

August 2008 Meeting News –

New Members

Inge was glad to have found our group after her doctor told her that she only had one year to live. She was encouraged to meet so many people in our group that are doing well 5, 10, and many more years after getting the MM diagnosis. Inge received her MM diagnosis in May after rounds of tests to determine the source of her anemia and fatigue. She is now considering her options for treatment, which may include finding a more supportive doctor!! **Tom** and his wife, Nancy, attended for the first time with their friend **Tim**, a long-time member of the group. Tom was diagnosed in April of this year after having walking problems and bone pain. He also made the rounds of tests and doctors, including a CAT scan that revealed lesions. Tom is now receiving Velcade.

Member Updates & Collaboration

Tim attended to bring his friend Tom and catch up with the group. Tim reported that he had been on “maintenance” Velcade for five years. He was also on Melphalan for several years, but stopped three months ago after his blood counts seemed to be affected. Tim noted that he had been previously cautioned by Cathy L. that extensive use of Melphalan can affect the bone marrow. Tim reported that his counts, especially platelets, are now improving. He stressed the need to have a good relationship with your oncologist and the advantage of having an oncologist who is willing to consider your ideas about treatment options. Tim was diagnosed in January 1996, has had two kidney failures, and dealing with diabetes throughout treatment.

Janice was at the meeting after receiving her transplant at Emory on May 9. She was diagnosed in 2000 and collected stem cells in Arkansas in 2001. Since Arkansas would not negotiate on the tandem transplant policy, she worked with Emory to use the Arkansas stem cells after failed harvest locally. She is feeling much better and looking forward to attending her daughter’s wedding near the end of August.

Mike reported that he has attempted stem cell harvest three times without obtaining enough cells for a transplant. He will be participating in a clinical trial, AMD3100, which has yielded excellent results in stem cell harvest. Under “compassionate care” he will receive the drug and not be randomized in the clinical trial. The MM levels in his bone marrow are below 10% as a result of two rounds of Cytosin and Velcade. He is coming out of the “chemo fog” and feeling much better.

Raphael said that he is not on treatment at this time and is doing well.

Doris, from the Southside Support Group, reported that the group now has about 24 members, including 10-12 myeloma patients.

Sharon, an MM patient for seven years and medical psychologist for 30 years, helps people manage stress from medical trauma. Many patients had never heard of Multiple Myeloma until they heard it from their doctor. We experience lots of thoughts and emotions at the time of diagnosis, concerns about treatment, along with family situations, all of which can build stress levels in the body. Researchers do not know much about what stress hormones do to the body, but along with the added attack of MM and the chemo, long term stress can take its toll. Sharon gave a program to the group on relaxation techniques to help the body relax and heal. She encourages all patients and caregivers to find their own way to relieve

stress through mindful meditation, yoga, long walks, hobbies, or any other outlet to help the body handle the medical stress.

Submitted by Nancy