

## July 2013 Multiple Myeloma Support Group Meeting Notes – Both Groups

### Southside Multiple Myeloma Support Group Meeting – July 27, 2013

The meeting was called to order by **Gail**. Doris was away attending the Annual IMF-sponsored Support Group Leaders Summit in Dallas, TX. Gail led the group in a moment of silence. There were 8 present.

The next meeting will be held **August 24th** and will feature Youssef Giles, PA at the VA Hospital. Also, Seketha Cannon will present information on the free supplemental health care offered by Well Care of Georgia for those enrolled in Medicare Part A and B.

### **Cancer Control Projects**

**Cancer Navigators, Inc:** Gail and Paulette made site visit made to Cancer Navigators, Inc. in Rome, GA in early July. Cancer Navigators, Inc. (CNI) is a nonprofit organization dedicated to guiding patients and their families through the cancer experience and serves individuals primarily residing in Floyd, Polk and Chattooga counties. Their mission is to complement medical expertise of cancer care providers by guiding those affected by breast cancer toward a better understanding of their diagnosis and care, and to connect them with needed resources. CNI offers free support including education, emotional support and assistance accessing resources. In collaboration with Georgia Tech, a grant from NIH and the local health care community, CNI is piloting a special project to determine the impact of providing breast cancer patients Android mini-tablets loaded with applications that specifically address their cancer. For example, the mini-tablet provided to patients were loaded with a well indexed breast cancer manual, archived webinars, nutrition app which tracked nutrient intake, breathing relaxation app, direct links to CNI staff and physician. Ultimately, they expect to provide these mini-tablets to approximately 200 breast cancer patients. The CNI staff was very generous in sharing their time and information regarding this innovation to support cancer patients and caregivers through their cancer journey. Several SS MM Support Group members expressed interest in having this type of resource available to them as they journey through MM.

**Member Updates:** **Andrew** is still having pain in legs; **Arthur** is getting stronger very day but remains at Westminster Rehabilitation on St. Charles Drive; **Janet** is 10 months out from stem cell transplant and is on Revlimid (10 mg/day) for maintenance and Zometa monthly -- she is scheduled for a biopsy in October and receiving care through Atlanta Cancer Care group bought out by Northside Hospital. Dr. Tamim is her oncologist. Members suggested Janet speak with her doctor about the monthly Zometa infusion and potential side effect, especially necrosis of the jaw; **Harold** described discoloration he began noticing in the palm of his hands as a dirty look and two other members **Janet** and **Selena** acknowledged they also had similar symptoms, that include rashes on the hands, arms, and feet, freckling discolorations on arms, etc. All are on Revlimid in different dosages. **Selina** and **Lonnie** reported they are doing okay.

**Brenda** was in attendance and graciously shared some of the details of Gerald's journey with MM and his final days. She said, during their 16 month journey with MM they found the Support Group invaluable; she said they learned a tremendous amount through both the SS and NS groups. Brenda said MM is an illness that so many people, particularly African Americans, are so unaware of and yet so highly impacted. She said part of what Gerald wanted to do was to share information and make people aware of MM. He did so in part with his exciting Celebration of Life, Retirement, and Graduation event held in April -- to a packed house at Lindsey Street Baptist Church. From the

pulpit, the many pastors representing several congregations spoke about MM, there was printed educational material in the common areas, and MM giveaways in the reception room.

Brenda said Gerald was very strong and healthy; he was a life-long athlete -- a runner beginning in high school, through military and after. He had never been ill; but had annual check-ups. With his 2011 visit, he was diagnosed with anemia; and this began journey with MM. She said he approached MM with calmness and was never afraid. Gerald's journey included a number of treatments: B12 shots, chemotherapy (Revlimid, Dexamethasone, and Velcade), radiation, a bone marrow transplant; but he never achieved remission and the cancer was very aggressive. He was a part of several clinical trials during his journey. Gerald last treatment included Pomalidomide. Two weeks before his transition Dr. Lonial said, we (Emory Winship staff) have directed your treatment so far; now you drive your own treatment -- you will lead us in how to proceed. She said Gerald knew what that meant. He prepared his family and friends. Family members and friends visited with him individually and received instruction and guidance from Gerald.

