

Deep Brain Stimulation

A nurse-eye view of a life-altering dystonia treatment.

BY BEKA SERDANS



Some people who contract an incurable disease devote themselves to finding a cure. I wasn't one of those people—I just wanted to keep working. When I was diagnosed with dystonia, in 1993, I was a 39-year-old registered nurse in the critical care division of New York-Presbyterian Hospital in New York City. Dystonia is a neurological movement disorder characterized by involuntary movements, tremors, and bizarre postures.

The cause of my dystonia has never been identified. I simply woke up one morning and it was as though some invisible force was pulling my neck. I quickly developed spatial disorientation and began falling. All the while I continued working in one of the busiest medical centers in the U.S.

Within months my head, which felt like a two-ton rock, hung to one side. Life became almost unbearable, but not a single physician was able to diagnose my symptoms. Eventually I found a picture of a woman with a similar condition in a neurology textbook. The doctors all

seemed puzzled when I entered their offices to announce that I had dystonia, but it was the right diagnosis.

By that time I was continually gripping my hair in an effort to stop the violent twisting of my neck and I walked like someone who had been in a bar for too long. When using public transportation I learned to run past people so that I could get an unoccupied seat and avoid the spots reserved for the “disabled”—after all, I wasn't one of “them”! Little did I know that my symptoms were classified into a group of disorders known as chronic disabilities.

Then began a 13-year ordeal of trying oral medications indicated for just about every neurological condition except dystonia—Tourette's, Parkinson's, seizures, tics, you name it. Dystonia was and remains as cureless as it was in the early 19th century.

Nursing was my livelihood and I loved it, but there I was, facing retirement in my mid-20s. I hated looking in the mirror; the person staring back at me seemed

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grotesque. To hide the physical distortion I saw each morning I stopped wearing dresses and began wearing scarves. And I hid the mental anguish I felt from family, friends, and colleagues.

Eventually I moved to Manhattan where Botox—a form of botulinum toxin, one of the deadliest poisons known to man—was available to patients. When injected into muscles, it would temporarily stop my spasms for a period of 10 to 12 weeks. After a while I developed immunity to Botox and began clinical trials with a newer form of botulinum toxin (type B) called MyoBloc. I derived benefits from this toxin for eight years.

In 2004 I developed immunity to MyoBloc. I grew tired of alternative care as well and wanted a more permanent treatment. It was at this point that I began investigating deep brain stimulation (DBS), which involves the surgical placement of a “pacemaker” in the brain. The device overrides the misfiring neurons that cause dystonia symptoms.

An online search brought me to Weill Medical College of Cornell University in New York City. Within an hour of leaving the office, I felt confident that the procedure would help diminish many of my symptoms. Dystonia had begun affecting my work performance as an ICU nurse, especially in the Open Heart Unit (where former President Clinton had recovered from his surgery). The idea of the procedure alone gave me much-needed hope: it would reduce the constant planning of daily activities; diminish the intense pain of dystonia; improve my quality of life, allowing me to enter a restaurant without being blatantly stared at; and, maybe, just maybe permit me to return to a life of bicycling, writing, and relationships.

My neurosurgeon was competent and compassionate. I embarked on my DBS journey on Dec. 30, 2004 (you can see photos at parasphotography.com/beka.html). The operating room was filled with anesthesiologists, nurses, doctors, and electrophysiologists. I recall being constantly asked by the staff if I was okay. At some point I began



joking that I was not. But I felt no pain during the procedure except for some vibration as my skull was drilled open.

Within 24 hours of the nine-hour operation, I was walking back to my apartment from the hospital, eating and laughing. The surgery had begun at 5:45 a.m. and was completed by 6 p.m. It seems hard to believe, but I was out on Fifth Avenue buying a new wardrobe that Sunday and attending mass at St. Patrick's Cathedral within 48 hours of undergoing major brain surgery. I didn't experience any of the possible complications, such as seizures, stroke, bleeding, or frontal lobe headaches.

The treatment uses a surgically implanted device, similar to a cardiac pacemaker, to deliver carefully controlled electrical stimulation to precisely targeted areas within the brain. The one I have is made by a company called Medtronic. Stimulation of these areas appears to block the brain signals that cause the motor symptoms associated with dystonia. It's essential that others considering DBS become as well-informed as they can. For starters, check out health.groups.yahoo.com/group/DBSsurgery and health.groups.yahoo.com/group/DBSforDystonia

I returned to Weill Cornell for programming of my pacemaker on Jan 12, 2005, with a new outlook. I was free to return to a life that had begun more than 15 years ago, a life filled with promise. It was like waking up from a bad dream. I've spent days just looking at the world around me, noticing how differently things appear when they aren't colored by the pain of dystonia. NN

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*Care4Dystonia, Inc. (Care4Dystonia.org) in 2000 to promote quality medical care and diagnosis of dystonia, and appeared on the first-ever television story on dystonia: NBC's Dateline in 1998 with Dr. Mitchell Brin, M.D. Beka has written two popular books, *I'm Moving Two: A Poetic Journey with Dystonia* and *I'm Moving On... Are U? She is also a Medscape.com blogger. Her third book, a memoir titled *Two Households, One Life*, will be published this year.**