

## Northside Meeting Notes – April 2015

### New Members

This month, our group welcomed 4 new members and their supporters: **Ed** was diagnosed with smoldering myeloma in 2010. He started treatment in January and he plans to receive a stem cell transplant. Ed was also considering enrolling in a clinical trial. **Mr. H.** was diagnosed one year ago. He received a Velcade-based induction regimen and had some response but his M-spike plateaued. He switched to a Revlimid-based regimen which he said has not helped and he is now considering options for relapsed/refractory myeloma, including a clinical trial or one of the newer approved agents—Pomalidomide (Pomalyst®) or carfilzomib (Kyprolis®). **Nan** was just diagnosed within the last few weeks after it was found during a blood test for an unrelated issue. She starts treatment on RVD soon and found our group through a close friend who happens to be a MM patient for many years and is a support group leader in Missouri. **Jackie** was also recently diagnosed and is trying to get educated about the disease and treatment options. She wants to learn about stem cell transplant and other treatments.

### Business & Announcements

**Nancy** led the meeting. She mentioned that the IMF is holding a Regional Community Workshop in Charlotte, North Carolina on June 6. Anyone who is interested in going can register here: <http://myeloma.org/EventPage.action?tabId=7&queryPageId=4&eventCategoryId=0&eventId=750> and contact **Nancy** with any questions. The **May meeting** will be an open general discussion forum. Please remember to get on the mailing lists for these free and informative IMF-sponsored publications (sign up at [www.myeloma.org](http://www.myeloma.org) or call the IMF Info line 800.452.2873): 1) “**Myeloma Today**” (hardcopy mailed quarterly) and 2) “**Myeloma Minute**” (emailed weekly on Fridays). The group’s **brochures** which are glossy, 2 color, and trifold need to be printed again, but will be ready shortly for distribution to doctor’s offices and clinics.

### Meeting Discussions

With the many new members present at this month’s meeting, there was much discussion about several key topics in myeloma treatment. One was what to expect for side effects of treatment. Another regarded differences between transplant centers in Atlanta (one has a more inpatient philosophy whereas another is more outpatient). There are pros and cons of each approach. Members shared their perspectives on the different approaches. The group also discussed some basic issues about clinical trial participation. **Nancy** emphasized that no patients receive a placebo as their only treatment. Instead, patients are assigned to receive either the standard of care (the most effective FDA-approved agents) or an investigational approach. **Gina** asked the group about kyphoplasty. This is a surgical procedure typically used to treat vertebral compression fractures. The IMF has a publication about kyphoplasty available at: [http://myeloma.org/pdfs/Understanding\\_Kyphoplasty.pdf](http://myeloma.org/pdfs/Understanding_Kyphoplasty.pdf). One member commented that she had refused kyphoplasty because she was concerned about the risk of infection, given her low white blood cell counts at the time. **Nancy** encouraged patients to be their own best advocates.

## Presentation

The presentation was given by **Geoffrey West**, a meditation and spiritual guide who led the group through a series of meditation exercises. Geoff has been a caregiver for several years for both his mother and grandmother, so he brought a unique perspective to the conversation. He explained the importance for both patients and caregivers of taking time to meditate and focus inward. Meditation is not passive but is rather an active process that involves focusing and working towards a state of awareness. A chime or bell can help bring focus. Geoff described two different types of meditation—one that involves being present in the moment and acknowledge whatever feelings are arising, and another that involves visualizing a pleasant memory or emotion (joy, gratitude) and focusing on that feeling. It will take practice to get comfortable with meditation and realize the benefits. Geoff interacted with the group during his presentation and answered questions that came up. One question was if there was a difference in meditation for men vs. women. Men are taught to handle things or just fix it. This leads to emotional numbness for men to handle everything and fix anything. They sometimes can't fix things on their own. We need each other. The culture of numbness is tough for males to get out of. Women as caregivers, hold back on emotions to protect the person they are caring for. This leads to stress and anxiety. Both men and women need to recognize what is going on in their lives and find a way to reduce the impact on them.

After the presentation, members said they felt relaxed, empowered, and more knowledgeable about meditation. Geoffrey is available for consultations and can be reached at:

678-982-9233; [Kenosiswithgeoff@gmail.com](mailto:Kenosiswithgeoff@gmail.com); [ITBworks.com](http://ITBworks.com)

"Creating a Tradition of Support and Connection."

