

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Meeting Minutes Northside Virtual MM Support Group August 7, 2021

Business News - The Northside group will continue to meet virtually for the remainder of this year. Earlier, we had thought we could have our annual luncheon this fall, but the COVID variant is spreading. Gathering in person would be much too risky for myeloma patients and caregivers or anyone in general! We appreciate your patience and understanding as we work to keep everyone safe and informed. If anyone needs help in connecting for the first time, feel free to contact Nancy (info at bottom of news).

Open Discussion - Thank you to **Nancy B.** who hosted the meeting with approximately 30 people attending. We had several people who joined the group for the first time. Welcome **Donna R, Dina S, Sarah R, and Scott H** and thank them for sharing their stories and good information.

Nancy B. recommended a book, called *Gut: The Inside Story of Our Body's Most Underrated Organ* by Giulia Enders. The book is updated every couple of years as more is understood about how gut bacteria affects your mood, your overall health, and your immune system. It's important for everyone's health (not just MM patients) to understand the entire digestive process, pay attention to feed it and treat it well. It is fascinating what has been learned about the biome in your gut and the association with your immune system.

Several members mentioned that they've had various types of skin cancers, some prior to MM diagnosis and some after MM diagnosis. Many patients mentioned that they go to the dermatologist twice a year for skin checks because treatments can cause skin sensitivities and can increase risk of skin cancers. This discussion served as a reminder of how important it is to maintain all regular medical checkups and routine procedures, such as regular skin checks with your dermatologist, colonoscopies, etc.

The meeting was an open forum where patients discussed updates on multiple myeloma (MM) treatments and shared information.

Ron R. was diagnosed 12 years ago and is doing well. He has achieved remission with Velcade and Dex and has not had a stem cell transplant (SCT).

Sandy B. was diagnosed nearly 32 years ago. She is taking Revlimid 14 days on and 14 days off schedule, after being switched from 21 days on and 7 days off regimen, to help with fatigue and improve quality of life. Sandy recently learned that she has stress fractures at the base of her shoulder blade, from the MM weakening her bones over time, which is very painful. Sandy said that the fractures will probably take several months to heal so she will need to use a sling or something to keep her arms stationary to support the healing process. This issue is a challenge related to longevity and she knows that she will need to deal with these challenges as they occur and do her best to improve them. Overall, she still feels humbled and grateful and has no complaints. Sandy's happy to be a part of her wonderful family and her church family.

Lory M. is doing well and feels good. She began to relapse while taking Revlimid and Daratumumab (Dara) 3.5 years ago. Her paraprotein and IGG numbers continue to increase but then level off and stabilize before going up again. She went back to Dara every two weeks to get the most MM control

out of that treatment. A recent PET scan showed no active disease, and she is continuing with her current treatment for now and is very happy that her treatment does not include Dex. Lory mentioned that she is considering EMPLICITI (Elotuzumab) and Pomalyst as future treatments and she is interested in hearing about the experiences of others who have taken these drugs.

Nancy B. pointed out that when you have a treatment that is working for you, you should continue on it for as long as you can while it is working.

Donna R. was diagnosed in December 2020 unexpectedly, as she had no symptoms. She had a SCT in June and said that she is feeling much better than she did before and is preparing for her daughter's wedding in September. She was offered several solutions from the group regarding the current hair loss from the transplant. Donna is also learning about maintenance drug options and deciding on what she might start with when the time is right.

Dina S. was diagnosed in October 2020 which took about 3.5 years to be initially diagnosed. She was in a lot of pain that would radiate throughout her body and never knew what was going to hurt on any given day. Dina went to many different doctors in the process and finally a CAT scan of her head (for a different reason) led to a MM diagnosis. She explained that a PET scan showed lesions everywhere, but her blood work was OK. Dina had a SCT in February 2020 and is currently on Zometa and Revlimid. She's doing well with her worst side effect being insomnia and is trying to stay organized to maintain a new routine. She is interested in being a part of a support group to be able to learn and share and get helpful tips and different perspectives. Dina understands the importance of one's attitude throughout this journey and said that she is back to enjoying hiking, biking, paddle boarding and yoga on good days.

