

March 2009 Meeting News –

New Members

The group welcomed some new members at the meeting this month. **John** was present representing his wife, **Kimberly**. She was diagnosed with myeloma in February 2009. Kimberly had a plasmacytoma a year ago that was treated with radiation, but then progressed to multiple myeloma. They are learning about treatment options. **Suzie** was diagnosed with myeloma in January 2009. Suzie explained that she had experienced a long period with broken ribs, and went to 4 or 5 doctors before obtaining a correct diagnosis. Suzie is currently being treated with Velcade, Revlimid, and Dex.

Business & Other Information

Nancy led the meeting. Approximately 32 members were present.

Guest Speakers

The group thanks **Rosalinda Ramirez**, a Program Manager from The Leukemia & Lymphoma Society, and **Terri Tayco**, an oncology nurse from Northside Hospital's Oncology department who presented "Milestones in Myeloma Therapy: An Overview for Patients and Caregivers". The program was developed to provide information and support for those who cope daily with myeloma. Rosalinda began by explaining that the Leukemia & Lymphoma Society's mission is to "Cure leukemia, lymphoma, Hodgkin's disease, and myeloma, and improve the quality of life for patients and their families." The Leukemia & Lymphoma Society offers a variety of services such as Family Support Groups, First Connection Program, Patient Financial Aid, and a Co-Pay Assistance Program. Details about these programs can be found at <http://www.lls.org>. Terri then reviewed the presentation with the group. She has been an oncology nurse for twenty years and provided insight into the diagnosis and treatment of MM. She noted that there are currently 63,000 people living with MM today. The program examined the following areas: Understanding Myeloma, Diagnosis and Staging, Treatment, Managing Side Effects, and Clinical Trials & Emerging Therapies. More specific information centered on Disease Development, Risk Factors, Symptoms, Finding a Specialist, Disease Complications, Related Disorders, Types of Treatment including Stem Cell Transplantation and Radiation, Treatment Planning and Goals, Disease Monitoring, and Measuring Response. A copy of the presentation was provided to group members that were present, and additional copies can be obtained through the Leukemia & Lymphoma Society. Both Rosalinda and Terri remained available after the meeting to provide additional and specific information to group members. Information from LLS will be in the group library and forms are available for reimbursement of co-pay amounts and medical expenses up to \$500. We look forward to hearing more from LLS in preparation for the Light the Night events in the fall. They are now taking applications for Honored Heros to be recognized in those programs. The 2008 Light the Night celebration at Centennial Park featured Andrew Jackson from the Southside MM Support Group.

Member Updates & Collaboration

The second part of the meeting was dedicated to obtaining updates from members. **Nancy** provided an update on her husband, **Mike**, who has been taking Revlimid. Mike has low blood counts currently and has experienced a lot of fatigue. He is getting Procreit to boost his counts. **Earnestine** mentioned that a transfusion can also be used to boost counts and

some other members responded that they have experienced feeling better almost immediately after a transfusion. **Dana** reported that he has been on Revlimid for about a year but it has stopped working, and so he is now consulting with his doctor on “next steps”, and is considering a second stem cell transplant. Dana has a limited amount of frozen stem cells from a prior collection but is not sure if there are enough available for a successful transplant. **Terri** responded that with a low number of stem cells to transplant one of the bigger risks is that of potential graft failure. **Raphael** reported that he has been on Bendamustine (trade names Ribomustin and Treanda). The results do not appear to be very good yet, but he will learn more next week. **Nancy** commented that sometimes it takes a while for better results to present after treatment. **Earnestine** mentioned that her myeloma numbers have been incrementing slowly since last summer. She had a recent MRI and is waiting for the results. **Carolyn** mentioned that she is scheduled to begin a Phase 2 clinical trial for HuLuc63. **Fran** reported that her husband **Frank** recently harvested nearly 8 million stem cells in preparation for a transplant, and that **Karyn** recently harvested about 12 million, and may have already transplanted, or will be very soon. **Greg** reported that his wife, **Suzanne** also has just received a stem cell transplant at Emory.

Submitted by Wendy