

February 2013 MM Support Group Meeting Notes – Both Groups

Southside Atlanta Area Multiple Myeloma Support Group Meeting – February 23, 2013

The meeting was called to order by Doris.

There were more than 20 present.

New members present were **Gregory** (wife Patricia) and **Patricia**; both Gregory and Patricia were diagnosed October, 2012.

Speaker was **Dr. Patrick Griffith**, Professor of Clinical Medicine, Division of Neurology, and Morehouse School of Medicine. Dr. Griffith spoke about Chemotherapy-Induced Neuropathy (CIPN).

Peripheral Neuropathy (PN) can be caused by diabetes, excessive alcohol, and can be drug related, as in chemotherapy. It manifests as numbness or tingling in the hands and feet, including a loss of sensitivity and reflexes or as overly sensitive nerve endings. The patient may not feel a pin prick or vibration in the foot or ankle. Their feet feel like they always have socks on -- or their hands feel like they have gloves on, both symptoms caused by reduced sensory response. The patient may also feel burning pain with muscle weakness. The nerve damage from PN may also cause balance problems. When a neurologist evaluates a patient with neuropathy, the doctor may look at all the possible causes of the PN, in addition to chemotherapy. Dex does not cause PN, but may elevate blood sugar, and diabetes is known to cause PN. Other causes of PN may include: infections, inflammation, radiation, amyloidosis*, vitamin deficiency, muscle weakness, or genetic influences. The known chemotherapy drugs for MM patients that cause PN are: Vincristine, Thalidomide, Velcade, Revlimid, and others. Patients, who are currently taking chemotherapy, should promptly discuss their side effects, including PN, with their healthcare team. They can make changes to therapy such as reduction of dosage or change to an alternate medication to reduce symptoms and reduce long term damage to the nerves.

After a full evaluation of PN, there are various treatments available to relieve symptoms of PN. Gabapentin (Neurontin) is frequently the first line of treatment. Lyrica and Cymbalta can offer relief to some patients. The patient may need to try different drugs to see which works best for them with the least side effects. Certain vitamins can help with PN symptoms: Vitamins B-12, B-6, and B-1 soothe the nerves. Vitamins A, D, E, and K can also help and are fat soluble, so should be taken with food. Thiamin (Vitamin B-1) deficiency may also affect nerves and balance. Some patients find relief from PN with acupuncture or massage therapy.

Below are guidelines*** from Dana Farber Cancer Institute (Harvard Medical School affiliate) **on the prevention and treatment of Peripheral Neuropathy:

- Multi-B Complex Vitamins with B1, B6, B12, folic acid and other. B6 should be approximately 50mg daily, not to exceed 100mg per day. Folic acid should be 1mg per day
- Vitamin E -- 400 IU daily
- Vitamin D -- 400-800 IU daily

- Fish Oils OMEGA-3 Fatty Acids (EPA and DHA)
- Magnesium -- Suggested doses include: 250mg twice a day (OTC). Alternatively 400mg daily by prescription with dose frequency dependent on serum Magnesium levels. May cause diarrhea in larger doses
- Potassium -- Either as provided by the treating physician or foods that are rich in potassium (e.g., bananas, oranges and potato).
- Tonic Water -- Drink one glass in evening and any other time cramping occurs
- Acetyl L-Carnitine -- 500mg twice a day with food. Can take up to 2000mg a day.
- Alpha-Lipoic Acid -- 300mg to 1000mg a day with food
- Glutamine -- 1g up to three times a day with food
- Cocoa Butter -- Apply to affected areas twice a day with gentle massage (rich in xanthenes, serotonin, Vitamin E and other emollients)
- Menthol Based Creams -- Apply to areas of numbness twice daily with gentle massage (e.g. Vick's Vapo-Rub)

**Dana Farber is a National Cancer Institute designated Comprehensive Cancer Center in Boston.

***Do not take supplements on days of Velcade infusions.

***Amyloidosis Definition** By Mayo Clinic staff

Amyloidosis (am-uh-loi-DO-sis) is a disease that occurs when substances called amyloid proteins build up in your organs. Amyloid is an abnormal protein usually produced by cells in your bone marrow that can be deposited in any tissue or organ.

Amyloidosis can affect different organs in different people, and there are different types of amyloid. Amyloidosis frequently affects the heart, kidneys, liver, spleen, nervous system and gastrointestinal tract.

Multiple Myeloma Month

This is a reminder to all that March is Multiple Myeloma Awareness Month. We will partner with IMF to encourage local governments to issue proclamations, and find other opportunities to increase the public awareness in Atlanta metro-area about MM. Please be sure to tell *SOMEBODY* about MM this month – through your social and civic groups, congregations, co-workers, friends, and family members.

Respectfully submitted by Paulette and Gail

Northside Atlanta Area February 2013 Meeting News

New Members

No new members were present at the meeting.

Business & Announcements

Nancy opened the meeting prior to splitting into separate patient and caregiver sessions for the

remainder of the meeting. **March** is **Myeloma Awareness** month with a theme of “**Tell One Person about Multiple Myeloma & Help Raise Awareness**”. Thank you to **Jeanette** who has arranged for some very knowledgeable oncology **nurses from the VA hospital to join our meeting as guests in March** to answer questions. The **IMF** has several upcoming events.