Submitted by Mindy T.

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## **Southside Meeting Notes, April 2015**

**Doris** welcomed the group and led us in a moment of silence. There were 11 present. The speaker for next meeting, Saturday, May 23<sup>rd</sup>, will be David Hargrove, Oncology-Transplant Network Manager with Sanofi Oncology and Danielle Spann, an MM patient who will discuss her journey with MM.

**Member Updates:** Members provided a brief summary of their status as they introduced themselves to the speaker. **Pat** had a Stem Cell Transplant (SCT) in 2012 and has been on maintenance with Revlimid for one year. **Karen** reported her husband, Larry, was diagnosed October 2013 and had a stem cell transplant (SCT) in July 2014; he now is on a maintenance regimen of Revlimid/Krypolis/Dex. **Yvonne** is a Breast cancer patient and a MM caregiver—she recently had an outpatient procedure, but is now doing well. **Lenora** has been diagnosed with

smoldering Myeloma; she was scheduled to begin treatment on March 4<sup>th</sup> -- her hematologist at Winship intervened and instructed not to treat. Lenora is also a survivor of stage 5 Kidney disease. **Gail** was diagnosed with MM in July 2008-- after four rounds of chemotherapy she had a SCT in December of that same year; Gail is treated quarterly with Aredia and receives medication for neuropathy and back pain. **Doris** was diagnosed in 2005 and obtained remission with Thalidomide. In 2006 Doris started the SS Atlanta MM support group. Last month Doris began treatment with Revlimid and Dex; she says she does not plan to have SCT. **Selina** receives care at Northside Hospital and had a SCT in 2010; she was on a 3 year clinical trial with Revlimid, and is now on maintenance with that same drug. Doris reported that **Lonnie** is doing better and is traveling; **Andrew** is continuing to hang-in-there; **Loretta** is temporally in a nursing home as she recovers from a fall resulting in a broken femur (thigh bone) and having received a tracheotomy from a collapsed windpipe. So far, doctors have not been able to identify a reason for the collapsed windpipe. **Montine** reported her cousin is doing well after having a SCT a few months ago. Paulette is a caregiver for Gail and has been a group member since 2008.

This month's Guest Speaker, **Taryn Tennyson RD, LD**, describes herself as a committed member of the Georgia Academy of Nutrition /Dietetics and Oncology Nutrition Practice. She is a staff member of the Cancer Wellness Center of Piedmont Hospital and is excited about food and nutrition and its role in health and wellness. Using evidence-based nutrition therapy and combining it with a love of healthy whole food, she helps cancer survivors heal, grow and embrace healthy eating as part of a balanced lifestyle of wellness. She does this through her work at Piedmont Cancer Wellness. The Thomas F. Chapman Family Piedmont Cancer Wellness Center is a non-profit entity that has been built from donations and grants from the Chapman Family and other donors to address needs of cancer survivors throughout life. A cancer survivor is anyone who has *ever* been diagnosed with cancer. Cancer Wellness was created as a complement (not an alternative) to the regular medical therapy established by the doctor.

**Three major points** she wanted us to know: (1) programs provided through Piedmont Cancer Wellness are FREE; (2) the program is not just for Piedmont cancer patients; and, (3) the programs are taught by professionals in their respective fields and well received by participants. Workshops include nutrition, massage therapy, arts, and exercise, and are detailed on a bimonthly calendar accessible on line ([www.piedmont.org/cancerwellness](http://www.piedmont.org/cancerwellness)).

The center offers professionally-led programs Including: •Cancer education •Nutrition workshops and cooking demos •Relaxation and stress reduction •Movement and exercise •Expressive arts •Meditation •Support groups •Individual nutritional and psychological counseling •Social events •Virtual classes coming soon through Cancer Wellness without Walls

Piedmont Healthcare offers Cancer Wellness at four locations: Atlanta, Fayetteville, Newnan and Henry County locations. For a calendar programs and schedule telephone Atlanta -404-425-7944 or Carolyn Helmer, LCSW 404-425-7940 [www.piedmont.org/cancerwellness](http://www.piedmont.org/cancerwellness) . Call to register for classes in advance – they fill up quickly.