On his last day, they went to the clinic to have fluid drained from his lungs. Coming home from the clinic Gerald began to become so ill that Brenda stopped the car at a service station and called for those around to call 9-1-1. He was alert after arriving at the closest hospital to the emergency, Emory at John's Creek. Because of electronic records, Emory at John's Creek could pull up all his records from Emory Winship, and she did not have to search for paperwork during this crisis time. She said Gerald passed away at 2:30 am the next morning. Gerald was in charge throughout his journey and prepared all of us all for his transition, she said. She found a note he had written to a classmate where he stated he was at peace and prepared for what was to come. Brenda emphasized the importance of having a Living Will, she said she did not have to think about what to do because Gerald had taken care of everything and the doctors knew his wishes. She said she felt the Support Group was invaluable to them as they went through their journey. We appreciate this sharing from Brenda with so many life lessons for us all.

**Fund Raisers:** The SS MM Support group participates in 2 major fund raisers each year: The annual, national Macy's Shop for a Cause and the Leukemia Lymphoma Society LLS Light the Night.

Macy's Shop for a Cause is the primary funder raiser as 100% of the value of tickets sold will be placed in the group's treasury. On Saturday, August 24, 2013, Macy's all across the country will host its 8th annual Shop for a Cause. Since 2006, "Shop for a Cause" has raised more than \$45 Million for charities across the country. All participating non-profit organizations receive special savings passes to sell for \$5 each. When your guests shop on August 24, 2013 using the tickets, they'll receive up to 25% off\* on regular, sale and clearance merchandise, including designer brands, throughout the store, as well as 10% off electronics, furniture, mattresses and area rugs. In addition, they will be eligible to win a \$500 gift card, no purchase necessary. See Doris or Paulette for tickets.

Light the Night is an activity sponsored by the LLS; the event raises funds for treatments that are saving lives of patients with blood cancers. Join the Southside Multiple Myeloma Support Group team or organize your own team with family and friends. Make sure you make your donation as part of the South Side Multiple Myeloma Support Group. In Atlanta the culmination event and walk will be held at Centennial Olympic Park on October 12th --Check-In is at 5:30 pm. Checks can be made payable to LLS -- be sure to place in the memo section, SSMM Support Group. You can view footage of last year's Walk by visiting. [www.lightthenight.org/ga](http://www.lightthenight.org/ga)

**Advocacy.** Support HB 1801- (Oral Parity) and HB 460 (Specialty Tiers). Rhode Island is the 26th state to pass Oral parity bill. We are in the midst of our campaign to encourage Georgia legislators -- at state and federal levels to support these pieces of legislation. Be sure to get your friends, neighbors, congregants, fraternities and sororities to sign postcards. We have all been touched in some way by cancers. See Gail or Jameca for more information.

Respectfully submitted by Gail and Paulette

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## Northside Atlanta Area Support Group July 2013 Meeting News

### New Members & Guests

The group welcomed **Rodger** who was diagnosed with smoldering myeloma in September 2012. A low platelet count was found during a physical exam and Rodger was sent to a hematologist. He has not had any treatment to date, however now that the disease has progressed he is considering treatment options. **Dana** attended the meeting with a friend, **Perry**, whose father and uncle both have myeloma. Perry explained that his father, 80 years old, was initially diagnosed several years ago with smoldering myeloma. He was on 25 mg. Revlimid recently that harmed his kidneys and he has just completed three months of dialysis. **Perry** mentioned that his father has spoken with **Sandy** who has been very encouraging and helpful and he is looking for new options. **Bob** suggested having his local doctors collaborate with Emory doctors to work together to create a plan, since his father would rather not travel.

### Business & Announcements & Presentations

**Nancy** led the meeting. Over 60 people attended.

The **IMF's Black Swan Research Initiative** is focused on finding a cure for myeloma by developing tests to accurately measure Minimal Residual Disease (MRD). A cure is achievable by being able to detect MRD and then remove it. This initiative is in early stages, but has gained great momentum and is being led by a multinational consortium of leading myeloma experts.

**Tom**, a retired chemistry teacher, gave a very thought-provoking presentation on the organic chemistry of drugs. It is interesting to note that the study of organic chemistry is only about 200 years old, with the major gains only realized in the last 50 years. For a perspective, consider that penicillin was found by accident in 1929. It was over 13 years before it was isolated and used for treatment in 1942. It was expensive until it became mass produced and more readily available in 1949. Gains continue to accelerate at a faster pace now as medicine and technology advance together. Computer modeling helps to exponentially increase and radically change drug research. There are tens of thousands of new compounds that are synthesized annually and most are found not to work initially and are shelved, with some finding usefulness later (such as Thalidomide). Possibilities of discoveries far outweigh the realities. For example, there are vast regions of compounds to discover, with possibilities of 10 to the 60<sup>th</sup> / with realities of 10 to the 7<sup>th</sup> (i.e. 9 million real possibilities of compounds to be synthesized in labs). These areas exist but are yet to be researched.

