

Kirk Mease

SARCOIDOSIS



“This is my new normal. With a positive mindset and the strong support of family and friends, I will continue to take life one shot at a time.”

My first symptoms of sarcoidosis began in June 2000 with a bout of optic neuritis in my left eye. I was a newlywed and avid golfer, teaching the game of golf and looking forward to starting a new life with my new wife.

The morning I awoke with the optic neuritis I quickly scheduled an appointment with my optometrist, who referred me to a neuro-ophthalmologist. The MRIs, CT scans, and blood tests began. My initial diagnosis was multiple sclerosis. There was scarring in the brain and also the spine. I began daily injections of the MS drug Rebif, which sent me to the hospital in an ambulance. The University of Colorado Hospital started to seem like a second home.

I was tested for Rocky Mountain spotted fever, Lyme disease, AIDS; any and all autoimmune system disorders were an option at this point. Following cerebral angiograms and more blood work, my doctor finally said that they needed to do a brain biopsy.

I was taken off Rebif and started on prednisone. I began to gain weight and ate everything in sight. The prednisone worked to restore my eyesight, and I am forever grateful. After more tests and seeing numerous specialists, I was by exclusion diagnosed with neurosarcoidosis.

I continued to work full time. Work was my sanctuary from the disease.

The next step was to start an aggressive drug, cyclophosphamide. I was on a very high dose for nearly three years. One of the side effects was possible bladder cancer. I was already having difficulty passing urine and was on medications for it. Cystoscopies were next on the list of procedures. The bladder battle continued for years until they

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Sarcoidosis is an inflammatory disease that most commonly involves the lungs but can impact any organ in the body including the eyes, nervous system, liver and heart. For some patients, the disease is mild and for others it may be progressive and devastating. The cause of sarcoidosis remains unknown. However, experts suspect that sarcoidosis develops when a patient's immune system overreacts to some type of exposure—occupational, environmental or infectious—and small clumps of inflammatory cells called granulomas are formed and deposited in affected organs.

Learn more from ATS Public Advisory Roundtable member the Foundation for Sarcoidosis Research. stopsarcoidosis.org

found a benign tumor in my bladder, which was removed. Immediately I was taken off Cytosan and started on CellCept.

I began to look for any information I could find to help me understand sarcoidosis. One night I found Shirley Holley of the Denver Sarcoidosis Awareness Support Group. Shirley happened to live a few blocks from my house. I joined the next meeting of the local support group, and we soon came up with the idea for Golf in the Darc for Sarc. The tournament raised \$11,000 in the first year, which was ultimately used by the Foundation for Sarcoidosis Research and funded the production of a neurosarcoidosis brochure. The tournament was a continued success for the next six years, raising a total of \$50,000 for the foundation. In the seventh year, the tournament was discontinued because of a life-changing event.

As my body suffered the harsh effects of the chemo drug, I developed a neurogenic bladder. The doctors tried everything they could but reached the last option—the removal of my bladder. It was the second scariest time of my life, next to brain surgery. The procedure, a cystoprostatectomy, the removal of my bladder and prostate, was performed on Oct. 12, 2012. The surgery would also take away my ability to have children.

Looking back on my experiences, I feel I've done OK. I knew I wasn't going to be a quitter. This is my new normal. With a positive mindset and the strong support of family and friends, I will continue to take life one shot at a time.