

Northside Meeting and Luncheon September 10, 2016

First, a reminder about Ed and Lory's Winship team - members can support them through donations or by joining the team (even as a "sleep-in warrior"!)." Info at <http://winship5k.kintera.org/faf/search/searchTeamPart.asp?ievent=1151418&lis=1&kntae1151418=8A354E22B30A4FC7955BA66EE8EB79BB&team=6838575>

Elizabeth Carter, RN, BSN, OCN, is a Takeda Clinical Nurse Educator. She talked about "Caring for the Caregiver". She called caregivers the "wind beneath the wings" of both individual patients and the healthcare system. These unpaid individuals provide the majority of long-term care in the US. There are 2.8 million people caring for loved ones with cancer. People spend an average of 39 hours per week and the majority of caregivers are helping with essential tasks of daily living. More than 40 percent are providing complex medical tasks without any medical training. It's essential for caregivers to also take care of themselves. She noted that caregiver stress rises with certain cancer types, including blood cancers like multiple myeloma, and with disease severity, symptom severity, and treatment intensity.

Here are some tips for caregivers:

A - Awareness. Know yourself and be aware of your needs. It's ok to ask "Why". Just being free to say "Why me, why now, why this?" can bring peace. This can be thought of as "living the question." Another mantra she discussed is the phrase "I can't go on, I'll go on." This was coined by writer Samuel Beckett and mentioned in "When Breath Becomes Air", the memoir of neurosurgeon Paul Kalanithi, who died from lung cancer at age 37.

B - Balance. Honor yourself and balance the your loved one's needs with your own needs.

C - Connection. Find your tribe. Surround yourself with people who know you and value you and can remind you of these things when you are down. It can be hard to ask for help but it is so important. It can also be helpful to surround yourself with people with whom you can laugh.

Find resources and ask for help. Many healthcare clinics are offering palliative care for patients with long term pain or other issues. Palliative care is very important as people are living longer with MM and the long-term effects of treatment are being realized. These effects are both physical and emotional as survival extends.

Southside Multiple Myeloma Support Group September 24, 2016

Doris opened the meeting for a moment of silence. There were 14 present.

Next month's meeting on Saturday, October 22nd: **Dr. James McCoy**, Vice Chair, Department of Psychiatry, Morehouse School of Medicine, will speak on "Plant-Based Diets and Your Health". Also, **Northside Hospital** Blood and Marrow Transplant Program, in collaboration with the Johns Hopkins transplant/myeloma program, has a new cutting edge **immunotherapy clinical trial** open to patients with newly diagnosed or relapsed myeloma who have not undergone a prior transplant: NSH- 1148 A Randomized Phase II Study of Autologous Stem Cell Transplantation with Tadalafil and Lenalidomide Maintenance with or without Activated Marrow Infiltrating Lymphocytes (MILS) in High Risk Myeloma. **Kathleen McNatt** will present information on this clinical trial.

We welcomed three new members, **Glenda** (patient) and her sister-in-law and care giver **Marie**; Glenda learned of the group through **Kimberly** who she met at the LLS conference in July. We also welcomed **LaChion** (patient) who met **Pat** at the LLS conference in July and invited her to our support group. Both have attended the Northside group previously. One of our members, **Patt**, has moved to California to be closer to family. We will try to connect her to one of the many MM Support Groups there. We will miss her.

"**Light The Night**"- Brianna White, Light the Night Campaign Specialist, The Leukemia and Lymphoma Society presented information about the October 8th Light the Night event at Centennial Olympic Park. All were encouraged to come out and participate. Bridgett raised \$300 for LLS and generously donated it through Southside MM Support Group. The Support Group will add to that donation.

Today's meeting agenda was an opportunity for members to share. **Glenda** was diagnosed in October 2015 after treatment in the emergency room for back pain. Pain presented at 2:00 in the morning and was too severe to wait for

