

ATLANTA AREA MULTIPLE MYELOMA SUPPORT GROUP, INC.

Northside Meeting

December 14, 2019

This meeting was our annual Holiday party and there were tasty treats and side dishes brought by everyone. Thanks to Jim M. for the ham that went so well with the other dishes. Yum!

Thanks also to those who brought new, unwrapped toys for the children in the hospital at Christmas. Molly and Bob delivered over 40 toys to Children's Healthcare of Atlanta (CHOA) and they were most appreciative.

We took some time to discuss programs for the coming year. The support group Board of Directors met before the regular meeting and wanted to get further input from the members. In 2020, we have the following monthly programs set:

- ASH at Winship on January 11
- Patient and caregiver separate sessions in February and again in November
- Myeloma Action Month (MAM) in March - Jim M. talked about the Resilience Project – see below.
- Binding Site to explain Free Light and the testing process in April
- Annual luncheon in August. Takeda can no longer sponsor, but the group will find a way to continue this well-attended tradition.

- Holiday party in December

Suggestions comments from group included:

- Return visit from Medicare broker who was most knowledgeable about that process
 - Co-pay assistance for commercial insurance
- Return of Eldercare attorney or Financial Advisor from a few years ago. They both talked about preparing paperwork for both patients and caregivers.
- Dr. Curseen at the Palliative Care team at Winship. This team helps to improve quality of life through a variety of practices.
- A medical discussion of supplements and herbs for managing side effects and improving quality of life.

Your input and suggestions are always welcome. Please reply to the email address on this newsletter or leave a phone message with Nancy 404-374-9020 or Jeannie 954-560-4610.

Jim M. talked about the Resilience Project that was introduced at the Support Group Leaders Summit in July.

Resilience Project: Support group members share or take a photograph of anything that represents resilience to them. Resilience is the quality that allows us to carry on and deal with adversity. We don't need to feel resilient all the time to be a resilient person.

The image can be of anything. Good ways to think about it are:

What keeps you going (with myeloma and/or life in general)?

Who keeps you going?

What does resilience mean to *you*?

Please send **ONE** photograph of high resolution, actual size (this should be very easy if the image is taken with your phone) to the support group email by the end of January 2020. Please

give the image a **TITLE** and let us know whether you are a patient, caregiver, or family member. You can also include a short description of the image and why it represents resilience to you. It does not need to be over one paragraph.

What are the photographs of?: Images can be of *anything at all*. Resilience is linked to social bonds, faith, hope, happiness. Photographs could feature what members value in their life e.g. nature, family, children, friends, pets, sports, hobbies, home. The aim is that the images capture a feeling or an idea, without having to overthink things too much. The image needs to be clear, but this is not a photography competition!

We are going to collect the pictures along with the descriptions. We would like to create some posters and hang them in our meeting room during the March meeting. We will also use them to raise awareness of myeloma with the church membership where we meet. You can think about Resilience over the Holidays and put your story together during January. Please plan to send by the end of January.

Submitted by Nancy Bruno

Southside Myeloma Support Group

December 28, 2019

A moment of silence was observed led by Doris. We keep all our members, friends, and family members in our hearts and minds during this holiday season. We especially keep in mind those who have suffered a loss, and who are themselves suffering from illness. We wish healing and peace for them all.

In this final meeting of 2019, the group looked at lessons learned and achievements of 2019.

- We say THANK YOU to all our supporters for helping us to exceed our fundraising goals for the Leukemia and Lymphoma Society (LLS). LLS benefits many in our group by assisting with insurance co-pays, medications, travel expenses for medical appointments, and

specific funds for myeloma patient expenses. We achieved 132% of our \$2,500 goal for \$3,296.

- Thank you, Pat, for taking the leadership with your congregation to provide an annual award to the IMF (International Myeloma Foundation). Pat did this in the midst of recovering from her third Stem Cell Transplant (SCT).
- The SS MM SG made their annual contributions to the IMF, LLS, and MMRF (Multiple Myeloma Research Foundation) for all they do in research, service, and education to improve the lives of those diagnosed with MM, and to find a cure.

We have secured the Macy's Community room for our meetings for 2020. Thank you to Paulette and Doris for their tag-team efforts and hours spent in line to accomplish this feat!

