

March 2013 MM Support Group Meeting News – Both Groups Included

Northside Atlanta Area March 2013 Meeting News

Business

Nancy gave a review of the Board of Directors meeting. Our February “Valentine” offering raised over \$1,000. We spend \$100/month on mailing and more than half goes to doctors. An audit of the doctor list may reduce the mailing costs. Members were encouraged to ask their doctors and nurses if they read the newsletter and if there is someone in the office who should get the newsletter or if it can be sent by email.

It was also noted that the group wanted to know where the patients and caregivers find out about the support groups: website, doctors, word of mouth, friend, etc. Brochures are given to Emory, the VA Hospital, Northside, and other places, which cost \$450 to print. Contributions are also made to the LLS, IMF, and MMRF. “Myeloma Awareness Month”: **Doris and Nancy** sent a Proclamation to the Atlanta City Council and it will be signed Monday March 4, recognizing March as Myeloma Awareness Month. Carolyn H. met with the Mayor of Dunwoody, who signed a Proclamation for Myeloma Awareness Month.

Events

The IMF will have a workshop at Vanderbilt University in Nashville, TN on April 13, 2013 (one day workshop). The latest updates in Multiple Myeloma will be presented. Dr. Kaufman and Charise Gleason will be presenting, along with Vanderbilt doctors.

New Members

Fred was diagnosed in January 2012. He had a tumor on his back a year earlier, but the doctor said nothing was wrong. He was in Alabama and suddenly could not walk. The tumor on his back was pressing on his spine, which led to his MM diagnosis. He has harvested stem cells, been treated with Revlimid and Dex, but has not had a transplant. The Dex treatment was stopped because it caused severe sinus problems. **Ben** is the son and caregiver for his mother, Ann. Ann has had treatment and radiation at the Mayo Clinic in Jacksonville, FL. Ben is also researching information with the Georgia Cancer Association.

Meeting Notes

Guest speaker, **Hazel Jackson**, is an Oncology nurse with the Veterans Affairs Hospital. She obtained a Masters degree in Oncology in 1992 and works as a Hospice Care Manager. She has worked in Oncology since 1989, having worked at Emory and Northside Hospitals with a background in critical care. She talked about Advance Care Planning. Each patient needs to decide what you want done, in case you get sick and can't make your own healthcare decisions. Write a legal document specifically stating your wishes.

Advance Care Directive

Do you have a Living Will? This is a written set of instructions that specify what actions should be taken by healthcare providers if a patient is unable to communicate their decisions.

Do you have a Healthcare Durable Power of Attorney? This is a legal document that identifies an agent who will speak for you; to ensure that your wishes are honored.

Decide NOW what you want done, and prepare documents that state your intentions in ANY situation; especially in the event that you cannot speak for yourself.

Examples:

- (a) I DO/ DO NOT want CPR, resuscitation
- (b) I DO/ DO NOT want to live in a vegetative state or coma state
- (c) I DO/ DO NOT want artificial fluids (IV)
- (d) I DO/ DO NOT want to be on a respirator
- (e) If I cannot feed myself, I DO/ DO NOT want to be fed
- (f) I DO/ DO NOT want to be placed in Hospice Care

TWO TYPES OF FORMS YOU SHOULD HAVE:

(1) Living Will

This document states what you want done. “If ___ happens to me.... I want ___...”

(2) Advance Directives for Healthcare (**make sure it's updated AND notarized**)

- Give a copy to your doctor/ PCP (Primary Care Physician)
- Give a copy to your assigned person/agent (speaks on your behalf)
- KEEP A COPY for yourself at ALL times

You are in charge of your life and decisions. Make the tough decisions NOW and communicate with your family, when there is no crisis and no emotions. It removes the burden on the family in a difficult situation.

Updates

Lori had a transplant and is on Day 50. She is walking 2-3 miles every day. No infections. Taking Ativan as needed. She has a complete response.

Submitted by Lana

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Southside Atlanta Area M M Support Group Meeting – March 23, 2013

Doris opened the meeting with all having a moment of silent prayer. There were 12 members present.

Mark your calendars. April's topic for our support group meeting is "Keeping the Wolf at Bay: Nutritional and Psychological Support for the Multiple Myeloma Patient" presented by Michelle Thomas. Michelle Mary Thomas has been an infusion nurse at the Emory University Winship Cancer Institute Ambulatory Infusion Center since 2006. This speaker was secured by Alma.

Gail led the discussion by asking: “**Are you being the best patient/caregiver you can be?**” with a focus on how well we incorporate the information from our great speakers into our practice. She outlined points of discussion that would help ensure you are doing the best for yourself and members participated in discussions surrounding each point. Some discussion points included:

1. **Do not be afraid to ask for a second opinion.** Second opinions have become standard practice. They are not only for your peace of mind, but allow for another professional to offer a different view. Your provider might offer the names of other physicians who are respected in the area for which you seek help. Insurers benefit by having the best chance for patient outcome.
2. **You should not suffer in silence.** It's important to share whatever pain you may be experiencing. Medication dosages can be decreased or medications can be changed altogether.
3. **“Out” poor bedside manner of doctors; let them know what you are feeling or thinking about their approach.** Be thoughtful about your decisions. Doctors are people too and are not perfect—you may choose to trade the less than optimal "bedside manner" for having "the best diagnostician in the business." It may also be that your personality and that of your doctor are not compatible for some reason.
4. **Keep good records between appointments and go into appointments with written questions and check off as they are answered.** Know when symptoms started, when they occur, what makes it better or worse.
5. **Take someone with you to appointments, if at all possible.** Four ears are better than two -- you can have someone to discuss what was said after the appointment and someone who can ask additional questions during the appointment. **Communication** is *key*. Remember, **YOUR** health is the most important outcome.