office hours. She had a biopsy confirming the diagnosis of MM and was treated with 4 rounds of chemotherapy (Revlimid/Cytoxan, Dex) which placed her in remission. She is on low dose Revlimid (15 mg)—3 weeks on and one week off – and monthly Zometa. Glenda is treated at Cancer Treatment Centers of America (CTSA). She is scheduled to harvest her cells for a SCT in October. She was also her husband's caregiver until his passing from cancer this past May. **LaChion** was diagnosed after a fall at work due to severe back pain in May 2015; She went the WellStar emergency room treatment and a series of tests including X-rays and CAT scan confirmed a diagnosis of MM. Her primary care doctor assisted her in finding an oncologist. No one in her family has had cancer – the diagnosis was difficult to take. She went through treatment at Piedmont Hospital and had a SCT in October 2015 at Emory. She is scheduled to have her immunizations soon. **LaChion** said she joined the Cardio Walkers at the Fulton County Darnell Center which she says helps build her blood cells and helps with her neuropathy. She also said swimming helped with neuropathy—she noticed the difference right away. There was discussion about potential infections that might come from use of public pools and facilities – with a compromised immune system from MM. She got permission to go into public waters, take all precautions to reduce infection risks and get the exercise. LaChion is also an avid bike rider. **Gloria** was diagnosed in 2009 after an emergency room visit and 2-3 days of tests. Myeloma had damaged her kidney so she was on dialysis during her induction therapy. She had a SCT in 2010, is on 5mg Revlimid for maintenance and has had ups and downs with 2 visits to the hospital this year for treatments for infections she could not fight off naturally. Gloria says is very cautious around children and people with colds. She watches for creatinine and other lab values faithfully. Says her oncologist encourages her to see her primary care provider (PCP) routinely so that if secondary cancers or other health issues develop they can be identified early. **Kimberly** was diagnosed in 2008, after an MRI of fibroids found a plasmacytoma on her sacrum. She went through maximum radiation treatment, standard treatment (Revlimid/Velcade/Dex), and a Stem Cell Transplant (SCT); she is in remission and but has some neuropathy. Kimberly is not currently on myeloma medications. She recently changed oncologists and is now in treatment at Emory Winship with Dr. Kaufman. Kimberly said she changed cancer providers because after years of being pleased with care at GA Cancer Specialists, she found important papers were not completed properly; as a result, an insurance coverage she had for many years was denied and one document was late getting to an agency that supplemented her health insurance. She said her first visit with Dr. Kaufman went very well; he reviewed her chart in detail and after 7 years without knowing her level of remission, she found out she has been in **stringent complete remission**. This means she has only a 20% change of MM returning. He also said her test showed she has a chance of developing MDS-Myelodysplasia Syndrome (a secondary cancer Robin Roberts of Good Morning America had and was treated with a stem cell transplant). All are reminded to get report of cytogenetics when bone marrow biopsy is performed. **Alma** was diagnosed in May 2006. She said she had severe anemia, spilling protein, some loss of kidney function, a back fracture and she was severely dehydrated. She was hospitalized for several weeks before she was ultimately diagnosed with MM. Then treated with the novel induction therapy of Thalidomide, Velcade and Dex for 6 weeks, radiation on her back and she was free of MM for 2 years. She had a SCT in 2008 and in 2010 began maintenance therapy using 5 mg Revlimid. In 2013 she was enrolled in clinical trials and is now on Daratumumab, 2mg Pomalyst and 40mg Dexamethasone. Alma commented she had shortness of breath on this regimen; but has noticed consuming fresh berries (foods high in antioxidants) seem to reduce the shortness of breath. Dr. Lonial at Winship Cancer Institute is her oncologist. **Gail** was diagnosed in May 2008 and was treated with Revlimid, Velcade and Dex. She responded well to the treatment, harvested cells in November, and in December 2008 had a SCT; in May it was determined she was in near complete remission. She was free from chemotherapy for 7 years; during that time, she was treated quarterly with bisphosphonate (Aredia), Oxycodone for pain and gabapentin for neuropathy. In October 2015 her MM markers began to increase; they watched for several months and in May 2016 she began an oral regimen of 4mg Ninlaro, 4mg Pomalyst and 40mg Dex 21 days on – 7 days rest. Her regimen was adjusted to 3 mg Ninlaro, 4mg Pomalyst, 8 mg Dex due to side effects of neuropathy and severe edema (Swelling in feet and ankles). She is monitoring shortness of breath events which may be due to pomalyst. The drugs are very expensive, but the office medical staff helped to navigate with insurance company to make co-pays more affordable. Her numbers have responded very well to this treatment. **Doris** diagnosed in 2006 and founded the SSMM Support Group. She was diagnosed via a regular physical with her primary care doctor, was referred to an oncologist, had a bone biopsy and was diagnosed with MM. She was treated with Thalidomide, Velcade and Dex. She chose not to have a SCT. She had been in remission for 9 years; earlier this year she began treatment with 25 mg Revlimid and 2 ½ Dex. **Vena** was diagnosed 2007 with smoldering MM by her primary provider at Kaiser; had a bone marrow biopsy which confirmed the diagnosis; she was treated with Thalidomide, Velcade and Dex. She has been in remission since; but learned she should not have been treated while smoldering. She said she has asthma, neuropathy and acid reflux. She said she recently had a major side effect from a blood pressure medication - Lisinopril which she has been taking for many years. She was treated at an urgent care facility, and her doctor changed her BP medication. **Vermell**, Oncology Nurse Practitioner and consultant for our group shared; there are times when one can have an allergic reaction to something they have been taking for a long period of time. When that happens you should not take that medication again.

There was much discussion about neuropathy—several members of the group stated they suffered. One member suggested that vitamin B12 helped her reduce the effects of neuropathy. Gail reminded us that the B Complex Vitamins were on the list of substances from Dana Farber that have been seen to impact the effects.

The IMF provided the following information for the Management of Peripheral Neuropathy (PN)-www.myeloma.org

For Prevention/Management: Make your provider aware as soon as possible—he/she may adjust chemo schedule or dosing; Massage feet with cocoa butter regularly and exercise; Supplement with B Complex Vitamins (B1, B6, B12) folic acid and/or amino acids (do not take on days when you take Velcade); Acupuncture; For Cramping: mustard, pickle juice, tonic water (watch sugar content if diabetic); Make sure your environment is safe: rugs, furnishings, shoes. Stay hydrated. (For cramps, a regular Calcium supplement tablet under tongue can help relieve symptoms in seconds).

