

## April 2013 Meeting News –Both Group Summaries Included

Joe and Tom led the meeting. 35 members were present.

### **Business news:**

March was a successful Myeloma Awareness Month, as Proclamations were signed in the Cities of Dunwoody, Atlanta, and East Point. The International Myeloma Foundation (IMF) is working on a study called the “Black Swan Research Initiative™.” The project is to look at finding a cure for MM from a new perspective. The focus is on minimal residual disease that remains after treatment and while in remission. Also, there was an IMF workshop at Vanderbilt University on April 13, which included Dr. Kaufman and Charise Gleason. It was also noted that Mirko Pasta wants to host our September luncheon. More details to come.

**Meet Your Members.** A member of our group and Multiple Myeloma patient, **Irvin**, brought samples from his extensive butterfly collection that he has accumulated since he was seven years old. He has a wide variety in his collection with over 20,000 specimens. He has a PhD in Art History and has taught at Queens College, Brandeis University, Southern Methodist University, and Georgia Southern University; retiring 13 years ago. His collection covers butterflies and moths from across the US and other countries. There were framed displays of his collection for the group to see. Here are some interesting questions:

#### **Q: Why are moths attracted to light?**

A: There is no definite answer for this.

#### **Q: How is a butterfly or moth preserved?**

A: Once the tissue dries (one week), it will usually stay the way it is. Also, it should be protected from direct light and sealed TIGHT. To ensure preservation -paradichlorabenzine (white crystallized moth repellent) is used.

#### **Q: What are the differences between a butterfly and a moth?**

A: A butterfly or moth begins its life as a caterpillar, eating only plants. Once it has fulfilled the first phase of its life, it creates a cocoon and will hang upside down. Through nature's process, it changes into a butterfly or moth, which then looks for a mate to repeat the life cycle. Butterflies have antennae for smelling and a narrow body. A moth's body is thicker and fuzzy with feathery antennae.

### **Patient Updates**

**Robert** has been taken off Dex by his doctors. When he took Carfilzomib, his protein spiked, he had shortness of breath, but he says it's starting to go away. He does have physical therapy for neuropathy. No nausea or fatigue. Nuclear Stress Test results are fine. **Carolyn** is still part of the clinical trial for Elotuzamib. Counts are coming up; was .2 and is now .54. Her IGG was 700 and is now 800. She will take a break from her current trial, and resume chemo without Revlimid. If she is able to stay on a clinical trial, she will begin a new one. **Gerald** was diagnosed April 2013 and had a transplant in August 2012. In Feb 2013, He was having severe back pain. Tests and CT were performed, showing fluid in the lungs and soft tissue revealed. He started radiation and chemo. **Dolores** is on Carfilzomib, which has caused many problems, including swollen tongue and no appetite. Her food is pureed. She has no allergies, her creatinine is 2.5, and her Dex and Carfilzomib have been increased due to her numbers going up. **Madge** started a clinical trial for Elotuzamib (Hulac) in October 2012 and is doing well. **Lory** had a transplant Jan 10 and is back to normal. She

feels great and is talking with her doctors about maintenance. **Christine** is no longer in remission. It has been less than two years since her transplant. She is back on Velcade, Revlimid, and Dex.

### **THINGS TO REMEMBER...**

- Be in control-- make decisions about your treatment and options
- KNOW what is going on -- it's YOUR life
- KNOW your options and choices
- Be a good patient
- Stay in touch with doctors, speak up about ANY changes

**“A good patient is involved in their treatment.”**

Submitted by Lana

### **Southside Multiple Myeloma Support Group Meeting – April 27, 2013**

Doris called meeting to order. There were 15 present.

#### **Announcements:**

Next month will have a Care Giver's Workshop. Joe Brown will lead the caregiver's portion of the workshop and Alice Mullins will lead the discussion with MM patients. The workshop will be held at the Ben Hill Recreation Center at 2405 Fairburn Road, Atlanta, GA 30331.

Topic: "Keeping the Wolf at Bay" - Speaker: **Micheline Thomas**, Lifestyle and Nutrition Coach, said her mission is to get people excited about what is going on with their health. She said the American Medical community does an excellent job of diagnosing and treating diseases and medical conditions; but, a poor job of focusing on prevention. Ms. Thomas advised us to be mindful of and avoid environmental pollutants as much as possible including carcinogens in common, everyday contacts -- water, plastics, and pesticides in/on food. She suggests that 99% of the time, we can prevent the cancer gene from being triggered by consuming foods with cancer protective properties such as fruits, vegetables, spices and herbs.

She referred us to The Environmental Working Group, ([www.ewg.org](http://www.ewg.org)) for information and guidance. EWG is the nation's leading environmental health research and advocacy organization. Their mission is to serve as a watchdog to see that Americans get straight facts, so they can make healthier choices and enjoy a cleaner environment. They provide cutting-edge research and advocacy that transform government policies and the marketplace in order to conserve land and water; produce and use energy responsibly; and ensure that food and consumer products are free of harmful chemicals.