Jim N. reported that he relapsed in May, but the MM did not show in his bloodwork. He experienced back pain and an MRI showed his T4 vertebrae was destroyed & T7 was damaged. He had radiation on T7 which helped and after one round of Dara and Dex Jim quickly went back into remission. He is continuing with Dara and is planning to begin Pomalyst. Jim especially wanted to caution everyone to not only check their blood work for MM, but also their bones.

Sarah R. was diagnosed in January and started treatment in March. She had 4 cycles of Carfilzomib and then started getting Zometa and taking Revlimid 21 days on and 7 days off. The Revlimid is causing side effects of a rash and swollen legs. She sees Dr. Nooka at Emory and also Dr. Andrew, a physician assistant. Sarah was also diagnosed with colon cancer this year. She had surgery in June and learned that the cancer had spread to two lymph nodes. She is now focused on completing colon cancer treatment, which will end in September, and then re-focusing on MM treatments. She was glad to hear about so many MM treatment options that are helping so many patients.

Scott H. was diagnosed via an MRI five years ago after experiencing chronic lower back pain for a long time. He mentioned that he was just about as healthy as anyone could be pre-diagnosis. His initial therapy was a 3-drug regimen in preparation for a SCT that he had 4 years ago, which was non-eventful, other than the resultant peripheral neuropathy in his feet which he still has. He is taking a drug holiday from maintenance drug Revlimid and is currently on no medication. Scott sees Dr. Reddy quarterly at Northside Forsyth for monitoring and Dr. Bashey annually visits the Tower in Dunwoody for bone marrow biopsies. He said that he is extremely pleased with his doctors and medical care and also has fantastic family support. Scott shared some information about a doctor he learned about who was diagnosed with MM in 2018 and given only a couple of months to live. Scott learned about him because they share the same profession. Dr. Danenberg did his own research and took a radical approach with his health care in order to improve his condition. It is an interesting perspective and Scott thought that others in the group would enjoy reading his story, which can be found by doing an internet search on ["Dr. Danenberg Multiple Myeloma"](#).

Tom H. was diagnosed in February and started a clinical trial (CT) at Emory in May. He was planning to finish 8 cycles of weekly subcutaneous Dara, and then have a SCT. He has completed 2.5 cycles on

the CT. His MM numbers are good, but a recent PET scan showed fractured vertebrae, and he is planning to have kyphoplasty surgery. Side effects included a mild case of shingles from which he is recuperating. He said that he feels better in general. Tom expects to change to a more traditional treatment regimen which his doctors are currently planning for him, and he's eager to know what they decide for planning purposes.

Anderson F. was diagnosed with smoldering myeloma in 2014. He recently experienced aches and pains and a scan at Emory found lesions on his hip. He has been treated with radiation only, no drugs to date. He is planning to start drugs soon, in preparation for a SCT in the fall. Anderson found out about our support group through **Gail**, and he mentioned that he sees doctors at both Piedmont (Dr. Jonas) and Emory (Dr. Kaufman) for his care.

Chuck M. reported that he is on Revlimid maintenance and doing well. Both he and his wife, **Susan** are fully vaccinated for Covid with the Moderna vaccine, yet Susan has contracted Covid. She generally does not feel that bad, with symptoms feeling similar to a mild cold with a cough. They are quarantining in their home and Chuck has not caught it. Chuck mentioned that they have no idea how this occurred. **Nancy B.** noted that **Dr. Durie** is very worried about Covid, and shared that she also continues to be very careful, double masking in public, etc.

Jeff W. is continuing on a study at Emory and has been told to continue to “wear your mask like it was July 2020”, as it is known that MM patients do not get the 98% protection from the Covid vaccines like the general population does.