Taryn shared a “My Food as Medicine Plate” handout which provided guidelines for healthy eating. She said fruits and vegetables should make up one half of our plate. These should be non-starchy vegetables and whole fruits. We should fill our plates with a rainbow of colors and herbs and spices to get the full spectrum of phyto-nutrients. Include raw, cooked and fermented varieties. Shop with the seasons and look for local sources. Stay hydrated with water and unsweetened beverages. Fats: Include healthy like avocados, nuts, seeds, olives, coconut and cold/expeller pressed oils. Enjoy butter in small amounts. Starchy vegetables and whole grains: Starchy vegetables like potatoes, peas and corn as well as whole grains like quinoa and barley provide texture and nutrients can take up to one fourth of the plate. Protein: will represent the other quarter of the plate. Plant sources of protein include beans, nuts and seeds. Most plants (vegetables, fruits, grains) have varying amounts of protein and amino acids. Animal sources of protein include fish, poultry meat, and dairy. Taryn says we should shrink or minimize food from animal sources -- go heavy on fruits and vegetables-- heavy on plant based foods. Foods from the plant kingdom rather than the animal kingdom have many protective botanical factors. These phyto (meaning plant) nutrients can be beneficial to us. Antioxidants, anticarcinogens and bioflavonoids are some of the terms used to describe the actions of phytonutrients. Foods rich in botanical factors or phytonutrients include berries, dark green leafy vegetables, citrus fruits, legumes (beans of all sorts including soy) and whole grains. Eating a variety of fruits and vegetables help you get the antioxidants we need from food sources rather than supplements. Talk with your doctor if you are using or planning to use supplements or herbal remedies.

**Question:** Are there some hints for achieving a diet that may help reduce risk for cancer?  
**Answer:** Some food groups have been noted to have cancer prevention properties. Scientific literature is showing that Cruciferous vegetables, Berries, Allium vegetables, Lycopene and Herbs and spices may have properties that fight or retard the growth of cancer – these are also referred to as “Super Foods.” Cruciferous vegetables such as cauliflower, cabbage, garden cress, bok choy, broccoli, Brussels sprouts and similar green leafy vegetables have been demonstrated to have cancer curative effects. Berries are best known for their accumulation of antioxidant components (mainly polyphenols, carotenoids and vitamin C) and have amongst the highest antioxidant capacity of commonly-eaten foods. The amounts of these antioxidant components vary between berry species. Any berry (black, blue, raspberries, strawberries will offer antioxidant benefits. Lycopene is a red-orange carotenoid found in tomatoes and tomato-based foods. Several studies show that consuming tomato products reduces the risk of some cancers (prostate cancer). Absorption of lycopene is enhanced when lycopene-containing vegetables are cooked and eaten with fat.

### **Old Business**

**Alma** thanked all who participated in the Health Expo held last month at Greenbriar Mall. She said there were at least 10 individuals who obtained specific information about MM. She thanked Nancy who served as the spokesperson for MM sharing information about the disease to the hundreds of individuals shopping and participating in the Expo. Alma shared that three newspapers (85 South, South Fulton Neighbor and Atlanta Daily World) ran event notices about Myeloma as part of Myeloma Awareness Month. **Lenora** attended the 3rd Annual Winship Medical Heroes Celebration

on 4/10/2015. She said it was a very good experience – two clinical trials patients spoke and she won a hotel stay at the Emory Conference center. The conference was sponsored by Winship Cancer Institute/ Emory University Clinical Trials Office; Paulette, Portia and Montine took advantage of free Braves tickets; several received tickets for the annual Renaissance Festival offered by LLS.

**Announcements:**

- IMF – “An Integrative Approach to transform your Mind, Body, and Spirit” – A webinar on Sustainable Wellness. Matt Mumber, MD. Radiological Oncologist, Rome, GA. May 7, 7:00PM. Archived at [www.replay.myeloma.org](http://www.replay.myeloma.org)
  - MMRF – Patient Symposium (May 16) 8:30- 2:30 at Emory Conference Center and May 17 – 5k walk/run at Piedmont Park.
  - LLS – First Annual Blood Cancer Conference. June 27. Save the Date.
  - Please remember our members who cannot be at meetings in your own way – phone calls, cards, thoughts and prayers. Thank you.
- Alma provided closing words—

***“No one cares how much you know, until they know how much you care.”— Don Swartz***

*Respectfully, submitted by Paulette and Gail.*