

I Rejoice in Being Old

A routine physical at the Mayo Clinic in late 1997 revealed elevated kappa light chain activity in my urine and disturbing heart wall thickness. The ensuing fat biopsy, handled by a local surgeon in early 1998, showed no abnormalities. In retrospect that failure to identify amyloid tissue was probably attributable to the laboratory's limited experience with Congo red staining techniques.

By late 1998 fatigue, fluid retention, breathing difficulty, and bruising prompted my internist to hasten me to the Mayo Clinic because his testing could not account for the symptoms. Fortunately, he is a wise and secure person who knew what he didn't know. With the clock ticking he in effect extended my life by not wasting time on a misdiagnosis.

At the Mayo Clinic I was quickly diagnosed as having Primary AL with extensive heart, pleural, and soft tissue involvement including peripheral neuropathy and disruption of my autonomic nervous system. My age (69) and extensive organ involvement precluded my inclusion in any of their aggressive treatments involving high dose chemotherapy. I was given a regimen of oral melphalan and prednisone and a bleak outlook for survival much beyond a year.

My son refused to accept that grim verdict and promptly used the internet to discover Dr. Martha Skinner and her brilliant staff at the Boston Medical Center. My treatment began April, 1999, with 140 mg melphalan and SCT. My inability to produce the requisite number of stem cells through ordinary harvesting methods resulted in removing plugs of bone marrow from my pelvis to reach the number needed. My extended (17 days) hospitalization was attributable to concern about my heart's ability to handle the stresses attendant to stem cell harvesting and chemotherapy.

The immediate aftermath was as forewarned, difficult, but bearable because my loving wife, a world class caregiver, anticipated my every need. I have little doubt the doctors' decision to include me in the trial was influenced by the strength they saw in her.

My recovery was complicated by bouts of pneumonia and chronic pleural effusions which required supplemental oxygen for nearly 18 months. After nearly six months of weekly fluid drainage (pleurocentesis) by pulmonologists at the local hospital, Dr. Berk of the BMC staff recommended implantation of catheters near each lung allowing drainage at home, again with the expert care from my wife. Drainage of 500 to 1000cc of pleural fluid daily added immeasurably to my comfort and freedom of movement. This problem was resolved in my left lung when after a year of usage a catheter valve failed leading to an infection in my lung cavity. The infection, controlled by antibiotics, led to scarring of the membranes around my left lung thus eliminating the troublesome accumulation of fluid which for months had diminished my ability to breath. Indeed, God works in mysterious ways. A few months later my right lung was healed by a laproscopic surgical procedure which produced essentially the same scarring and result. From that point until now I have been blessed by steady improvement in all aspects of my life.

Annual evaluations by the BMC doctors continue to find me in "complete hematological remission." Words cannot capture the humanity and brilliance of Dr. Skinner and her magnificent staff. My 17-day hospitalization allowed me to experience just how special they are.

Daily with few exceptions Drs. Skinner, Seldin, Sanchorawala, Berk, Falk, Kathy Finn and others took time from demanding schedules to monitor my progress, lend encouragement and help me anticipate what was ahead.

From the outset of my encounter with this dreadful illness I have been comforted in the certainty that whatever happened would be a part of God's good and perfect plan for me. Events of my life to that point had shaped me into a spiritual person. In the years since treatment, the prayers of family, friends, and business associates have strengthened and sustained me.

Today I live a near normal life. I do try to live as fully and sensibly as I know how. In the years that have been given me no joy surpasses that of being a part of the lives of seven dynamic teenagers who call me grandpa. My wife and I remain active in our church, my company prospers as never before, we travel, I find time for golf (18 holes w/cart) three times a week in season, and on off days I walk a little over a mile and lift weights. When frustrated by flagging stamina, I rejoice in being old enough to blame it on my age.