Nancy Y. was diagnosed in 2007 and had two tandem SCT's in 2009. In 2015 her kappa ratio rose, and she was on EMPLICITI (Elotuzumab) for two years which didn't help. She has now been off all MM medications for 3.5 years and her kappa numbers are good without any treatment. She feels fine and explained that she stays active, eats well, and follows a strict diet. **Nancy B.** commented that another group member had MM numbers that went way down once she retired from her job. She had less stress and became more active, and her numbers improved without treatment.

Submitted by Wendy R.

Meeting Minutes

Southside Virtual MM Support Group

August 28, 2021

Business News

Have your cup of morning tea or brunch and let's chat! Join us for great conversation.

September meeting, it's *Our Voices* – shared experiences, challenges, successes, new resources on exercise and more. There are short new videos and information on advocacy to share.

Doris opened our meeting with a moment of silence. The Southside ATL MM Support Group celebrates 15 years since Doris created it after her diagnosis in 2006. Like most of us, Doris had never heard of myeloma, found out during her regular physical exam. She inquired around among her many friends and organizations, and they had never heard of it either. Doris visited a myeloma support group on the northside of Atlanta. This group was also founded by a myeloma patient about 5-6 years before southside. After attending those meetings, Doris decided to create a group closer to home rather than trekking more than 40 miles round trip. The initial group included ‘friends of Doris’ – not just myeloma patients, but good friends, her family, and a nurse. ATL Myeloma north and southside support groups work well sharing resources, a monthly newsletter, and 501©3 designation. **Thank you, Doris and Happy 15th Anniversary to SS ATL MM SG!** September Health Observances are Blood Cancer Awareness, Healthy Aging, and Sickle Cell Awareness.

We welcomed a new member **Sarah R.**, who was diagnosed with myeloma in March 2021. She is being treated by Dr. Nooka at Emory. She had to interrupt her myeloma treatment for four sessions of be treated for Stage 3 colon cancer. Her MM treatment includes Dara (Daratumumab/Darzalex), Rev(limid), and a steroid. She is unsure of getting a Stem Cell Transplant (SCT) because she is over 70. Sarah remains in great spirits. She enjoys walks in the new and beautiful Westside Park, her sister is her caregiver, and close friends check in on her. Sarah had to request a lower dosage for MM meds and has learned to adapt to the pic line. Sarah has also taken advantage of the LLS co-pay assistance and is approved for \$15,000. Welcome Sarah! We were sad to report the passing of a long-term and very active member since we went virtual, Sallie S. Janice. Also, get well soon wishes to Alma who is in the hospital.

Guest Speaker

Our speaker this month was nurse practitioner, **Tara Roy, MS, NP, AOCNP** on **Cancer Survivorship: Optimizing Your Wellness**. Tara is the Patient Advocacy Liaison - Multiple Myeloma from Takeda Pharmaceutical for the southeast US. This was Tara’s second visit following her July presentation on lab values.

What is Survivorship? The act of surviving; Anyone who has been diagnosed with any cancer –from date of diagnosis for the remainder of their lives. Many years ago, the National Coalition for Cancer started the work to remove the “victim” status from survivorship. Six dimensions of wellness are: Physical, Mental, Emotional, Social, Occupational, and Spiritual.

Stages of Survivorship include:

- Acute - at the time of diagnosis and through the initial treatment
- Extended – the effects of the cancer and treatment
- Permanent – focus on long-term effects of the cancer and treatment

It is estimated that there are over 15 million cancer survivors in the United States. *For Georgia, the estimate is 447,000 cancer survivors (Georgia CORE -Survivorship Connection).*

What are the needs of people living with the cancer diagnosis? Why do we need survivorship care or a Survivorship Plan?

Some cancers, including myeloma are becoming more like chronic diseases.

- Evolving therapies. 14 new MM drugs have been approved by the FDA in 15 years!
- Americans living with cancer continue to grow. The number of those living with cancer will increase by 25% by 2029.
- Since more people are living longer **Survivorship Plans** are needed.

Why a Survivorship Plan?

Navigating your survivorship journey is complex and always evolving. Discuss survivorship with your healthcare team.

