

Northside Meeting Notes - August 2014

Business & Announcements

Nancy led the meeting; approximately 40 people attended. The September (9/6) meeting will be replaced by a luncheon held at “The 57th Fighter Group Restaurant” <https://www.the57threstaurant.com>. We plan to meet there at 11:30 and lunch will be served at noon. This is a social event without focus on discussing myeloma, and all members and their family members/friends are invited to join but a headcount is required. **Please RSVP to Nancy if you plan to attend but did not already sign up to attend at the August meeting.** Regular meeting times and locations will resume in October and that meeting will be held as a separate patient/caregiver session. In the November meeting Joan Giblen, MSN Director of Winship Survivorship Program/Staying Fit will join the group. The December meeting will be a combination meeting and holiday party. There was not a formal member update at the meeting, however **Barbara** mentioned that she is about to begin treatment with Carfilzomib (a.k.a. Kyprolis) and asked if others in the group who have been on Carfilzomib can offer any helpful information to her.

New Members

The group welcomed **Scott** and his wife, **Tricia**. Scott was diagnosed in June. He had experienced bone and rib pain in February and had X-rays which did not reveal a problem. A month later he had shoulder pain. He continued to be active and working out and thought he had a sports injury. His legs began hurting and he went to a sports doctor who found a tumor in his arm and weak bones. A day later his arm broke and he went to the hospital where a biopsy was performed and a myeloma diagnosis was confirmed. For preventative purposes a rod was placed in his arm and leg. At diagnosis he had no other symptoms other than an M-spike, with all markers on the low end. Scott is now beginning a third cycle of Revlimid, Velcade, and Dex and plans to harvest stem cells soon. He just learned that he has a blood clot and others in the group mentioned that it could be related to Revlimid.

Guest Speaker

Thank you to **Hazel Jackson**, a Registered Hospice Nurse, at the Atlanta VA Hospital, who joined the group to educate us on hospice care. Hazel explained that hospice is a philosophy of care when cure is no longer realistic, and comfort and quality of life is the goal. Hospice care is for all family members, not just the patient. In order to medically qualify for hospice care, the patient must be given a prognosis of six months or less to live (by a medical provider), and not be receiving any aggressive treatment to prolong life. Hospice care does not hasten or postpone death; i.e. it cannot change a diagnosis or prognosis, but can only change how one will continue to live during their transition period. This is done by providing physical and emotional comfort and support to the patient as well as the patient’s family members (caregivers). The care can be provided in the home, nursing home, and at inpatient hospice facilities, depending on what is best for the patient and family at any given time during the care. Since this care is designed to be a holistic experience it is

provided by a team that consists of (at the very least) a nurse, social worker, home health aide, and chaplain. The hospice care team has a medical obligation to do no harm and not to let anyone suffer without doing something about it. Hazel kindly answered many questions that follow. **What is the difference between palliative care and hospice care?** Palliative care is provided to assist with comfort management and side effects and to discuss diagnosis and prognosis when death is not imminent. Hospice care is a part of palliative care but in cases where the prognosis expectation is six months or less to live. **How does one decide on hospice care once they qualify medically?** Hospice is a care option, not a necessity. The two qualifications for hospice care are 1) medical, and 2) it is wanted. It is a choice that is best made by the patient and the patient's caregivers – i.e. what is best for everyone? If hospice care is chosen, the patient and caregivers can decide on the location that is best as well. There is no situation that cannot be dealt with by hospice and they will strive to keep a person at home if that is what is preferred. Unless something acute occurs that requires a short term hospital stay, then the patient can return home or at another hospice location, whichever is preferred. It is important to note that a patient will not always know that they want hospice care. Sometimes hospice care is decided upon by caregivers when they only know what the patient does not want. **How long does it take after a patient is referred for hospice care for the hospice assessment to begin?** This process occurs within 24 hours, and care is not delayed while the paperwork is being processed. **How is hospice care paid for and how are insurance benefits affected by beginning hospice care?** Medicare, Medicaid, and private health insurance pay for hospice care. The hospice care agency will work with each type of insurance coverage. Hospice care waives Part A Medicare benefits. If you have Medicare Part B benefits it is retained under hospice care. **Are there other expenses with hospice care?** With hospice, nothing is provided that will cost you unless you are made aware of the expense and agree to it. **Can you retain both in-home long-term healthcare arrangements along with hospice care?** No, once you opt in to hospice care it then replaces the other type of care. **If a patient is currently in a Medicaid nursing home are they eligible for hospice care?** No, because the facility is considered their home care. If they qualify for hospice care they can opt for it, and hospice will bill Medicaid. **If the patient begins hospice care at home, then has to move because of an emergency, once better can they return to their home?** Yes, if there is a medical emergency while the patient is receiving hospice care at home and for example, they have to go to a hospital or other hospice location for care, once they become stabilized they may return to their home if that is their choice. Only when it is not safe for the patient to remain in their home are they moved to a hospice facility, unless there is a choice made by the patient and/or caregiver to move. **If a patient qualifies for, and begins receiving hospice care and then gets better and the prognosis changes, what happens?** This is something that is evaluated on an ongoing basis. In cases where hospice care is received, and the patient continues to live beyond six months, they can continue with hospice care as long as the medical evaluation still qualifies them at the time of reevaluation. They will need to recertify for hospice care at this time. If the patient improves enough so that their medical evaluation no longer qualifies them for hospice care, hospice care is discontinued and their Medicare Part A benefit will return. **If the patient opts to go to a hospice care center, rather than to remain at home does the family have access to visit them?** Yes families and friends of the patient have access to visit

