

## October 2011 Meeting News

### New Members

The group welcomed three new members this month. **Dolores** attended the meeting with her two sisters. Prior to diagnosis, Delores was experiencing extreme fatigue and acute shoulder pain. Her sister brought her to a doctor, which led to being admitted to the hospital with kidney failure and a severe heart rate drop. An oncologist then diagnosed myeloma. Delores harvested stem cells in April and then had a stem cell transplant in May. She is doing well now. **Barb** is a teacher from MD, currently staying in Atlanta with her daughter. In August Barb tripped and broke her arm. Paramedics arrived and discovered that she was experiencing kidney failure which led to a very quick myeloma diagnosis. Barb is planning to do four rounds of subcutaneous Velcade and Dex, and then a stem cell transplant. Barb also mentioned that she has not taken Revlimid because it could affect the healing of her broken arm. **Jorge** was diagnosed in October 2008 after experiencing anemia and severe headaches for over two years. An internist sent him to various specialists and he was diagnosed by a hematologist. Jorge achieved a complete remission using Revlimid, Dex, and Velcade, and was also on Revlimid (only) for a while. His myeloma has just recently relapsed and he is now experiencing kidney failure. He has harvested stem cells and is planning for a stem cell transplant in February.

### Business and Other information

**Nancy** led the meeting; approximately 55 members were present. Prior to the meeting, the group's Outreach committee met, **Sandy** led the meeting with 4 out of 10 volunteers attending. The group's goals include contacting all members on a regular basis and reaching out to members who are not able to attend meetings. The committee is currently in the process of collecting information from all members via an email survey or a print mail survey, with self-addressed stamped envelope. When you receive the survey, please respond as soon as possible.

Upcoming events include:

- 1) The **LLS Light the Night** event will be held on November 5<sup>th</sup> at Centennial Park. Join other families for activities, food, music, and a walk around the city. Join at [www.lighththenight.org](http://www.lighththenight.org)
- 2) The **MMRF Race for Research** will be held on November 12<sup>th</sup> at Piedmont Park. 90% of the funds donated to the MMRF are used for research, significantly reducing the time to market for drug availability. You can donate and/or solicit donations, either by using the Team Together main page, or by creating your own site from the main page: <http://support.themmr.org/goto/TeamTogether>

Various members spoke of their experiences soliciting donations from various sources such as family, friends, co-workers, employers (who often have donation matching programs), and other organizations and businesses that you may belong to or associate with. **Carolyn** summarized by saying that all you have to do is ask. As an example - as a result of simply asking for a small donation - Carolyn's dentist's office is supporting the **MMRF Race**.

A few members attended the **BMT survivorship symposium** and all mentioned that it was exceptionally good with good speakers and topics including managing fatigue, pain, and stress, employment rights and disability, patient and caregiver stress and support, integrative therapies, and chemo brain. We look forward to future events from [BMTinfonet.org](http://BMTinfonet.org).

***The December meeting will be held at a different time and place this year!*** Discussion was held about having two meetings in December or changing the monthly meeting to Emory so that everyone can get the latest news from Dr. Lonial. Since everyone gets busy for the holidays and we would like to have our Holiday Luncheon, it was agreed that we would have one meeting where lunch will be provided and family members are welcome to join.

It will be held on Saturday, December 17<sup>th</sup> at Emory Winship. Dr. Lonial will provide information that he gathers from the annual American Society of Hematology (**ASH**) conference that he and his team will attend the previous week. Additional details will be provided in the near future.

### **Speakers (“Meet Your Members”)**

Thank you to group members Arch and Linnis who shared their interesting life experiences. Arch and Linnis lived in Brazil for 22 years; from 1987-2009. Arch, 70 mentioned that he likes to walk a lot. In 2003 he noticed that he was getting tired easily, which eventually led to a myeloma diagnosis, much later. Arch is originally from the mid-Atlantic area of the U.S. and has lived in various states including PA (where he grew up), NJ, MA, GA, and ME. He is an ordained minister with a PhD in biblical studies. He knows a variety of languages and likes to learn them for fun! He has been a school bus driver, hospital chaplain, college professor, and a missionary. When he was in Brazil not feeling well he learned that his primary care physician had retired and since primary care physicians are not plentiful in Brazil he went to a cardiologist complaining of fatigue. In 2004 he returned to the U.S. very fatigued and a physical led to a myeloma diagnosis. He has since had 3 stem cell transplants; 2 at a center in DeKalb and 1 (more recently) at Northside. While living in Brazil, Linnis went back to law school and then worked in social areas with many poor people, where she learned a different set of values and gained a different perspective. She retired in 2009 and she and Arch moved back to Atlanta at that time. Linnis mentioned that she is grateful for Arch’s grace in dealing with myeloma, and her freedom in retirement to care for him. She “lives for the day” and mentioned that she is especially thankful for lots of good group support.

### **Updates**

**Jeanette** recommended an article entitled “A Time of Hope”, which is the cover story in a recent version of “Emory Winship” magazine, published twice yearly by Winship Cancer Inst. **Jim** had a recent and unexpected experience while traveling. He became sick – congested with a fever while at an airport. He went to MD Anderson and mentioned how impressed he was with the organized and immediate care that he received there.

Submitted by Wendy