If Symptoms Worsen, your provider may: Change your treatment, Prescribe medications (pregabalin, gabapentin, duloxetine or amitriptyline); or Suggest Physical Therapy.

WE SHOULD REPORT SYMPTOMS EARLY TO YOUR HEALTH CARE PROVIDER. NERVE DAMAGE FROM PN CAN BE PERMANENT IF UNADDRESSED.

For more, go to: www.dana-farber.org/Health-Library/Tips-for-Managing-Neuropathy.aspx

Announcements/Resources/Upcoming Meetings

- **Mental Health Conference**, October 22nd Spelman College. 9-5pm. "My Cry in the Night" - anger and stress management, loss of loved one-grief, and suicide prevention. FREE, but register. Flyer or [404.344.8280](tel:404.344.8280) – submitted by Debora Thompson, RNP.
- **MMRF - Patient Summits**. Archived for 2015-2016. <https://www.themmr.org/living-with-multiple-myeloma/education-programs/patient-education/>
- **Telephone Support Groups**. CancerCare's telephone and online support groups are free and professionally facilitated for people living with cancer and their loved ones. To join a telephone support group, contact us at 1-800-813-HOPE (4673). To join an online support group, please register through our website at www.cancercare.org
- **IMF Request**. Volunteer to contribute to scientific literature complete this Survey. Pierre Sayad would greatly appreciate your participation in completing a survey. The purpose of this study is to examine the possible correlation between different personality types, stages of therapy, or gender and the levels of perceived stress that patients with multiple myeloma experience. This dissertation is focused on psychosomatic symptoms experienced by multiple myeloma patients- Psychoneuroimmunology (PNI). The study is entitled, “Do personality traits, stages of therapy, or gender predict levels of perceived stress experienced by multiple myeloma patients?” **Please contribute to Myeloma Research by answering these questions.** To begin the survey, please click on this link: <https://www.surveymonkey.com/r/7K6FRVX>. Estimated time to complete is 20 minutes.
- **IMF - Smart Patients** is an online peer-to-peer program – get daily emails from patients and caregivers regarding their MM treatment journey. They share experiences from preparation for SCT to hints on increasing energy to discussions on new medications, side effects, and more. <http://www.smartpatients.com/imf>
- **MM Vocabulary for today: Which Myeloma Drugs are in the Monoclonal Antibody Class?**

Clinical Trials - Updates (clinicaltrials.gov)

Smoldering Multiple Myeloma

- Trial of Combination of Elotuzumab and Lenalidomide +/- Dexamethasone in High-Risk Smoldering Multiple Myeloma
- Study to evaluate 3 Dose Schedules of Daratumumab (Darzalex) in Participants with Smoldering Multiple Myeloma
- Lenalidomide or Observation- Treating Patients with Asymptomatic High-Risk (smoldering) Multiple Myeloma

Participation: Power to the Patients, *article in Nature scientific Journal. Targeted Therapy, Precision and Personalized Medicine, September 8, 2016.*

Sandra Soo-Jin Lee, a biomedical ethicist, is looking at how diverse communities feel about projects that link electronic health records with biobanks for research. Her group at the Stanford Center for Biomedical Ethics in California is still analyzing the results, which are based on surveys of 20 focus groups, including Hispanic, Asian and African American people, but already she has found “a tension” in people's attitudes. There is excitement that the data might lead to fresh targeted therapies or discoveries that are possible only with large pools of data. But some worry that the information will be used by the government for non-medical purposes, and others, says Lee, simply feel “a loss of control”. And many are nervous about who will profit. “There's concern about who's actually going to use the data,” she says — particularly that a third party will use the information to develop an expensive therapy. Donating data and tissue for the public good is one thing, but often the benefits are not distributed equally. The HeLa line of immortal cancer cells, for instance, derived without consent from the ovarian tumor of African American woman Henrietta Lacks, has long been a workhorse for cancer researchers. But the benefits of this research have not been distributed equally: cancer mortality

rates for African Americans are still higher than those of any other ethnic group in the United States. Source: **MMRF News -September 2016, NATURE | OUTLOOK**

Answer to Today's Question: Daratumumab/**Darzalex**; Elotuzumab/**Empliciti** are **monoclonal antibodies** that were approved by FDA in November 2015. The drugs will stimulate the patient's immune system to fight myeloma cells.

Multiple Myeloma Classes of Drugs/Therapies:

1. Proteasome Inhibitors - Bortezomib/**Velcade**; Carfilzomib/**Kyprolis**; **Ninlaro**/Ixazomib
2. Immunomodulating - Thalidomide, Lenalidomide/**Revlimid**; Pomalidomide/**Pomalyst**
3. Monoclonal Antibodies - Daratumumab/**Darzalex**; Elotuzumab/**Empliciti**
4. Histone Deacetylase - Panobinostat/**Farydak**

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.