at any time. Some group members commented on their own personal experience with hospice care for family members and they were positive. Hazel mentioned that it is often the little things that hospice can do to help that are the most important to individuals. For example, generally home health aides work Monday-Friday during regular business hours. Hospice health aides work 24x7. In cases where a death occurs at a residence, and the patient is in hospice care, the hospice agency notifies the medical examiner and the death is considered automatic and expected. Otherwise, when the patient is not under hospice care, the death is automatically assumed suspicious when authorities are notified. Police and an ambulance arrive and individuals will be interrogated until "no foul play" is determined. Hazel mentioned that hospice is a huge business and that there are different types of hospice organizations. Some are small and non-profit, and others are large for-profit organizations. It is best to be aware of this, as she indicated that how the organization operates may affect how the care is provided, and some are better than others. Nancy B. mentioned that this is a good discussion topic to have with your family members, along with healthcare power of attorney and living wills so that your family will feel comfortable with this topic.

-Respectfully submitted by Wendy

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Southside Multiple Myeloma Support Group Meeting – Meeting Minutes August 23, 2014

There were 18 present at the meeting with two new Myeloma patients, Donald I. and Edwards S.

Donald was diagnosed with myeloma in August 2014 after experiencing intense back pain -- and undergoing many different diagnostic tests. He had a mass behind his heart, and was referred to thoracic surgeon, then to oncology-hematologist. He has multiple lesions. He is 79 years old -- is currently undergoing radiation -- 12 treatments are scheduled. He is being treated at Wellstar/Kennestone, and he and his family will be going to Emory Winship for a second opinion. His family team consists of his wife, Carolyn, his son, Brian, and family friend Michelle.

Edward is 56 years old, and is 60 days out from his stem cell transplant (SCT). He was diagnosed in March 2013 at Grady Hospital after seeing a number of specialists, and was sent to Northside Hospital for the SCT. He had been experiencing back pain for at least 15 years, but each time would sent home with muscle relaxers, etc. He was getting annual physical exams, and in the past 2 years went to the ER at least 8 times with back pain. He is scheduled for an additional biopsy at 100-days post SCT, and is seeing, Laura Weekly, MD (hematology-oncology), with the Georgia Cancer Specialists at Camp Creek. He has peripheral neuropathy (PN).

Vermell, retired Nurse practitioner, had an agenda to continue Debra Thompson's review of the manual from the Patient and Family Seminar held in Atlanta in May. Because we had two new myelomas patients, she conducted a Myelomas 101 session, including: What is Multiple Myeloma?

What tests are used to diagnose myeloma? What is MGUS? What is Smoldering Myelomas? Information about immunoglobulins -- IgG, IgA; kappa or lambda; light chain or heavy chain. She encouraged everyone to know the kind of Myeloma they have and to follow their lab test results along with their healthcare providers.

She explained that the terms M-spike and para-protein are used interchangeably. Vermell reviewed that newer testing for free light is available. More targeted therapy or personalized therapy means that the treatment regimen for multiple myelomas patients will be more individualized.

All members are encouraged to go to the Support Group's website and make suggestions for improving. www.ssatlanta.myeloma.org

Announcements

- On September 23rd at 7:00 PM EST, the IMF will host a Medicare 101 Webinar. To register, go to Myeloma.org and click on the teleconference under New and Noteworthy.
- IMF - Living Well with Myelomas Series: Understanding the Immune and Lab Values in Myeloma - August 28, 2024. To hear the replay, go to Replay.Myeloma.org, click on teleconferences and select the Living Well with Myeloma series for 2014
- On Velcade, subcutaneously? Go to Myeloma Minute for precautions for proper injections
- New publications from IMF - The “Understanding Serum Free Light Chain and Serum Heavy/Light Chain Assays” booklet is devoted to two tests used in the diagnosis and monitoring of myeloma, the serum free light chain assay (Freelite®) and the serum heavy/light chain assay (Hevylite®).
- The IMF’s “Understanding Fatigue” booklet contains a thorough examination of coping strategies and causes of myeloma fatigue, as well as suggestions for discussing fatigue with your doctor.

Respectfully submitted,

Gail M.