- Long-term and late effects from cancer and its treatment can impact *quality of life*.
- A survivorship plan helps guide you in *monitoring and maintaining* your health. Continuously be updated as needed.
- *Communicate* with your healthcare team about all health changes challenges: physical, psychosocial, and spiritual.
- Survivorship means *optimizing wellness* wherever you are.
- Know your resources and *be your own advocate*.

Providers have been strongly encouraged by National Cancer Institute, American Cancer Society, Centers for Disease Control and Prevention, American Society of Clinical Oncology (ASCO) and others to provide a Survivorship plan for all patients. Since very few providers do, patients and their caregivers must create their own.

In the plan, you include all your lab reports, scans, and therapies. You should also include your symptoms – physical, psychological, spiritual, social, financial, etc. You can use a

three-ring binder with tabs to create your survivorship plan. Resources where you can find a guide for your Survivorship Plan follow. Also look for a copy in your email.

Long Term and Late Effects of Cancer and Treatment include:

- **Physical well-being** – functional activities, sleep and rest, fertility health, pain, strength, and fatigue
- **Social Well-being** – family distress, appearance, roles and relationships; sexual function, finances, work, and isolation
- **Psychological Well-being** – control, anxiety, depression, fear of recurrence, cognition, diagnosis distress, and treatment
- **Spiritual Well-being** – meaning of illness, hope, uncertainty, and inner strength

Long-term Physical symptoms might include neuropathy, chemo brain, depression, sexual dysfunction, and anxiety. Many of these symptoms start during treatment.

Late effects of treatment might occur months or even years later. Keeping records in your “Plan” will help guide you in future conversations about your health and well-being. Examples include cardiovascular disease, metabolic syndrome, hearing loss, lymphedema, lung problems, and secondary primary cancers. *You may not ordinarily link these late effects to your cancer if you do not keep records.* **The most prevalent lingering symptoms for cancer patients are fatigue and pain.** 25% of patients report some type of psychological symptoms.

Maintenance – work with your healthcare team to schedule regular health assessments and screenings to monitor:

Tumors/cancerous growths	Cardiovascular Health	Endocrine disorders
Nutrition	Bone health	Hearing and vision
Cognitive changes	Depression	Fatigue

– Be sure to maintain regular contact with your doctors. Ask your doctors about any emerging treatments. Ask about resources and a referral network based on your individual needs. Know the role of each member of your team. Report any side effects or changes you experience immediately.

All providers should be in your Survivorship Plan. Include oncologists, primary care providers, nurses and nurse navigators, Social Workers, Pharmacists, and others.

Remember other parts of your plan to include medications, scans, lab reports, and notes of significance on reports, check with providers for any missing information. Finances

should also be included in your Survivorship Plan. Finances may be a cause of distress. Set personal health goals. Review your Plan with your Provider.

How Survivors can Adapt to a New Normal

- Identify what you can change and what you cannot
- Be open to your emotions – both positive and negative
- Learn techniques for coping with and reducing stress
- Learn relaxation techniques

Caregivers are survivors who experience physical, emotional, financial stressors.

Sexuality and Intimacy. Don't be afraid to initiate a discussion with your mate and with your providers. Provide enough information for providers to be able to help. Are medications the source of problems? Are the changes psychosocial or even financial? Ask for referrals to specialists if needed.

Survivorship Resources

- [American Cancer Society](#) – personal care manager; caregiver resources; insurance resources; Survivorship care plan; Guidelines for Nutrition and Physical Activity for Cancer Prevention
- [National Coalition of Cancer Survivorship \(NCCS\)](#) – advocates for quality cancer care; provides resources and guides for survivors
- [Livestrong at the YMCA](#) – promotes importance of physical activity after a cancer diagnosis, provides free or low-cost customized exercise regimens for survivors
- [Georgia's Survivorship Connection](#) (Georgia CORE)

Survivorship Plan Booklets available on ***Physical Health*** (When will I feel better), ***Mental and Emotional Health*** (Why Can't I shake this feeling?), ***Practical Health*** (How am I going to manage everything?), and ***Spiritual Health*** (Why did cancer happen to me?)

Respectively submitted, Gail