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VOICE OF THE PEOPLE

Fighting one of the fastest-growing blood cancers

A decade ago I was diagnosed with multiple myeloma, an incurable blood cancer that erodes bones and suppresses the immune system.

At the time, the outlook for long-term survival was bleak, and I was given 2 1/2 to five years to live.

This sobering news came to my husband, George, and me in the summer of 1990, as we were planning our youngest daughter's wedding. Confronted with this ominous diagnosis, we had to contemplate some very harsh realities.

I would probably not be around to see my daughter's children born, or to see our other grandchildren graduate, get married and have families of their own. With time against me, we made it through the wedding and began to get our personal affairs in order.

Unlike a prisoner who is given a death sentence, those of us with multiple myeloma have no process for appeal. So with the grim news that our life together was soon to be cut short, George and I set out on a journey to quickly learn as much as possible about multiple myeloma and how to survive this terrible disease. Back in 1990, however, there was no Internet. So we went to the library, made telephone calls and reached out to anyone with an understanding of this strange disease in hope of finding some useful information.

But this search only seemed to confirm my doctor's initial report that there is no cure for multiple myeloma,which kills 11,000 people each year, about half of whom were diagnosed in the previous 2 1/2 to five years.

Since this disease represents "only" 1 percent of all cancers, it was considered an orphan disease that failed to attract the major research funding of the better-known cancers, such as those which attack the brain, colon, lung and breast.

Left with few choices, I was told that chemotherapy was really the only potentially useful treatment for multiple myeloma with the last resort being an allogeneic bone-marrow transplant, a treatment that could prove fatal. Then, just when I was running out of hope, Dr. Harold Schrifter, a physician friend of ours, told us about a multiple myeloma patient he had treated with melphalan and prednisone, the only chemotherapy available at that time, and that the patient had survived more than 20 years.

This good news was the inspiration I needed to enlist in a clinical trial and begin my war on the enemy from within my body. So I gathered my medical troops—the Mayo Clinic, which organized the clinical trial, was my general, and my local oncologist was its lieutenant. Together, we bombarded the enemy with ammunition in the form of chemotherapy and phytochemicals while I helped attack the foe by totally changing my eating habits. I counterattacked with prayer and visualization, and my whole outlook on life changed. Every waking hour I would visualize Pac-Man going through my veins and gobbling up all the myeloma cells. Chemotherapy left me with several side effects, including nerve damage, ongoing leg cramps and I lost most of my eyelashes. Ultimately, after two years, my doctors declared that my disease was in remission. I had at least won that battle and I am still alive today, 11 years later, to tell my story. But my fight against multiple myeloma continues to be a war of attrition.

Geraldine Ferraro recently announced that she is waging her own personal campaign against multiple myeloma. Even with excellent advances in the use of chemotherapy, Thalidomide and stem-cell transplant research, treatment options for blood-cancer patients like Ms. Ferraro and me are still very limited due to lack of funding. Her personal story mirrors the struggle of the legions of blood-cancer patients with whom I work through the Midwest Action Committee, a Chicago-area patient awareness group I co-founded in conjunction with the International Myeloma Foundation.

With multiple myeloma now becoming one of the fastest-growing hematological cancers in the Western world, creative research is needed now. That's why we have formed a new foundation to seek out pioneering research ideas and organize private funding partnerships that we expect will ultimately lead to cures for cancer and other catastrophic diseases.