Topics for 2020 meetings will include Palliative Care, the role of clinical trials in finding a cure, updates on research, treatment, and outcomes for Myeloma in those of African descent, the significance of scans in MM treatment, things we should know about Medicare/Medicaid and MM, and others.

African Americans and Myeloma

Myeloma occurs in blacks at 2-3 times the rate in whites. Why does it happen? Is there current research to help answer this question? Dr. Nooka at Emory Winship is conducting laboratory research to help answer the question. We will invite him to our meeting to share updates. Gail is one of the patients featured on the newest edition of Standing in the GAAP, a publication about MM in African Americans first produced by Celgene about four years ago. For those who wish to join the Diversity and Inclusion section of the IMF to be a part of more discussion and research in this area, please do. You may sign up at <https://www.myeloma.org/diversity/diversity-inclusion>.

The **PROMISE Study** is designed to help answer the question as well. This is a multi-center trial seeking first degree relatives of myeloma patients (mother, father, sister, brother), but not myeloma patients. Those who enroll must be 40 – 75 years of age, and are considered to be at higher risk of developing MM. A major aim of the study is to make myeloma a preventable cancer. Some of the research centers include the Mayo Clinic, Harvard, and Dana Farber, and Stand Up to Cancer. We have brochures available. More information can be found at their website: <https://www.enroll.promisestudy.org/>.

The IMF has a short 5-10minute survey we encourage all to take as soon as possible. The survey is looking to determine differences and obstacles in diagnosis and treatment of MM. Please share your experiences in order to help solve these issues.

<https://www.research.net/r/IMFPatientSurvey>.

Patient Updates

Each of the patients and caregivers provided an update on their treatment. Some points of interest included: Gloria was told when she was diagnosed in 2009 that she would never work again. She has been happily employed, and will voluntarily reduce her hours to 20/week as of January 6; Marcia continues to get stronger after her transplant this past August; after seeing several doctors, diagnosed with smoldering myeloma, and taking a "wait and see" approach to therapy, Danmora's labs showed an increase in clonal plasma cell in the bone marrow. This is a part of the newer criteria for treating myeloma and results from research on smoldering MM. The older criteria included one of the following symptoms, called CRAB criteria (CRAB = high

Calcium in blood/urine; Renal/kidney disfunction; unexplained Anemia; and Bone lesions). Even without the presence of the CRAB symptoms, treatment in earlier stages might reduce the progression of MM, and is called SLiM CRAB (SLiM = Sixty percent or more plasma cell in bone marrow; Light Chain ratio of greater than 100; and M for MRI with more than one lesion); Bridgette has retired and will be able to commit more time to assist her Mom (Doris) and the Support Group; Vena is entering a new phase of therapy, and asks for additional prayers from the group.

Gail suggested that we explore the possibility of creating a more user-friendly **Cancer Survivorship Plan**. These Cancer Plans were at one time a requirement of Cancer Centers – that each cancer survivor be given a Survivorship Plan. Most patients have never heard of this. We have had several presentations over the years, including 2019. There are templates for the Plan on websites like CDC, ASCO, and ACS. However, they are not easy to follow, nor do they stimulate patients or providers to include possible cancer contributors to future mental, emotional, or physical results from cancer, such as the fear of relapse, secondary cancers, or unexplained symptoms.

The Group agreed to lend their support to an effort to create a better document. Deborah shared that the V.A. Hospital had recently hired a Navigator whose sole responsibility is to create Survivorship Plans. She will see if it is possible to get a copy of their template. Gail will check to see if there are sources that can help us to develop a document that is patient/caregiver-initiated, that we feel inspired to keep updated.

Announcements

- Weekly #AskDr.Durie Topics: – **Is it possible for bone lesions to progress even if all other tests look good?**
- LLS. Archived Webinar. **Ways to Reduce Financial Burden of Cancer and Improving Bone Health for Myeloma Patients.** <https://www.lls.org/patient-education-webcasts>
- MMRF MM highlights from ASH- December 18; Archived Webinars: **Maintenance for MM patients** - November 20; **What does the newly approved drug, XPOVIO (Selinexor) mean to MM patients** - October 17.
- **Smart Patients.** A monitored blog of discussions on many topics for MM patients – new and seasoned. www.smartpatients.com

Thought for the day – from Deborah

“We live our lives by looking forward. We understand our lives by looking backwards.”

Respectfully submitted, Gail