

Northside Meeting Notes - September 2014

Business & Announcements

The Northside Atlanta September meeting was our annual luncheon held at the 57th Fighter Group Restaurant on Clairmont Road, near the Peachtree DeKalb airport. The setting was perfect as we watched the airplanes take off and land. We also watched the biplane take guests for a ride in the open cockpit! There were over 70 people present.

We all really appreciated John Schwarz and Millennium, who picked up the cost of the luncheon. Many thanks to Millennium. The food was great!

The Board of Directors met prior to the luncheon and reviewed committee activities as well as the programs for the remainder of the year. **October** will be patient and caregiver sessions. **November** will feature Joan Giblin from Winship partnership with the YMCA and the Winship Celebration of Living program. **December** will be our annual Holiday party with gifts for the children in the hospital at Christmas at Children's Healthcare of Atlanta. The **January** meeting will be on January 10 at Winship for a review with the doctors on news from ASH (American Society of Hematology) meeting in December. This is where the new drugs are announced and results of clinical trials are reviewed.

New Members

Tom from Canton, GA, was attending the luncheon with his parents (from New York). Tom was diagnosed in June with severe back pain. He has had radiation and started treatment in preparation for a transplant later this year.

Don was not able to attend, but his wife, daughter, and son attended to meet the group. Don was recently diagnosed and had his first chemo treatment the day before the luncheon.

--Submitted by Nancy B.

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Southside Multiple Myeloma Support Group Meeting =

Meeting Minutes September 27, 2014

September is Blood Cancer Awareness Month. There were 17 members present at the meeting. This was the first meeting for **Karen** She is caretaker for her husband – and conducting research for him. He was diagnosed two months ago at Emory Winship.

We discussed options for our annual Support Group meeting that Millennium will host for us. Some venues are under consideration and will be discussed further at the October meeting.

Fundraising

We decided not to participate as a group in the LLS Light the Night. Bridgette, Montine, and others may participate as individuals, and we can contribute on the website under the name of SS Myeloma Support Group. We have not been able to have the staff person -- replacing Rosalinda and since LLS restructuring -- attend our meeting in over a year. The IMF will host their annual Comedy Fundraiser in LA. They have invited the more than 140 Support Groups across the US to take out an ad in the event program. We decided to contribute \$100 to the event, and another \$100 to the general IMF fund. As a new fundraiser, we formed a Committee to develop an activity to take place in Myeloma Awareness Month (March 2015). The concept would be the promotion of physical activity for everyone to promote wellness -- and Integrative Medicine (nutrition, exercise, acupuncture, etc.) -- survivors, caregivers, families, and healthy people alike. It will build on the usual 5K walks/runs -- many cannot participate. The event will Yoga, etc., as well as the walk/run event. The working title is "Movement on the Green" --tentatively held at Greenbriar. The Committee is led by **Kim**, with members **Portia, Pat, Deborah, and Gail**. Additional entertainment could include a Gospel/Jazz concert, similar to those held by car Dealerships and Praise 102.5.

Discussion

Led by **Deborah T**, ONS, our discussion was a potpourri of topics -- insurance and ACA (Affordable Care Act); End of Life Care Decisions; and Palliative Care and Hospice Care. She also encouraged all Group members to make recommendations for discussion topics. Please submit topics to Group leadership by the end of November, so they can be scheduled in advance. On the topic of **Insurance** -- make it a point to review your insurance coverage each year -- during enrollment period is a good time to review. Most insurance carriers make changes to coverage annually -- e.g., doctor visit co-pays, prescription co-pays, in-network/out-of-network, etc. What doctors accept Medicare/Medicaid can change from year-to-year. Be very deliberate about planning for retirement. Know that you cannot go on disability *after* retirement, you must be disabled prior to retirement. Insurance Navigators (hired for ACA recruitment) are excellent resources for that topic. **End of Life Care Decisions** -- Be sure to plan; have family discussions about your own desires -- would you want to stay on respirator or not? Identify a place for all your papers -- Advanced Directives...Living Wills...Estate, Wills, etc. Be sure family members know your "place." So much of this sounds like common sense, but many of us put it off this difficult discussion until 'later.' **Pat C.** shared how much pain and confusion among family members was spared when her in-laws had all their documentation in a designated location. **Palliative Care/Hospice Care**, is now a medical training specialty, as are cardiology, oncology, etc. Palliative care in a team approach that focuses on providing patients with relief from the symptoms, pain, and stress of a serious illness--whatever the diagnosis. As a (cancer) patient, you should not have to be "sick." Side effects from medicines and the disease, like fatigue, are expected for short terms. In some facilities, you might have to ask for support to follow your symptoms of pain, fatigue, poor nutrition, etc. The V.A. Hospital employs a palliative team, not all facilities do. You should have a good Quality of Life (QoL) the majority of the time -- and throughout your survivorship. The definition of **Hospice Care** has changed, and is

no longer simply a “death watch.” Again QoL is the uppermost consideration, and patients can be on Hospice Care for months or years – or go on and off of Hospice Care (**Dorothy**), as appropriate. **Vena’s** Dad was recently on Palliative Care prior to his passing – and the Team prepared the family for Hospice. The team made a home visit, and included a Social Worker, Physical Therapist, and Nurse. His source of care was Kaiser Permanente. There is in-patient hospice and out-patient hospice.

Updates/Announcements

Health Fair, sponsored by NPU-P – at Ben Hill Recreation Center on October 11; LLS – Light the Night, October 11 at Centennial Park; LLS – Blood Cancer Conference in Savannah – Saturday October 25; Living Well with Myeloma: Management of Bone Disease teleconference on Thursday, Nov 13 at 7:00 PM. This will feature Dr. Drake, who spoke at the Atlanta Patient and Family Seminar in May. He will offer insight into maintaining bone health. Register at **BoneDisease.Myeloma.org**

Respectfully Submitted, Gail M.