

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside SG Virtual Meeting November 7, 2020 Meeting Minutes

The Northside MM group held two sessions- one for patients and the second for caregivers. These were back-to-back to accommodate those homes that have only one computer with a camera. The discussions were meaningful and interactive.

Group business meeting

For our December meeting on 12/5, we will certainly miss coming together with delicious dishes from our great cooks. We would like to do something cheerful to connect with other members. Please plan to attend with a cookie or a snack, maybe bring a family picture, a funny story about a family gathering, or a special recipe that has a family tradition. For those who are interested in sending gifts to kids in the hospital over the holidays, we will provide information about sending the gifts directly to CHOA and let them know that they are from AAMMSG. Also, please use Amazon Smile and designate that a percentage of your purchase price go to Atlanta Area Multiple Myeloma Support Groups. Please pass this along to friends and family to direct donations to our group from their purchases.

We are so glad to be able to connect virtually with members of our group. We would like more to join the monthly meetings and provide an update on your treatment status and quality of life. The shared stories are so important, especially to newly diagnosed patients. We had several new patients join our group this year and have benefitted from members answering their questions and support.

Patient Session

Patients relayed stories about different treatments. Several discussed Pom experiences that were both positive and negative. We had a new patient who had a transplant in July and had infections. There was discussion about Dex dosage levels and length of treatment. Many patients are maintaining stable disease with an M-spike of 0.3 or 0.4 for extended periods. One patient recommended Benadryl 50 mg for sleep on Dex nights. Check with your doctor. Discussion on diarrhea yielded many recommendations: organic banana flakes from Too Good Botanic has helped when added to oatmeal and other foods; Welchol or Colestipol every day and Lomotil for break-through issues is one plan discussed by patients; Lactaid with Rev helps since the tablets contain lactose; some eliminated dairy; others note certain foods as triggers. Patient Updates Carolyn is doing well on Dara and has a new doctor at Emory – a cardiologist/oncologist for her fatigue. Sandy B. had her first lesion in over 30 years with MM. It is in her upper arm and she is getting radiation. Jim is doing well on Dara/Pom and monitoring markers for colon cancer that was treated earlier this year. Sandy W. is on clinical trial with Ninlaro/Rev/dex for one year.

Caregiver Session

The group helped a new caregiver whose patient is heading to a transplant the first week of December. He heard many suggestions from the caregivers in the group about preparing the home for post-transplant patient. One caregiver is retiring at the end of the year and had questions about Medicare coverage of Revlimid and the co-pays. Another caregiver is dealing with severe dementia for her long-term patient. One caregiver said that she and her husband flew to Washington DC in March as the virus started spreading. When they got back, they were sick for weeks, but doing better now. Joe B. said that he takes Sandy for rides to small towns outside of the city. They do not go into stores or restaurants, but it is a change of scenery to drive through these towns and see the sights. They recently enjoyed a trip to Oxford

GA. That reminded everyone to take the time to enjoy the beautiful fall weather we are having and get out to see something different.

Upcoming events

The IMF is having a workshop on November 21 at 10:00 AM eastern. It was recorded and posted to the web site at www.myeloma.org There is also the replay of the IMF Comedy Gala with the cast from Everybody Loves Raymond reading scripts from some favorite episodes. Very Funny.

Myeloma Crowd is having a round table discussion November 21 on two topics: newly diagnosed and high-risk disease. Details at www.myelomacrowd.org

ASH will be virtual this year and the IMF will post videos from MM expert doctors on what new research shows promise at ASH. They will be over 900 abstracts (each a summary of a research project) on myeloma topics this year. With all that research going on, there will be some exciting news. We will hear about some of it at our January meeting, which is an ASH review with the Winship myeloma team. This will be January 9 or 16. Details soon.

Submitted by Nancy B.

Meeting Minutes

Southside Virtual MM Support Group

Saturday, November 28, 2020

Doris opened the meeting with a moment of silence, and encouragement to express gratitude for all the good that is a part of our lives.

The agenda for this meeting included (1) updates and conversations with patients and caregivers, (2) a presentation from the Leukemia and Lymphoma Society (LLS) on available services, and (3) brainstorming ways to let others know we are here to help.

In October, **Vermell** Sanford (retired nurse practitioner and volunteer/member of the Southside ATL Support Group) provided a presentation on the importance of knowing your lab results with a brief Multiple Myeloma (MM) overview. She urged each of us to know the definition of our own MM. So many of the newer medications are targeted medications. Knowing as much as possible about our MM can make us better partners and contributors to decision-making for our treatment regimens. The definition includes whether it is active myeloma or a precursor (i.e., MGUS or smoldering), the immunoglobulin (heavy chain) and light chain combination, and what cytogenetics are involved, including whether you have a high-risk kind of MM.

Myeloma cells make **immunoglobulins** – abbreviated **Ig**. A small sampling of those present reported heavy chain IgG, which along with IgA are the most prevalent of the five heavy chains (IgD, E, and M are rarer). Both light chains, lambda, and kappa, were reported. **Alma** follows her free light chain, lambda. About 15% of patients have light chain myeloma. In this type of myeloma, the myeloma cells secrete only light chain protein and no heavy chains. It is also known as "Bence-Jones myeloma" (after the doctor who discovered it). She has been a part of a Daratumumab (an antibody also called Dara or Darzalex) clinical trial. She is currently on the trial using CC220, which is in the same class as Pomalyst and Revlimid; **Marcia** has Plasma Leukemia, an aggressive form of MM. She was in stringent complete remission (sCR). Currently, she is taking Kyprolis-Pom-dex. She started on 40 mg dex, and at her request, she has now reduced the dosage to 8 mg. For those with smoldering myeloma, if they are not high-risk, treatment may be delayed

and monitored closely. Treatment is now indicated if they are defined as high-risk. We should keep a record of our myeloma type in an easily accessible place in our personal medical records.

