

## Northside Meeting Notes - February 2014

### New Members

The group welcomed **John** and **Amy**. John was diagnosed with MGUS in 2007 and has not received any treatment to date. His numbers have remained stable with the exception of plasma cells which have increased. His doctor recommends starting treatment but he is not convinced that he should do that at this time and has joined the group to get some ideas for next steps.

### Business & Announcements

**Joe** opened the meeting prior to the split into separate patient and caregiver sessions for the remainder of the meeting. **March** is **Myeloma Awareness** month, and **Dr. Kaufman** from Emory is scheduled join our March meeting as a guest speaker to discuss stem cell transplant and treatment. To promote myeloma awareness, support group leaders and members are working with local towns and counties to proclaim March as **Myeloma Awareness Month**. If you are able to work with your local government, please let **Nancy** know if the proclamation is passed; and when and where the ceremony will be. Group leaders can provide support to help raise myeloma awareness and alert the media to publish stories about myeloma and the proclamations. The April meeting will be an open discussion/knowledge sharing forum

### Member Updates

**Sandy** shared some information on members that she has spoken with recently through the Outreach Program. **Tim** has been on Velcade for nine years. He recently suffered kidney failure and had been on dialysis but is better now, and hopes to be able to attend the March meeting. **Loretta A.** has pneumonia but is improving. Sandy has also been trying to reach **Earnestine** but has not been successful in her attempts. Additionally **Sandy** and **Joe** will visit a patient in Mableton after the meeting to offer encouragement.

### Discussions

**Alice**, a clinical social worker from Emory led the patient discussion. **Joe** led the caregiver discussion. Caregivers were reminded that in order to provide adequate support to someone else you must first take good care of yourself, including managing the stress and anxiety associated with the caregiving role. We discussed the negative effects of long-term stress and anxiety and some ways to cope with these effects and better manage the stressful situation from the start. Ongoing effective communication skills provide a way to manage and overcome barriers, including ways to get help for yourself when you need it. Being transparent in your actions and in the way that you cope with the situations that caregiving presents may naturally provide others with a means to be able to better assist you. Rather than hiding your anxiety and fears from others, sharing your feelings can help others better understand what is important to you and how they can assist you better. We also discussed solutions to common stressful situations and ways that we can alter our own behavior to best handle these types of situations. Members described setting goals, writing notes and letters and journaling as ways to stay organized. Some of these practices offer a means to “brain-dump” which can help clear anxiety. Meditation and deep breathing are good ways to obtain and maintain a sense of calmness. Practicing these tips and slowly integrating them into your life will help to make them become automatic.

Submitted by Wendy R

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## Southside Multiple Myeloma Support Group Meeting February 22, 2014

Doris M. opened the meeting and led the group in a moment of silence. There were no new members; 12 members present.

### **Business**

**Doris M.** shared a conversation she had with a gentleman whose wife has myeloma and he did not know of the support group before now. Doris solicited ideas to reach more people and communicate information out about MM and support groups. She encouraged us to become more proactive and let people know about the disease and the support groups. **Brenda R.** said she will be writing an article for the **English Avenue Community Newsletter** about MM. **Montine W.** suggested, attending neighborhood association meetings to make announcements about MM and the support group. She suggested each member, share information about MM with groups they belong to and people they know, particularly this month. **Gail M.**, although not present, is planning an article for the consumer version of the Georgia CORE Newsletter which is circulated across the Georgia. Georgia CORE (Center for Oncology Research and Education) has a website ([www.georgiacore.org](http://www.georgiacore.org)) to address most cancer needs in Georgia. One newsletter is primarily directed at health professionals – the other at patients, caregivers, and others. The website for consumers is [www.georgiacancerinfo.org](http://www.georgiacancerinfo.org).

