

November 2011 Meeting News

New Members

The group welcomed two new members this month. **Joseph** was diagnosed in September 2011, after having smoldering myeloma for 18 years. He and his wife used to live in Monaco, but are now local; and Joseph sees Dr. Lonial at Emory. Prior to the diagnosis of active myeloma in September Joseph experienced low hemoglobin and passed out. Also attending for the first time this month was **Sriti**. Sriti attended the meeting to gather information for her father, who was diagnosed earlier this year, and who lives in India. Sriti's father initially experienced back pain which was not alleviated by drugs, and worsened quickly. His hemoglobin was also low and he was admitted into ICU for a month with kidney failure. He remained hospitalized for three months where he stabilized and slowly recovered. He had a stem cell transplant in October and is doing well now, but is very fatigued. Sriti commented on the similarity of research and treatment options in both the U.S. and India and also mentioned that she was impressed with the collaboration between doctors in both countries.

Business and Other information

Nancy led the meeting; approximately 50 members were present. The December meeting will be held on **Saturday, December 17th at 10:00 AM** at the **Emory University Winship Cancer Institute / Fifth Floor Conference Room**. Dr. Lonial will present information gathered from the annual American Society of Hematology (**ASH**) conference. Lunch will be provided after the presentation. ***Important: space is limited! If you did not register at the November meeting then please RSVP to aammsg-2@comcast.net, provide your name and the number attending the meeting and lunch and enter "Winship" in the subject line. Call 770-451-8341 if no email.*** Also during this event, toys will be collected for the **Eggleston/Children's Healthcare of Atlanta**. If you wish to donate, please bring a **new, unwrapped toy** to donate to a child who is hospitalized during the holiday season. Nancy attended the **Multiple Myeloma Research Foundation's (MMRF) 15th Annual Fall Gala** on Saturday Oct. 29, in Connecticut. This event occurred during the weekend of the early snowstorm in the northeast. Nancy said that it was a very good, encouraging event with good entertainment by Stevie Wonder and others. President Obama congratulated **Kathy Giusti**, (Founder and CEO of the MMRF and a myeloma patient) and Time Magazine has also recognized Kathy G. as one of the top 100 influential people. More information about the event can be found [here](#). Nancy has been invited by the International Myeloma Foundation (IMF) to attend the American Society of Hematology (**ASH**) conference in December! There is a Patient & Family seminar sponsored by the IMF in February 2012 in Boca Raton, FL. - [Link](#). These seminars are highly recommended by group members who have attended them, and it is recommended that you get reservations early if you are interested in attending. The group now has a paver in the Emory Gardens behind the fountain. The group recently donated \$500 to support Emory (paver), the IMF, and the MMRF. Nancy provided copies of several articles that were reviewed during the meeting. 1) "Gene Therapy Advance In Leukemia Suggests New Treatment Options For Multiple Myeloma" [Link](#) 2) "Onyx Pharmaceuticals Submits New Drug Application for Carfilzomib in Relapsed and Refractory Multiple Myeloma" [Link](#) 3) "Subcutaneous Velcade: Information For Multiple Myeloma Patients" [Link](#) 4) "Stem Cell Transplants May Be Feasible In Elderly Multiple Myeloma Patients" [Link](#)

Speakers ("Meet Your Members")

Thank you to group members **Sandy and Joe** who shared their interesting life experiences. Cassandra "Sandy" and Joe have known each other since they were young children who met in Sunday school. Joe said he always knew he would marry Sandy, even when she became engaged to

someone else! They married in 1966, have two grown children, and lived in Raleigh, NC for a while, moving to Atlanta in the 1990s. Sandy and Joe recently celebrated their 45th wedding anniversary in Niagara Falls. They like to travel, having visited London, Canada, Bermuda, and the Bahamas, and Sandy also recently attended her 50th high school reunion. Sandy has a BS degree in Commerce and was a teacher, and retired from Hewlett Packard in 1991. Joe has a BS, Masters, and PhD in Health & Physical Education. He has taught at a variety of universities including GA Perimeter College, Morris Brown, and Spellman. He currently teaches at three different colleges and is also a Deacon at his church. Sandy was diagnosed with smoldering myeloma in 1989 which continued for five years, during that time receiving no medication. Since then she has endured a variety of treatments and has lived with myeloma for 22 years, citing her relationship with God as the reason. Sandy mentioned that she has a deep appreciation for the caregiver role, as she and Joe were devoted caregivers to her Aunt with Alzheimer's, who they moved from Washington, DC to Atlanta to care for her. Sandy and Joe became group members in 1988 and met **Cathy**, the founder of the group, who Joe described as a "jewel". Joe also mentioned his deep appreciation of our current leader, **Nancy**, who has continued with her devotion to the group; keeping the group growing and strong.

Updates

There was discussion about bisphosphonates, specifically Aredia and Zometa. To diminish kidney impact, the group was reminded to ask their doctors to administer Zometa slowly, in 45 minutes rather than 15 minutes. There was also discussion about subcutaneous (sub-Q) Velcade, which is not approved yet, but you can request this means of administering the drug. Sub-Q Velcade has the same effectiveness as IV, and the side effects are lessened. An FDA approval date of subcutaneous Velcade is expected in January 2012. There was additional discussion about coverage provided by insurance carriers. **Tom** mentioned that his wife was the first patient of her doctor's to use subcutaneous Velcade and it was covered by her insurance plan with no issues. **Dale** mentioned that his neuropathy has not been reduced with the use of subcutaneous Velcade. Dale also mentioned that he suffers from Restless Leg Syndrome (RLS), as does **Rick**. **Dolores** mentioned that she had been on Velcade which worked well for her but caused a lot of neuropathy. Since her stem cell transplant her lab reports are showing stability and she is not currently on maintenance drugs. **Dana** is doing well. He explained that he has had two stem cell transplants – one in 2001 and another in 2009. He had tried a lot of different treatments between 2005 and 2009, and was able to harvest stem cells again for the transplant in 2009. **Virgil** has been receiving intravenous immunoglobulin therapy every 6-8 weeks to prevent infections. Prior to receiving this treatment he gets Benadryl and steroids to help prevent chills and high blood pressure, which is a side effect. **Rich** was on Revlimid, which worked well to control his myeloma, but he stopped all chemotherapy in May because his white blood count was low. He is planning to begin Velcade therapy soon. **Dominick** just began a new clinical trial with a known side effect of lowering white blood counts. To counteract this he is getting neupogen injections. **Earnestine** mentioned that her lab report numbers are increasing. She has not begun treatment but is considering beginning Zometa again. **Tom** warned the group that his wife **Latain** had an infection recently, but with no fever, which we frequently use as an indicator for seeking medical treatment. He said that Latain seemed normal during the day with the exception of fatigue, but had been talking in her sleep at night, which was out of the ordinary for her. At the doctor's office her blood pressure and platelet counts were very low. She remained in the hospital for five days and was given fluids and antibiotics. This is a great reminder of how important it is to pay attention and listen to our instincts. **Jeanette** mentioned that there is a good article in Cure Magazine about vitamins and supplements.

Submitted by Wendy