Doris shared that she is a 19-year survivor. Her daughter, **Bridgette**, is her caregiver. “When you have strength behind you – you will make it.” Bridgette and Doris shared their recent experiences with COVID-19. Doris was having respiratory issues – could not breathe and ended up going to urgent care twice. Then they went to the ER for cancer patients at Emory (Rosa Pruitt, PA recommended to us in February) where her blood pressure and temperature were fine. It was initially thought it was bronchitis or pneumonia. Doctors also considered it might be a blood clot. It took 2 EKGs and 2 MRIs to get a correct diagnosis. Doris was admitted for overnight observation. Ultimately, it was determined that Doris had COVID. Breathing problems persist to a much lesser degree. Bridgette urges us all to Be Safe out there. Even though COVID is not on the front page any longer there are still variants, cases, hospitalizations, and deaths.

Joyce reported that she has been wearing two masks to get in her 10,000 steps. Even with double protection she developed pneumonia. She is on maintenance therapy, but her WBC (White Blood Count) was low, and her immune system was weakened. She was admitted and kept in the hospital—and on antibiotics. **Flora** has been on maintenance for two years on *Ixazomib* (Ninlaro) with Dex infusion once per month. She has anxiety considering what are her next steps. Dr. Nooka is her hem-oncologist. Gail suggested several questions to ask and to schedule a comprehensive conversation with Dr. Nooka very soon. **Joe** was encouraged to attend the “For Men Only” group coming up on Tuesday evening and get their perspectives and support. **Geraldine** had Car-T therapy in May 2022 and is doing very well. Car-T treatment followed two unsuccessful transplants in 2018 and 2019. There has been no sign of myeloma after two biopsies. During the procedure, she was in terrible pain everyday with body aches for 30 minutes at a time. Geraldine was prescribed low dose Percocet from her doctor at Northside Hospital handling the pain management. Geraldine has also had an increase in dental problems and visits a periodontist. **Cynthia B.** also received Car-T therapy and has been in remission for eight months. She went to Arkansas for a second SCT before Car-T treatment. Cynthia shared that a healthy diet and staying hydrated goes a long way to fighting myeloma and the side effects of the medications/treatment. She has also received acupuncture. Cynthia has had four relapses, but remains happy, joyful, and thankful to the Lord.

Glenda is on *Pomalyst* (Pomalidomide - *iMid*) immunomodulatory agent class) for maintenance and has developed *vitiligo* (the loss of melanin in the skin). Prescribed cream seems to be 45% effective. Joyce is also on Pomalyst and has not had any problems. Someone else reported hives with Pomalyst as many have experienced with Revlimid. Gail urged everyone to continue reporting their side effects to this group and to their doctors. Our voices can be stronger together. **Jeff W.** is on venetoclax and has had a Very Good Partial Response (VGPR). **Kyle** reported a critical case of heart failure in

response to *Kyprolis* (Carfilzomib – (PI) proteasome inhibitor class). The toxicity from Kyprolis is included on the label in the list of side effects, so we all must be vigilant. Initially, his appointment with the cardiologist was delayed for almost a month at Emory Winship. He had maintained his relationship with his Primary Care Physician at another location and was able to get in immediately. His cardiologist says heart failure is completely reversible. **Alma** was on Kyprolis as a part of a clinical trial with CC-220 (now called Iberdomide). She also had cardiac problems and was taken off within a month. She is much better now, allowing herself to heal physically and mentally as she studies her next possible therapy. Ninlaro and Pomalyst did not work for her. Last year was really rough health wise for Alma. She had both pneumonia (bacterial and difficult to diagnose) and COVID – lasting for 6 weeks each. We all trust that Kyle, Alma, Flora, and all those seeking their next step, find a path that is suitable for them and their myeloma.

Respectfully, Gail