

December 2017

## **Northside Multiple Myeloma Support Group Meeting December 2, 2017**

### **Business**

Your Board of Directors met before the December meeting. We worked on program planning and other administration issues for the support group. We appreciated those who responded to the survey and that has helped us to understand your interests. We also appreciate all the comments about the value of the discussion meetings and the value of the group. The friendship and camaraderie are important to so many of you and the Holiday gathering is a part of that. We had many great dishes to enjoy from our members. Thanks to all who brought the great food. We also a collection of 21 new toys for the children who are in the hospital at Christmas. They were taken to Children's Healthcare of Atlanta (CHOA) after the meeting with great appreciation from the reception staff at the hospital. A thank you note was received from CHOA.

We had four new members at the meeting.

Alberdina was diagnosed a few months ago with anemia, back pain, and kidney issues. She came with her aunt and mother to help her learn about her options. She was overwhelmed by the diagnosis and received generous comfort from the group that there is so much good news about the treatment and lots to look forward to.

Mark came with his wife, Elaine, and was also diagnosed a few months ago with anemia. He was in the military and spent time at Camp Lejeune in North Carolina. It is a known fact that Camp Lejeune water was contaminated from the 50's until 1987 and the VA is providing benefits to military personnel impacted. Although Mark was not stationed at Camp Lejeune, he spent many months there in training.

Bhagu was attending with his wife, Roopa. He had many collapsed vertebrae and was on a clinical trial. He is not eligible for a transplant due to age and is learning about other options. Nell, diagnosed in 2016, went on a clinical trial. She is now on maintenance and doing very well.

Nancy received a letter from Amazon Smile that group members have designated Atlanta Area Multiple Myeloma Support Group to benefit from charitable donations through online purchases. Nancy confirmed the account and linked it to our tax ID. It is a little late for the Holidays, but we urge you to indicate our support group when you make Amazon purchases. Please pass this along to your family and friends to benefit our group. Thanks!!

Nancy passed out the IMF Patient Handbook and urged members to review that information prior to the Emory meeting on January 6. Many people have said that the presentations are difficult to understand. Reviewing this booklet will give you information about the structure of Myeloma, tests, and treatments. There is also a glossary in the back of the book. You can also access a digital copy of this booklet on the IMF web site at <https://www.myeloma.org/publications>, or go to Myeloma.org and click on Publications at the top of the home page.

Nancy was able to attend the American Society of Hematology (ASH) conference in Atlanta the second weekend in December. There were 26,000 hematologists attending from around the

world for five days. Nancy went with a group of support group leaders from the US and they tweeted and blogged about their experiences. The group blogs are at -- <http://ash2017blogs.myeloma.org/> There are videos from doctors at this link -- <https://www.myeloma.org/understanding/imf-tv/medical-meetings> or go to [Myeloma.org](http://www.myeloma.org), click on Education at the top of the page, click on IMF TV and select Medical Meetings. The IMF webinar from Dr. Durie on the Best of ASH will be on January 11, 2018. Register at [Myeloma.org](http://www.myeloma.org) and scroll down for the announcement about this event.  
Submitted by Nancy

## **Southside Multiple Myeloma Support Group Meeting Saturday, December 23, 2017**

**January 27 Meeting:** Speaker - Aaron Streufert, MSN, FNP-BC, Clinical Nurse Consultant, Nursing Education, Celgene, South Region. Topic: Caregivers in the Myeloma Journey

In this meeting on the eve of Christmas Eve, we had 12 people present. Carol brought some great desserts for us to indulge upon while we covered a potpourri of topics. Thank you, Carol!

One of our members, Vena, had a fall recently. This was a reminder for all of us to take special care in focusing on our balance – and our fitness/exercise regimens. Many of us have had bone issues – lesions, fractures, breaks, and bones in myeloma patients can be especially at risk. The other reminder from Vena’s fall is for us to keep our cell phones charged at all times, and close by, especially if we are not feeling well.

### **Exercise/Nutrition**

Carol shared her exercise regimen, which is admirable and a definite inspiration to us all. It is, however, more than most of us will do. Carol has a trainer, and her fitness mentor has run a marathon in almost every state. Carol travels (“trots”) 4-6 miles each day. She does not stress herself to run for time, as she might have in the past. She also does strengthening exercises with weights – also much lighter than she used in the past. Carol wakes up daily with her exercise program on her mind. If the weather does not permit outside activity, she has a treadmill near her bed. It is not a competition, but we must move. Carol says being consistent is the most important thing. “Sitting is the new smoking” says Dr. James Levine, Mayo Clinic/AZ.