Important Medical Update

Pomalyst (Pomalidomide) in combination with dexamethasone, was approved by the US Food and Drug Administration (FDA) on February 8, 2013. Pomalyst is similar to thalidomide and Revlimid and approved only for patients with relapsed/refractory myeloma who have received at least two prior therapies including Revlimid and Velcade® (bortezomib), and have demonstrated disease progression on or within 60 days of completion of the last therapy. FDA approval was based on response rate. There are side effects to this drug, as with all other medications. No formal drug interaction studies have been conducted with Pomalyst. Cigarette smoking may reduce Pomalyst exposure. Patients should be aware that smoking may reduce the efficacy of Pomalyst. Any concerns or questions about possible drug interactions should be discussed with your doctor and pharmacist. Pomalyst is metabolized in the liver. Pomalyst and its metabolites are excreted by the kidneys. The influence of kidney and liver impairment on the safety, efficacy, and pharmacokinetics of Pomalyst has not been evaluated. The following patients should not take Pomalyst: • Patients whose serum creatinine is >3.0 mg/dL • Patients whose serum bilirubin is >2.0 mg/dL • Patients whose AST/ALT is >3.0 x ULN. Patients must be aware of these and other warnings and precautions before taking Pomalyst. Speak with your doctor or nurse if you notice any changes in your health. Being a “good patient” doesn’t mean suffering in silence; it means accurately and promptly reporting any problems or changes in your health to your healthcare providers so that they can take appropriate steps. For a more comprehensive overview of Pomalyst, please read the IMF’s new

Understanding Pomalyst® (Pomalidomide) capsules booklet, available on the IMF website myeloma.org or by calling 800-452-CURE (2873) or Read more: Myeloma Today: Spring, 2013.

Myeloma Updates

The Black Swan Research Initiative is the name given to the efforts to seek a cure for MM. At one time, no one thought black swans existed, and yet they did and do exist. This project takes a look at the cure with a group of internationally recognized experts.

Secondary Primary Malignancies (SPM) - are side effects from "plerixafor" (Mozobil) used to mobilize cells prior to a SCT. This was a small study, but of 43 patients, 4 developed MDS (myelodysplastic syndrome) and one developed AML (acute myelogenous leukemia).

Myeloma Awareness Month

We had a successful campaign during the month of March to bring awareness to Multiple Myeloma: The Atlanta City Council presented a Proclamation acknowledging Myeloma Awareness Month; present were Nancy, Doris, Joe and Sandy, Lonnie, Mary, and Jeanette. (Council member Keisha Bottoms' grandmother died from MM); Gail, Doris and Alma were present as Ernestine Pittman, Mayor of East Point, presented a proclamation from the city acknowledging MM month; Gail and Doris were guests on Morehouse School of Medicine's program on WYZE radio, **Community Connections;** Gail was invited guest speaker for Wellness Group-West End Mall-Gail spoke about Myeloma at the group Tuesday; Lonnie petitioned to have flyers on Myeloma signs and symptoms put up at the VA. Atlanta was prominently featured in IMF publications --Myeloma Minute, IMF Advocacy, and Myeloma Today (Jameca, Nancy, and Subar, along with the ASH review).

Member Update

J.L. at Stone Mountain nursing home -- please call to check on him; **Andrew** still suffering with leg pain; **Montine:** Brother has severe nose bleeds; platelets low once the platelets come up, it's okay... poor appetite and anemic -- suggested making their own smoothies to increase nutrition. Says he is on a new medication -- Kyprolis (Carfilzomib) going to Northeast Cancer Center for treatment; **Lonnie** said "he is here" so he is doing okay ; **Mr. Lewis-** Myeloma came back- has back pain -- may need to have Kyphoplasty (treat collapsed spine from bone fractures)-had been in remission; **Doris** -- not on medication, her numbers were creeping up a little-- still watching her numbers; **Selina** - says she has to be her own advocate because she is seeing a new oncologist in Stockbridge, Atlanta Cancer Care. They are not communicating with doctors at Northside, where she had her SCT and was on clinical trial; **Alma:** seeing four specialists; but gets copies of blood work so she will not need to have blood drawn for each visit. She says it is tough because various providers often want to collect their own labs. She maintains folders with all medical information, including Vitamin D deficiency. When Emory prints out a list of drugs, she keeps it so all doctors were aware of what she was taking; **Loretta:** doing okay; **Pullen-** says he was receiving care at Georgia Cancer Specialists, and their merge with Northside is causing problems for him.

Announcements

Folami's aunt sent a donation of \$50 for the support group. LLS, Millennium/Takeda, and Genentech will co-sponsor a FREE seminar; **"Survivorship for Blood Cancers"** includes integrative medicine. April 27th in Athens, GA 8:-2:20. Registration at georgiacenter.uga.edu. Phone: 706.542.2134. Rosalinda, 404.720.7807.

Members had booths at the Greenbriar Mall Health Fair sponsored by the Delta Sigma Theta Sorority and the East Point Annual Health Fair on Saturday, April 13.

Shared Savings Program for Medicare. April 23. cms.gov - Completing a Successful Application

Southside Support Group Calendar: April 27th: “Keeping the Wolf at Bay: Nutrition and Psychological Support.” May 25th: Care Giver’s Workshop may be held at the **Ben Hill Rec Center**. June 22: New Regional Support Group Leader: Nancy Bruno; November: TGI Friday breakfast meeting at 9 am – 11 am.

We closed the meeting with the recitation of The Serenity Prayer.

Respectfully submitted by Paulette and Gail