**Report on March as Myeloma Awareness Month (MAM).** We should each “**Tell One Person about Multiple Myeloma**” to help raise awareness. **Alma R.** chaired the committee to promote **MAM**. She shared so far we have three municipalities that have presented Multiple Myeloma Proclamations. The cities of **Atlanta, East Point, Forest Park, College Park, and Lithonia** have provided proclamations so far. During the February 17<sup>th</sup> **Atlanta** presentation, Councilman Ivory Lee Young announced he has been diagnosed with Multiple Myeloma and Keisha Lance Bottom shared her grandmother had MM and passed away three years ago. In attendance were **Alma R., Vermell S., Nancy B., Dr. Sagar Lonial, Montine W., Brenda R., Doris M., Sandra and Joe B.** The **Forest Park** presentation was attended by **Alma R., Pat C. and Gail M.**; there were two individuals among the 30 in attendance who were aware of MM. **Alma R.** reported she sent out letters inviting 12 municipalities for proclamations and heard from eight. On **Thursday March 20th at 7:00pm the Fayetteville City Council** will present a proclamation at City Hall, during the City Council meeting; **March 24<sup>th</sup>, both the city of Fairburn and city of Riverdale** will present proclamations during their City Council meetings. We need members to be present to support Alma and represent the MM Support Group. Also, we need your help contacting city leaders in Jonesboro, Riverdale, Union City, Hapeville and Palmetto. The MAM slogan is “**Tell One Person about Multiple Myeloma**” -- If we all ask family members and friends to “tell one” we will reach a significant number of people. **Alma R.** said as part of the proclamation she asked cities to place an article about MM in their newspaper.

**John Schwarz, from Millennium, makers of Velcade (Bortezomib),** presented information about resources available through his company. Mr. Schwarz said that Millennium has resources available for MM patients and supporters. A diagnosis or relapse of cancer can create many questions and concerns—from understanding your diagnosis to paying for treatment. In addition there are other helpful materials: (1) A DVD titled Multiple Myeloma in the African American Community. This DVD explores MM and highlights its impact on the AA population; an MM oncology specialist also provides a medical perspective with this rare form of cancer that is twice as common in the AA community as in White Americans. The DVD has a companion brochure that describes what

Millennium can do to help even persons with insurance and a decent income with financial assistance, so that cancer does not force anyone into bankruptcy; (2) Understanding Your Lab Tests --This guide offers an overview of lab tests that may be given to patients. The Lab trackers is a form to be used to place results of lab tests so that the values can be reviewed over time; and, (3) The Purple three-ring binder allow us to organize the multitude of various documents gathered during doctor's appointments. John will be providing Doris with some of these materials and she will distribute during the next Support Group Meeting.

Mr. Schwarz reminded us of the other resources available through Millennium to help support those on Velcade: (a) VELCADE Reimbursement Assistance Program -- If you have questions about your insurance or are having trouble paying for treatment, the makers of VELCADE (bortezomib) may be able to help work with your doctor to obtain a supply; (b) Transportation Assistance -- If you are in need of financial assistance for transportation to and from your medical appointments, the organizations on this list may be able to help; and, (c) co-pay Foundation -- If you need help paying for prescription drugs, co-insurance, co-payments, deductibles, health insurance premiums, or other out-of-pocket healthcare costs, there are organizations that may be able to help. To obtain more information, go to VELCADE.com. MyMultipleMyeloma.com will also provide links to other resources, stories from patients, and to obtain more information.

### **How Cancer Drugs Work**

There have been several novel drugs approved for treatment over the past 10 years. The drugs various cancer drugs attack the disease in different ways; some are proteasome inhibitors, like **Velcade (Bortezomib) and Kyprolis (Carfilzomib)** which was approved in 2012. They work by depriving cancer cells of nutrients like protein causing the cell to die. The action blocks or slows down the action of proteasomes inside cells. The function of proteasomes is to break down proteins in both healthy and cancerous cells. When proteasome activity is blocked or slowed down, proteins in the cells accumulate. This accumulation may cause cells—especially cancerous cells—to stop growing, dividing, and multiplying, causing them to die. Because cancer cells divide and multiply more rapidly than most other cells, the goal of treatment with VELCADE is to target these rapidly dividing cells and stop them from thriving and multiplying. Excess protein or calcium in the blood or urine is one indication of the presence of MM.

**Revlimid (Lenalidomide)** are in a class of medications called immunomodulatory agents or IMiDs. IMiDs work against cancer cells partly by impacting the functioning of the immune system. Lenalidomide affects the way the immune system works, although the exact way it works is not completely understood yet. It also works by blocking the development of new blood vessels. Making blood vessels is called angiogenesis. **Pomalidomide (Pomalyst)** was approved in 2013 and is in the IMiD group.

### **Patient Updates:**

Please keep **Andrew J.** in your prayers; he has had two operations on legs and is in a lot of pain; Andrew has had MM for more than 22 years. Also **Sheryl B.** had knee replacement surgery and is recovering well.

**Harold P.** closed the meeting by reading one of his poems “Wolf in Sheep’s Clothing”.

Respectfully submitted by Gail M and Paulette N.