Nina Logan, MD is the Senior Manager of Patient and Community Outreach, LLS. She came to share some of the programs and resources offered by LLS to myeloma families and for blood cancers, in general. LLS is one of the leading sources of free blood cancer information with an extensive library of one-pagers on topics. There are three parts to their services – education, research, and advocacy. In 2017, LLS invested \$1.3 billion in cancer research. They were involved in the FDA’s approval of 56/66 medications to treat blood cancers. Dr. Logan encouraged us to learn more about available resources at lls.org.

Some of their programs include:

- **100 Day Agenda** – a blueprint for advocacy. This effort includes 29 specific steps for legislators in 16 main areas.
- **Personalized Nutrition Program.** This program is for both cancer patients and caregivers. Cancer nutrition information is provided on how to mitigate the impact of cancer or cancer therapy. Exercise is an essential part of the recommendations.
- **Clinical Trial Support Center.** Staff can help families navigate potential clinical trials for patients.
- **Educational Materials.** This extensive library includes videos, webcasts, and transcripts. Print materials can be shipped at no costs. Other materials can be downloaded at no charge.
- The **Patti Robinson Kaufmann First Connection Program** is a free service for patients and their families. This peer-to-peer program offers support for special populations, including Caregivers, the LGBTQ community, and younger myeloma patients. There are also online chat groups for patients and

families. **Doris** and **Pat C.** are long time volunteers with the First Connection program.

- **Financial Assistance Programs.** There are many different programs to help cancer patients and their families manage this very expensive and stressful disease. The Co-pay Assistance grant is for 12-months – up to \$11,000; Travel assistance is \$100/6 months and can be used not only for transportation, but for personal needs, like car repair, haircuts, lawn care, and utilities. Urgent need grants can be \$500/12-months. Sometimes these programs run out of funds. There are times when funds are replenished in weeks or months. Please take advantage of these funding opportunities.

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In response to one of our monthly discussion questions, *“What do you know now that you wish you had known much earlier?”*, several people agreed with **Carolyn W.** – “I wish I had known about this Support Group”, and with **Ted**, “I wish I knew how expensive cancer is ...” To spread the word about our meetings, we should increase awareness that we are meeting virtually – that travel to meetings is no longer necessary. While we use a virtual platform, people can join the meeting with just a phone. We can do a targeted awareness campaign, focusing on communication channels recommended by this Group.

We have brochures – and need to add a flyer to announce our virtual meetings. We can place information at Winship in the infusion center and ask our providers about ideas for sharing Support Group information with myeloma patients and families. Sheryl suggested including information on their community monthly newsletter. Doris also has a community newsletter. If we can locate someone at the Cancer Treatment Centers of America, we can spread the word there. For our group, we can ask Health Ministries of congregations and sororities/fraternities to place announcements in their information

channels. **Gail** asked members to send contact information to Paulette, and we will develop a consistent MM awareness message. Please send information within the next four weeks. Also, use the “Next Door” e-news to share information. **Paulette** will share with nurses at Camp Creek medical offices. We must get the information to the right person (s). in each organization. We have to do what we can to ensure that no patient or family is suffering unnecessarily from lack of information.

Additional Discussions

The month of November has several different health foci. It is National Caregiver Awareness Month, Diabetes Awareness Month, National Alzheimer’s Disease Awareness Month, and Lung Cancer Awareness Month. **Vena**, who also has lung cancer, reports that both her myeloma and lung cancer are stable. A side effect of the OPDIVO she is taking makes her very tired, without much energy. Still, she says, she is willing to get the COVID-19 vaccine if it is recommended for her. She has a lot of skepticism, based on the rush to production, and all the politics surrounding the vaccine. However, she thinks she will be more comfortable taking the vaccine than not.

The Group discussed others’ thoughts about the COVID-19 vaccine. Gail provided copies of a “Love Letter to the Black community from Black physicians and nurses.” The purpose of the letter is to address concerns communities of color and indigenous communities have about the vaccine. We will continue to share resources for people to become more informed about the vaccines’ progress. Continue to look at the IMF website for updates on the vaccine’s safety for myeloma patients.

Announcements/Resources/Upcoming Meetings

- **COVID-19 Vaccine – Love Letter to Black America:** <https://blackcoalitionagainstcovid.org/loveletter-read-more/>

- **Emory Winship Update on ASH- Annual Meeting.** January 9, 2020. Over 600 abstracts on myeloma were accepted for presentation during this year’s hematology meeting. Approximately 150 abstracts were about research on Blacks and myeloma.

- **IMF. Charity Navigator.** Most reliable charity – 4 – Star rating.

- **The Power of Vitamin D. for Myeloma – for COVID-19.** Get your Vitamin D levels checked. Bones, joints, heart health, immune system

- **Patient Empowerment Network (PEN).** 5 min Educational sessions. Why Myeloma Patients Should Speak Up; How a Second Opinion Saved a Patient’s Life; Myeloma targeted therapy- Why Identifying Chromosomal Abnormalities is Key.

- **Patient Power.** What’s Next after a myeloma diagnosis? 3:04’.; Myeloma and COVID-19 – What the Experts Have Learned

- **AMAZON Shopping?** [Smile.amazon.com](https://smile.amazon.com) – You can choose IMF, Atlanta Area MM SG, or a charity of your choice.

- **Smart Patients.** IMF. <https://www.smartpatients.com/conversations>.

Respectfully submitted, Gail