Some perspective on myeloma drug progression:

- **1950s-60s** – Alkylating agents (i.e. Melphalan) are characteristically strong, attacking everything,

and killing all cells (bad and good).

- **Later** – mitotic inhibitors – (i.e. VAD and Dex) – Dex enhances the effects of other agents but unknown why.
- **2000s** - a) “IMiDs” (i.e. Revlimid, and Pomalidomide; a.k.a. next generation drugs of Thalidomide)
  - b) Proteasome inhibitors (i.e. Velcade, Carfilzomib) that use different pathways than the IMiDs.
  - c) HDAC inhibitors (i.e. Vorinostat and Panobinostat)
  - d) Monoclonal antibodies (i.e. *Elotuzumab* and *Daratumumab*, which has just been given breakthrough status from the FDA).
  - e) KSP inhibitors – i.e. ARRY-520

The two areas that drug researchers concentrate on are 1) the cell’s pathways (to either shut down the bad or encourage the good), and 2) the mechanism. Researchers usually understand if the agent works before understanding how it works. The dilemma is that if you don’t fully understand how the mechanism works on the pathway, then you can’t allocate the resources properly. It is common to use a combination of drugs and drug types when treating myeloma for the purpose of covering multiple pathways because cells are like weeds in that they will find a way to survive, so you want to shut down multiple pathways. It is typical for a treatment to involve three types of myeloma drugs, along with Dex. This makes the treatment more tolerable and effective. There is some overlap where drugs discovered to help one cancer can also help other cancers. For example, *Elotuzumab* has been found to have a broad success with blood cancers. *The latest myeloma drugs are very specific for treating myeloma.*

### **Member Updates & Discussion**

Sadly, some group members shared news of the passing of **Sandy**, and **Frank**. **Sandy** also shared news that both **John** and **Kathy** are seriously ill and are being treated in Arkansas and Emory clinics respectively. **Bruce** asked about caregiver services for those who do not have designated caregivers. **Lana** mentioned that she has heard about “Visiting Angels”. **Carolyn** has been in a clinical trial and in remission for over five years. She feels good and is only bothered by the Dex. **Inge** was diagnosed in 2008 and is doing well, currently on Thalidomide daily and Dex; with shakiness experienced as a side effect from the Dex. **Madge** is doing well in a clinical trial for six months using *Elotuzumab*, Dex, and Revlimid **Gene**, who had two stem cell transplants in 2007, is doing well on 5 mg. of Revlimid daily that he began for maintenance in 2011. He explained that he cannot tolerate a larger dose of Revlimid. **Barbara** is doing well and has reduced her 25mg. Revlimid to 15 mg. every other day due to neuropathy. She also took a month off drug break. **Suzanne** is currently taking Carfilzomib and Panobinostat and doing well. **Nancy** reported that she is near complete remission and is currently taking 5 mg. Revlimid daily with a 21-day on/ week off schedule. **Vinnie** has reached his 10<sup>th</sup> anniversary of being diagnosed with smoldering myeloma. He takes Curcumin and his numbers are better now than they were at diagnosis. **Chuck** was diagnosed about three years ago. Originally it was thought that his disease was a low risk version, however it now appears to be an aggressive form of myeloma. Chuck tolerated two rounds of DCEP in late 2012 which put him into a full remission, but he explained that he has not been able to maintain remission beyond 6-8 months. He said that the alkylating agents seem to work the best for him and he has no neuropathy or bone involvement; and has good overall health and stays well informed. **Multiple members** in the group have reported trouble breathing as a side effect of taking Carfilzomib. There was some discussion about myeloma as a **hereditary** disease as several members in the group have family members with myeloma. **Bruce’s** father had myeloma and passed away about six months ago. Also,

there was discussion of **environmental** factors as it relates to myeloma. Both **Bob** and **Joe** have careers as architects where they have spent a lot of time on building sites. **Bob** also knows five other architects with myeloma. **Gene** commented that he has learned of six other people in the past year who have developed myeloma that reside in a three mile radius of where he lives. **Don** mentioned the **Myeloma Minute** had good information on the Black Swan initiative and also the Stockholm conference. Others in the group also noted that this conference resulted in good information that can be played back on [replay.myeloma.org](http://replay.myeloma.org). Someone else mentioned that the recent issue of **Cure** magazine contained an excellent article on treating myeloma and mentioned two new proteasome inhibitors.

Submitted by Wendy