

## Our History

January 2008

We have been advised that it is likely my husband, Tim, had amyloid deposits starting in early 2004, when he was having heart arrhythmias as he lifted weights; and jogged after work; so he was told to cut off the caffeine. Then he had carpal tunnel; and surgery; again, just the job. In 2008, my 49 year old husband, Tim, was admitted to a local hospital with congestive heart failure as the diagnosis. After a week, they sent him home, treating him with CHF. Tim was athletic, a marathon runner; had his regular checkups every year and a stress test done by his general physician in 2007.

After three months of testing; he was properly diagnosed with Primary AL Cardiac Amyloidosis with a heart biopsy procedure; his Cleveland Clinic heart specialist; stated, this is really bad news. You need to see the cardiac amyloid specialists in Boston, they have the lowest mortality rate in the nation; we needed to hear nothing else.

That March 08 diagnosis sent us to Boston, to the Boston Medical's Amyloidosis Treatment and Research Center where we were informed Stem Cell Transplant (SCT) and High Dose chemotherapy was the needed immediate treatment; and they had to run several tests to see if he was physical capable of living through the procedure. If not, he would be sent home and possible not live to see his 50<sup>th</sup> birthday in August.

We were blessed to be a member of society where we could pick up and move to Boston with little consequence. We were only able to find temporary housing after a full 3 days of searching the internet. However, living in Boston came at a great emotional and financial cost. We left at the end of 6 weeks, but had to pay for the entire 8 weeks of housing; cost was over \$9,000.00 just for room and board not to mention the transportation costs to and from the clinic while he went through the outpatient SCT and High Dose Chemotherapy. We are so grateful for the Amyloidosis team @ BUMC, Tim survived the treatment. Many others going through the same procedure endured stays at hotels without the comforts of a kitchen; or at places that housed college bound people and the quiet needed for the rest after high dose chemotherapy was non-existent; the requirements after your immune system is taken to zero is a very serious business; needing very structured accommodations for recovery of the patient.

In November 2008, we learned Tim did not benefit 100% from the SCT treatment, and the disease is so far advanced; he has no option for a second transplant; his only option; a clinical trial, taking high doses of dexamethasone (a steroid dose equivalent to 256 doses of Prednisone) and oral chemotherapy (21 days on 7 days off); every two weeks blood draws sent to Boston, and a required trip to Boston every 3 months for testing. He has lost most of the quality of life he once enjoyed, has had a ICD implanted in early May after becoming unconscious in the wee hours of the morning; contracts pneumonia several times a year since May 2008; hospitalized over 50 days in 2009, is now on disability; and struggles to stroll a mile, let alone dream of his marathon days when he placed 3<sup>rd</sup> and 4<sup>th</sup> in the finals. His children in their final years of high school; have a tough time coping with his continued struggle and barely recognizing their once athletic dad.

**We are committed** to our mission to help educate families of the early stages of Amyloidosis in hopes that one family benefits from our efforts and can avoid the life altering situation we are now facing. Supporting them during treatment is essential for families afflicted with this disease because of the special requirements needed for outpatient treatment.

We meet family after family who are devastated by the knowledge that the financial burden of housing and transportation is out of their reach in Boston, and we had to do something about this for they were walking away from life saving treatment.

Please help us help them. The entire world helps cancer victims because cancer is such a well known dreaded disease and **Amyloidosis** is not recognized as a cancer.

Please help us make Amyloidosis a household word; to encourage physicians to become more aware of the symptoms; and give back people their ability to live with dignity with Amyloidosis. Together we can find a cure for our future generation.