She suggests that the health benefits of a diet rich in fruits and vegetables outweigh the risks of pesticide exposure. Eating conventionally-grown produce is far better than not eating fruits and vegetables at all. The Shopper's Guide to Pesticides in Produce™ will help you determine which fruits and vegetables have the most pesticide residues and are the most important to buy organic. **The Dirty Dozen Plus** are the foods most contaminated, and **should be purchased organic**. **These include Peaches, Apples, Sweet Bell Peppers, Celery, Nectarines, Strawberries,**

**Cherries, Pears, Grapes (Imported), Spinach, Lettuce, Potatoes, plus domestically-grown summer Squash and Leafy Greens**, specifically kale and collards. The other group of fruits and vegetables called the **Clean Fifteen** include **Asparagus, Avocados, Cabbage, Sweet corn, Eggplant, Grapefruit, Kiwi, Mangos, Mushrooms, Onions, Pineapples, Sweet peas-frozen and Sweet potatoes. Also, cantaloupe and water melons are considered safe because of their thick skin.**

Ms. Thomas referred us to two videos featured on the EWG website one with Chensheng (Alex) Lu, Harvard professor explaining why people should avoid pesticides and the other with CNN's Dr. Sanjay Gupta who tours a grocery store to show us which foods have the highest levels of pesticide residue. She says avoid white sugar and flour, choose whole grains, use filtered water, vinegar and real lemon juice to soak fruits and vegetables to clean them. She advises us to drink filtered water to decrease as many pollutants as possible. MS. Thomas says carrots have a substance that encourages body to cleanse internally. Parsley cleans and granny smith apples have high antioxidant properties. You can contact Ms. Thomas at 404-200-7446 or [coachmicheline@gmail.com](mailto:coachmicheline@gmail.com) also, you can view her web site [www.journeyinfinitehealth.com](http://www.journeyinfinitehealth.com).

### **New members**

There were two new members **Patricia** and **Dorothy**. Pat was diagnosed in October, 2012. She was treated with chemotherapy and harvested cells for an unscheduled stem cell transplant. Pat gets support from her son who lives in San Francisco, CA; but has come back to go to doctor's appointments with her. She lost considerable weight during the chemotherapy treatment and was hospitalized twice for dehydration and a blood clot in her right leg. Pat says she needs to gain weight to obtain further treatment. **Dorothy** was diagnosed after a trip to Florida in 2010. She had a cold while visiting in Florida and went to a doctor who drew blood. Later when she got back home, she was contacted by the Florida doctor and told her she should contact her Atlanta doctor because her protein levels were elevated. Her doctor referred her to a specialist who diagnosed her with Multiple Myeloma. She said, her MM was stable and she was not on medication; but is under the care of Dr. Lonial at Emory Winship Cancer Institute.

### **Member Updates**

**Bridgett** is the daughter and care giver for Doris Morgan and is recovering from surgery on her arm (carpal tunnel syndrome). **Loretta** was diagnosed with MM in 2003; had a stem cell transplant on April 20, 2012, she has some neuropathy but Gabapentin/Neurontin provide some relief from the pain. Loretta takes Velcade administered subcutaneously. She said she was able to retire from Bell South after 32 years before her transplant and immediately applied for and received Social Security disability. Loretta's sister from New Jersey came down and spent 2 weeks with her during the stem cell transplant. Her daughter also provides support. **Alma** recently retired from the Atlanta School System. She worked at Grady High school with Doris for several years. She was diagnosed in 2006 and had a stem cell transplant in 2008. She has no children but was cared for during the transplant by her sister with whom she lives. She is on Revlimid, Dex, and subcutaneous Velcade. She has gone back to work part time, doing some consulting work for a charter school in Atlanta. **Lonnie**, diagnosed in 2005, is being treated with Revlimid, Velcade and Dex. He says he does not plan to ever have a stem cell transplant. He is looking for a new place for treatment as VA is overcrowded. He says he has no energy. **Selina** says she is married and takes care of her husband who is also ill. She has 7 grandchildren; she said she was diagnosed with stage 3 MM in 2010. She had pneumonia in January, and was hospitalized but is doing okay. **Doris** was diagnosed in 2004 and received no treatment for two years. She started treatment with Thalidomide and Dex, and harvested cells in

2007, but has not had a stem cell transplant. She said in 2006 when her IGG was 4500 when diagnosed and went down to 1600, just recently it went up slightly. She has 2 children, 2 grandchildren, and 5 sisters. This month, Doris had a stent placed in a blood vessel to open a blockage near her heart. She recovered well. **Vena** says her caregiver is her sister. She said she was diagnosed in 2007. She said she was feeling tired all the time, but has always been a very active, busy person and had been diagnosed with anemia years ago. She was referred to a specialist who did not diagnose right away; but scheduled her for a bone marrow biopsy. Her son went with her for the follow-up appointment and had to provide details of the doctor's visit because after he said cancer, she did not remember anything else. She was treated with Revlimid, dex, and Velcade. She is now in remission and is doing well. **Gerald** reported on his year's journey with MM. In February 2012 he was diagnosed with stage I MM and began chemotherapy at Winship. He had a stem cell transplant in August 2012. He reports feeling good after a successful transplant and was able to complete work for his Doctorate of Ministry Degree. Gerald was able to retire from his position as a Social Worker with Children's Health Care of Atlanta. In December he learned a bone marrow biopsy had detected myeloma and he began another series of chemotherapy with Revlimid. There were challenges obtaining the medication in a timely manner. By January he began experiencing pain difficult to control with morphine. Several visits to the ER in February 2013 found fluid around his lungs, and a MRI found soft tissue mass growing from his spine, pressing on his lung. He was paralyzed in the lower part of his body. Radiation and high doses of chemotherapy provided some relief and he is recovering with physical and occupational therapy. In early May, Gerald and Brenda hosted a celebration of Life, Retirement and Graduation at Lindsey Baptist Church with lifetime friends and family, co-workers, friends of the ministry, and MM family in attendance. Gerald is looking forward to becoming a full-time minister.

Submitted by Paulette and edited Gail and Alma