- On February 21, there will be a teleconference on Novel Therapies, including the latest information on Pomalyst, Velcade Sub-Q, and Kyprolis. Register at <http://noveltherapies.myeloma.org>
- On **March 1st and 2nd** there will be an IMF Patient & Family seminar in Boca Raton, FL.
- On **March 7th** there is an hour-long free teleconference at 7 PM eastern time. Preregister for “**How to Prevent Infection in Myeloma Patients**” at <http://infectionprev.myeloma.org>

On March 4th, **Nancy** and **Doris** will meet with the **Atlanta City Council** to discuss Myeloma Awareness in support of a recognition of Myeloma Awareness Month.. **Nancy** also supplied printed information to the group, “**Vitamin Cocktail for Neuropathy**”, which is now available in the library. **Sara** recommended an LLS-sponsored telephone/web education program by Dr. Ken Anderson (Dana Farber) which can be replayed. She said that the session was easy to understand and discussed new therapies including T-cell therapies, neuropathy, etc.

Member Updates

Bob and **Molly** raised over \$5,000 and were in Tybee Island at the time of the meeting walking a 10K marathon to support our entire group, and especially thinking of **Dominick** who passed in November and in support of **Lori** who just completed a stem cell transplant, and is now home recovering well. **Roslyn** recently fell a couple of times and got bone spurs, so she is currently having some difficulty getting around. She is not certain of what caused the falls, although she had been sick for some time before the falls and possibly weakened by the prior illness. This led to some discussion about the necessity of trying to determine what may have caused certain accidents and to possibly discuss with your doctor to determine if testing should occur to rule out any other health-related issues. **Virgil** just received recent test results and is continuing to do well!

Patient Session led by Alice Mullins

Patients discussed processing feelings and differences with illness, such as fears and frustrations, staying positive and being positive, trying to not be angry, and dealing with sadness.

Alice mentioned a book called “Healing with Dark Emotions” that talks about dealing with anger, grief, and anxiety. We all know the term “dark” does not mean anything negative, but we live in a society that perceives dark feelings are not acceptable. If someone feels sad or something is wrong, society thinks, “you need medication” and that will “fix it.”

“Dark” in this context refers to feeling sad and overwhelmed; being emotional because of the reality of the illness you are living with. It is NORMAL to feel sad and overwhelmed.

There are times when a person needs medicine to HELP. For example -- Mr. Jones is going through a tough time and should be in a better mental and emotional state, but he just feels so sad and unhappy. After consulting a doctor, it is determined that Mr. Jones is clinically depressed and taking anti-depression medication can HELP. **It’s NOT about a person having a problem, so prescribe a drug to “fix it.”** It is knowing and understanding that a patient is dealing with

something difficult. He should be feeling better, but he just can't do it alone, so he needs "a boost" to help. Sometimes, our bodies need an extra "boost or kick" and taking medicine can HELP the body produce that needed chemical, resulting in a better, happier person.

It is also important to acknowledge the impact the illness has had on your life and to keep moving forward. There are good days and bad days. Some days you will feel overwhelmed and just want to cry because it IS emotional and you just need to cry and be sad about it. Some days, you are ready for a challenge!!

Question: "What happens if you talk about fear?"

Answer: You feel vulnerable and you fear the unknown.

Patients also spoke of several situations that can bring about thoughts and feelings. When they see another patient who is very sick. Thoughts of "I could be much worse" or "that makes all my worries seem so small." Others spoke about feelings of unforeseen circumstances, such as having to retire and not being ready. Thoughts of being in pain and feeling helpless, becoming a vegetable, not wanting to suffer or become a burden on others. Others talk about fears of having a transplant. Some do not want to deal with it; trusting their faith and God's will. Some mention that when they feel a "twitch" or some type of random pain, they wonder, "is this a side effect" or "is it me?" Many read medical pamphlets and research medical documents, looking for those "aches and pains" listed as a side effect, hoping for reassurance that it's not "just me", but the illness.

Question: "How do I respond to being diagnosed and living with cancer?"

Answers: "Denial. I don't have anything." "I won't sit down and give in" and "I feel down."

Patients also discussed how friends and family will do their best to be there and help. Having someone there to help and /or be a companion is great. It should be said that **caregivers and friends are not expected to "fix" this situation.** It was also noted, for patients, that it can be empowering to know that you can be resilient and "come back" from the experience and be there to testify and help someone who has just been diagnosed. You can share your experience and help another person on this journey.

Patients offered some personal thoughts and advice:

- You can't heal until you feel
- Pain is a part of life. You feel it, You deal with it, and You move on.
- TRY different methods and do NOT jump to "I need medicine"
- IT TAKES COURAGE TO BE VULNERABLE

Submitted by Lana

Caregiver Discussion

Joe, a "48 year health educator" led the caregiver discussion, with a topic of "**Managing Stress and Taking Care of You**". We discussed the sources and signs of stress and how to be more proactive in trying to avoid those sources and/or how to best manage them if they are unavoidable, so that they do not "hijack your life". We also discussed solutions to common stressful situations and ways that we can alter our own behavior to best handle these types of situations. In our discussion it became clear that one size solutions do not fit all, and individuals should identify their own custom solutions over time and as experience is gained. Also, managing stress is generally easier, and with the best results achieved for those that choose to maintain ongoing healthy lifestyles; essential for keeping both mind and body strong. Remember that to be able to provide adequate

support to someone else you must first take good care of yourself.

Submitted by Wendy

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