It is important to start any exercise program slow – and be sure to talk with your primary care and oncology doctors about your plans to exercise. Good balance comes from strong “core” muscles. Some of the daily exercises should include strengthening your abdominal/stomach muscles. Learn to do these safely – opposite muscles to abdominals are the low back muscles. You have to protect them. Push-ups from the wall are good starting exercises for the whole body, including the abs (abdominals). Darcell demonstrated wall pushups and reported she could feel not just chest and arms, but buttocks and abs, as well. Proper exercise form is essential to prevent injury and to be effective. At the very least, if you aren’t

confined to a wheelchair, get up and move, every 30 minutes. If you are in a wheelchair, start from your toes and work up to your head/neck stretching contracting every muscle group, including your sitting muscles.

**Resource:** Emory Winship and the YMCA. To enroll and receive a referral to a wellness coach or to learn more about Winship at the Y, please send an email to [survivorship@emoryhealthcare.org](mailto:survivorship@emoryhealthcare.org) or call (404) 778-1900. This program is available free of charge to all cancer patients – you do not have to be an Emory patient.

Exercise and nutrition go hand in hand. Be sure to eat in color – lots of greens, reds, yellows – fruits and vegetables. Also, drink lots of water. Medications need water to do their job most effectively. All the organs need water to do the best job for you.

### **More discussion...**

**Should I have a Stem Cell Transplant (SCT)?** At least two members have struggled with the decision to have a Stem Cell Transplant. This term is being changed in favor of High Dose Therapy (HDT) stem cell **rescue**. Members who have gone through the SCT reviewed the process, and shared their experiences. They encouraged members to go through the orientation offered by their hospitals (Emory Winship or Northside). They were told to pay attention to all the counseling and advice from your myeloma team -- that the nurses, doctors, and technicians, Social Workers. After all, they have been through this many, many times. The “transplant” itself, is much like a blood transfusion – takes minutes to perform. It is the preparation and activities before and after that will require more from you and your caregivers. Give thought to your recovery period -- how you will get nutritious meals, water, medications, appointments, monthly bills, etc. in first few weeks after transplant. **Studies presented at international conferences in 2016 and 2017 show that people who are eligible and have transplants have better outcomes than those who do not. They achieve remission and remain in remission longer with maintenance, than those who do not get transplants (IMF).**

**We should have informed discussions with our myeloma team about our transplant procedure.**

Emory Winship and Northside have different approaches for the transplant. Patients have expressed personal bias for each. At Northside, after the High Dose Therapy (HDT), patients go home and return to clinic early each day for several hours of treatment/observation. Many patients find it comforting to return home each day. At Emory, patients are admitted to the hospital for the 2-3 weeks following the HDT. For some who may live long distances away, or do not have someone to provide transportation each day, there may be resources, like the Hope Lodge, that will provide transportation and a place to stay during this period. Please ask for a Social Worker who should help you through this process. If you are not eligible for the Hope Lodge, please inform your team of the hardship with daily trips to the facility. You should not have an added stress of arranging twice-a-day transportation, while going through myeloma treatment – request to remain in the hospital. Always ask for help with what you need – allow your team to help support you.

### **Brief recap of Dr. Bernal's November Presentation**

Research and clinical trials continue to inform us about new medications, dosages, and multiple ways to target or kill the myeloma cells. Each category of drugs has a different approach to targeting the myeloma cell. As patients and concerned friends and family, we should follow the progress of these therapies before we need them.

We reviewed some of the vocabulary from Dr. Bernal's presentation: antigen, antibody, Clinical Trial phases 1, 2, and 3. CAR-T, the classes of drugs and how they work, and some of the newer drugs being used in trials and treatment. There is a **Patient Handbook** from IMF that has a definition of myeloma terms in the back. It is also a great A-Z resource to help describe most aspects of myeloma diagnosis and treatment. You can order a hard copy or access a digital copy at <https://www.myeloma.org/publications>. Myeloma is 2-3 times more present in African Americans than in whites. The response to certain classes of drugs may be better in whites than blacks. More African Americans have a genetic abnormality or damage –NFkB2. More studies are being conducted on racial disparities in myeloma to better understand the best treatment options.

We encourage everyone to participate in as many myeloma webinars and in-person presentations as possible. With each presentation, there seems to come a greater understanding of this complex disease. Most webinars are archived for you to view at your leisure. For more information, go to: International Myeloma Foundation -[www.myeloma.org](http://www.myeloma.org); Leukemia and Lymphoma Society – [www.lls.org](http://www.lls.org); and Multiple Myeloma Research Foundation – [www.mmrf.org](http://www.mmrf.org)

Respectfully Submitted by Gail

Please Note: Meeting notes are anecdotal only and not intended to replace advice from your doctor. Feel free to review the discussion topics with your healthcare team.